EVIDENCE REPORT AND EVIDENCE-BASED RECOMMENDATIONS

CANCER PREVENTION AND TREATMENT DEMONSTRATION FOR ETHNIC AND RACIAL MINORITIES

PREPARED FOR: U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

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Executive Summary

A: Project Goals and Approach

The December 2000 BIPA legislation (Section 122), "Cancer Prevention and Treatment Demonstrations for Ethnic and Racial Minorities" requires that the Centers for Medicare and Medicaid Services (CMS) conduct demonstrations that explore how Medicare might reduce racial and ethnic (racial/ethnic) minority group disparities in cancer prevention, treatment, and outcomes. Nine demonstrations will be developed, including eight projects that address African Americans, Latinos, Asian Americans, and American Indian/ Alaskan Native beneficiary populations living in both urban and rural communities, and a project in Guam.

The Schneider Institute for Health Policy at Brandeis University was contracted to conduct a thorough review of evidence and to provide guidance to CMS on the design of these demonstrations. The project sought to identify concepts and models that have a high probability of reducing risk factors, increasing use of Medicare-covered services, and improving health and cancer-related outcomes for elder of color Medicare beneficiaries. To achieve these goals, the project team primarily considered information derived from (1) systematic reviews of epidemiological and intervention research on race/ethnicity and cancer disparities in elders, and (2) case studies of emerging models and innovative programs targeting cancer control in traditionally under-served communities. In addition, Olgivy Associates conducted a series of 17 focus groups in nine cities with 153 Medicare beneficiaries from five racial/ethnic groups to explore their response to possible demonstration services. A summary of the focus groups findings appears at the end of this Executive Summary.

Preliminary study findings and recommend-ations were reviewed and approved by a national Technical Advisory Group in October 2002. The Technical Advisory Group was comprised of 12 experts in the areas of cancer prevention and control, health issues and

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outcomes among racial/ethnic groups, health policy, and delivery systems.

An emerging consensus from the literature on racial/ethnic and other socio-economic disparities indicates that unequal health care access and outcomes arise through multiple pathways. In considering published literature and emerging models, the project sought evidence for potentially effective interventions to reduce or eliminate racial/ethnic cancer disparities among elders across the continuum of prevention, detection, and treatment that target patients themselves, practitioners, provider organizations, and larger financing and delivery systems. The recommendations for Medicare demonstrations developed in this study also address the multiple participants in the cancer control continuum.

This report describes the conceptual frameworks adopted, methods used in systematic reviews and case studies, findings on barriers to equitable care and potential solutions to racial/ethnic disparities in cancer prevention and treatment. The study develops preliminary recommendations for demonstration design and cost-effectiveness assessment, while also noting gaps in current knowledge that may be explored in other contexts.

B: Cancer, Medicare, and Race/Ethnicity

Accounting for over 440,000 deaths among older persons in the United States in 1999, cancer is the leading cause of death for Americans between the ages of 60 and 79, and is the second leading cause of death for persons over the age of 80 (Jemal et al., 2002). The risk of developing cancers increases significantly with age. From the ages of 60 to 79, 1 in 3 males and 1 in 4 females will develop cancer. Given the cancer incidence among elders, the disease is likely to be expensive for the Medicare program, yet it has proved difficult to develop broadly accepted estimates. Using linked Medicare and SEER data for 1984-1990, Riley and colleagues (1995) found the total costs of cancer care from diagnosis to death to vary by age of diagnosis and stage at diagnosis. As expressed in 1990 dollars, the average Medicare costs from diagnosis to death per case of lung cancer is $29,184; for female breast cancer, $50,448; for prostate cancer, $48,684; for colorectal cancer, $51,865.

The 2000 Census found 35 million persons age 65 and older, and indicates that this elder population has grown rapidly and become more diverse. Continued increases in the US population of racial/ethnic elders are anticipated based on the growing diversity of younger cohorts. The burden of cancer is not borne equally across this diverse nation, although the patterns of disproportionate impact vary by cancer site. Yet a consistent pattern emerges: African American men have the highest relative risk of cancer death and lowest rates of cancer survival, followed by White men, African American women, and White women. Although men and women in Latino, American Indian/Alaskan Native, Asian American, and Native Hawaiian/Other Pacific Islander groups have lower rates of cancer at many anatomical sites, they still often experience lower survival rates than do Whites.

C: Conceptual Frameworks

An impressive body of literature and practice experiences has demonstrated broad disparities in cancer prevention, treatment, and health outcomes across racial/ethnic and socio-economic status groups in the United States. Social and medical researchers have offered at least five sets of explanations for health disparities (Smith, 1998):
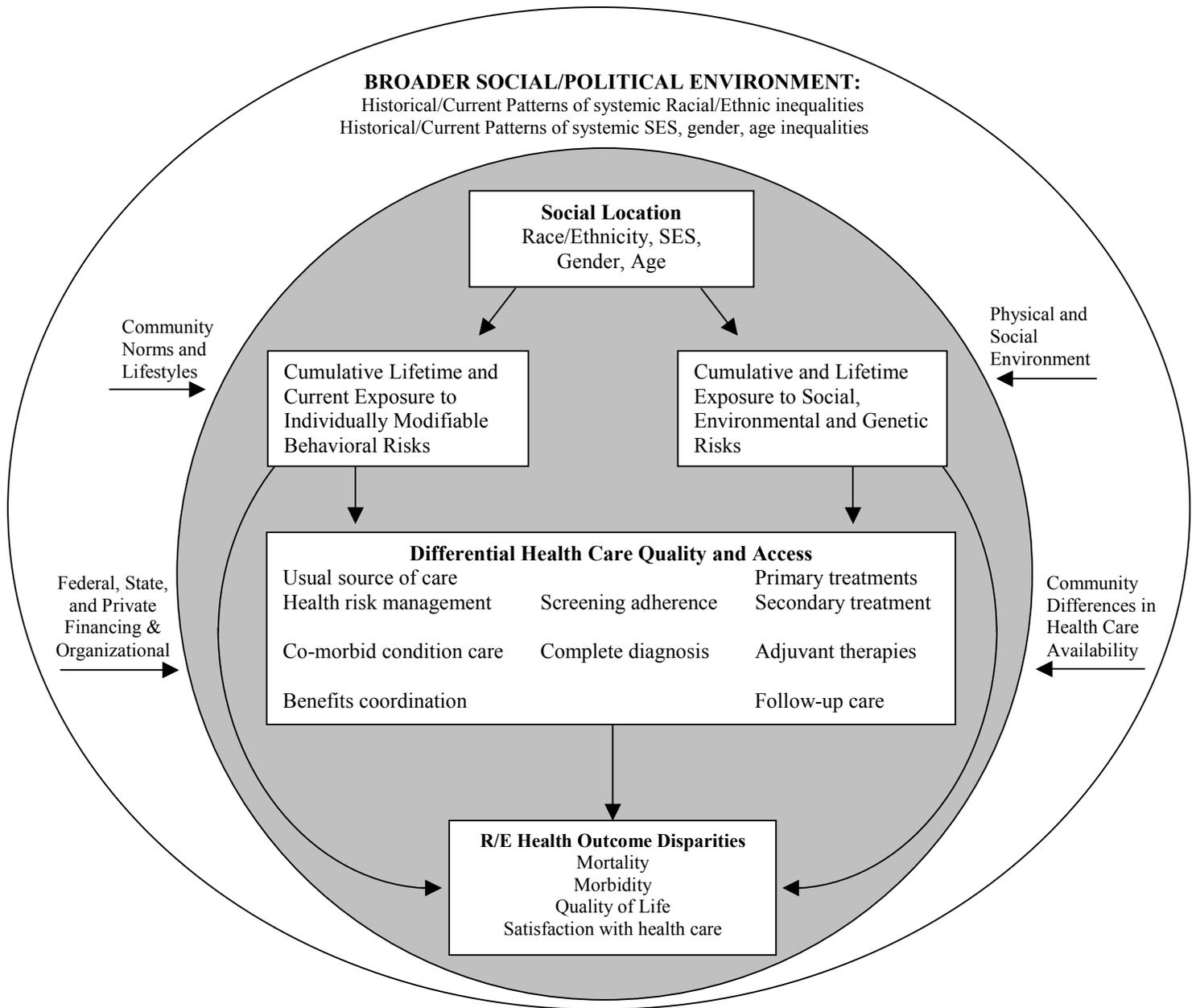
- Individual/Cultural Factors
- Practitioner Factors
- Provider-organization Factors
- System of Care/Financing Factors
- Community Factors

While these dimensions are useful for identifying potential determinants of health and health care disparities, they do not highlight where Medicare demonstrations or program enhancements might most cost-effectively reduce racial/ethnic disparities in elder cancer and health outcomes and cancer-related service use. The Figure below suggests a conceptual model of health care disparities and health outcome disparities that seeks to distinguish components potentially influenced by Medicare policies. The Figure suggests six key concepts that guided the evidence review and development of recommendations for this report:

1) Race/ethnicity encompasses social and contextual variables;
2) Race/ethnicity and other social factors (socio-economic status, gender, etc) have inter-connected influences on health and health care;
3) Race/ethnicity and other social factors are associated with lifetime exposure to both behavioral risks individuals may modify as well as environmental and genetic risks;
4) Behavioral and contextual/genetic risks may influence health outcome disparities directly;
5) Current health care system access and quality disparities also influence health outcome disparities;
6) Health outcome disparities arise in each phase of cancer control continuum.

Guided by the framework, the evidence report focused on identifying opportunities for changes in Medicare policies and programs that in turn would reduce health care disparities. The report does not focus on ways that cumulative lifetime exposures for Medicare beneficiaries could be altered before joining the program, nor does it address health care service distribution, other support service availability and workforce diversity issues that are outside the scope of Medicare's authority. Further, because 85% of Medicare beneficiaries access providers and receive care on a fee-for-service (FFS) basis, the study focused on FFS Medicare only.

Because the cancer prevention and treatment process differs at least to some extent by type of cancer and the potential exists that disparities arise differentially by racial/ethnic

BROADER SOCIAL/POLITICAL ENVIRONMENT:
Historical/Current Patterns of systemic Racial/Ethnic inequalities
Historical/Current Patterns of systemic SES, gender, age inequalities

Social Location
Race/Ethnicity, SES,
Gender, Age

Community
Norms and
Lifestyles

Physical and
Social
Environment

Cumulative Lifetime and
Current Exposure to
Individually Modifiable
Behavioral Risks

Cumulative and Lifetime
Exposure to Social,
Environmental and Genetic
Risks

Federal, State,
and Private
Financing &
Organizational

Community
Differences in
Health Care
Availability

Differential Health Care Quality and Access

Usual source of care   Primary treatments
Health risk management   Screening adherence   Secondary treatment

Co-morbid condition care   Complete diagnosis   Adjuvant therapies

Benefits coordination   Follow-up care

R/E Health Outcome Disparities
Mortality
Morbidity
Quality of Life
Satisfaction with health care

Figure 1: Racial/Ethnic Cancer Disparities

group at any point in the cancer control continuum, the study has sought to detail the process specifically for each cancer. It is possible that different racial/ethnic groups among the Medicare beneficiary population experience barriers to appropriate care at different phases in the process. The following Figure exemplifies the sequential models that were developed for each cancer and used to organize our work.

Basic Sequential Model

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  ┌──────────┐    ┌──────────────┐   ┌──────────────┐   ┌──────────────┐   ┌──────────────┐
  │          │    │    Cancer    │   │  Diagnostic  │   │   Primary    │   │   Relapses   │
  │   Risk   │ →  │  Screening   │ → │   Testing    │ → │     and      │ → │     and      │
  │ Factors  │    │     and      │   │     and      │   │  Adjuvant    │   │ Complications│
  │          │    │ Preventative │   │  Treatment   │   │  Treatment   │   │  Monitoring  │
  │          │    │  Treatment   │   │   Planning   │   │              │   │              │
  └──────────┘    └──────────────┘   └──────────────┘   └──────────────┘   └──────────────┘
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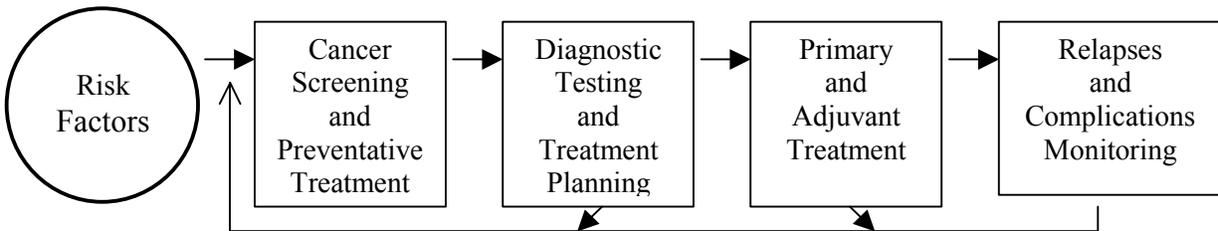
D: Overview of Methods:

This evidence review was derived from two principle methods, systematic literature reviews and case studies of emerging models. More detailed descriptions of methods are provided in relevant sections of this report.

Systematic Literature Reviews

The literature reviews were organized around five areas of potential cancer prevention (physical activity, nutrition/weight loss, smoking, excessive alcohol consumption, and supplemental insurance/usual source of care, cancer detection, and cancer treatment and follow-up. The reviews focused on the cancer sites with the greatest impacts on mortality and morbidity for Medicare beneficiaries (lung, breast, cervical, colorectal, and prostate) and several less prevalent cancer sites associated with notable racial/ethnic disparities (stomach, oral, pancreas, and leukemia). For each cancer, evidence was sought on the roles of modifiable and other factors and racial/ethnic group in cancer incidence and course. For the behavioral risk factors, evidence was sought for racial/ethnic differences in elder and lifetime exposure, interventions to change behavior among racial/ethnic elders, interventions to change behavior among racial/ethnic adult populations, and interventions to change behavior in elder populations. In this context, behavior change interventions with elders of color that included quantitative measures of impact in a controlled design were highlighted, while prior reviews were the principal information source in considering behavior change interventions more generally. For the major cancers and less prevalent sites, evidence was sought for consensus on screening, diagnostic and treatment approaches, racial/ethnic differences in use of screening, timely diagnosis, treatments, and interventions to reduce racial/ethnic differences in screening, timely diagnosis, and treatment. Literature on relapse monitoring and quality of life/survivorship issues that addressed racial/ethnic disparities was not reviewed in most cases.

For both prevention and cancer site reviews, literature was identified using multiple strategies, including: electronic data base searches using Medline, PsychLit, CancerLit, Web of Science and Cochrane group reviews; backwards searching using Social Science Citations Index to identify studies that had cited relevant papers; manual review of bibliographies in relevant papers; search of selected government and private websites; search in NCI, AHRQ and other Federal cancer and related funded project databases; recommendations of consultant experts on each topic; and reports identified by screening interview participants. The study focused on identifying published studies and widely disseminated reports, but in several cases, unpublished reports cited in prior reviews were obtained. If, after review, abstracts suggested relevance to the project, full text articles were obtained and reviewed. In those few cases where sufficient numbers and consistency of available studies could support quantitative syntheses, standardized effect sizes were computed and assessments of heterogeneity of effect and potential moderator variables were performed.

Analysis of 2000 NHIS

In addition to these activities, an analysis of the unweighted results of the NCHS 2000 National Health Interview Survey was performed to provide more current data on racial/ethnic group membership, behavioral risk factors, and self-reported screening participation. Systematic reviews of evidence for racial/ethnic differences in supplemental insurance, usual source of care, and the implications of these factors for preventive and screening service use complemented these analyses. A series of interviews with Indian Health Service and other AI/AN population experts explored the intersections of Medicare fee-for-service programming with the financing and delivery of health care for these groups.

Case Studies of Emerging Models

It seemed likely that many potentially efficacious and effective interventions to reduce racial/ethnic disparities in cancer care and outcomes for Medicare beneficiaries are currently operational and not yet the subject of published reports. Further, published studies on many interventions do not provide sufficient operational and organizational detail to address demonstration design and implementation questions. For these reasons, the study drew on multiple sources to identify emerging models for increasing participation of elders of color in cancer prevention and screening activities and/or increasing their access to appropriate and timely diagnostic, treatment and follow-up services. Outreach to multiple sources, including: federal agencies and federally-sponsored programs, health payer/delivery systems organizations, racial/ethnic identity and professional organizations, conference proceedings, foundation initiated programs, cancer centers, and mass distribution of requests for referrals were all used to identify these programs. Screening interviews were conducted with 115 programs. Based on these interviews, an intentional heterogeneity sample of 26 sites was selected for case studies. Case studies were tailored to each site and were conducted by two-person teams and usually included an expert in cost-effectiveness issues. The case studies generally addressed questions such as: program history and theory of intervention, organizational

and financing issues, perceptions of sources of disparities, intervention design and operations, measurement of program costs and outcomes, and findings with regard to volume of services and impacts. Not all case study sites could provide data on all issues. Case study reports were developed and reviewed by subject representatives. Qualitative analyses sought learnings on each of the intervention design, operational and organizational topics, while available cost and impact data were used to develop a model for cost-finding and cost-effectiveness evaluation.

E: Summary of Findings and Conclusions

<u>Cancer risk factors and prevention strategies for racial/ethnic elders:</u>

The major findings from our review of reports on cancer risk factors, racial/ethnic differences in modifiable risks, and interventions to change physical activity levels, nutrition, smoking, and excessive alcohol consumption are summarized below.

1. There is epidemiological evidence linking one or more of the behavioral risks to each of the cancers.

2. There is some evidence that racial/ethnic differences in behavioral risk factors do explain some of the racial/ethnic differences in cancer.

3. Available epidemiological studies do not generally differentiate cumulative lifetime exposure to behavioral risks from current behaviors as influences on cancer.

4. There appear to be no examples of intervention studies that demonstrate a link between behavioral change and cancer incidence in elders, but studies of smoking cessation and reduction in lung cancer in younger populations are relatively conclusive. Prevention of breast, cervical, and colorectal cancer reoccurrence through lifestyle change for general populations is receiving increasing support

5. Increased rates of participation in behavioral risk management activities, cancer control, and management of chronic health conditions are all associated with owning any Medicare supplemental insurance and maintaining a usual source of care.

6. Both primary care practitioners and social/supportive service providers can be effective in motivating health risk management activities. Primary care practitioners may not be as effective as other health and human service professionals in supporting behavior change and maintenance of new behavior. Further these practitioners often miss opportunities to encourage or support elder patients in deciding to use formal behavior modification resources or maintain lifestyle changes.

7. There are very few studies of physical activity, nutrition/weight management, and multi-component interventions with elders of color. There appear to be no published reports on health risk appraisal/multi-component behavior change programs, smoking cessation and alcohol use reduction interventions with most elder of color groups.

8. There is a clear need for new research on how to engage and maintain participation of elders of color in effective and efficacious physical activity, nutrition/weight management, smoking cessation, and multi-component interventions.

9. Available studies from both elders of color and other populations underscore the challenges associated with engaging persons in behavioral risk factor management and suggest the use of motivational interviewing and techniques that individualize messages about prevention based on stages of change and related frameworks.

10. For elders and elders of color, health promotion interventions seem more effective when they highlight health improvement rather than disease avoidance, and when they can be individualized to preferences on activities, group participation, timing, and effort.

11. There are many examples of linguistically and culturally adapted materials and programs, as well as guidance for healthcare, social service, community and religious organizations on their implementation. Cultural adaptation can be consistent with application of intervention approaches that are working in general populations.

Thus, we find strong evidence from epidemiological studies for the importance of individually modifiable behavioral risks in cancer etiology and severity but almost no experimental evidence that altering behaviors influence cancer rates or outcomes. Nonetheless, because there is evidence that behavioral risks can also influence co-morbid conditions and treatment outcomes, it seems likely that increasing the engagement of racial/ethnic elders in management of behavioral risks and other modifiable determinants of health can alleviate some racial/ethnic disparities in cancer and health. We found no examples of proven behavior change strategies for racial/ethnic elders and a few studies showed real difficulties in engaging such persons in behavior change. But there is compelling evidence from studies with general aged populations and racial/ethnic adult populations to suggest that racial/ethnic elders could be engaged in a broad array of effective behavior change activities.

As with all attempts to change behavior, the problem of motivation and engagement needs to be addressed. The link with a usual source of care and access to benefits and services is well documented. Hence, we propose the need for tailored health risk management in order to overcome issues of mistrust and barriers to basic access to primary care. Cultural tailoring of this assistance seems to require the intervention of a person with enduring connections to the community being served and armed with motivational skills, skills in benefit counseling and enrollment, and links to primary care practitioners, health care systems and community prevention resources. Community health workers –or similar paraprofessionals –can offer linguistic and cultural translation while helping beneficiaries get coverage, develop more continuous relationships with a usual source of care, understand current risk behaviors, motivate them to engage in risk management, and receive support and encouragement for maintaining these efforts.

<u>Racial/Ethnic disparities in cancer treatments and outcomes</u>

Our literature review of racial/ethnic differences in cancer incidence, detection, treatment and outcomes produced several major findings.

1. African Americans and other traditionally underserved groups are at greater risk for getting cancer and/or having poorer treatment and survival outcomes. In general, differences in incidence are smaller than differences in outcomes.
2. Evidence for the role of late stage at diagnosis and racial/ethnic differences in survival was mixed. For the better-studied cancers---breast, cervical, prostate, colorectal, and lung---there was evidence that racial/ethnic differences in stage at the time of diagnosis accounted for a significant share of mortality or survival disparities.
3. Consensus recommendations for use of screening methods were found for breast, cervical, colorectal, and oral cancers and consensus recommendations on timing of screening were found for breast and cervical cancers.
4. The detection and treatment of pre-cancerous lesions in some anatomical sites (most notably, breast, colorectal, cervical, and oral diseases) is curative.
5. Prostate cancer screening remains controversial but there is evidence for targeted screening for some high-risk groups, particularly African American men with family histories of prostate cancer. There is broad support for a new focus on informed decision-making with respect to this screening service.
6. Rates of adherence to screening protocols – for breast and colon -- are lower than desirable for all Medicare beneficiaries, but notably lower for persons of color. Similarly, prostate cancer screening rates are lower than recommended for African American men.
7. For each of the cancers examined, final diagnosis and staging of cancer treatment requires a multi-step process involving multiple tests, procedures, and professional consultations.
8. For breast, cervical and prostate cancer, there is evidence that women of color and African-American men are less likely to receive a complete screening follow-up and diagnostic process.
9. For breast cancer there is evidence that African American women are less likely to receive complete diagnostic work-ups and valid clinical staging. For both breast, cervical and colorectal cancer, there is evidence that older persons are less likely to receive complete diagnostic processes.
10. For breast, cervical, prostate, and colorectal cancer, there are reports of culturally tailored interventions to increase screening that typically involve use of community health workers to conduct educational programs using culturally and linguistically adapted materials. In some multiple component programs, education is linked to operational enhancements that address access barriers.
11. Our meta-analysis of these studies shows that culturally tailored programs yield modest, significant effects (RD 8-10%)but they are heterogeneous in their findings. Projects that combined Chows with operational enhancements to reduce barriers to access were significantly more effective.

12. There were insufficient culturally tailored prostate and colorectal screening to support meta-analysis, but qualitative reviews indicated that there was at least some evidence that techniques similar to those used to increase breast and cervical screening by women of color could be adapted to other screening tests.

These findings suggest that interventions aimed at both reducing racial/ethnic disparities in cancer detection and racial/ethnic disparities in cancer treatment have the potential to influence overall differences in outcomes. The available research shows that both differences in stage at diagnosis, detection and cure of pre-cancerous lesions and differences in treatment influence cancer and health outcomes. Improving screening participation and adherence for racial/ethnic elders are clearly worthwhile goals in light of these findings. Although the evidence could be stronger, it appears that culturally tailored screening interventions that focus on adherence to detection protocols and interventions based on in-reach have somewhat greater potential to influence racial/ethnic differences. Unlike prior efforts, new demonstrations might focus on programming that specifically targets screening adherence to detection across the range of cancer screens, and such a model could also be extended to adherence to other recommended and Medicare-reimbursed screening and preventive services.

For cancers without accepted screening mechanisms, however, it appears that addressing the stage-at-diagnosis differences requires ensuring medical care use and attention on the part of both patients and practitioners to health risk management. The racial/ethnic interventions proposed in Chapter II to involve racial/ethnic elders in health risk management with the dual goals of increasing engagement in lifestyle modification and increasing appropriate primary care utilization would also be beneficial in addressing these cancers.

Further, some of the differences in survival and treatment appear to occur because of failure to complete follow-up of suspicious lesions and diagnostic work-ups, thus missing full staging of disease and potentially making poor treatment planning choices. This is not surprising since diagnosis for most cancers was found to be a multi-step process involving multiple practitioners and procedures with ample opportunities for failures in care continuity. Interventions that increase the likelihood that patients and practitioners follow-up on suspicious screening findings, perform complete diagnostic work-ups and complete standard of care for diagnosis and treatment appear largely missing in the literature for racial/ethnic elder populations.

No less important than complete diagnosis is timely completion of all recommended primary and secondary treatments. These findings underscore the potential to improve cancer survivorship by ensuring that patient and practitioners complete the process. A treatment management intervention, that draws upon a knowledgeable and trusted community health worker, serving as a patient navigator, holds potential to increase the share of elders of color who receive the current standard of care. Although demonstrations and evaluations of cancer treatment management services, such as navigators, were not identified in the literature, this review highlights therapeutic

compliance facilitation is a potentially important mechanism for achieving cost-effective reductions in cancer care disparities.

<u>Emerging interventions to reduce Racial/Ethnic disparities in cancer</u>

Findings from 26 case studies of emerging interventions, identified through screening interviews with 115 emerging models are described. The sites were selected to address a range of racial/ethnic groups, cancer sites, and geographical regions. The case study sites are based in diverse organizational settings and are sometimes hampered by the demands of grant funding cycles and research requirements. The programs address racial/ethnic cancer disparities by focusing on health risk management, screening education, screening adherence, and treatment facilitation. All of the programs culturally tailor their interventions as a strategy for overcoming attitudinal and systemic barriers.

Programs use a variety of activities for cultural tailoring. These activities include outreach in community settings/churches, small group educational approaches, addressing co-occurring social and economic challenges as well as specific transportation or related barriers to care, cultural competence training of the provider and use of adapted materials and protocols, among others. However, perhaps the most striking finding from the case studies is *the predominance of introducing community health workers (CHWs) as the primary mechanism for cultural tailoring*. These programs view the CHW as an essential strategy for engaging elders of color in appropriate cancer prevention, detection, and care. However, the way case study sites utilize CHWs is extremely diverse with respect to use of volunteer or staff positions for this role, experiences with recruitment and retention of these workers, scope and scale of work, training and supervision procedures/resource requirements, and relationships of the paraprofessionals with the health care team.

Because of the great variability or roles, responsibilities and training of CHWs across case study sites, there is a tremendous opportunity to shape new expectations for the roles played by these workers and increase their effectiveness in influencing service use. This finding is directly linked to current debates about the definition of a community health worker role within the US healthcare system. In addition, programs that incorporate both management information system, decision-making support and clinical leadership seem to increase the effectiveness of CHWs in helping community members receive the services they need throughout the continuum of care. Our findings suggest that combination interventions hold the greatest promise for addressing the disconnect between communities of color and the health system components most believe are to reducing racial/ethnic disparities in cancer control.

CHWs and Addressing racial/ethnic Disparities in Medicare: Our case studies revealed the range of activities that CHWs can perform in the context of cancer control initiatives. Programs active in the field universally acknowledge the utility of using CHWs. In our case study investigations, we repeatedly observed instances where, in keeping with the findings from the Pew report, CHWs provided "bridge" services by reducing barriers to access and increasing motivation to access preventive services.

In addition to highlighting the value of CHWs, our case studies also suggested that CHWs are an underutilized resource. We found that most programs trained CHWs to perform a very narrow scope of service—focusing on screening education without attention to ensuring individual follow-through – specific perhaps to one disease or one population. However, our study also hinted at how much more CHWs could potentially do. It is clear that CHWs could assist with each of the goals of health risk management, screening education, screening adherence, and treatment facilitation. What is not clear, however, is whether an individual CHW could or should perform all of these roles. The facilitation of diagnostic and treatment processes may require a different set of skills/knowledge than health risk management and cancer education, and may require affiliation with different sorts of institutions. While an individual CHW does not need to serve in all of these capacities at once, it is clear that CHWs could be an important resource and linkage in meeting program's goals of addressing racial/ethnic disparities in cancer.

The case studies do highlight several obstacles to these models of care. Perhaps the most obvious one was the discrepancy between need and supply. The supply issue was one both of adequate human resources: difficulties with recruiting, but also one of adequate financial resources for training and retention. Traditional funding streams for health care are not designed to compensate either for this kind of worker, nor for the services they deliver. A lack of standardization and evaluation creates a barrier to sustainability, as funders seek evidence of improved health outcomes, reduced costs, or both. While these models may work best when the CHW is able to become the conduit to the established health care system, this requires mutual trust from all parties. It also requires leadership and advocacy that is not always available. For example, traditional health care professionals may neither comprehend the role of the CHW nor value it. But, an important element in the success of the CHW role is its incorporation into the health care system. The CHWs' capacity to act as a conduit between patients, the community and the health care system may be severely limited if they are not integrated. Advanced practitioners could fail to communicate or cooperate with the CHW in a way that might most benefit community members seeking services.

In addition, many of the programs we studied confronted problems in tracking and documenting the success of the CHW model primarily because of lack of organizational capacity to support the program and to ensure its sustainability. Therefore, a successful CHW model must take into consideration the commitment from leaders in the medical community, as well as infrastructure and capacity building of the organization through support in decision-making and management of information systems.

Despite these issues, this analysis shows that the role of the CHW is crucial if one is to make a difference in disparities in cancer prevention and health promotion. A model of care in which CHWs are an essential and integral part of any such program of care has a long history of success in developing countries. CHWs can be the bridge between the underserved and the health care system in the U.S.

Medicare demonstrations to reduce racial/ethnic cancer and health disparities:
Recommended models and issues in assessing cost-effectiveness.

The literature reviews and case studies of emerging, promising interventions suggest that opportunities exist for improving participation in lifestyles and health risk management, cancer detection, prevention and diagnostic services, and cancer treatment across racial/ethnic populations of Medicare beneficiaries. The literature also highlights the central importance of culturally determined beliefs and attitudes as well as practitioner, provider systems, and financing barriers as determinants of less adequate health care access, treatment, and outcomes. Strategies particularly targeted to how elders of color are offered access to-- and are treated within -- the health care system appear to be required to address disparities. The available evidence, however, does not allow clear determinations of the relative importance of primary prevention, detection, and treatment oriented measures in reducing disparities. Further, the available studies --- primarily in the context of breast and cervical cancer screening participation---and experiential and anecdotal evidence from the emerging programs highlight the importance of:

a) Introducing new workers (such as community health workers, promoters de salud, or patient navigators) with strong understanding and empathetic relationships with elders of color and the health system.
b) Focusing the efforts of community health workers on improving accessibility and continuity of cancer prevention, detection and treatment services rather than only patient education.
c) Backing up these workers with new health care system information systems and decision-making supports.

Understanding the short and long-term costs and impacts of CHW models is critical for efficient resource allocation and implementing cost-effective strategies for reducing racial/ethnic disparities in cancer among the Medicare population. Reliably capturing the start-up and recurring costs of the service, estimating relative cost-offsets in health care utilization, and accurately measuring changes in health-related behaviors and outcomes are vital for providing necessary cost-effectiveness evidence to decision-makers. The case studies provided an opportunity to investigate the type of resources (and associated costs) used in delivering varying educational, diagnostic, and treatment management services for reducing racial/ethnic disparities throughout the United States.

There appears to be a high level of variation in types of programs using a CHW model in the delivery of services, varying amounts of data available, as well as different measures of service volume captured at each site depending on the service rendered. Nine major findings regarding current resource use and the state of cost and impact data pertaining to most sites are:

1. Use of in-kind resources are significant
2. Many programs are currently in development or embedded in research efforts

3. Programs used the CHW role to a greater or lesser extent as part of a team approach
4. Role of the CHW varied
5. Programs had varying funders or resources over time
6. Insufficient data on outcomes
7. Intermediate process measures more readily available
8. Costs of management information systems were difficult to allocate
9. Wide range of training resources supporting lay health advisor models available

From these major findings, we conclude that there is a lack of sufficient evidence upon which to construct a formal cost-effectiveness analysis from the site visit data. Therefore, we recommend the three possible models for reducing racial/ethnic disparities in cancer among Medicare beneficiaries, and discuss cost-effectiveness assessment considerations in assessing these models.

Based on these findings and findings from the literature reviews, programmatic findings from case studies, and ongoing discussions with CMS and consultants on feasible structures for Medicare fee-for-service benefits, three possible services with the potential to reduce racial/ethnic disparities in cancer and health among elders were identified. These models include health risk management (HRM), screening adherence and detection facilitation (SADF), and treatment and follow-up facilitation (TAFF). Each of these services would be performed as an integral component of and link to the local health care system. For this reason, in a demonstration context, a particular health system might be able to reconfigure two or more of these roles as the responsibilities of a single worker or group of workers. While the following discussion emphasizes how they are different and the importance of exploring each of these roles, community health workers in the context of a racial/ethnic cancer disparities reduction program might perform two or more distinct billable services. In each role, the community health care worker would collaborate both with other health care clerical, financial, and administrative staffs and with health care professionals such as physicians, nurses, social workers, and case managers on patient education, care continuity, and self-care empowerment, but also provide specific support and linkage services. Furthermore, each role would include the use of data management technology to improve the accuracy of data collection and reduce the amount of administrative time spent by each community health worker. The three separate models are described below.

- Health risk management – (HRM) is a service that targets three specific behavioral health changes and three system level changes that would be most effective in improving the health of Medicare beneficiaries from a primary care perspective. The three behavioral health improvements are weight management, increased physical activity and smoking cessation. System level activities include linking Medicare beneficiaries to a regular source for their primary care and facilitating enrollment in all appropriate supplemental insurance.

- Screening adherence and detection facilitation – (SADF) is a service with the objective of ensuring Medicare beneficiary adherence to breast, cervical, prostate and colorectal cancer screening as well as follow-up of questionable screening results, including treatment of pre-cancerous conditions and complete diagnostic work-ups, and completed referral for initiation of treatment in a timely fashion. This is accomplished by assisting the Medicare beneficiary through the screening process and detection process, while working with multiple health care system actors to facilitate timely task completion and documentation. To accomplish this task, the community health worker may notify the patient or provider regarding the need for a particular screen, follow-up for a missed screening appointment, and link the beneficiary to further preventive services and diagnostic work-ups in a timely manner and treatment as needed. For example, the navigator will perform activities such as making telephone calls to beneficiaries and providers, completing referrals, setting up appointments, explaining the process to the Medicare beneficiary and providing emotional support, and linking the beneficiary to needed services such as transportation or interpreter services

- Treatment and follow-up facilitation– (TAFF) is a service that involves navigating patients from the definitive diagnosis of cancer at any anatomical site through the treatment and recurrence monitoring process. Additional objectives of this service include tracking for cancer recurrence, facilitating referrals to complementary health risk management programs, and assisting with benefits coordination, and health and social service referrals.

The following table summarizes the three possible Medicare demonstration services, all of which could be performed by community health workers with appropriate training, supervision, and information management/clerical supports. It also describes for each model a service description, recommended staffing requirements, necessary training/certifications, possible staff reimbursement ranges, potential delivery sites and technological support, along with a description of productivity and quality assurance measures.

We recommend that CMS develop demonstrations that allow for separate assessment of each of these linked services. Furthermore, we recommend that each demonstration site implements and tests two or more of the proposed services. Such an approach is indicated because of uncertainty as to their relative effectiveness in reducing racial/ethnic disparities and improving health as well as their impact on Medicare expenditures. As part of the demonstration, we recommend an evaluation of the implementation process and of the intermediate outcomes for each service.

As highlighted in the table below, the services would be based in different organizational settings, address different phases in the cancer process, and thus would be assessed against distinct intermediate outcomes. Individual and small group primary care

practitioners, public health offices, community clinics, and larger multi-level health care systems may find alternative ways of organizing these new roles and their associated supports.

We recommend that CMS set forth a series of demonstrations to test each of these models in one or more racial/ethnic groups against customary care receipt for that same racial/ethnic group using a rigorous research design with random assignment. Such a design would enable a more complete and compelling evaluation of both the costs and impacts associated with each service. As for a specific research design, we recommend comparing each of the individual services separately against a control case leading to three separate clinical trials. This type of design is important for several reasons. First, under its current structure, Medicare reimburses for specific services. This design would inform CMS about the costs and impacts of each individual service. Secondly, the organization of the current health care delivery system allows for easier implementation of this type of design. More elaborate, hybrid models would be more complicated to implement. Lastly, it is anticipated that the immediate outcomes best measured in a demonstration context differ across these models. As the demonstration framework and implementation plans develop, it may be appropriate to reconsider the best combinations of these models for further exploration.

The length of the demonstrations will impact the type of questions that can be addressed regarding cost-effectiveness of the interventions. Shorter-term (2-3 years) clinical trials are less costly but and can yield analyses involving intermediate outcomes. Longer term community and clinical trials would provide greater evidence for the cost-effectiveness of each of the proposed interventions including more reliable estimates of cost-offsets in health care utilization, long term impacts on mortality and potential improvements in quality of life. Economic modeling of these variables is possible based on shorter-term studies but are often less reliable. Estimating the potential increase in survival based on long-term data is critical but would take several years. This tradeoff should be carefully considered due to the current lack of knowledge in the field regarding potentially high cost-savings in acute care and inpatient hospitalizations and late stage cancer treatments due to these types of services.

Three Possible Medicare Demonstration Services for Reducing Racial/Ethnic Disparities in Cancer: Service Descriptions and Recommended Requirements		
Type of Service	**I. Health Risk Management (HRM)**	**II. Screening Adherence and Detection Facilitation (SADF)**	**III. Treatment and Follow-Up Facilitation (TAFF)**
Primary Role	Performs Health Risk Assessment (HRA), conducts motivational interviewing, tailored lifestyle counseling, assists with benefit coordination, referral to primary care and screening, referral to social and prevention services	Maintains individual record of adherence to all Medicare-reimbursed screens, sends personalized reminder letters, calls and arranges for service on schedule, follows-up on missed visits, facilitates referrals out to other providers for cancer detection, prevention, and treatment services, tracks patient till definitive resolution	Maintains individual record of progress and facilitates access to standard of care services from suspicion of cancer through definitive diagnosis, primary and secondary treatments, adjuvant care and reoccurrence monitoring. Assists with benefits coordination, health and social service referrals.
Organizational Affiliation	Community Health Center, CHHA, Health Dept., group practices	Community Health Center, screening provider, cancer center	Hospital, safety net health system, cancer center
Operational Supports	Patient registry, MIS to track service referrals, actions and follow-up, computerized HRA, adapted health education materials	MIS to track use and completed referral, personalized letters, links to financial offices, interpreter services, adapted health education materials	MIS to track use and completed referrals, decision supports to track standard of care completion, interpreter services, adapted health education/discharge summary materials
Training/ Certification	40-60 hours in class plus extra training in motivational/tailoring techniques and use of computerized HRA and registries	40-60 hours in class plus extra training in screening issues and MIS use; extra clinical training re screens and benefits	40-60 hours in class plus extra training in screening issues and MIS use; extra clinical training re cancer treatment and benefits
Intensity	4-6 hours per year per eligible person	2-4 hours per year per eligible person	20-30 hours per year per eligible person
Immediate Outcome Measures	% of HRAs with tailored action plans; % with supplemental insurance, % with usual source of care, % of cases engaged in weight management, smoking cessation, and physical activity programs; % adherent to overall lifestyle recommendations	% of cases adherent on all screens; % of cases brought to resolution, % of cases with standard of care detection and prevention services, reduced Screen-to-resolution lag time, patient satisfaction health-related quality of life	% of cases completing standard of care diagnosis and treatment; time to completed treatment; % of cases tracked annually, patient satisfaction and health-related quality of life

Summary of Medicare Beneficiary Focus Group Findings

The Olgivy Associates focus groups encouraged consumers to discuss their experiences with health promotion, cancer prevention and cancer treatment services, their expectations from Medicare as a source of health promotion/disease prevention information, and their reactions to the proposed demonstration services.

Nearly all respondents mentioned being exposed to an abundance of health-related information in the media and from other sources. However, seniors admit that awareness and knowledge do not *always* influence their behaviors and they recognize that behavior modification is not easy. Cancer is viewed by these respondents as an important and serious health condition. They also worried about chronic diseases such as heart disease, diabetes, Alzheimer's and high cholesterol.

Respondents noted that their healthy behaviors are linked to overall good health and wellness rather than prevention of a specific disease and that they are doing a variety of things to be healthy as well as to prevent cancer. Most respondents stated that nutrition, exercise and regular check-ups and screenings are the best way to ensure optimal health. Nonetheless, they often doubted the effectiveness of preventive behaviors if a person was predisposed to the disease, citing genetic links as a cause of cancer. Some also felt that health advice is often contradictory and confuses them.

When asked about cancer prevention specifically, most respondents felt that regular screenings were important in addition to a healthy lifestyle and most respondents described medical screenings/tests as a routine part of their health care. The most commonly mentioned tests were mammograms, prostate screenings and Pap tests. Many senior respondents said they depend on their physicians to ensure that they stay on-schedule with all types of medical screenings, and that often their physician will schedule their screenings for them. Respondents do not strongly differentiate cancer screenings from other types of screenings.

Medicare is viewed primarily as an administrator of health care services, and not a provider of health care information, yet all are very grateful that the program exists and there were many positive things said about Medicare. Respondents agreed that their opinions of Medicare would improve if the agency took a more active role in disseminating credible, timely health care information. Nearly all respondents would welcome additional assistance from Medicare, viewing different merits of each of the three proposed concept services. The health navigator model was strongly endorsed by respondents in racial/ethnic minority and lower-income groups; however, Caucasians were less supportive. In fact, help of any kind was perceived as "very important" to minority groups, even if some seniors felt they themselves were not yet in a position to need the services. For the most part, Caucasians did not perceive the health navigator model or the three services favorably. Yet, many Caucasians agreed that such services would be appropriate and important for others in need.

While minority respondents embrace additional Medicare assistance, respondents from all groups have concerns regarding the implementation of such services, and many respondents – primarily Caucasians – question the feasibility of implementing such a large-scale program and whether this is the best use of Medicare funds. There was concern that there would be increased costs associated with the services, even though there was agreement among many respondents in the groups that these services should be offered for free. Many felt that Medicare should focus its funding on prescription medication.

Moreover, since Medicare is currently seen as an administrator of health care services, attitudes toward Medicare could improve if the program was implemented. Respondents felt that attempts to help inform seniors would be beneficial and appreciated. Respondents are interested in information about all diseases as well as wellness promotion, and feel the scope of the program should be broadened beyond cancer prevention. However, all groups were concerned with the cost of implementing such a program, as well as how this would affect the possibility of a prescription drug program.

Chapter 1: Overview and Approach

A: Project Goals and Approach

The December 2000 BIPA legislation (Section 122), "Cancer Prevention and Treatment Demonstrations for Ethnic and Racial Minorities" requires that the Centers for Medicare and Medicaid Services (CMS) conduct demonstrations that explore how Medicare might reduce racial and ethnic minority (R/E) group disparities in cancer prevention, treatment, and outcomes. Nine demonstrations will be developed, including eight projects that addressing African Americans, Latinos, Asian Americans, and American Indian/Alaskan Native beneficiary populations living in both urban and rural communities, and a project in Guam.

The Schneider Institute for Health Policy at Brandeis University in collaboration with Boston University Center of Excellence in Women's Health (BUCEWH) and other consultants were contracted to conduct a thorough review of evidence and to provide guidance to CMS on the design of these demonstrations. The project sought to identify concepts and models that have a high probability of reducing risk factors, increasing use of Medicare-covered services, and improving health and related outcomes for elder of color Medicare beneficiaries. To achieve these goals, the project team considered information derived from (1) systematic reviews of epidemiological and intervention research on race/ethnicity and cancer disparities in elders, and (2) case studies of emerging models and innovative programs targeting cancer control in traditionally under-served communities. As a complement to this effort, CMS also contracted for a series of focus groups with diverse Medicare beneficiaries. Expert consultants and a national advisory panel reviewed drafts of the evidence report and focus group study, and their suggestions and recommendations have been incorporated.

This report describes the conceptual frameworks adopted, methods used in systematic reviews and case studies, findings on barriers to equitable care and potential solutions to racial/ethnic disparities in cancer prevention and treatment. The study develops preliminary recommendations for demonstration design and cost-effectiveness assessment, while also noting gaps in current knowledge that may be explored in other contexts. This Chapter provides a context for the study, defines conceptual frameworks to be used in guiding the evidence review, and outlines the subsequent sections of the report.

B: Cancer, Medicare, and Race/Ethnicity

Accounting for over 440,000 deaths among older persons in the United States in 1999, cancer is the leading cause of death for Americans between the ages of 60 and 79, and is the second leading cause of death for persons over the age of 80. Of the 555,000 persons dying from cancer each year, about 80% are over the age of 60 (Jemal, Thomas, Murray, & Thun, 2002). The risk of developing cancers increases significantly with age. From the ages of birth to 39, 1 in 64 American males and 1 in 51 females will develop

cancer. From the ages of 60 to 79, 1 in 3 males and 1 in 4 females will develop cancer (ACS, 2001).

Given the cancer incidence among elders, the disease is likely to be expensive for the Medicare program, yet it has proved difficult to develop broadly accepted estimates. Using linked Medicare and SEER data for 1984-1990, Riley and colleagues (1995) found total costs of cancer care from diagnosis to death vary by age at the time of diagnosis, and clinical stage of the disease at diagnosis. As expressed in 1990 dollars, the average Medicare costs from diagnosis to death per case of lung cancer is $29,184; for female breast cancer, $50,448; for prostate cancer, $48,684; for colorectal cancer, $51,865 (Riley, Potosky, Lubitz, & Kessler, 1995). Estimates of costs for specific diagnoses are complicated by ongoing methodological refinements (Brown, Riley, Potosky, & Etzioni, 1999; Etzioni, Riley, Ramsey, & Brown, 2002, Hogan, Lunney, Gabel, & Lynn, 2001), but current estimates of annual total Medicare expenditures or average individual expenditures on cancer do not appear to be available.

The 2000 Census found 35 million persons age 65 and older, and indicates that this elder population has grown rapidly and become more diverse. Continued increases in the US population of elders of color are anticipated based on the growing diversity of younger cohorts. The current federal race categories are white, African American, Asian American, Native Hawaiian/Other Pacific Islander (NHOPI), and American Indian/Alaskan Native. Moreover, Hispanic/Latinos are included as a separate category that cuts across racial groups. It is, however, difficult to accurately assess the population growth for elders of color between 1990 and 2000, because of R/E classification and other changes for the 2000 count. Among these were the placement of the "Hispanic" question prior to the "Race" question, splitting the Asian/Pacific Islander groups into Asian and NHOPI, and the multiple race option. Despite the challenges in assessing the actual growth of elders of color in the US, demographic projections show, for example, that Latino elders will make up almost 20% of the elderly population by 2050 (Day, 1996).

The burden of cancer is not borne equally across this diverse land, although the patterns of disproportionate impact vary by cancer site. Whereas 7.5% of White males will develop cancer between the ages of 60 and 79, 9.1% of Black males will develop cancer.[1] From age 70 to 79, 13.9% of whites versus 15.3% of Blacks will develop cancer. For females the burden is reversed, with white females from 60-79 developing cancer at greater rates than Black females (Mariotto et al., 2002). Although older Black females develop cancer at lower rates than their white counterparts, Black survival rates are significantly lower. Five year relative survival rates for African-American males are also lower. Five-year survival rates for white males, ages 65-74, are 66.7%, for African-Americans of the same age, 61.8%. Five-year survival rates for white females, ages 65-74 are 58.9%, versus 44.2% for African-American women of the same age (NCI, 2002c).

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[1] Throughout the text, a preference has been given to reporting racial/ethnic categories using the current Census groupings and definitions. When source documents, however, use different labels or categories, the language of the source document is used.

Table 1.1 provides a broader view of racial/ethnic group differences in cancer-related mortality by summarizing Federal accumulations of state death records, on all deaths and death rates for the four cancers that are responsible for the greater share of all cancer mortality: lung, colorectal, breast (female), and prostate (male). The tables report a consistent pattern: black men have the highest relative risk of dying from cancer, followed by white men, black women, and women. Men and women in Latino, AI/AN, and API groups have much lower rates of cancer, although they may still experience lower survival rates. Since these numbers are age-adjusted to the 1970 population standard they may overstate group differences. A focus on the largest causes of death among African Americans and whites, however, may mask other R/E disparities. For example, stomach and liver cancer among Asian Americans, colorectal cancer among Alaskan Natives, and colon and cervical cancer among Hispanic and Vietnamese-American women are notably higher than in other groups (Haynes & Smedley, 1999). For Korean men, stomach cancer replaced prostate as the most frequently diagnosed cancer, and for Vietnamese men liver cancer replaced colorectal as one of the most frequently diagnosed cancers. Stomach cancer among Korean men (48.9 per 100,000) and liver cancer rates among Vietnamese men (41.8 per 100,000) were higher than those for any other racial or ethnic group (Parker, Davis, Wingo, Ries, & Heath, 1998). Cancer rates for Native Americans living in urban environments are experiencing increases in cancer rates whereas whites are experiencing declines in prevalence (Forquera, 2001).

Nonetheless, cancer and R/E differences observed in death records and SEER data must be viewed with caution, since both sources may underestimate mortality for Latino, AI/AN, Asian, and NHOPI populations because of inaccurate or missing coding of R/E group (Blustein, 1994; Izquierdo and Schoenbach, 2000, Becker, Bettles, Lapidus, Campo, Johnson, Shipley and Robertson, 2002). Further, the SEER data may not be fully representative of the health care experiences of persons of color in the United States because it is based on selected service areas. For example, 69% of the Hispanic SEER program population lives in California, and Mexican-Americans account for the majority of the Hispanic population in that area. Current representation for SEER of African-Americans in rural areas is limited primarily to the 10 rural counties in Georgia. Although new SEER sites and upgraded state registries are starting to come on line, available data is still subject to prior concerns (Haynes & Smedley, 1999). Furthermore, there are gaps in the secondary data that make it difficult to cross-tabulate incidence, prevalence, and mortality by race and age for specific sites. These issues are expected to become more vexing issues as other portions of the Federal government adopt the racial/ethnic categorization schemes being used to analyze R/E data from Census 2000.

C: Reports on Cancer, Race/Ethnicity, and Preventive Care

Four recent reports have focused new attention on health disparities and potential Medicare initiatives. These reports have underscored the potential for individual responsibility (for patients and practitioners), organizational initiatives, and public policy to address cancer care and health outcome R/E disparities.

1. <u>The Unequal Burden of Cancer (Haynes and Smedley, 2000):</u> This 1999 assessment of NIH research and programs for ethnic minorities and the medically underserved highlighted the broad differences by R/E and socio-economic groups in cancer prevalence, morbidity, survivorship, and quality of life. The report recommends a shift in research focus to socially defined ethnicity and its correlates rather than race as a biological construct and the need for new research on behavioral interventions to manage risks for cancer across R/E and socio-economic groups. Another major recommendation was for CMS to participate in clinical trials that address the additional diagnostic and therapeutics costs associated with prevention trials.

Table 1.1. Number of deaths and death rate by type of cancer, sex, and race ethnicity-US, 1998 (rates per 100,000) (CDC, 2002)

Type of Cancer	Gender	Race	Number of Deaths	Rate per 100,000
Lung and Bronchus				
	Men		91397	65.4
		Whites	79606	64.2
		Blacks	10280	68.8
		AI/AN	325	45.3
		Hispanics	2245	28.6
	Women		63075	34.6
		Whites	58342	35.3
		Blacks	5813	34.7
		AI/AN	202	22.5
		Hispanics	1104	10.5
Colorectal	Men		28023	19.6
		Whites	24381	19.2
		Blacks	3074	26.2
		AI/AN	474	12.9
		Hispanics	1051	13.0
	Women		28950	13.7
		Whites	24936	19.2
		Blacks	3506	19.4
		AI/AN	93	9.2
		Hispanics	842	7.7
Prostate				
	Men		32203	21.5
		Whites	26416	19.6
		Black	5436	48.7
		AI/AN	80	11.3
		Hispanics	1089	14.7
Breast				
	Women		41736	22.7
		Whites	35756	22.2
		Blacks	6281	29.6
		AI/AN	120	12.0
		Hispanics	1591	14.2

Data from the National Vital Statistics System
Rates are age adjusted to the 1970 US standard million population

2. <u>Voices of a Broken System: Real People, Real Problems: (Freeman and Reuben, 2001)</u>: The 2000-2001 report from the President's Cancer Panel drew upon evidence reviews and testimony by diverse individuals around the country. The report concludes that "most people in American receive neither the most appropriate care when faced with a cancer diagnosis, nor adequate cancer prevention and detection services" (p.1). The findings point to several determinants of inadequate access to cancer control services for many, including system of care barriers such as fragmentation of providers and limitations on benefits, financial barriers even for those with Medicare, and lack of accessibility of care for rural residents. Among the recommendations of this report are: immediate medical coverage for uninsured persons upon a diagnosis of cancer to ensure that no person with disease goes untreated; insurance coverage for anti-cancer agents and supportive medications regardless of method of administration; and reimbursement for non-physician personnel to assist with cancer screening and case management.

3. <u>Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care (Smedley, Stith, and Nelson, 2002)</u>: The Institute of Medicine's Board on Health Sciences Policy reviewed literature and commissioned expert analyses to understand how racial and ethnic minorities tend to receive lower quality health services even when insurance-status, income and other access-related factors are controlled. The report considers how clinical encounters and the contexts in which these encounters occur can result in less than standard care. The study emphasizes the roles of Medicare and Medicaid financing and administrative systems in increasing access barriers while decreasing practitioner incentives for appropriate care for persons who rely primarily on public insurance. The report calls for numerous changes at multiple levels to address this problem, including: equal-access to high-quality financing and delivery plans that limit fragmentation, encourage stronger doctor-patient relationships and encourage more stable patient-provider relationships in publicly-funded programs, enhanced financial support for interpreter services, and reimbursement for community health workers

4. <u>Reducing Disparities in Health Outcomes: Effective and Promising Outpatient Interventions with Underserved Populations (Center for Health Care Quality, 2002).</u> As part of the CMS and Medicare Quality Improvement Organizations' (QIO) efforts to improve care quality and address health disparities for Medicare beneficiaries, this compendium report highlights health promotion interventions that have the potential to reduce health disparities. Among the 33 published studies reviewed were 12 breast (and cervical) cancer control projects. Several features of potentially effective programs noted in this review were: being evidence-based, formative approach leading to socio-cultural relevance, grass roots outreach, community advisory boards and partnerships, community health workers, small group educational approaches, physician engagement, and avoidance of attrition. The report recommends that all quality improvement efforts aimed at underserved Medicare recipients build on the experiences of these programs.

In addition to these studies, the project also drew upon several major evidence review activities. First, the CMS Healthy Aging project that already completed comprehensive meta-analyses of interventions to support smoking cessation, interventions to increase use of selected Medicare preventive services (including breast, cervical, and colon cancer screening), and health risk assessment. Though these assessments of the literature do not focus exclusively on elders of color, they underscore the dearth of studies focused on special populations among the elders. The preventive services report concludes that service use can be stimulated by health care organizations making changes in staffing and clinical procedures and by encouraging patient self-management through financial incentives and reminders. Because of the broad and inclusive approach adopted by the Healthy Aging project, it was possible for this effort to draw upon its primary findings and the specific source materials identified. Second, the Institute on Medicine's has lead a review of prevention strategies from the social and behavioral sciences (Smedley and Syme, 2000) while the Task Force on Community Preventive Services (TFCPS) is conducting systematic review of community preventive services (Zaza et al, 2000; Carande-Kulis et al, 2000). Both initiatives have provided important perspectives on consensus assessments of the efficacy of specific preventive services and the characteristics of effective approaches.

D: Conceptual Frameworks

An impressive body of literature and practice experiences has demonstrated broad disparities in cancer prevention, treatment, and health outcomes across racial/ethnic and socio-economic status groups in the United States. Social and medical researchers have offered at least five sets of explanations for health disparities (Smith, 1998):

- Individual/Cultural Factors: Cultural norms within R/E groups may lead individuals to adopt a range of health-related beliefs and behaviors that increase their risks of disease and reduce appropriate use of health services (Suarez, 1994; Thomas et al, 1996). R/E groups also differ in education, income, wealth and other socio-economic factors that influence how individuals participate in disease prevention and self-care activities as well as use of screening and treatment services.
- Practitioner Factors: Physicians and other health care practitioners may lack adequate cultural competence or face other barriers to addressing the care needs of R/E populations (Hannan et al, 1999; Hawley et al, 2000). Speaking in a second language or using interpreter services may limit their effectiveness (Kravitz et al, 2000).
- Provider-organization Factors: Health care provider organizations may not adopt care delivery and quality assurance systems that are responsive to R/E differences in health needs and use patterns. Providers serving low-income communities may lack adequate resources, operational systems, and inter-agency linkages to ensure continuity of care.
- System of Care/Financing Factors: Some preventive and treatment services may not be covered, available, or accessible to R/E minorities (Potosky et al, 1998; Schoen et al, 1997). Health care financing and quality assurance systems may

not provide adequate information, incentives/sanctions, or reimbursement to promote targeting services to R/E minorities. Barriers to health care professional entry for R/E group members and lacunae in biological and medical care research may have limited the development of prevention/treatment options with optimal impacts on R/E group members.

- Community Factors: The physical and social environments faced by R/E groups may include specific health risks (pollution, marketing of potential harmful products). Formal and informal organizations within these communities may lack resources or interest to support individual and institutional health promoting activities.
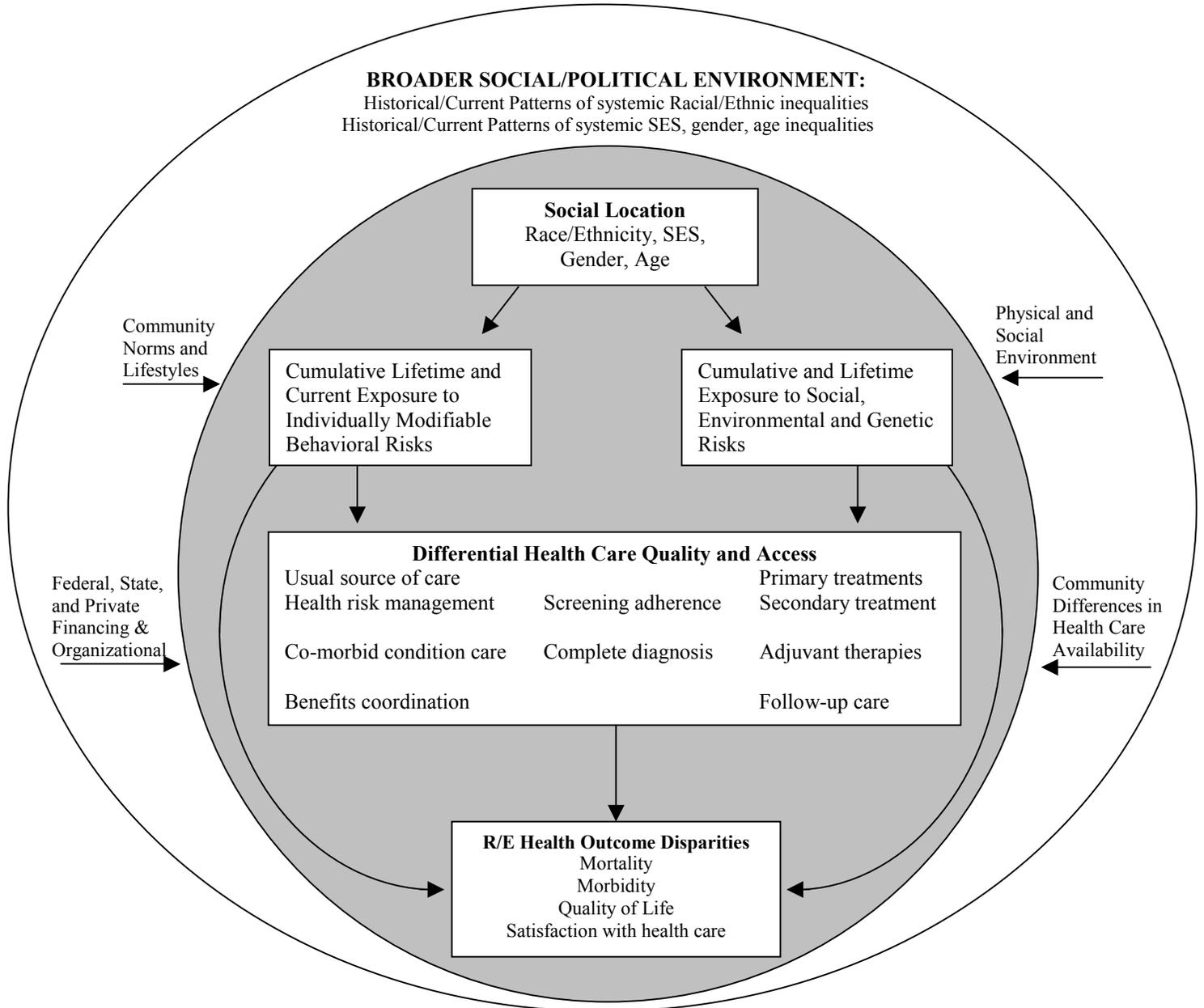
An emerging consensus notes that these potential determinants of health inequalities are inter-related and parts of larger social processes that extend well beyond health care (Mutaner, 1999).

While these dimensions are useful in identifying potential determinants of health and health care disparities, they do not highlight where Medicare demonstrations or program enhancements might most cost-effectively reduce racial/ethnic disparities in elder cancer and health outcomes and cancer-related service use. Figure 1-1 suggests a conceptual model of health care disparities and health disparities that seeks to distinguish components potentially influenced by Medicare policies. The Figure suggests six key concepts that guided the evidence review and development of recommendations:

1) Race/Ethnicity References Social and Contextual Variables: An emerging consensus emphasizes the ways in which racial/ethnic categories are socially constructed and historically specific. These categories have come to be associated with patterns of health, social-psychological, economic and political inequalities created and maintained through culture, institutions, interpersonal behavior, and personal beliefs and attitudes. Bonilla-Silva and others have described this process as "racialization." Average life chances –the typical amount and quality of life— have come to vary by racial/ethnic groups in our society. Individual Medicare beneficiaries who are of African, Latino, American-Indian/Alaskan Native, Asian, or Native Hawaiian and Other Pacific Islander descent have already experienced full lives that have been at least partially shaped by their groups' experiences of inequalities.

2) Race/Ethnicity and other Social Factors are Linked: It has not been possible for modern health and social research to fully disentangle the influences of racial/ethnic group membership and other indicators of social location such as gender, age, education, socio-economic status (SES), and rural residence for individual Medicare beneficiaries. Each of these other social location factors is also associated with gradients in life chances –and each beneficiary currently experiences and has already experienced a lifetime of unique combinations of these influences (Capitman, 2002). Rather than debating the relative importance of race/ethnicity and other social and economic determinants of health and health

care use, the focus can shift to identifying how these factors together influence care targeting, processes and outcomes.

3) <u>Race/Ethnicity and Other Social Factors Are Associated with Lifetime Exposure to Behavioral and Contextual/Genetic Risks.</u> For Medicare beneficiaries, racial/ethnic group and social factors at least in part determine both current and cumulative lifetime exposures to potential self-injurious behaviors and lifestyles (poor diet, physical inactivity, tobacco use, alcohol use, and lack of insurance or usual source of care). In the same way, socially defined race/ethnicity and other

BROADER SOCIAL/POLITICAL ENVIRONMENT:
Historical/Current Patterns of systemic Racial/Ethnic inequalities
Historical/Current Patterns of systemic SES, gender, age inequalities

Social Location
Race/Ethnicity, SES,
Gender, Age

Community Norms and Lifestyles

Physical and Social Environment

Cumulative Lifetime and Current Exposure to Individually Modifiable Behavioral Risks

Cumulative and Lifetime Exposure to Social, Environmental and Genetic Risks

Federal, State, and Private Financing & Organizational

Community Differences in Health Care Availability

Differential Health Care Quality and Access

Usual source of care		Primary treatments
Health risk management	Screening adherence	Secondary treatment
Co-morbid condition care	Complete diagnosis	Adjuvant therapies
Benefits coordination		Follow-up care

R/E Health Outcome Disparities
Mortality
Morbidity
Quality of Life
Satisfaction with health care

Figure 1: Racial/Ethnic Cancer Disparities

social factors are at least partially correlated with a host of individual exposures to context features, such as environmental pollutants, occupational exposures, and food additives. Socially defined R/E groups and groups defined by other social factors are largely heterogeneous by most biological measures.

Nonetheless, emerging genetic research has suggested that socially defined R/E and other social factors are sometimes correlated with genetic features and /or tumor characteristics that directly or through contextual interaction considerably increase the risk or severity of certain cancers (Jackson, 2002). At this point, there is insufficient research on the population distribution of genetic and tumor characteristics features or their interaction with other contextual factors to derive clear policy and practice implications. This study neither sought to evaluate current literature on cancer genetics in general, nor the specific evidence for association between socially defined R/E group, other social group membership, and genetic markers of increased risk for cancer or cancer severity, although related initiatives when clear findings have been noted.

4) <u>Behavioral and Contextual/Genetic Risks May Influence Health Outcome Disparities:</u> Differences by racial/ethnic group in average all-cause and cancer-specific mortality morbidity, as well as health-related quality of life and satisfaction with health care have been documented. To some extent, these health outcome disparities are shaped by current and cumulative lifetime exposure to behavioral and contextual/genetic risks and are not mediated by the current health care system. Current data are inadequate to assess the independent effects of behavioral, genetic and contextual risks from those that are mediated by the health system. This report does not assume that elimination of R/E health care disparities are in the short run sufficient to eliminate all R/E disparities in disease incidence and health outcomes.

5) <u>Current Health Care Disparities Also Influence Health Disparities</u>: There is adequate evidence that cancer treatments and modification of risk factors through the provision of health care services financed through Medicare and other payers does appear to influence health outcomes for elders. There is mounting evidence of unequal use of Medicare-reimbursed health care experiences across racial/ethnic and other socially defined groups after controlling for appropriateness of care (Shavers and Brown, 2002; Bach et al, 2002). Many factors largely outside of Medicare influence may also influence these patterns such as: availability of health care professionals who are members of R/E groups, cultural/racial attitudes of white health care professionals, mal-distribution of health care resources, safety net social service availability. This project sought to understand the particular health care disparities that influence cancer health disparities for older people and that Medicare might influence.

6) <u>Health Care Disparities Care Arise in Each Phase of the Cancer Prevention and Treatment Process:</u> The health care system and health service delivery are complex and they offer multiple opportunities to increase or decrease the
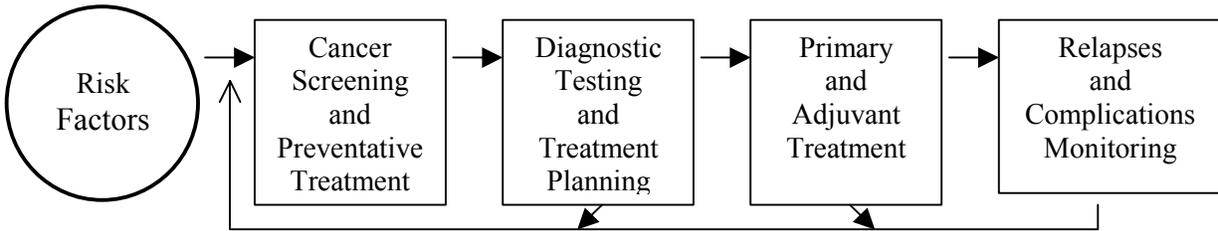
likelihood of appropriate service use and positive health outcomes. With respect to cancer, health care delivery occurs in multiple phases from prevention through treatment. Health care disparities may occur with respect to health risk management, benefit coordination, screening adherence management, appropriate diagnostic procedures and timely diagnosis, primary treatments (such as surgery), secondary treatments (radiotherapy) and adjuvant treatments, and follow-up/relapse monitoring. The report assumes that there is a potential to both increase equitable access to appropriate care across R/E groups and reduce health care disparities at each phase in the prevention-detection-treatment -follow-up process. As such, the project recognized the potential for variation across cancer sites and R/E groups as to the phases in the cancer process where interventions might make the most cost-effective impact.

Guided by the framework in Figure 1-1, the evidence report attempts to stay focused on identifying opportunities for changes in Medicare policies and programs that in turn would reduce health care disparities. The report does not focus on ways that cumulative lifetime exposures for Medicare beneficiaries could be altered before they join the program, nor does it address health care service distribution, other support service availability and workforce diversity issues that are outside the scope of Medicare.

Because the cancer prevention-detection-treatment process differs at least to some extent by cancer site and the potential exists that disparities arise differentially by R/E group at any phase in this process, the study has sought to detail the process specifically for each cancer. For example, in the case of breast cancer, disparities might arise in management of health risks, screening participation, timely and correct diagnoses, primary treatment planning and delivery, secondary treatment planning and delivery, and relapse monitoring. In the case of lung or stomach cancer, by comparison, screening is not currently recommended by consensus panels or performed widely and there has been less call for secondary treatments. This difference in available treatment technology suggests the possibility of different strategies to reduce inequalities in cancer prevention, treatment, and outcome. Further, it is possible that different R/E groups among the Medicare population experience barriers to appropriate care at different phases in the process. These sequential models were refined throughout the literature review process, and an effort was made to identify the patient, practitioner, provider, system and community influences on disparities at each phase. In most cases, however, the available research did not offer consistent evidence on each of these possible explanatory factors for each R/E group.

Figure 1-2 provides an example of the basic sequential model. Taking a population perspective that includes identifiable risk factors, the model is predicated on the assumption that disparities can arise at every key decision point. For example, is the population more or less likely to be identified as being at risk? If yes, is it more or less likely to be referred for a screening test (SCR), followed potentially by diagnostic testing (DXT), treatment (TRT), potential complications (COM), and relapse monitoring (RMon) services? Table II provides illustrative examples of the kinds of risks or service activities that might be associated with each step in the process.

Figure 1-2: Basic Sequential Model

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┌──────────┐   ┌──────────────┐   ┌──────────────┐   ┌──────────────┐   ┌──────────────┐
│          │   │   Cancer     │   │  Diagnostic  │   │   Primary    │   │   Relapses   │
│   Risk   │──▶│  Screening   │──▶│   Testing    │──▶│     and      │──▶│     and      │
│  Factors │   │     and      │   │     and      │   │   Adjuvant   │   │ Complications│
│          │   │ Preventative │   │  Treatment   │   │  Treatment   │   │  Monitoring  │
│          │   │  Treatment   │   │   Planning   │   │              │   │              │
└──────────┘   └──────────────┘   └──────────────┘   └──────────────┘   └──────────────┘
```

Table1.2. Illustrative Elements by Four Cancer Types*

	Lung	Breast	Prostate	Colon
Risk Factors	➢ Smoking	➢ Family history ➢ Alcohol	➢ Family history ➢ African - American	➢ Diet ➢ Family history ➢ Polyps
Screening (SCR)	➢ X-ray	➢ BSE/CBE ➢ Mammography	➢ DRE ➢ PSA	➢ DRE ➢ FOBT
Diagnosis (DXT)	➢ Bronchoscopy ➢ Bronchial biopsy ➢ Lymph node biopsy	➢ Mammography ➢ Fine needle biopsy	➢ Fine needle biopsy ➢ MRI ➢ Bone scan	➢ Colonscopy ➢ Angiography ➢ Biopsy
Primary and Secondary Treatments (TRT)	➢ Pulmonary resection ➢ Radiation ➢ Chemotherapy	➢ Lumpectomy ➢ Modified radical mastectomy ➢ Radical mastectomy ➢ Axillary node dissection ➢ Radiation ➢ Chemotherapy	➢ Prostatectomy ➢ Radiation ➢ Orchiectomy ➢ Chemotherapy	➢ Segmental resection ➢ Partial colectomy ➢ Total colectomy ➢ Lymph node dissection ➢ Colostomy ➢ Radiation ➢ Chemotherapy
Relapse Monitoring (RMon) and Complications (COM)	➢ Re-screening ➢ Radiology studies	➢ Re-screening ➢ Mammography ➢ Hematoma	➢ Re-screening ➢ Biopsy ➢ Bone scan ➢ Incontinence ➢ Impotence	➢ Colonoscopy ➢ Radiology studies ➢ Bowel block ➢ Perforation

* Note: This table provides selected examples of the elements considered in sequential models.

Our approach to Medicare cancer disparities was shaped in two additional ways:

a) Fee-for-service Medicare Focus: Although a sizable minority of Medicare beneficiaries are members of managed care plans, most elders use fee-for-service Medicare. Because of the contractual relationships with Medicare+ Choice plans, different mechanisms would be required for altering service use

and outcome patterns for elder R/E group members than in fee-for-service Medicare. The CMS project team determined that a focus on the fee-for-service context would afford an opportunity to explore care continuity and quality assurance issues that may also need to be addressed in managed care settings in diverse community settings. Studies specifically addressing opportunities for reducing disparities in Medicare managed care plans were generally not included in the reviews.

b)   Health Care Access Focus: Two major recent review of cancer treatment studies found that with few exceptions, whites and persons of color (primarily African Americans) do not receive similar care for similar disease. But when whites and persons of color do receive similar care for similar disease they also have similar health outcomes. (Bach et al, 2002; Shavers and Brown, 2002). This implies that on average, racial/ethnic differences in cancer outcomes are more likely associated with access to quality care than with the relative efficacy of cancer diagnostic and treatment technologies across racial/ethnic groups. As a result, our primary focus has been on identifying mechanisms to create more equal rates of appropriate utilization of existing technologies and treatment protocols and not on whether and how treatment guidelines, regimens or technologies need to be adapted for multicultural applications.

E: Overview of Methods:

This evidence review was derived from two principle methods, systematic literature reviews and case studies of emerging models. More detailed descriptions of methods are provided in relevant sections of this report.

Systematic Literature Reviews:

The literature reviews were organized around five areas of potential cancer prevention (physical exercise, nutrition/weight loss, smoking, drinking and supplemental insurance/usual source of care), the cancer sites with the greatest impacts on mortality and morbidity of Medicare patients (lung, breast, cervical, colon, and prostate), and several less prevalent cancer sites associated with notable R/E disparities (stomach, oral, pancreas, and leukemia). For the behavioral risk factors, evidence was sought for R/E differences in elder and lifetime exposure, interventions to change behavior among R/E elders, interventions to change behavior among R/E adult populations, and interventions to change behavior in elder populations. In this context, behavior change interventions with elders of color that included quantitative measures of impact in a controlled design were highlighted. Because there were few appropriate studies, we examined prior reviews and original papers that offered hints on effective program components for elders of color based on research with other population groups. For the major cancers and less prevalent sites, evidence was sought for R/E differences in prevalence, incidence, severity of disease, established risk factors and survival, R/E differences in risk factors, consensus on screening, diagnostic and treatment approaches, R/E differences in use of screening,

timely diagnosis, treatments, and interventions to reduce R/E differences in screening, timely diagnosis, and treatment. Literature on relapse monitoring and quality of life/survivorship issues that addressed R/E disparities was not reviewed in most cases.

For both prevention and cancer site reviews, literature was identified using multiple strategies, including: electronic data base searches in Medline, PsychLit, CancerLit, Web of Science and Cochrane group reviews; backwards searching using Social Science Citations index to identify studies that had cited relevant papers; manual review of bibliographies in relevant papers; search of selected government and private websites; search in NCI, AHRQ and other Federal cancer and related funded project data bases; recommendations of consultant experts on each topic; and reports identified by screening interview/case study participants. The study focused on identifying published studies and widely disseminated reports, but in several cases, unpublished reports cited in prior reviews were obtained. In all cases, after review of abstracts suggested relevance to the project, full text articles were obtained and reviewed. In those few cases where sufficient numbers and consistency of available studies could support quantitative syntheses, standardized effect sizes were computed and assessments of heterogeneity of effect and potential moderator variables were performed.

Analysis of 2000 NHIS

In addition to these activities, an analysis of the unweighted results of the NCHS 2000 National Health Interview Survey was performed to provide more current data on R/E group membership, behavioral risk factors, and self-reported screening participation. These analyses were complemented by systematic reviews of evidence for R/E differences in supplemental insurance, usual source of care, and the implications of these factors for preventive and screening service use. A series of interviews with Indian Health Service and other AI/AN population experts explored the intersections of Medicare fee-for-service programming with the financing and delivery of health care for these groups.

Case Studies of Emerging Models

It seemed likely that many potentially efficacious and effective interventions to reduce R/E disparities in cancer care and outcomes for Medicare beneficiaries are currently operational and not yet the subject of published reports. Further, published studies on many interventions do not provide sufficient operational and organizational detail to address demonstration design and implementation questions. For these reasons, the study drew on multiple sources to identify emerging models for increasing participation of elders of color in cancer prevention and screening activities and/or increasing their access to appropriate and timely diagnostic, treatment and follow-up services. Outreach to multiple sources, including: federal agencies and federally-sponsored programs, health payer/delivery systems organizations, R/E identity and professional organizations, conference proceedings, foundation initiated programs, cancer centers, and mass distribution of requests for referrals were all used to identify these programs. Screening interviews were conducted with 115 programs. Based on these

interviews, an intentional heterogeneity sample of 25 sites was selected for case studies. Case studies were tailored to each site and were conducted by two-person teams that included an expert in cost-effectiveness issues. The case studies generally addressed questions such as: program history and theory of intervention, organizational and financing issues, perceptions of sources of disparities, intervention design and operations, measurement of program costs and outcomes, and findings with regard to volume of services and impacts. Not all case study sites could provide data on all issues. Case study reports were developed and reviewed by subject representatives. Qualitative analyses sought learnings in each of the intervention design, operational and organizational topics, while available cost and impact data were used to develop a model for cost-finding and cost-effectiveness evaluation.

F: Organization of the Report and Major Findings:

The remainder of the report is organized in four major sections.

Chapter II: Cancer Risk Factors and Prevention Strategies for Elders of Color: Chapter II focuses on major health related behavioral, R/E differences in these behaviors among elders, the relevance of these risk factors to specific cancers, and interventions to alter risk behaviors in elders of color. The Chapter finds strong evidence from epidemiological studies for the importance of behavioral risks in cancer etiology and severity but almost no experimental evidence that altering behaviors influence cancer rates or outcomes (because of temporal censoring and other challenges for such studies). Nonetheless, because there is evidence that behavioral risks can also influence both co-morbid conditions and treatment outcomes, it seems likely that some R/E disparities in cancer and health can be alleviated by increasing engagement of elders of color in management of behavioral risks and other modifiable determinants of health. Further the Chapter reports almost no examples of proven behavior change strategies for R/E elders and real difficulties in engaging such persons on behavior change. But there is sufficient evidence from studies with general aged populations and nonelderly adults of color populations to suggest that elders of color could be engaged in a broad array of effective behavior change activities. Features of successful behavior change programming are described. Recommendations in this chapter focus on culturally tailored strategies (use of adapted materials, motivational interviewing, use of promotoras de salud/community health workers, connection to both health system and community) for increasing elder of color engagement in health risk management.

Chapter III: Racial/Ethnic Disparities in Cancer Treatment and Outcomes: The study examines evidence for R/E disparities in receipt of appropriate screening, diagnostic, and treatment services as well as any evidence for interventions to address these gaps. In this context, strong differences across cancers in consensual views of appropriate screening, diagnostic, and treatment services are highlighted. In the context of prostate cancer, for example, the available research on screening and treatment indicates that informed individual decision-making rather than service use may be the most appropriate measure of care quality in assessing disparities, while in the case of colorectal cancer there is agreement about the need to increase use of several alternative

screening strategies and treatment regimens, but less consensus on screening protocols and timing. The review found extensive evidence for each of the cancers for Medicare R/E differences in use of these services. The Chapter identifies evidence for factors at the individual, practitioner, financing, and service organization levels as potential causes of these differences in service use. Evidence for culturally tailored interventions for Medicare beneficiaries with respect to service use for most cancers was largely unavailable, and efforts to facilitate efficient progress through the phases of cancer treatment subsequent to suspicious screening results were generally not found. Nonetheless, an impressive set of studies that explored the use of promotoras/lay health workers and culturally-adapted/translated materials in breast and cervical cancer education and screening adherence management was identified. Meta-analysis indicated significant heterogeneity in intervention effects using these approaches, but models that focused more on in-reach to an existing patient cohort rather than broad outreach to the population, use of multiple intervention strategies along with CHWs, and a focus on screening adherence were all associated with stronger program impacts. Recommendations from this Chapter emphasize the potential for Medicare to increase adherence to screening guidelines, facilitate completion of diagnostic work-ups and treatment planning, and facilitate completion of appropriate primary and secondary treatments through the use of community health workers and improved care management information strategies.

Chapter IV: Emerging Interventions to Reduce Racial/Ethnic Disparities in Cancer and Health: In Chapter IV, the approach to identifying and collecting data on emerging models and findings from 25 case studies are reported. The case study sites are based in diverse organizational settings and have often been hampered by the demands of grant funding and research requirements. The programs address R/E cancer disparities by focusing on health risk management, screening education, screening adherence, and treatment management. All of the programs culturally tailored the interventions as a strategy for overcoming barriers, whether attitudinal or systemic. Although programs used a variety of mechanisms for cultural tailoring, perhaps the most striking finding from the case studies was the predominance of the community health worker role as the primary mechanism for cultural tailoring. Most case study sites utilized promotoras de salud/community health workers, but they were diverse with respect to use of volunteer or staff positions for this role, experiences with recruitment and retention of these workers, training and supervision procedures/resource requirements, and relationships of the community health worker with the health care team. The Chapter indicates that while lay health workers are now viewed as an essential strategy for engaging elders of color in appropriate cancer care, that there is a tremendous opportunity to shape new expectations for the roles played by these workers and increase their effectiveness in influencing service use. In addition, programs that incorporated a management information system and decision-making support seemed to be effective in ensuring that community members, once motivated, actually received the services they required. Our findings suggest that combination interventions hold the greatest promise for addressing the disconnect between communities and the health system that programs perceived as playing a key role in R/E disparities in cancer control. An appendix contains summaries of each of the case studies.

Chapter V: Medicare Demonstrations To Reduce Racial/Ethnic Cancer and Health Disparities: Recommended Models and Issues in Assessing Cost-Effectiveness: Chapter V continues the analysis of the case study findings by reviewing evidence obtained on costs of training CHWs, salaries and other costs associated with their efforts, and the volume and potential impacts of their efforts. Based on these findings, the Chapter outlines three possible Medicare demonstration services: health risk management (HRM), screening adherence and detection facilitation (SADF), and treatment and follow-up facilitation (TAFF). It details issues in assessing the costs, intermediate process of care and longer-term health and cost-effectiveness outcomes associated with each of these services. The Chapter addresses three goals: 1) Summarizing and assessing evidence from the case studies on the costs and cost-effectiveness of community health workers; 2) Proposing model roles for community health workers and associated systemic supports that might be explored in a Medicare demonstration to reduce racial/ethnic cancer and health disparities; and 3) Developing a framework for assessing the immediate and longer-term cost-effectiveness of these three new services under Medicare.

Chapter II: Cancer Risk Factors and Prevention Strategies for Elders of Color

Increasingly, cancer prevention has come to include assessment of risk factors, including potentially modifiable behavioral mediators such as smoking, excessive alcohol consumption, lack of adequate physical activity, nutrition and diet, overweight, and lack of a source of usual care. Causal pathways and the direct and interactive effects of environmental and behavioral factors with genetic or other biological factors in initiation, progression, and reversal of carcinogenesis are less clear for specific anatomical sites. Prevalence of potentially modifiable behavioral risk factors varies by racial/ethnic (R/E) group. These differences may have an influence on cancer incidence rates. Interventions for risk factors exist and are offered and used differentially by R/E, age, gender and SES groups as well. Thus, it is important to assess what is known about differentials in modifiable risk factors, efficacy of and utilization of interventions to address lifestyle and other behaviors, and applicability of interventions to for elders of color. This chapter focuses on major health-related behavioral risks, R/E differences in these behaviors among elders, the relevance of these risk factors to specific cancers, and interventions to alter risk behaviors in such elders.

This Chapter will explore three related questions:

(1)   Among elders, do R/E groups differ in modifiable risk behaviors?
(2)   Is there evidence that potentially modifiable behavioral risk factors are associated with cancer for elders in traditionally underserved R/E groups?
(3)   Is there evidence to support the effectiveness of behavioral interventions addressing physical activity, nutrition, body mass, tobacco use, and alcohol use with these elders?

To address these questions, new analyses of the 2000 NHIS and reviews of literature on risk factors for cancers of the breast, cervix, prostate, lung, stomach, oral cavity and pancreas, and leukemia were performed. In addition, we conducted systematic reviews of interventions to reduce behavioral risks in elders of color and also explored published reviews and meta-analyses of behavioral interventions with the general adult and aged population, and R/E adults.

It has been 20 years since McKeown noted, "The role of individual medical care in preventing sickness and premature death is secondary to that of other influences; yet society's investment in health care is based on the premise that it is the major determinant. It is assumed that we are ill and made well, but it is nearer the truth that we are well and made ill..." (McKeown, 1979). The important role of prevention is better recognized among younger patient populations and in the context of infectious disease. The role of prevention is considered almost paradoxical in older adults and chronic disease, because of the presumed cumulative negative effect of years of risky behavior. However, there is growing epidemiological and experimental evidence that prevention activities can have beneficial health effects along the continuum of aging, as well as in

the presence of chronic disease. Smoking cessation, physical activity and exercise, a healthy diet, and alcohol use cessation or moderation have all been shown to be associated with improved cardiovascular and respiratory health as well as improved quality of life. Notwithstanding this emerging consensus, the care our health systems provide to older adults focuses primarily on the management of acute illness and acute exacerbations of chronic disease rather than on health promotion. The negative consequences of this approach are particularly apparent among R/E elders, because health financing and delivery system, provider organization, practitioner, and individual factors combine to create barriers to engagement and maintenance of lifestyle change.

While smoking cessation, increased physical activity, weight management, and dietary changes have all been associated with health and quality of life improvements and better response to health care interventions, including those for some cancers, there is no empirical evidence that lifestyle and behavior change at a later stage in life will result in a change in cancer incidence. For example, by raising surgical risks associated with smoking and obesity, these lifestyle factors can affect recovery and survival post-surgery. Further, Chapter III provides numerous examples of evidence for the argument recently posed by Bach et al (2002) that differentials in cancer survival that cannot be attributed to access to care or quality/completeness of care, can be attributed to R/E differences in co-morbid conditions. Therefore, the focus in this review was on these potentially modifiable factors.

A: Evidence That There Are Racial/Ethnic Differences In Major Behavioral Risks

Since the connection between lifestyle factors and cancer is recognized although not always understood, it is important to determine whether there are differences in the prevalence of behavioral risks across R/E groups. To explore this further, we conducted an analysis of the public use files of the 1999/2000 National Health Interview Survey (NHIS) and Cancer Control Supplement. The analysis selected only respondents age 65 or older and classified them by R/E groups---Hispanic of any racial group, African American or other African descent (AA), American Indian/Alaskan Native (AI/AN), Asian, Other. Both the Asian and Other categories were heterogeneous and included some persons of Native Hawaiian and Other Pacific Island heritage, since the public use NHIS 1999/2000 data do not currently support use of the Census 2000 racial categories. Further, since the "other" sample size was so small for elders, it was dropped from the analysis presented. With un-weighted data, we crosstabulated R/E groups with selected modifiable risk behavior variables. Table 2.1 shows that risky behaviors appear to differ by R/E group. Where sample sizes permitted, gender differences in smoking with R/E groups were also examined, although these are not shown in the table. Only those group differences that were statistically significant at the $p < .05$ level in one-way analyses of variance are highlighted in the following discussion. A caveat is that this reflects current behavior rather than cumulative lifetime exposure. It seems likely that the incidence of cancer is influenced by lifetime behavior, even if cancer progression and response to

treatment are influenced by current behavior. No current methods or data to assess lifetime exposures have been identified, and thus current rates of smoking may not accurately reflect smoking-related risks for lung cancer.

Physical activity: AI/AN elders were least likely to report participation in moderate physical activity, and Asians were most likely. Men were somewhat more likely than women to be active in all groups. In the table, moderate physical activity was measured as "at least once a week" which is considerably less than recommended levels. But the R/E group patterns reflected here remained when other measures physical activity frequency were used, although the proportions reporting higher levels of physical activity were very low in all groups. Across all R/E groups, notably small proportions of elders engaged in daily moderate exercise, the level that may be required for positive effect. These patterns are also reflected in other studies. For example, in a national survey of 2912 US women aged 40 and older from various racial/ethnic groups, over half the sample were currently in regular exercise, 25% in the pre-contemplative stage, and 15% in the contemplative stage (Seefeldt et al, 2002). AA women were significantly less likely to be in the active stage even when age, BMI, education and smoking were controlled.

Obesity: Rates of being overweight were highest among AI/AN and AA, and lowest among Asians. Since weight, diet and exercise are related, this may be a reflection of dietary practices and genetic influences on metabolism. In all groups, but especially among Hispanic, AA, and AI/AN elders, women were more likely to be overweight than men. Similarly, according to information collected through the BRFSS in 1997, over one-quarter of AA, and AI/AN women were obese (Bolen, Rhodes, Powell-Griner, Bland, & Holtzman, 2000).

Table 2.1
Modifiable risk factors by Race (NHIS 1999/2000. Persons age65 and over)

	White	AA	AI/AN	Asian	Hispanic	Total
Sample Size (N)	4807	696	16	71	573	6180
Gender (% Female)	62.68%	64.66%	56.25%	52.52%	59.34%	62.39%
Smoking	10.1%	12.6%	6.3%	7.0%	9.8%	10.3%
Moderate physical activity (1+/week)	46.7%	27.2%	6.3%	63.4%	33.2%	43.4%
>20% Overweight	32.4%	45.4%	56.3%	5.6%	34.6%	33.8%
Current Drinker	42.5%	22.3%	31.3%	28.2%	31.1%	39.0%
Source of sick care						
Clinic/health center	10.6%	13.9%	18.8%	9.9%	18.3%	11.7%
Doctor office/ HMO	82.7%	72.7%	68.8%	84.5%	69.8%	80.3%
Could not afford prescription drugs in last 12 months	3.7%	7.9%	6.3%	4.2%	5.6%	4.3%
Spoken to doctor in last 12 months	92.3%	90.8%	81.3%	94.4%	89.2%	91.9%

Tobacco use: In NHIS as in other surveys, AA elders reported the highest rate of tobacco use and Asian, AI/AN had the lowest rates. The pattern of smoking among younger AI/AN cohorts suggests that this pattern may be changing. Across all R/E groups, male elders are more likely to smoke than females, and this is especially true for the diverse Hispanic populations, where older men have among the highest smoking levels while older women have among the lowest.

R/E group differences in smoking may be more complex than indicated by the NHIS analysis. A growing literature indicates that among women, there are R/E, age, education or SES interactions in determining smoking patterns. For example, in one study (MacDowell, Guo, & Short, 2002) using the 1998 Ohio Family Health Survey, the authors assessed health behaviors and health of college educated and non-college educated African American and white women. Over 9000 women were telephone surveyed using a random digit method that included oversampling of women of color and low SES. The authors found that college educated AA women were less likely to have smoked over 100 cigarettes in their life time as compared with non-college educated AA women ($p < .05$). However, amongst women who smoked over 100 cigarettes during their lifetime, current rates of smoking were higher among college educated than non-college educated AA women ($p < .05$).

Alcohol use: White elders in the NHIS were most likely to report being current drinkers, and African-Americans were least likely to be so. These results do not adequately account for quantity and frequency of alcohol use or other life problems associated with drinking. If there are no good studies documenting this, cite them. Otherwise it will be seen as week anecdotal evidence and should be left out or cited in the Site Visit section.

The estimated prevalence of problem drinking among non-institutionalized elders ranges from one to 15 percent (Barry et al, 2001). Prevalence estimates of problem drinking for elders who are either hospitalized or in nursing homes are higher, ranging from 15 to 44 percent (Widner & Zeichner, 1991; Kennedy et al, 1999; Johnson, 2000). Several studies note the appearance of a significant decline in the overall consumption and the abuse of alcohol among elders as they grow older (Finlayson & Hurt, 1998; Johnson 2000). Yet there is little agreement as to why this decline occurs. Some reasons offered for the wide range of prevalence estimates and the decline in alcohol consumption as people get older include: 1) elders do not disclose the amount that they drink because of fears of stigma (Bercsi, et al., 1993: Blow, 1998; Zucker, 1998; Johnson, 2000); 2) health care providers fail to recognize problem drinking habits (Adams et al., 1993; Coniligiara et al, 2000; Barry, Oslin, & Blow, 2001); and 3) physiological changes associated with aging make drinking less enjoyable (Finlayson & Hurt, 1998). Lack of standard metrics and definitions for the terms alcohol dependence, alcohol abuse, alcoholism and problem drinking are also problems with this research.

There is a growing literature describing low income and underserved R/E group elder drinking patterns in both institutional (Booth et al., 1992) and community settings (Gomberg & Nelson, 1995; Bucholz et al, 1995; Jackson, Williams, & Gomberg, 1998;

Gomberg, 1999). All report R/E group differences in alcohol consumption (with non-white elders having higher prevalence rates of lifetime problem drinking and alcohol disorders) and corresponding adverse alcohol related health consequences. For example, in their review of epidemiological studies, Bucholz et al., (1995) note that in general AA elders were less likely to be drinkers than their White peers. However, the lifetime prevalence of alcohol dependence among AA male elders was much higher (21.6 %) than white male elders (12.5%). In a similar review, Jackson, et al., (1998) report AA male elders have much higher lifetime prevalence of alcohol disorders (24%) compared to White male elders (13%). In a small study (n= 169) examining the consequences of such lifetime abusive drinking patterns, Gomberg and Nelson (1995) report that AA male elders (69.6%) have significantly (p <.05) more self-reported alcohol-related health problems than their White peers (41.7%). In one of the few published studies to include Latino and Asian elders as comparison groups (Lubben, et al 1989), there do not appear to be significant differences between Latino elders and Whites in either current or lifetime drinking patterns. However, Asian elders were less likely to have either a history of drinking or be current drinkers than either their AA, Latino or white peers (Lubben et al, 1989).

Usual Source of Care: These NHIS data point to a number of important, inter-related patterns in health care insurance coverage, access to care, and receipt of health promotion and cancer detection services. Among Medicare beneficiaries race and ethnicity are closely associated with having received preventive services and cancer screenings. People of color are more likely to report delaying care because of cost, less likely to have private supplemental Medicare coverage, less likely to have a usual source of care, and as a result, are less likely to receive preventive treatments. For example, Dunlop et al examined the effect of economic access barriers on the 2 – year utilization of 6512 men and women of Hispanic, African American, and White ethnic/racial groups aged 70 or older using longitudinal data from the Asset and Health Dynamics Among the Oldest Old (AHEAD) survey (Dunlop et al, 2002). They found significant gender and R/E disparities in the use of physician, hospital, outpatient, home health, and nursing home care, with adjustment for economic access factors doing little to reduce these disparities. Compared with non-Hispanic White men and controlling for predisposing factors and measures of need, African American men had significantly fewer contact with physicians, minority and non-Hispanic White women used fewer hospital or outpatient surgery services, minority men used less outpatient surgery, and Hispanic women were less likely to use nursing home care. Ease of access to primary care is a critical predictor of receiving preventive services, and minorities experience greater difficulties in accessing primary care, which results in differential rates of preventive screenings.

Using data from the 1996 Medicare Current Beneficiary Survey (MCBS), Pourat et al. report that race and ethnicity consistently and significantly determine supplemental coverage. Medicaid is available as a Medicare supplement to some low income and disabled elders depending on state policies and practices, while most elders draw upon privately purchased or retirement benefit-related supplemental policies. Although many cancer detection services are not subject to Medicare co-payments, having a supplemental policy may impact an individual's access to primary care and cancer diagnostic or

treatment services. Medicare beneficiaries of AA, Latino, and Asian descent have much smaller odds of possessing any supplemental coverage compared to whites. Nine percent of whites have Medicaid as their only supplemental coverage while 27% of AA , 16% of Latino, and 17 % of Asian elders. This does not appear to reflect preferences, however, since when given the chance to participate, the uptake rates of employee retirement policies by minorities is equivalent to that of whites (Pourat, Rice, Kominski, & Snyder, 2000). Pezzin and Kasper (2002) extend these analyses of the 1996 MCBS data, showing that less than 50% of very low income Medicare beneficiaries living in the community were enrolled in Medicaid, and that enrollment rates varied by as much as 18% between states with high and low investment in community care. Controlling for other factors, Latino elders were more likely to be dually enrolled than others. Across all groups, having Medicaid as a supplement to Medicare was associated with greater service use and expenditures for non-institutionalized elders. Another analysis of the 1996 MCBS also reveals that elders of color are more likely to report cost as a factor in delaying care than whites. Approximately twice as many AA males as white males reported delaying care because of cost, 9.3% versus 4.7%. The same was true of AA and white females, at 11.1% and 6.5% respectively (Janes et al., 1999).

This differential insurance status is significant because lack of supplemental coverage results in fewer prevention services being received by Medicare beneficiaries. This result is robust and is replicated in the 1992 National Health Interview Survey-Cancer Control Supplement (Potosky, Breen, Graubard, & Parsons, 1998) and the 1996 Medical Expenditure Panel Survey Household Component which was derived from the 1995 National Health Interview Survey (Carrasquillo, Lantigua, & Shea, 2001). Carrasquillo reports that elders without supplemental coverage were approximately 10 percentage points less likely to have influenza vaccination, cholesterol testing, mammography, or Pap smears than those with supplemental coverage. In general, a Medicaid supplement was better than no supplement, but beneficiaries who had either a private supplemental policy or HMO coverage were most likely to have received all recommended screening services. Reviewing Medicare claims for 4,100 women from 1991 and 1992, the first years that mammograms were a covered benefit, Blustein reports that 44.7% of women with supplemental coverage had mammograms versus just 14.4% of women without supplemental coverage (Blustein, 1995). Although this gap may have narrowed over the last 10 years because of efforts by CDC and others to increase access to low-cost and free screening services, it still suggests that elder groups with less insurance coverage may be at greater risk of missed cancer detection opportunities.

The association of insurance status and preventive service use may be largely a reflection of less access to a usual source of care among those with inadequate supplemental insurance. The link between preventive services and primary care is well established. Using data from the 1994 National Health Interview Survey, Christensen and Shinogle report that ambulatory visits among Medicare beneficiaries with supplemental coverage is seven to ten percent higher than among beneficiaries without supplemental coverage (Christensen & Shinogle, 1997). Having a regular source of care can double the likelihood of a physician giving prevention advice on diet, tobacco cessation, and physical activity. Similarly, Gentry et al. report that patients in Missouri

were more likely to disclose behavioral risks for disease if they had a usual source of care (Gentry, Longo, Housemann, Loiterstein, & Brownson, 1999).

The engagement of a Medicare beneficiary with a usual source of care is strongly associated with an increased likelihood of preventive medical visits and reduced risk behavior. Ettner reports that respondents without a usual source of care report being three times as likely to have a preventive medical visit during the year, and they have half the likelihood of engaging in behaviors related to substance abuse (Ettner, 1999). However, AA, Hispanic, and Asian elders report worse experiences with primary care on seven of eight indicators studied in the 1997-1998 Medical Expenditure Panel Survey (Shi, 1999). AA elders were less likely to have a specific doctor they saw at a facility, potentially impoverishing their experience of primary care (Janes et al., 1999).

Although these studies emphasize the importance of Medicare supplemental insurance and a usual source of primary care as a strong determinant of access to preventive and cancer detection services, it is important not to over-emphasize the role of physicians and other high-end medical practitioners in promoting lifestyle change. In the case of smoking cessation, there is accumulating evidence that physicians do not counsel all smokers to quit (Frank, Winkleby, Altman, Rockhill, and Fortmann, 1991; Goldstein, Niaura, Wiley-Lessne, et al., 1997) and even successful smoking cessation interventions that meld physician referral with targeted paraprofessional interventions have been difficult to sustain without ongoing reimbursement and systemic supports (Hollis, 1999). These findings do not speak to the efficacy of particular primary care interventions to reduce smoking, such as the use of physician counseling only vs. other approaches. This issue is addressed later in this chapter. Similarly, lack of time and staff support for physical activity counseling continues to be a concern of physicians (King, 2001). In addition, lack of reimbursement, lack of skill and confidence in counseling for behavior modification is a common concern voiced by physicians for physical activity counseling. Using data from the 1995 National Health Interview Survey, Wee and colleagues found that only 34% of participants received counseling about physical activity from their physicians. Physicians were less likely to counsel those patients who were only moderately overweight and those from lower socioeconomic groups (Wee, 1999). Nonetheless, in an interview of 2507 community-dwelling Medicare beneficiaries aged 65 and over, 40% of the 301 elders who initiated activity said that their physician was a very important influence (Burton, et al, 1999).

B: Cancer and Modifiable Health Risks

Public health experts have long proposed that modifiable risk factors such as smoking, diet, physical activity levels and excessive alcohol consumption are associated with increased risk of carcinogenesis and thus the incidence of cancer (McGinnis and Foege, 1993;Colditz and Gortmaker, 1995.) New research points to these same potentially modifiable risk factors as important direct or interactive determinants of tumor growth, metastasis, response to treatment, and re-occurrence (Tamimi, Lagiou,

Adami, Thrichopoulos, 2002). It is understood that multiple risk factors contribute to the causation of cancer, and confounding and interaction effects between lifestyle, environmental, and genetic factors are difficult to unravel.   Yet our efforts at intervention usually begin only once the clinical conditions manifest themselves, rather than forestalling their occurrence through prevention. Once again, even once symptoms are manifest, systemic, provider and patient barriers are more profound for R/E groups. For example, many studies have shown that higher socioeconomic status (SES) is a protective factor; one of the mechanisms is through the increased access to and utilization of currently available screening and prevention services (Link, 1998), but other material aspects of poverty and the allostatic load of social stress gradients associated with SES also have being identified (Karlamangla, Singer, McEwen, Rowe, and Seeman, 2002; Seeman, McEwen, Rowe, Singer, 2001).

In this section, the evidence for the roles of specific modifiable behavioral risk factors in breast, cervical, prostate, lung, colorectal, stomach, head/neck and pancreatic cancer incidence is reviewed. The primary question addressed is whether or not the epidemiological associations between specific behaviors and cancer incidence are sufficiently strong to justify Medicare reimbursement for behavior change interventions. Because much of the literature on behavioral factors and cancer has shied away from the aged population and because some current older adults under age 65 persons will join the Medicare rolls over the next few years, studies that include persons age 50 and older were considered in these reviews. Although this section also notes evidence from cancer treatment efficacy and re-occurrence studies on the roles of behavioral factors when these findings significantly extend or contradict the incidence literature, the primary focus is on the links between elder behaviors and cancer incidence. Further, with the exception of tobacco use studies, there is little available evidence focusing on cumulative exposures to these factors as distinct from the current behaviors of older people. Cumulative exposure presents conceptual difficulties, and there is uncertainty whether or not dose-response relationships between current behavior and incidence reflect threshold responses to current behavior or cumulative effects. This review is primarily focused on evidence for current behavior and cancer incidence, but notes evidence for cumulative effects when possible. In a similar vein, the bulk of the literature reviewed, points to the roles of behavioral risk factors for elders in general rather than their impacts on specific R/E groups. There is much less experimental evidence for interactions between R/E group and specific behaviors in cancer incidence. Again with a few and somewhat speculative exceptions, there is little reason to believe that R/E group differences in cancer incidence by site reflect differential biological response to behavior rather than differences in behavioral factors. Table 2.2 provides a summary of the relationships of lifestyle factors and cancer incidence among elders.

Table 2.2
Summary of Evidence for Modifiable Risk factors and Type of Cancer*

	Tobacco	Alcohol	Physical Exercise	Obesity	Diet
Breast	No	Mixed	Mixed	Mixed	Mixed
Cervix	Mixed	Mixed	No	No	Mixed
Prostate	Yes	No	Mixed	Yes	Mixed
Lung	Yes	No	No	No	Mixed
Colorectal	Mixed	No	Yes	Yes	Yes
Stomach	Yes	No	No	No	Yes
Head/Neck	Yes	Yes	No	No	Yes
Pancreas	Yes	No	Mixed	Yes	Mixed

- Based on prior research syntheses and this review, each potential risk factor is coded: "Yes" if the bulk of evidence supports its association with cancers at the site; "Mixed" if there is contradictory evidence, active debate, inconclusive evidence on the association with cancers at the site; and "No" if the bulk of evidence indicates little or no association with cancers at the site.

Breast Cancer Risk Factors

Breast cancer is a major public health problem for all five R/E groups considered. Its incidence, however, varies by age with 65% of breast cancer occurring in women 65 years or older. Although the profile (the range) of known risk factors is the same for all women irrespective of R/E, incidence rates vary widely by R/E group. For example, for the period between 1992-1998, the reported incidence rates for breast cancer were highest for white women and lowest for Asians/Pacific Islanders (API) and were: 115.5 for White women, 101.5 for AA women, 78 for Hispanic women, 68.5 AI/AN women, and 50.5 API women (SEER, 1998).

Risk estimates based on these incidence rates vary similarly by age and R/E. For example, Morris et al (2001) used life tables and 1973-1997 incidence rates from California Cancer registry to obtain risk estimates by R/E, for women currently aged 50 and over. They found 10-year risk estimates to be 2.9% (1 in 34) for white women, 2.3% (1 in 43) for AA women, 2.0% (1 in 51) for API women, 1.6% (1 in 63) for Hispanic women. Five-year risk estimates varied similarly ranged from 1.3% (1 in 75) among white and 0.8% (1 in 133) among Hispanic women (Morris, 2001). This wide variation in incidence or 10 year risks can be explained partly by differences in access to screening and partly by differences in exposure to lifestyle and environment risk factors. The risk is higher among older women; women who have a personal or family history of breast cancer (including breast cancer genes), biopsy-confirmed atypical hyperplasia, a long menstrual history (early menarche and late menopause), obesity after menopause, or recent use of oral contraceptives or post-menopausal estrogens and progestins; (hormone replacement therapy). It is also higher among women who have never had children or had their first child after age 30, or who consume alcoholic beverages (ACS, Cancer Facts and Figures, 2001), and in women with higher breast density. R/E variation in breast cancer rates does not appear to arise from differential impact of these risk factors, but rather to differences in length of exposure and prevalence of these risk factors (Pathak, 2000; McTiernan, 2000; Hahn, 1998). The variation in risk estimates by R/E

despite similar risk factor profiles suggests that there are potentially modifiable risk factors.

This section, discusses the evidence regarding the association between breast cancer and three potentially modifiable risk factors among older adults-- 1) *hormone replacement therapy* (HRT); 2) *nutrition/obesity,* diet low in fruits and vegetables, high fat diet, high meat diet*,* excessive alcohol consumption; 3) *health behavior* -alcohol consumption, tobacco, lack of physical activity. Reproductive factors, genetic factors and environmental factors are excluded from this review because reproductive risk factors and genetic factors are currently not modifiable and except for radiation little is known about the role of environmental factors such as polycyclic hydrocarbons in the risk for breast cancer. Questions addressed in this section include:

1) Is there a significant association between breast cancer and (HRT); obesity, diet low in fruits and vegetables, high fat diet, high meat diet; excessive alcohol consumption and lack of physical activity?
2) Is there a differential impact by these risk factors on older R/E women compared to white women?

The following databases were searched --Medline, CDC, NCI, ACS Cornell University breast cancer project –for articles addressing breast cancer risk factors. Both review and original articles were reviewed. Because the studies were primarily epidemiological and multivariate, the approach here is a narrative review.

Diet and breast cancer: To determine the role of diet, articles that examined the role of dietary fat, fruits and vegetables, whole grain cereal and fiber, micronutrients, meat, poultry, and dairy foods, hormones in food and pesticides in food were included. Diets low in fat and high in fiber, fruits, vegetables, and grain products are associated with reduced risks for many cancers (Clifford et al., 2001). Much of this evidence however, comes from country correlation and case control studies rather than from randomized controlled studies and may therefore require further research. About 35 percent of cancer deaths may be related to dietary factors (Doll and Peto, 1981). Diets high in fat have been associated with increased risk of breast cancer (USDHHS, 1988; National Research Council, 1989). The association between fat and breast cancer has been more with total fat than with specific type of fat. For example, Hursting and colleagues (1990) found a much stronger association between breast and total fat intake compared to the specific type of fat, i.e., saturated, monounsaturated, or polyunsaturated fat. For example, a meta-analysis of 12 case-control studies showed a significant positive association between breast cancer risk and saturated fat intake in postmenopausal women (Howe et al., 1990), while other studies of the same population (Willett et al., 1990, 1992) reported that increased intakes of total saturated and monounsaturated fats were associated with increased colon cancer but not breast cancer.

The role of fruits, vegetables, whole grains, and micronutrients: There is no consistent evidence regarding protective role of fruits and vegetables. There is conflicting evidence regarding a protective effect of fiber against breast cancer (Cornell

University BCERF, 2001; Jacobs, Marquart, Slavin, & Kushi, 1998). Jacobs et al. (1998) performed an in-depth review and meta-analysis of 40 case-control studies that studied diets high in whole grains and cancer. They found that the case-control literature supported the hypothesis that whole grain intake protects against some cancers. Specifically, they reviewed two studies of whole grain bread and pasta intake and breast cancer that produced a pooled odds ratio of .86 (95% CI .67-.86) for individuals with high whole grain versus low whole grain intake. They noted that the confidence intervals for the pooled odds ratios might be unreliable.

Protective effects from fruits and vegetables have been reported for breast cancer. It is suggested that vitamins (especially carotenoids and vitamin A, alpha-tocopheral (vitamin E), vitamin C, vitamin D and minerals found in these foods may have a role. The evidence of protective effects of carotenoids and vitamin A E, is however not strong. (Wu, 1999). However, other studies such as a prospective study of 61,463 women (Terry, Suzuki, Hu, & Wolk, 2001), found no increased risk of breast cancer with a western style diet over one high in fruits and vegetables. Sellers et al. (2001) found a small increase in breast cancer rates amongst women with the lowest 10^{th} percentile of folate intake as compared to those with >50^{th} percentile of folate intakes (RR 1.21 95% CI .91-1.61).

There is currently no strong evidence regarding risk or protective effect of Vitamins A and E, and Folic Acid (Wu, Helzhour et al, 1999). There is evidence for Vitamin C, D and B, particularly B12 and B6. Vitamin C is seems to be protective only in obese postmenopausal women but not in the general population (Levi, 2001, Michels, 2001).

The role of dietary fat and meat: There is no evidence regarding the association between breast cancer and a specific fat type. There is however evidence for the positive association of total fat on breast cancer (Barrett-Connor, 1993). According to a 1999 reviews by the Cornell University, 25 cohort studies that looked at the effect of total fat are were inconsistent, only two of the studies reported that high fat diet was significantly associated with the risk of breast cancer. None of the cohort studies on the role of dietary fat reported an effect on breast cancer (Cornell University BCERF, 2001). Significant association between dietary fat and breast cancer has however been consistently reported in about 95 animal models. The lack of association between dietary fat and breast cancer however may be due to measurement problems rather than the lack of effect (Cornell University BCERF, 2001). A review focused on elderly for this report also showed inconsistent evidence regarding the role of dietary fat and Vitamins A, E, and fiber. There is evidence regarding the risk of breast cancer and red meat but no evidence for poultry (chicken) and pork, fish (Cornell University BCERF, 2001).

Obesity--Total body fat, weight gains and fat distribution: Articles that included any of the following closely related measures of obesity: Body Mass Index, body weight, and waist to hip ratio were sought to determine the risk associated with obesity. The literature reviewed shows strengthening evidence in support of obesity; weight-gain as potentially modifiable risk factors in older women. One critical question is: when in one's lifetime are obesity and weight gain risky for postmenopausal breast cancer? Three

closely related measures of obesity---total weight, body mass index (defined as weight (in kg) divided by height in meter squared, (Kg/m^2), waist to hip ratio have been linked to breast cancer. Body weight captures both lean mass and body fat irrespective of distribution; body mass index is a standardized measure of body weight, adjusting for height, while waist to-hip ratio measures central fat deposit. It has been hypothesized that central fat deposit is also an indicator of hormonal disturbances (e.g. insulin resistance, decreases in sex hormone binding globulin, levels, androgen levels and conversion of androgen to estrogen) that have also been associated with breast cancer. In addition, increased body fat can store toxins and can serve as a continuous source of carcinogens (Friedenreich, 2001).

The risk posed by obesity and weight gain depends on menopausal status. Although higher body weight and body mass index are protective in pre-menopausal white women they are positively associated with breast cancer in postmenopausal women. Adult weight gain and increases in central body fat, which commonly occur during menopause, have been associated consistently with an increased risk of postmenopausal breast cancer. Increased relative weight (compared to young adult weight) and weight gain after menopause have been associated with the largest increases in relative risks (Ballard-Barbash, 1999).

The association of breast cancer with waist to hip ratio is stronger than that with body weight or with body mass index, perhaps because waist to hip ratio is more precise measure of body fat—particularly central adiposity. A population-based case-control study of white and black women in North Carolina from 1993-1996 showed that associations between BMI, waist/hip ratio, and breast cancer were similar for white and black women (Hall, Newman, Millikan, & Moorman, 2000). Cases included 350 black and 523 white women. There were 352 black and 471 white controls. Subjects ranged in age from 20-74. The authors found a positive association between higher waist/hip ratio for all women when adjusted for BMI. Odds ratios for post-menopausal women were 1.62 (95% CI .70-3.79) for blacks and 1.64 (95% CI .88-3.07) for whites. Barnett and colleagues (2001), in a study of 106 healthy pre-menopausal African American, women found that body fat distribution was a better marker of a hormonal pattern associated with increased breast cancer risk than was obesity.

The breast cancer risk from obesity seems greater for women after menopause and to increase with age (La Vecchia, 1997). Maintaining a healthy adult weight (after age 20) and regular exercise in young adulthood after age 35, and avoiding weight gain around the menopausal period would reduce the risk of postmenopausal breast cancer. Limitations of current obesity studies include inconsistencies regarding the strength of association particularly when body mass index is used. The most recent review by Friednreich (2001) shows that inconsistencies in the literature are attributable to measurement errors (especially self reported measures), failure to account for changes in these measures that occur over one's lifetime, and differences in the definition and cut-off points for measures of obesity and central adiposity (Friednreich, 2001). There is currently compelling evidence from larger sample size, and designs using direct rather than self reported measures and ones that account for period in one's life when these

measures were taken. There is also strong evidence from studies that pooled the original studies and applied uniform measures (Friednreich, 2001). It should be pointed out, however, that the preventive effect of reduction in dietary fat has not been demonstrated, but two recent reviews have examined the weight loss as an adjuvant approach in women diagnosed with breast cancer (Chlebowski, 2002; Chlebowski, Aiello, McTiernan, 2002). Although this evidence does not speak to prevention as such, it does suggest that women with better weight management may fare better during cancer treatment. This is not prevention.

Physical exercise and breast cancer: The evidence is also strengthening for the role of physical exercise in reducing postmenopausal breast cancer risk. Much of this evidence however comes from observational studies. Few studies examine the role of race. Most studies reviewed, both national and international, found significant inverse association between physical exercise and breast cancer in postmenopausal women (Adams-Campbell, 2001;Breslow, 2001; Carpenter, 1999; Drake, 2001; Friedenreich, 1995 Friedenreich, 1998; Friedenreich, 2001; Gammon, 1998; Gilliland, 2001; Matthews, 2001; Thune, 1997; Thune, 2001; Verloop, 2000). A few studies, however, did not find a significant association (Albanes, 1989; Dorgan, 1994; Lee, 2001; Luoto, 2000; Moore, 2000). Postmenopausal women with high levels of physical activity have lower body and abdominal fat and physically active women are less likely to gain body fat and abdominal fat after menopause than sedentary women (Astrup, 1999). There are very few randomized controlled trials (RCT) comparing exercise with no intervention, and diet with diet plus exercise, and the results do not allow a firm conclusion as to whether physical activity may prevent or limit the gain of total fat and abdominal fat after menopause, or whether it may be effective as part of an obesity treatment program (Astrup, 1999)

Critical questions again include what type of exercise, how much exercise and when in one's life is it beneficial? Studies that have examined these two issues show that occupational and household exercise of at least moderate intensity has inverse relationship with breast cancer and not recreational exercise. For example, a Canadian study found that "moderate-intensity occupational and household activities decreased breast cancer risk, whereas recreational activity, at any intensity level, did not contribute to a breast cancer risk reduction" (Friedenreich, 2001).

With regard to timing, exercise seems to be beneficial if done in young adulthood about 20-40 years. For example one study evaluated the association between physical exercise and the risk of breast cancer risk among 64,524 black women age 21-69 who were part of the Black women's study. They found that likelihood of breast cancer for women who were exercising for seven or more hours per week (as compared to less than one hour) at age 21 significantly reduced risk for breast cancer overall and pre-menopausal breast cancer, at age 30 for breast cancer overall, and at age 40 for postmenopausal breast cancer (Adams-Campbell, 2001). Lifetime exercise seems to be beneficial in women who do not gain considerable weight in adulthood. Lifetime exercise may prevent considerable weight gain in adulthood. For example Carpenter (1999) found that exercise activity was not protective for women who gained considerable (> 17%)

weight during adulthood. However, among women with more stable weight, breast cancer risk was substantially reduced for those who consistently exercised at high levels throughout their lifetime (OR = 0.42; 95% CI 0.24-0.75), those who exercised more than 4 h per week for at least 12 years (OR = 0.59; 95% CI 0.40-0.88), and those who exercised vigorously (24.5 MET-hours per week) during the most recent 10 years (OR = 0.52; 95% CI 0.32-0.85). Strenuous exercise appears to reduce breast cancer risk among post-menopausal women who do not gain sizable amounts of weight during adulthood".

Smoking: Khuder, Mutgi, & Nugent (2001) performed a meta-analysis of peer-reviewed studies on the association of smoking and breast cancer that took place between 1984 and 2001. They found that relative risk (RR) for ever-smokers was 1.10 (95% CI 1.02-1.18). The authors found that the association between smoking and breast cancer was strongest amongst pre-menopausal women (RR 1.21 95% CI 1.08-1.36). Based on their meta-analysis, Khuder et al. concluded that smoking was a weak risk factor for breast cancer with higher risk for pre-menopausal women and those who began smoking at an early age.

Hormone replacement therapy: Overall the use of HRT is low (about 39%) with older white women being more likely to use HRT (about 60% more) than women of color (Connelly, 2000; MacDougall, 1999; MacLaren, 2001; Marsh, 1999; Stafford, 1997, Stafford, 1998). Two studies suggest that more white women are recommended to use HRT than woman of color (Schneider, 2000, Weng 2001). Past studies have shown that HRT poses a small to moderate risk of breast cancer (Pathak, 2000, Ross, 1980, Au, 2000 Neves-e-Castro, Samsioe, Doren, & Skouby, 2002)). The risk however, is related to length of use (over 3 years) (Genazzani, 1999, Bergkvist, 1996, Ross, 2000, Faiz, 1998), and the type of hormone used (Ross, 2000). Nonetheless, one study, found that the risk associated with HRT use was not distinguishable from that due to increasing age. Recent evidence from studies of the association of HRT and breast cancer have shown an increased risk of breast cancer with extended use of HRT (Kolata & Peterson, 2002). Other recent studies on other effects of long term HRT use such as cardiovascular disease have also shown unfavorable outcomes (Hulley et al., 2002). (Chen, Weiss, Newcomb, Barlow, & White, 2002) studied 705 post-menopausal women aged 50-74 who were enrolled at the Group Health Cooperative (GHC) at Puget Sound for at least two years prior to the study and who were diagnosed with breast cancer between 1990 and 1995. The authors age matched these women with 692 randomly selected controls. GHC pharmacy records and a self-report questionnaire were utilized to ascertain HRT use for a five-year period ending one year prior to diagnosis. The authors found that risk of breast cancer increased 60-85% for recent long-term users of HRT. Rates were increased whether the women had used estrogen or estrogen plus progestin therapy. They found that HRT use particularly increased the risk for lobular tumors.

In light of recent findings on the relationship between HRT and breast cancer (Marsden, 2002) performed a review of the recent literature on the association of HRT and breast cancer. Marsden reviewed the Collaborative Group for Hormonal Factors in Breast Cancer (1997) reanalysis of 51 case-control studies of the association between HRT and breast cancer and concluded that long-term use (10+ years) of HRT does

increase risk of breast cancer but that risk of breast cancer decreases with cessation of HRT. Studies published after 2001 were not included in Marsden's analysis.

The role of estrogen-progesterone combinations and their sequencing in the dosage is also controversial. Some studies suggest that addition of progesterone lowers the risk while others suggest that use of estrogen alone lowers the risk. Nonetheless, there is no evidence that HRT use increases mortality due to breast cancer. In contrast, breast cancer survival for women who use HRT is better than that for women who do not use HRT (Schairer, 1999; Gajdos, 2000; Bergkvist, 1996; Bonnier, 1998; Peter, 2000; Verhuel, 2000). This is partly because HRT use is associated with histologically favorable tumors, including smaller tumors, favorable histology, positive ER status and disease free survival, and early stage-t diagnosis (Bonnier, 1995; Bonnier, 1998; Bonnier, 2000; Cobleigh, 1999; Delgado, 1995; Gajdos, 2000, Gapstur, 1999; Jones, 1994; Magnusson, 1996; Manjer, 2001; Salmon, 1999).

Alcohol: Excessive alcohol consumption (Blot, 2001) has been found to be associated with increased risk of breast cancer (Schatzkin et al., 1994, Singletary, 2001, Terry et al. 2001, Stoll, 1999; Hiatt, 1984; Hankinson, 1995(b); O'Connell, 1987, Longnecker, 1995). (Sellers et al., 2001) found increased risk of breast cancer amongst heavy drinkers who also had low folate intake (RR 1.59 95% CI 1.05-2.41). It is not established if the association between alcohol and breast cancer is causal in nature (Blot, 2001). Over 50 epidemiologic studies have found small to modest increases in risks of breast cancer associated with drinking alcoholic beverages (Schatzkin et al., 1994). The excess risk of breast cancer associated with alcohol varies by amount consumed, with 20-30% excess risk associated with consumption of about one drink per day and 60- 70% excess risk associated with heavy drinking (Blot, 2001; Colditz et al., 1990; Garfinkel et al., 1988). Some studies, however have found no association between alcohol and breast cancer. Four of these studies were European studies (Ranstam, 1995, Royo-Bordonada, 1997, Sneyd, 1991; Ferraroni, 1998) and two were US studies (Kinney, 2000, Zhang, 1999).

Cervical Cancer Risk Factors

HPV and Cervical Cancer: The major risk factor for uterine cervix cancer is the Human Papilloma virus (HPV). Since the association between HPV and cervical cancer was first suggested by Harold Zur Hausen in 1974 (Zur Hausen, 1974) several studies have supported an association between HPV and cervical cancer (Reeves et al., 1989b; Koutsky et al., 1988). Women who are infected with HPV are at higher risk of developing cervical intraepithelial neoplasia (CIN) (a benign precursor of cervical cancer) as well as cervical cancer. Women infected with HPV are 10 or more times more likely to develop cervical cancer than are HPV-negative women (Koutsky et al., 1988; Reeves et al., 1989a). Not all HPV, however are associated with developing cervical cancer, only certain subtypes. Of the more than 100 types of HPVs, about 30 can be transmitted from person to person through sexual contact [NCI Cancer facts -Date reviewed: 01/08/2001.)

Only the high risk, sexually transmitted HPVs have been associated with abnormal growths related to cervical cancer. They include HPV types 16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 59, 68, and 69 (NCI, (2001) Cancer facts). Subtypes 16, 18, 31, 33, and 51 of the human papilloma virus (HPV) are associated with 95% of cervical cancers (Schoell, Janicek, & Janicek, 1999). Different strains of HPV may be more common and play a larger role in cancer risks in certain groups. For example, to determine risk factors for pre-cancerous CIN II/III among Alaska Native women, MacLehose et al. (1999) conducted a pilot case-control study of 26 cases and 52 controls. They found that HPV 16 infection increases the risk of CIN II/III (OR 40.8 95% CI 1.3-11.3). A small sample size limits the value of this study in generalizing to other AI/AN communities. The type of HPV has might also impact on prognosis for invasive cervical cancer. Schwartz et al. (2001) studied 399 women diagnosed with invasive cervical cancer between 1986 and 1997 in Washington for the association between type of HPV and mortality from cervical cancer. They found that women with HPV-18 had higher total mortality (TM) and cervical cancer specific mortality (CCSM) rates than those with HPV-16 (TM 2.2 95% CI 1.3-3.6; CCSM 2.5 95% CI 1.4-4.4).

Several factors increase a woman's chance of contracting HPV. Among those are early age of sexual activity, multiple sexual partners, and male partner(s) having other multiple partners and having HIV (Miller, 1996; NCI, 2002). Giuliano and colleagues (1999) studied the risk of HPV infection among Mexican-American women. They found that Mexican born women, despite fewer risk behaviors such as multiple partners and later age of first intercourse, were significantly more at risk of HPV infection than United States born Mexican American women (AOR 1.9 95% CI 1.2-3.2). The authors' hypothesized that some unmeasured factor such as the sexual behavior of male partners might influence HPV risk (Giuliano, Papenfuss, Schneider, Nour, & K, 1999). Oral contraceptives may also increase the risk of HPV through the mechanism of progestins stimulating HPV gene expression (Smith et al., 2002). Smith et al. (2002) using cervical and or vaginal specimens from 429 women seen in routine gynecological practice found that users of estrogen/progestin HRT were at increased risk of HPV (AOR 1.5/year 95% CI 1-2.3) for longer duration of use and for longer latency (AOR 1.2/year 95% CI .9-1.7) among past users. Duration of HRT use did not increase risk for current users.

Although the link between HPV and uterine cervix cancer is obvious, studies that have tried to link high-risk sexual activity to uterine cervix cancer have been inconsistent. This is perhaps partly because not all HPV leads to cervix cancer, only certain subtypes and most of the pre-cancerous lesions caused by low risk HPVs tend to regress (NCI Cervical cancer prevention PDQ, 2002). There are currently no commercially available tests that distinguish various sub types of HPV, although there is a test that has been approved by the Food and Drug administration identifies the presence or absence of HPV. Given this technical limitation, it is not possible to ascertain R/E patterns for HPV subtypes. It is however, possible to ascertain R/E patterns in high-risk cytology (pre-cancerous lesions i.e. CIN 2-3). These are discussed under R/E patterns in detection rates.

Other Cervical Cancer Risks: Most women who contract HPV do not develop cancer. For this reason, it is commonly held that HPV alone is not capable of inducing cervical cancer; exposure to cofactors, are important determinants of which HPV infected

women will develop the disease (NCI, 2002). Possible cofactors include 1) smoking (passive or active), 2) oral contraceptive use, (Brinton, 1984), 3) poor diet (poor nutrition), 4) parity (high parity), 5)other sexually transmitted diseases, including herpes simplex virus_2 (HSV-2) and immunological status such as infection with HIV (Shopland, 2001, Blot, 2001, Clifford et al 2001). The evidence with respect to nutrition and smoking and cervical cancer are reviewed below.
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Diet and Nutrition: Several studies of dietary factors and cervical cancer risk have been performed, but they provide relatively weak evidence for the potential to reduce cervical cancer in older women through dietary interventions. Nonetheless, an older comprehensive review of fruits and vegetable consumption and cancer did show some evidence (Block et al., 1992). In a case-control study of serum carotenoids and risk of CIN in American Indian women aged 18-45, Schiff et al.,(2001) found that increased carotenoid levels reduced the risk of CIN. The authors recruited 81 cases diagnosed between 1994 and 1997 and 160 controls from Indian Health Service clinics in New Mexico. Blood samples were taken to assess serum carotenoid levels. Control variables included age and HPV infection, and income. Smoking was not included as a control variable because less than 15% of the sample smoked and those that did averaged fewer than five cigarettes per day. HPV was found to be a significant risk factor for CIN (OR 9.0 95% CI 4.7-17.5. Low folate levels were found to increase risk of cervical cancer in a multiethnic case-control study of 150 cases and 179 controls aged 18-84 recruited from clinics in Oahu Hawaii between 1992 and 1996 (Goodman et al., 2001). Information was obtained from blood samples and in person interviews. Highest quartile of foliate intake versus lowest quartile intake significantly reduced risk for cervical SIL (OR .3 95% CI .1-.7 p< .002). In a RCT intervention to increase fruit and vegetable intake amongst pre-menopausal women with CIN, Rock et al. (2001) studied 53 women, 27 of whom received individualized dietary counseling to increase consumption of fresh fruits and vegetables. Outcomes were assessed by use of food intake questionnaires and serum carotenoid and homocysteine levels at baseline and post-intervention. The authors found that 1 year of weekly individual counseling via Internet or telephone to promote consumption of 8-10 servings of fruits and vegetables per day significantly (p< .01) increased plasma carotenoid levels. Long-term impacts on either cervical cancer or re-occurrence of CIN were not reported.

Smoking: The evidence for the roles of cigarette smoking and cervical cancer is also inconclusive, because it has been studied both as independent determinant and as a co-factor along with HPV. Nonetheless, a review of the literature, also cited several large studies that showed increased risk of cervical cancer with smoking in a dose dependent manner (Moore et al., 2002). Cigarette smoking has also been reported to substantially elevate the death rates for cervical cancer (Shop land, 2001).

Wyatt and colleagues (2001) used 1997-1998 data from the Kentucky cancer registry, which includes information about history of tobacco use. Analysis included 520 cases of invasive cervical cancer. 61% of cases reported a history of smoking tobacco. A multi-center case-control study of the association between smoking and adenocarcinomas and squamous cell carcinomas of the uterine cervix was performed by(Lacey et al.,

2001). The study included 124 cases of adenocarcinoma, and 307 community controls that were age, race residence matched to the cases of adenocarcinoma and 139 cases of squamous cell carcinoma that were matched with the adenocarcinoma cases by age, disease stage, date of diagnosis, and clinic site. The authors found an inverse association between current smoking and adenocarcinoma (OR .6 95% CI .3-1.1) but a positive association between smoking and squamous cell carcinoma (OR 1.6 95% CI .9-2.9) and a stronger association between smoking over one pack per day and squamous cell carcinoma (OR 1.8 95% CI 1.0-3.3).

An interaction effect between smoking and HPV was found with regard to increased risk of high-grade cervical squamous intraepithelial lesion (HSIL) (Coker, Bond, Williams, Gerasimova, & Pirisi, 2002). Coker et al. used a case-control design with 59 HSIL cases, 313 low-grade SIL (LSIL) cases and 427 controls recruited from South Carolina Health Department Clinics. The authors looked at both active and passive smoking, their interaction with HPV and the development of SIL. Information on HPV and SIL were taken from Pap smear samples. Smoking and passive smoke exposure histories were assessed by telephone or in person interviews. Analysis included only HPV positive women since the authors consider HPV to be a necessary cause of cervical carcinoma.

Prostrate Cancer Risk Factors

Prostate cancer's etiologies are unknown but genetic and environmental factors have been proposed as playing important roles. Age is the most important risk factor. The probability of developing prostate cancer increases with age. Under the age of 40, it is a very rare event, being observed in 1 out of 10,000 men. In the 40-59 age group, the probability of developing this malignance is 2.1%. The cancer probability increases sharply for men in the 60-79 age group (12%), and is highest in men over 80, where 1 out of 6 develop clinical prostate cancer. (Jemal, 2002) Men with a family history of prostate cancer have a higher risk of prostate cancer. A man with one or two first-degree family members with prostate cancer is twice and five times (respectively) as likely to develop prostate cancer than a man without family history (Office of Technology Assessment, 1995).

A recent systematic review analyzed the roles of vegetables, fruits and micronutrients in prostate cancer. Fruits do not appear to correlate with prostate cancer risk. Vegetables, including tomatoes, beans and legumes may be inversely associated with prostate cancer. Vegetables are the primary source of carotenoids such as lycopene. Beta-carotenes and vitamin E may have a protective effect on the risk of prostate cancer. However, beta-carotene intakes have been associated with a 25% risk increase of prostate cancer among cigarette smokers (Albanes, 1995). In all cases, further research is needed for definitive evidence (Chan, 2001).

The relationship between dairy products and calcium intakes with prostate cancer was analyzed as part of the Physician's Health Study, with a cohort of 20,855 males followed for 11 years. The overall incidence of prostate cancer was 4.8%. Men who

consumed more than 2.5 servings a day of dairy products had a 34% higher risk of developing prostate cancer than those who consumed less than half a daily serving. Similarly, men who consumed more than 600 mg a day of Calcium experienced a 32% higher risk of cancer than those who consumed less than 151 mg of calcium a day. The group with high intakes of calcium from dairy products also had lower levels of 1,25-dihydroxyvitamin D3, a hormone that might have a protective effect against prostate cancer (Chan, 2001). Race differences were not reported in this study.

Men with low serum levels of selenium are twice as likely to develop prostate cancer as men with high serum levels of this element. In a randomized trial, 1,312 patients were followed for 4.5 years to observe the effect of supplemental selenium on the development of cancer. The study observed that men who were administered a selenium supplement experienced a 66% reduction in the incidence of prostate cancer (Clark, 1996). Race/ethnicity of participants was not reported in this study. In summary, more evidence is needed to establish the role of dietary factors on prostate cancer. A randomized clinical trial on the effect of vitamin E and selenium on prostate cancer risk is underway. This trial plans to enroll 32,400 healthy men and results are expected by 2013 (Klein, 2001).

Racial/Ethnic Differences in Prostate Cancer Risk: Men of African descent are at a higher risk of developing prostate cancer, with risks among AA men 30- 60% higher than non-AA men. This higher risk occurs even at earlier ages. In the 50 to 54 age group, African American men are twice as likely to develop this cancer than Whites (Office of Technology Assessment, 1995).

A literature review suggests genetic factors as possible explanations for R/E differences in risk of prostate cancer with two potential types of R/E variation identified: differences in prevalence of some alleles of specific genes and differences in rare germline mutations. The former, potentially responsible for differences in serum levels of androgens or their metabolites, might be associated with a small risk increase of cancer, and could account for the largest proportion of the ethnic differences in that risk. By contrast, rare germline mutations appear to be associated with a significant risk increase, and yet might account for only a small fraction of those ethnic differences in prostate cancer risk (Shibata, 1997

Families with high risk of prostate cancer have linkage of a marker, HPC11, with a putative gene on the long arm of Chromosome 1. Among families with at least three members with prostate cancer, the prevalence of this marker has been greater in AA compared to White men (over 50% vs. 34%). This could explain in part the high incidence of this cancer among African Americans (Powell, 2001).

Androgens influence both the development and progression of prostate cancer. African Americans have testosterone levels higher than any other ethnic group. The CYP17 gene appears to play a key role in the biosynthesis of androgens. The prostate is an androgen sensitive organ. Certain genetic polymorphisms of CYP17 have been reported to be associated with an increased risk of developing prostate cancer. African

Americans with prostate cancer are 2.8 times more likely to have a genotype homozygous for the C allele in CYP17 than healthy controls of the same race/ethnicity. When this genotype is present in patients with prostate cancer, there is a 700% greater likelihood for higher grade lesions. This finding could also explain part of the more aggressive histology observed for some persons in this ethnic group (Kittles, 2001). Other genetic variations, such as those observed in the HSD3B2 gene, could be a risk factor for prostate cancer and explain part of the racial/ethnic variation in this cancer risk (Devgan, 1997).

High-grade prostatic intraepithelial neoplasia (PIN) is considered the most predictive precursor of invasive prostate cancer. African American have a higher prevalence and greater extent of PIN, which could explain more rapid progression of this cancer for this group (Montironi, 1999).

Modifiable factors, such as diet and physical activity have not been conclusively shown as risk or preventive factors of prostate cancer. If their role in prostate cancer is established, they could explain why AA men seem more vulnerable to the development of this cancer. This ethnic group is likely to eat fewer vegetables and more saturated fat than Whites, potentially increasing their risk for prostate cancer. However, AA groups consume fewer dairy products than Whites, which could provide them a protective factor against prostate cancer (Basiotis, 1998).

The relationship of fat and total calorie intake with prostate cancer has been studied in animal experiments and epidemiological studies in humans. Resulting evidence is contradictory and far from being conclusive (Bosland, 1999). One of the epidemiological studies that has shown an association between total saturated fat intake and risk of prostate cancer in all of the ethnic groups studied (Blacks, Whites, Chinese-Americans and Japanese-Americans), estimated that saturated fat intake could explain about 10% of the differences in the incidence of prostate cancer between Blacks and Whites (Whittemore, 1995).

Results from a cohort of 5377 men, followed for an average of 15 years by the National Health and Nutrition Examination Survey, show that AA men, with a daily low level of non-recreational physical activity, have a risk of prostate cancer 3.7 times higher than AA men who report being very active. This study failed to show however, a similar significant correlation among Whites, or any significant correlation between exercise (recreational activity) and cancer. Moreover, there were no significant correlations between any of the following anthropometric measurements, height, elbow width, body mass index, weight, or skin fold thickness, and prostate cancer in either R/E group (Clarke, 2000).

Current smoking status was associated with a 30% increase in death risk from prostate cancer among 348,874 men screened for this cancer and followed for an average of 16 years. The same cohort study showed that Blacks had a 2.7 times higher risk of prostate cancer-specific death than non-Blacks (Coughlin, 1996). A potential interaction effect between race and smoking was not reported in this study.

Colorectal Cancer Risk Factors

Colorectal cancer, the second most common cause of cancer-related deaths in the United States, is well suited for prevention efforts. While it has relatively high incidence and is fatal when diagnosed at later stages, it typically emerges after an extended pre-cancerous stage. Prevention of colorectal cancer is possible through detection and screening of pre-cancerous adenomatous polyps (Lewis, 2000). A large body of literature has documented that the transition from normal colonic mucosa to adenomatous polyps to adenocarcinoma is a gradual process that can take decades and offers multiple opportunities for intervention (Alberts, 2002). The key molecular events in this process have been characterized (Schulman, Reiser, and Schmeigel, 2002). Although much of the research has focused on the relatively rare polyposis syndromes, detection and removal of polyps, even in asymptomatic persons is now viewed by the US Preventive Services Task Force as an effective colorectal cancer prevention strategy (Pignone and Levin, 2002).

There have been numerous efforts to address the chemoprevention of polyp development and progression to invasive cancer. Clinical trials have addressed both calcium and fiber as dietary supplements in patients who have already had polyps. Asano and McLeod (2002), Pignone and Levin (2002) and other reviewers have concluded that the five relevant clinical trials, involving over 4349 subjects, provide no evidence that increased dietary fiber intake reduces the incidence or recurrence of polyps within a 2-4 year period. By contrast, Pignone and Levin (2002) and Schulman et al (2002) conclude that the clinical trials do suggest that calcium may be effective in preventing reoccurrence of adenomatous polyps. More recently, attention has focus on aspirin and other non-steroidal anti-inflammatory drugs (NSAIDs) as prevention agents, but there are potentially serious gastrointestinal side effects of these. One possibility is that these drugs inhibit the expression cyclooxygenase-2 (COX-2). COX-2 has been associated with tumor progression in animal models. As a result, attention has been focused more recently on selective COX-2 inhibitors such as Celecobrix, and these drugs have been recently approved for the management familial polyposis syndromes and are being studied as potential mechanisms for management of sporadic colorectal polyps (Alberts, 2002).

While the removal of polyps and their relationships with NSAIDS and COX-2 inhibitors are the primary current foci of current colorectal cancer prevention initiatives, there is compelling evidence for potentially modifiable health behaviors in the development and progression of this disease. The primary known and modifiable risk factors for colorectal cancer are physical inactivity, obesity, and diet. A review of published studies estimated that the risks of colon cancer could be attributed to being physically inactive (13%), eating a Western-style diet (12%), and having a first-degree relative with the disease (8%) (Slattery, 2000). Regarding physical inactivity, an analysis of prospective longitudinal data from over 80 thousand participants in the nurses' health study and found that the relative risk of colon cancer was 0.54 for women who expended 21 metabolic equivalents (Meets) per week versus women who expended 2 MET-hours/week (Martinez et al., 1997). Similarly, a prospective study of 47,723 male health professionals age 40 to 75 found that physical activity was inversely associated with risk

for colon cancer in a six-year follow-up (.53; 95% CI, 0.32-0.88 for high versus low quintiles in terms of expenditure of energy on leisure activities) (Giovannucci et al., 1995). Another study (White, Jacobs, & Daling, 1996) created a comparison group matched by age/sex/geography to 251 men and 194 women diagnosed with colon cancer in the Seattle area and compared physical activity twelve to two years prior to the diagnoses. Men and women who had moderate to intensive recreational or work activity two or more times a week were 0.7 times as likely to have colon cancer as those who did not exercise. A case-control study examined 1,993 cases and 2,410 controls to determine if exercise level was an independent risk factor, controlling for a range of dietary factors, smoking, drinking, BMI, and use of aspiring and/or NSAIDS (Slattery & Potter, 2002). Higher levels of exercise maintained independent importance, but prediction was improved by an interaction term of activity with other variables. Also, high vegetable diets were much more protective in sedentary populations (RR 0.6) than active ones (RR 0.9).

Obesity is an independent risk factor for colorectal cancer, but it appears that physical activity can offset the risk. One study of deaths from colon cancer 12 years after baseline in the American Cancer Society's Cancer Prevention Study II (496,239 women and 379,167 men) found that, after controlling for multiple covariates, men with BMI $\geq$ 32.5 were 1.90 times as likely to die from colon cancer as men with BMI of 22.0-23.5 (Murphy, Calle, Rodriguez, Khan, & Thun, 2000). Among women, BMI of 30.0-32.4 was the highest relative risk (1.37) to the 22.0-23.5 BMI group (Slattery et al., 1997) report on an observational study of 2,073 first primary cases of colon cancer and 2,466 age/sex matched controls. Both men and women were found to be at higher risk if they had relatively large body mass index (BMI) (OR 1.94 for men and 1.45 for women), low lifetime activity intensity (OR 1.63 for men and 1.59 for women), or high calorie diets (OR 1.74 for men and 1.70 for women). Being in the higher risk category on all three domains increased the odds ratio to 3.35. However, high physical activity was found to offset being in the high-risk diet and BMI groups. Another case-control study of 1,983 colon cancer cases and 2,400 age- and gender-matched controls found that the third of the cases with the highest BMI compared to the third with the lowest were at higher risk for both men (1.70 OR) and women (1.53) (Caan et al., 1998). A family history of colorectal cancer greatly increased these odds (7.76 and 4.85 respectively). Two of the studies of activity levels in the previous section also showed independent risks for obesity: Martinez and colleagues (1997) found that women with a BMI $\geq$ 29 were at 1.45 times the risk of colon cancer as women with BMI $\leq$ 21. Giovannucci and colleagues (1995) found the OR for colon cancer was 2.56 for men with waists of 43 inches or more compared to those with waists of 35 inches or less.

Diet is also a well-established risk factor for colorectal cancer. A six-year prospective study of 32,051 non-Hispanic whites found that food intake characteristic of a "Western-style" diet is associated with colon cancer (Singh & Fraser, 1998). Those eating red or white meat once or more a week had risk ratios of 1.90 and 3.29 respectively compared to those with no meat intake. An inverse risk was found with legume intake. Another study of the multi-center case control cancer study cited under exercise found that colon cancer patients with a mutation of the p53 tumor suppressor

gene were more likely to eat a Western-style diet compared to controls (OR 2.03) (Slattery & Potter, 2002).

There is one study that associates risk for CRC with poverty. A study of 1,219 CRC patients in the Connecticut tumor registry found that patients who came from census tracts with a poverty rate of 20% or higher had the highest risk of death. The study controlled for age, stage or disease, and comorbidity (Polednak, 2001).

The evidence for smoking as a risk factor for colorectal cancer is mixed. A 12-year prospective study of 25,369 women (Sandler, Sandler, Comstock, Helsing, & Shore, 1988) found that compared to non-smokers, women smokers had lower risk of colorectal cancer (OR .76). Among older women, smoking was even more protective: ORs were 0.42 for smokers and 0.66 for nonsmoking women who lived in houses with passive smoke. The authors suspect that smoking has an antiestrogenic effect. Longnecker (1989) studied data on 9,101 individuals in the MA Cancer Registry, including 2,788 current smokers, and found that the relative frequency of disseminated colorectal cancer was 45%

Lung Cancer Risk Factors

Modifiable risks for lung cancer include smoking, second hand smoke, and occupational exposures to asbestos, radon, and other carcinogens. Lung cancer risk is associated with the number of cigarettes smoked, number of years smoking, the age smoking began, tar content, and depth of smoke inhalation. 1 out of 10 smokers will develop lung cancer. Smoking cessation lowers the risk but the risk ratio is 1.5 after 10-15 years of abstinence. Approximately 3000 deaths from lung cancer per year are attributable to exposure to second hand smoke. Variables in exposure include the size of the room, ventilation, and concentration of smoke (Chandy, Lesser, & Rashid, 2001). Jemel, Chu, & Tarone (2001) stated that cigarette smoking accounts for 80% of lung cancer cases in men and 70% of lung cancer cases in women. (ACS, 2002a).

Stewart (2001) reported that menthol cigarettes also may increase lung cancer risk. Menthol combustion produces benzo-a-pyrenes, which are a powerful carcinogen and that menthol cigarettes have higher tar content than regular cigarettes. Lee and colleagues (1998), in a non-randomized retrospective study of 328 patients at Massachusetts General Hospital presenting for thoracic surgery, found an inverse relationship between upper lobe location of lung cancer and intake of yellow-orange vegetables. While a diet high in fruits and cruciferous vegetables may reduce the risk of lung cancer, simply adding vitamins through nutritional supplements may actually increase the risk of lung cancer in some cases. The CARET study that focused on 18,000 high-risk smokers found that a combination of beta-carotene and retynol palmitate supplementation increased lung cancer risk by 28%. The ATBC trial in Finland had similar results (Goodman 2000). In a case-control study of 356 participants of the Beta Carotene and Retinol Efficacy Trial were matched with 456 controls by age, smoking status, treatment arm, and year of blood draw. There was no significant selenium in cancer cases as compared with controls. Consuming the serum concentration of selenium

was not seen as a risk of lung cancer (Goodman, Schaffer, Bankson, Hughes, and Omenn, 2001). Similarly, beta-carotene may possibly increase risk of lung cancer among smokers (Patrick 2000).

Pope and colleagues (2002), in a longitudinal study of 1.2 million adults from 1982 to 1998, found that long-term exposure to fine particulates was a risk factor for cardiopulmonary and lung cancer mortality. Their study involved linking air pollution data for metropolitan areas with vital statistics data. Because more people of color reside in urban areas as compared to whites, fine particulate air pollution may be an increased risk factor for lung cancer for those individuals.

Stomach Cancer Risk Factors

Stomach cancers arise in several anatomic locations, take several distinct histological forms, and are now viewed as distinct conditions. Although there is some evidence for differentials across R/E groups in the US and abroad in the incidence of these different forms and emerging hypotheses about distinct etiological processes, this is an area of rapid research change. In the following, evidence for behavioral risk factors linked to any of the stomach cancers are discussed, but the potential differences in etiology across subtypes receives little attention. There are a number of known modifiable risk factors in the literature. Foremost of these is diet. Diets high in fresh fruits and vegetables reduce risk while diets high in salt, nitrates and preservatives, and smoked foods increase stomach cancer risk (ACS 2002). Individuals with low socioeconomic status are twice as likely to develop stomach cancer than those of higher socioeconomic status. In a review of 72 epidemiological studies tomato intake appeared to decrease cancer risk for stomach cancer across 3 US studies at a statistically significant level (Giovanucci, 1999). The studies cited were observational, but did adjust for incomes, age, sex, and other factors, such as neighborhood. A literature review on animal and in vitro studies of the anticarcinogenic effect of garlic on stomach and other cancers by Fleischauer and Arab (2001) found case control studies of stomach cancer that point to a protective effect of a high intake of cooked or raw garlic. Garlic supplements did not seem to lower stomach cancer risk.

Stomach surgery for benign causes is thought to be a risk factor from a review of VA records for 17,077 men who were hospitalized between 1970-1971 (Fisher et al, 1993). Excluding patients who had died within one year of surgery, the authors included 7609 individuals who had received gastric surgery and a control group of 8374 who had not received gastric surgery. The groups were matched for age, race, hospital, and year of admission. The authors then tracked mortality through three data sources, and found death certificates for 99% of deceased subjects. They found a significantly increased risk of stomach cancer up to 20 years following stomach surgery, beginning in year two. The risk was greatest for those treated by gastrectomy for ulcers. In a comparison of 4147 subjects with stomach cancer and 89,082 subjects without stomach cancer at VA Hospitals using multivariate analysis Molloy and Sonnenberg (1997) found that old age, male sex, non-white ethnicity, history of gastric ulcers, and gastric resection were risk factors for stomach cancer. A mortality study of 4577 predominately white males who

received treatment for ulcers at the university of Chicago Medical Center between 1936 and 1965 by Griem at al (1994) divided individuals into two groups for comparison, those who received radiotherapy and those who were treated with other means. They found that gastric ulcers increased the risk of stomach cancer. Radiation therapy combined with surgery, or given to treat a gastric ulcer, increased the risk of stomach cancer ten times.

An increased risk for stomach cancer in individuals who had a family history of the Ewing's Sarcoma family of tumors was found (Novakovic, Goldstein, Wexler and Tucker, 1994). These findings were based on a review of records of individuals treated at the National Cancer Institute between 1965 and 1992. Individuals or their family members were asked to fill out a questionnaire on the cancer history of first and second-degree relatives.

The World Health Organization has classified Helicobacter pylori as a carcinogen for gastric cancer. Imrie et al. (2001) reviewed the literature on Helicobacter pylori in an attempt to determine the association between H. pylori in childhood and the development of distal gastric adenocarcinoma in adulthood. The major risk factor in incidence of H. pylori is poor socioeconomic conditions in childhood. The authors did find an association between H. pylori and gastric cancer. However, they concluded that children should not be screened and treated for H. pylori because it would not be cost-effective.(Alexander & Brawley, 2000), in a review of the literature, cited that several U.S. studies had found highest frequencies of stomach cancer in areas with the highest rates of helicobacter pylori infections in the population. They also reported that H. pylori infection was highly prevalent in black and Hispanic populations. Morales et al. (2001) completed a pilot study to determine if treatment for helicobacter pylori would reverse associated intestinal metaplasia (IM). The authors recruited 84 Hispanic subjects from the Tucson area who had a mean age of 54 years. 29% had gastric IM and 77% had H. pylori. They found that treatment did not significantly reduce gastric IM lesions. They stated that their results suggested that treatment for H. pylori did not reduce the risk of gastric cancer once gastric IM had developed. However, a recent report in NEJM showed a decreased risk of gastric cancer in persons who had joint replacements and the prophylactic antibiotics associated with such surgery (Akre, Signorello, Engstrand, Bergström, Larsson, Eriksson and Nyrén , 2000) In addition, a rare type of gastric lymphoma, MALT, is now initially treated by antibiotics (Fishbach, 2002).

R/E Differences in Stomach Cancer Risks: Wu, Wan, & Bernstein (2001) conducted a population- based study in Los Angeles County of whites, blacks, Hispanics, and Asian Americans with esophageal and gastric cancers to determine if alcohol, smoking, and being overweight were risk factors. Subjects included 222 individuals with esophageal cancer, 277 with gastric cardia, and 443 with distal gastric adenocarcinomia and 1356 controls. They found that current cigarette smoking was a risk factor for all three cancers. Alcohol was not a risk factor for any of the tumor types. High body-mass index (BMI) was significantly associated with esophageal and gastric cardia adenocarcinomas. Burns & Swanson (1995) conducted a population-based case control study of risk for stomach cancer among blacks and whites. Over 700 individuals with

stomach cancer and 3750 controls were interviewed using a telephone survey to obtain occupational and smoking histories. Black men and black and white women had increased odds of stomach cancer if they had ever smoked. Occupations that increased risk of stomach cancer were: agricultural jobs (Odds ratio (OR) of 2.6), driver sales (OR 3.8), assemblers (OR 2.0), mechanics (OR 2.2), and material movers (OR 2.9), black women working as assemblers (OR 5.4), and white women working as food workers (OR 4.0). They found no association between occupations with heavy dust exposure and stomach cancer.

Consecutive cases of gastric adenocarcinoma in patients presenting for treatment at the University of California Irvine Medical Center between 1989 and 1998 were analyzed by Theuer (2000) to assess whether Asian patients had better outcomes from gastric adenocarcinoma than did other racial groups. During the study period they found 52 cases in individuals of Asian origin. All but one was born abroad. They found several notable differences in Asian versus non-Asian patients. Asians were more likely to be diagnosed before age 60. They were less likely to have distant metastases and were more likely to undergo surgery than other racial groups. Three- year survival rates were significantly higher than those for non-Asians. The authors attributed greater survival rates for Asians with regional disease to higher rates of surgery. They also hypothesized that Asians had a less aggressive tumor biology than non-Asians.

Oral Cancers Risk Factors

Oral cancers are between 4 and 5 times more common in men than women (Yang et al., 1989). These cancers also are more common in people over 60 years of age, usually because they take many years to develop (American Cancer Society [ACS], 2001). Use of tobacco and alcohol abuse are the major modifiable risk factors for the development of head and neck cancers (ACS, 2001; Williams & Horn, 1977). A recent study shows that among the US veterans, the risk for laryngeal and pharyngeal cancers is increased in the presence of Gastroesophageal Reflux Disease (GERD), independent of age, gender, smoking, and alcohol intake (El-Serag, et al., 2001). Poor nutrition is considered responsible for approximately one-third of all cancers, including oral cancers (Long, 1999). In fact, a systematic review of the literature regarding nutrition and laryngeal cancer shows that the risk seems to increase with low intake of vitamin C, beta-carotene and vitamin E (Long, 1999; Riboli et al., 1996). Similarly, increased consumption of fruits and vegetables, and of vegetable oils and fish was associated with lower risk (Riboli et al., 1996).

There is some evidence that poor oral health is associated with increased risk of oral cancer (ACS, 2001; Rubright et al. 1996). Individuals with oral cancer, evidently, show high prevalence of painful or ill-fitting dentures (Rosenberg, 1990; Young et al., 1986) due to anatomical changes of the oral cavity. In fact, for males, increased risk of oral cancer is associated with painful or ill-fitting dentures. Whether these associations are causal or due to the lack of detection and treatment of precursors lesions in persons with poor or no dental care is unclear. It is well established that leukoplakias –pre-cancerous lesions in the mouth—are amenable to early detection and treatment

(Schwartz, 2000). Thus uncertainty about the role of denture fit in oral cancer parallels the age and stage patterning of cervical cancer in that current data does not permit distinguishing differences in disease process from differences in treatment quality and access.

Age is a non-modifiable risk of oral cancer. Individuals diagnosed with late-stage oral cancers tend to be older (ACS, 2001; Rubright et al., 1996) screening or examination. A 1999-2000 analysis of Medicare coverage for "medically necessary dental services" suggested policy changes to allow Medicare coverage of dental services related to surgery, chemotherapy and radiation in head and neck cancers and in leukemia (Patton et al., 2001).

Cancers of the larynx and hypopharynx are about 50% more common among AA patients than among whites (Muir & Weiland, 1995; Shiboski et al., 2000). These differences are mainly attributed to higher smoking rates among African Americans (Roach et al., 1992). Studies show that survival rates are lower for AA, as compared to whites (Arbes et al., 1996; Moore et al., 2001). The greatest racial disparity in mortality is observed among individuals under 60 years of age, and in AA men compared to white males (Moore et al., 2001). Whites and individuals younger than 65 are more likely to have an oral cancer examination in the past year than other R/E and age groups (Horowitz & Nourjah, 1996; Martin et al., 1996). A dental visit is one of the most advocated settings to screen and diagnose oral cancers, however, older people, particularly elders of color, report not having seen a dentist in the past year (Yellowitz et al., 1997). Medicare does not cover many basic dental care services (e.g., treatment, filling, removal or replacement of teeth).

Pancreatic Cancer Risk Factors

Pancreatic cancer affects more men than women in all R/E groups. Regarding modifiable risk factors for pancreatic cancer, cigarette smoking has been constantly recognized as an important risk one (Chiu et al. 2001, Miller et al., 1996; Stolzenberg-Solomon et al., 2001). Other risk factors which have been suggested include: elevated BMI and caloric intake (Michaud et al., 2001b; Silverman, 2001), high fat diets, low folate intake (Silverman, 2001), low levels of physical activity (Michaud et al., 2001b), diabetes mellitus, peptic ulcer surgery (Tascilar et al., 2002) and some occupations. Two prospective studies conducted in the US show no association between drinking coffee and alcohol and risk of developing pancreatic cancer (Michaud et al., 2001a).

Both incidence and mortality rates are higher for African American males and females, compared to their white counterparts. Native Hawaiians show slightly higher incidence rates than whites, whereas rates for Hispanics and the Asian-American groups are generally lower (Miller et al., 1996). A recent study using SEER data from 1973-1995 in Hawaii, San Francisco and Seattle showed no racial differences in survival after adjusting for age (Longnecker et al., 2000). Overall, pancreatic cancer risk increases with age particularly among African Americans and Japanese.

C: Review of Behavioral Interventions

Two major themes arise from the literature on cancer and potentially modifiable risk factors. Epidemiological evidence indicates the importance of behavioral risk factors (physical activity, nutrition/weight loss, smoking, drinking) in many of the most prevalent cancers as well as co-morbid health conditions that influence cancer treatment and other health outcomes. At the same time, there is evidence that racial and ethnic minority elders sometimes experience greater cumulative lifetime or current exposure to these risks. The potential thus exists to reduce racial/ethnic disparities in cancer and health by increasing engagement of elders of color in health risk management activities and lifestyle/ behavior change programs. Based on these findings, the study team conducted a systematic review of interventions addressing these behaviors in elders of color. The identification and findings of these studies are examined first. Because the literature proved so sparse in this area, the study also examined a broader range of review and original papers on increasing engagement of elders, regardless of R/E, increasing engagement of adults of color, regardless of age, and increasing engagement by general adult populations in health risk management.

Selection and Identification of Interventions

We conducted electronic searches of Medline and PsychInfo from 1985 to 2002, supplemented by backward search using Social Science Citation Index/Web of Science for selected papers. All searches used the following key words to locate studies of elders of color: interventions, RCT, minority elderly, elders of color, elders, minority, older adults, adults, African-American, Blacks, Hispanic, Latinos, American Indians/Native Americans, Pacific Islanders, and Asian American. For the search on physical activity interventions, additional key words included physical activity, exercise, exercise programs, and health promotion programs. Another source of information was the Evidence Report and Evidence-Based Recommendations on Health Risk Appraisals prepared by RAND and the reports of the Task Force on Community Preventive Services reviews on physical activities. For the search in dietary and weight loss interventions for R/E elders, additional key words included diet, nutrition, weight, and body mass index. Another source of information in this review is the Evidence Report 25 from the Agency for Healthcare Research and Quality entitled, "Efficacy of Interventions To Modify Dietary Behavior Related to Cancer Risk". The review of smoking cessation interventions with elders of color included the additional key words smoking, smoking cessation, tobacco, and tobacco control. The Rand Healthy Aging report "Interventions to Promote Smoking Cessation in the Medicare Population" offered an additional resource.

In order to be considered for this review, source documents needed to (1) have a study population primarily composed of persons of African American, Latino, Asian, AI/AN, or NHOPI decent and/or separate analyses of intervention impact by R/E group, (2) have a study population primarily composed of persons age 50 and older and/or separate analyses for this age group, (3) use a controlled design and offer at least pre- and

post-test measures for a treatment group or treatment/control group post-test measure. In this literature, studies use both behavioral measures and clinical measures to assess outcomes, and we considered studies of both kinds. For example, with respect to nutrition and weight loss, we considered studies with behavioral measures such as consumption of dietary fat, fruits, vegetables, and fiber, as well as studies with clinical measures such as change in cholesterol level, weight, BMI, and blood pressure. All papers that appeared to meet these criteria based on abstracts were obtained in full text, and reviewed by a principle reviewer and the PI for meeting study criteria. Evidence tables were created for these studies only and appear in Appendix I. As will be noted below, there were insufficient studies of behavior change with elders of color to support meta-analysis

Elders of Color and Behavioral Interventions

Physical activity interventions:

We were unable to find general review articles on physical activity interventions and elders of color and examined 10 papers involving elders of color and interventions to change physical activity. We rejected one paper as it discussed physical activity effectiveness for diabetic outcomes in older adults and minorities, and four other papers, as subjects were less than 50 years of age. We reviewed one paper which used focus group discussions to explore issues surrounding physical activity participation and weight loss success among AA older women, resulting in a 6-month culturally appropriate physical activity intervention (Young et al, 2001). Based on the focus group discussions, the intervention is conducted in churches, physical activity plans are individualized and the intervention is based on social cognitive theories which include increasing self-efficacy, learning self-management skills, goal-setting, and modeling experiences. The intervention is designed to optimize social support, group goals are incorporated, and class times are compatible with the church schedule. Sessions begin with prayer and inspirational scripture messages. They are accompanied by gospel music and led by AA instructors. Participants are encouraged to exercise rather than increase their physical activity, as participants preferred this terminology. However, we rejected this paper since it did not report physical activity outcomes. Another paper by Baskin and colleagues discusses the benefits of public health organizations collaborating with black churches to conduct health promotion programs since the majority of adult African-Americans regularly attend church. Churches are excellent meeting spaces and have resources to run outreach programs, and health programs often fit into the mission of the church. (Baskin et al, 2001). Although the paper discussed program examples, we rejected this paper, as it did not report physical activity outcomes

Three papers were accepted involving elders of color aged 50 years or greater and focusing on physical activity and/or multicomponent lifestyle behavior change. Papers needed to have at least pre- and post-test measures of behavior or a treatment/control post-intervention design (Kachevar et al, 2001, Damush et al, 2001, Agurs-Collins et al, 1997). Kachevar and colleagues (2001) conducted a pilot randomized controlled trial with AI elders, ages 55-75 that demonstrated the efficacy of a community-based six-week exercise program in significantly improving self-perceived frequency in exercise

participation in the intervention group while the control group showed no significant changes in self-perceived exercise activity. Damush and colleagues demonstrated how merging of primary care referral to a community-based physical activity program based on social-cognitive theory resulted in improved participation of physical activity in a sample of 500, primarily low-income, AA women, ages 50 or over (Damush et al, 2001). This study was a prospective, single group study where the intervention resulted in physical activity participation of 28% and 9% attending exercise classes after 1 year. A randomized controlled trial of a culturally-sensitive community-based intervention with 64 AA women aged 55-79 years reported a mean physical activity score increase of 22 points at 3 months of the intervention group and significant net increase in physical activity scores (intervention minus control subjects) at 3 months. However, no significant changes were found at 6 months (Agurs-Collins, et al, 1997). The intervention consisted of a 12-week exercise and nutrition education group and was based on the Social Action theory. This study is also described further in the next section on dietary interventions where its results on weight-reduction and HbA1C are discussed.

Although we are unable to draw firm conclusions about effective and efficient program designs to promote physical activity programs for elders of color, the studies examined here offer some evidence to suggest that interventions that are effective with general elder populations can be effective for elders of color. It does seem clear that educational interventions alone will not work to promote physical activity change in elders. Although social-cognitive approaches to physical activity promotion in elders may have some applicability and can help focus the programs, alternatives to traditional group-based intervention may be more effective in promoting physical activity in older adults. These approaches allow older adults to have maximum flexibility in planning the activity and appear to recognize that older individuals are diverse in terms of what type of program will work for them. Successful lifestyle interventions in elders of color may be explained not merely by the intervention, but by the created environment of social support and resulting self-initiated behavior generated within the intervention group (Gregg and Narayan, 1998).   Initial face-to-face contact led to development of individualized personal physical activity plans that included either a traditional group activity or home-based lifestyle activity or a combination, followed-up with repeated ongoing telephone contact appears essential. Telephone contact needs to be problem-solving oriented and motivational. This follow-up could be delivered by a number of community organizations linked with primary care via physician referral with regular reports sent back to the physician (Eakin, 2001). There is also evidence that linking primary care interventions (by physicians, nurses or paraprofessionals based in the primary care setting) with community-based resources existing outside the health care system can support physical activity for older adults (Leveille, 1998). This is essential for the initial engagement of the lifestyle change, tracking, and reinforcement and enhances the motivational and implementation support that is needed.

More research is needed on physical activity promotion in elders of racial and ethnic minority groups as well as effects of physician counseling. Physician counseling on physical activity to ethnic minorities may be very effective, because of the esteem accorded physicians by minorities. Physicians may believe that counseling patients with low socioeconomic status is less effective, but data demonstrate that low-income patients

are actually more likely to attempt behavioral change based on physician advice (Taira, 1997). Offering an option of a primary care referral to a home-based program should be explored. . Models using interventions by mail and telephone need to be tested and lifestyle approaches need to be tested in older individuals and those with chronic disease. More research is needed on long-term effectiveness of physician counseling and group-based interventions to promote physical activity and on lifestyle programs in elders with chronic disease.

Dietary interventions:

There are few studies focusing on dietary interventions for elders of color and all of the identified intervention reports on this topic were variants of controlled trials. Of the seven randomized controlled trials identified in the literature search that did focus on this population, five focused on AA elders, one included 41% AA elders, one included both white and AA elders, and only one study included Hispanic elders. Because these studies utilized such a diversity of outcome measures, meta-analysis was inappropriate: for example, 4 studies included a weight loss or change in BMI measure while 3 offered data on fat consumption. Studies also varied with respect to time frames considered, with some considering only change from the beginning to end of the intervention and others considering longer-term outcomes. None considered outcomes over more than 18 months.

Findings from these studies do suggest that an intervention including individualized counseling, can result in improvements in both behavioral and clinical outcomes measured over the course of the study period for persons who enroll. For example, Kumanyika and her colleagues studied 333 AA adults ages 40-70 with elevated blood pressure and a desire to change their behavior. The found that those randomly assigned to an intervention of counseling to reduce intake of dietary fat, cholesterol, and sodium, had a greater decrease in cholesterol levels than those randomized to the self-help group (Kumanyika et al, 1999).

The Women's Health Trial Feasibility Study in Minority Populations examined 2,208 women ages 50-79 (28% of the population was AA and 16% was Hispanic) (Coates et al, 1999). Coates and colleagues showed significant decreases in fat intake after 6 months among women who were assigned a personal fat gram goal and participated in group sessions for 18 months (Coates, 1999). The intervention was successful in maintaining and 80% participation rate by 18 months. The group sessions in this intervention included discussions of behavioral and nutritional change strategies. The results also showed that there were no significant differences in the results of the intervention between black women and white women. However, the study results did show that the intervention was less effective for Hispanic participants.

Resnicow and colleagues conducted a randomized controlled trial with members of 14 African American churches with an intervention including motivational interviewing (Resnicow, 2001). In this study, churches, rather than individuals, were randomly assigned to 1) comparison group, 2) self-help intervention with 1 telephone cue call, or 3) self-help with 1 cue call and 3 counseling calls. The telephone counseling in

third group was based on motivational interviewing. The self-help portion of the intervention included a video, cookbook, printed health education materials, and several cues imprinted with project logos. At the one-year follow-up period, 861 participants (85% of the initial sample) were assessed and outcomes were measured using food frequency questionnaires. In the pre-intervention period, the number of servings of fruits and vegetables consumed by groups 1, 2, and 3, was 3.61, 3.91, and 3.78, respectively. In the post-intervention assessment, consumption for these three groups was 3.91, 4.38, and 5.17. The significant increase in consumption of fruits and vegetables among those receiving motivational interviews highlights the impact that an individualized level intervention can have on behavior change.

Other studies focusing on dietary interventions for elders of color include an intervention by Ard et al., which was a modified version of the 1000-calorie/day Rice diet (Ard, et al, 2000). Of 56 AA older adults who enrolled, 44 completed the study. After 8 weeks, participants receiving the intervention lost an average of 14.8 pounds, had a decrease in BMI or 2.5kg/m^2, and a decrease in cholesterol of 13.7mg/dL. A recent Kumanyika study looked at 421 overweight white elders and 163 black elders with controlled hypertension (Kumanyika, 2002). Participants were randomized to counseling for weight loss, sodium reduction, both weight loss and sodium reduction, or to usual care which included the use of an anti-hypertensive drug. For those in the weight loss group only, there was a 2.0 kg decrease in weight for AA elders at the end of 36 months compared to a 4.9 kg decrease for whites. For those in the weight loss and sodium reduction group, there was a 1.9 kg decrease in weight for blacks and a 1.7 kg decrease for whites.

Interventions targeting adults of color have found that diet interventions can successfully change behavior. For example, the Southeast Cholesterol Project (Keyserling et al., 1997) used the "Food for Heart Program" consisting of dietary risk assessment, clinician counseling materials, and culturally specific patient education materials. Patients in 21 rural health centers (of whom 40% were over age 50 and 40% were AA) were randomized to usual care or to the dietary intervention. Significant improvements were found for total serum cholesterol, LDL, and dietary change in the intervention group. At one-year follow-up, the reduction in cholesterol was 0.09 mmol/L greater for the intervention group compared to the control group. Similarly, the North Carolina WISEWOMAN Project developed an intervention including three counseling sessions with printed educational materials geared to individuals of low-socioeconomic status (Rosamond et al, 2000). The intervention group (including about 30% women over age 50) had statistically significant dietary changes compared to the control group. After 6 months of follow-up, changes in total cholesterol levels, HDL-C levels, diastolic blood pressure, and BMI were observed (-5.8mg/dL, -0.9 mg/dL, -1.7mmHg, and –0.3 kg/m2, respectively). However, these changes were not significantly different from the minimal intervention group, which was the control group.

Other Weight Loss Interventions:

Like the dietary intervention literature, the literature on weight loss interventions for elders of color is small. Agurs-Collins and colleagues conducted a weight loss

intervention for 64 overweight African Americans with non-insulin dependent diabetes ages 55-79 (Agurs-Collins, et al, 1997). The intervention included twelve weekly group sessions, 1 individual session and 6 biweekly group sessions. There were two comparison "usual care" groups in this study. The first received 1 individual session and 6 biweekly sessions. The second received 1 class and 2 informational mailings. At three months, there were statistically significant differences between the intervention and the usual care groups for weight, level of physical activity, dietary intake of fat, saturated fat, cholesterol, nutrition knowledge, and HbA1c. At six months statistically significant differences were found for weight and HbA1c.

No review paper on weight loss interventions with adults of color was identified. Other studies of weight loss interventions in populations of color have focused on the under 65 population. For example, one study looked at physiological responses of inactive obese pre-menopausal AA and Caucasian women to a 13-week exercise training and behavior modification program (Glass, 2002). The average age of the 29 women participating in this study was 36 years old. The results of the study showed that there were similar outcomes across R/E group for number of exercise sessions completed, total minutes of exercise for the entire intervention, the average minutes of daily exercise, and total estimated exercise energy expenditure. Other results showed similar and statistically significant results in changes in body mass reduction, BMI, girth measurements, and increased VO2max. These results indicate that the higher prevalence of obesity in AA women is not due to physiological responses to diet and exercise, and it seems reasonable that these findings may be generalized to elders.

A study of the effects of dietary counseling for fat and/or energy reduction and weight loss in 86 AA and white pre-menopausal women showed that a low-fat, low-energy diet resulted in similar, statistically significant decreases in BMI, percent body fat, and waist circumference in both R/E groups (Djuric, 2002). However, the results also showed that the extent of weight loss varied depending on baseline weight. McMahon and colleagues studied the efficacy of the use of sibutramine, a weight-loss drug, in obese white and African Americans patients with hypertension (McMahon, et al, 2000). One-hundred-and-fifty participants received the drug sibutramine and 74 patients received the placebo for 52 weeks. Thirty-six percent of the patients in the study were African-American. Patients receiving sibutramine experienced weight loss within the first 6 months and maintained weight until the end of the 12-month treatment period. Of those treated with the drug, 40.1% lost 5% or more of their body weight and 13.4% lost 10% or more of their body weight compared to 8.7% and 4.3% of those receiving the placebo, respectively. Changes in body weight were similar for both white and African-American patients.

Another study looked at the impact of motivational interviewing in improving adherence to behavioral weight-control programs for older obese women with non-insulin dependent diabetes (Smith, et al, 1997). Forty-one percent of the 22 women participating were black. Participants were assigned to one of two groups. The first group was assigned to a standard 16-week behavioral weight-control program providing instruction in diet, exercise, and behavioral modification. The second group was assigned to the

same group behavioral program with three individualized motivational interviewing sessions added. Outcome measures for this study included weight loss, attendance at group meetings, recording food diaries, and recording blood glucose levels. The results showed that those receiving the motivational interviews were more likely to attend group meetings (13.3 vs. 8.9 meetings), more likely to complete food diaries (15.2 vs. 10.1) and more likely to record blood glucose levels (46.0 vs.32.2). Members of both groups experienced weight loss, but there was not a statistically significant difference between the groups.

In a pre-test post-test one group study, 23 African American women (mean age = 38 years) participated in a 32 week culturally sensitive lifestyle enhancement awareness program of 16 weekly sessions on weight loss (setting goals, monitoring eating behavior and addressing factors influencing weight loss) and 16 weekly sessions on weight loss maintenance (addressing relapse); factors associated with both weight loss and weight loss maintenance were studied (Walcott-McQuigg, et al, 2002). Women completing the weight loss program showed significant reductions in BMI, percentage body fat, waist/hip ratio, and a significant increase in exercise activity, with weight loss being significantly correlated with attendance and dietary readiness to decrease emotional eating. Women who completed the weight maintenance program maintained a significant loss in BMI, and increased their HDL and dietary readiness to monitor hunger and eating cues.

Tobacco use reduction interventions

Literature reviews reveal almost no published studies of tobacco use reduction interventions conducted with elders—irrespective of R/E group. Elders have been included in general populations studies of a wide range of tobacco use reduction interventions (clinical treatment, community-based interventions and mass media programs) and in studies of culturally tailored programs directed at specific R/E communities. There appear to be no published studies that report separate impact findings for elders of color of behavioral, NRT, or anti-depressant interventions. CMS staff report that Medicare is planning a demonstration project with smoking cessation and elders, which includes telephone counseling, nicotine replacement therapy, and anti-depressant therapy (buproprion). This plan was stimulated in part by the findings of the Rand Healthy Aging study that concludes that there is sufficient evidence to support the efficacy and effectiveness of smoking cessation programming with elders.

The 1998 U.S. Surgeon General's Report and the meta-analyses of elder smoking conducted by RAND, and of African American tobacco use reduction by Pederson et al, respectively, suggest two general themes which may apply to treating tobacco use among minority elders. Effective treatments for the general population should be similarly effective with minority elders. The Public Health Service guideline, Treating Tobacco Use and Dependence (Fiore et al, 2000) identifies effective treatments and specific responsibilities for clinical practice sites, for cessation specialists and for health care systems. Notwithstanding the potential differences in the ways in which some racial/ethnic groups might absorb and metabolize constituents of tobacco smoke, dose-

related counseling for elders of color will be effective as will pharmacotherapy; and health care systems must support the continuing clinical treatment of tobacco use.

The other theme is that strategies for tobacco use reduction among racial and ethnic minority elders require cultural tailoring. In the general population, only a fraction of current smokers seek out assistance in tobacco cessation. Engaging the current smoker in treatment is a formidable challenge across all populations; and since smokers in communities of color may respond to mass media and tobacco cessation messages differently from whites (Warnecke et al, 1991), specific cultural tailoring of programs, and promotion of those programs, can assist in engaging minority elders.   Research conducted by the NCI-funded Programa Latino Para Dejar de Fumar, for example, on the attitudes, norms, expectancies and values of Hispanic smokers led to strategies that incorporate familism (the normative and behavioral influence of relatives) and *simpatía* (a social mandate for positive social relationships). Setting a positive example for grandchildren is a theme that could reinforce the motivation of an Hispanic elder to engage in treatment. As noted in the Pederson et al review of African American tobacco reduction studies, and as demonstrated in the Massachusetts tobacco control program, the African American inner-city church can play an effective role in engaging minority members in smoking cessation and as a location for cessation treatment.

A 1998 Surgeon General's Report addresses tobacco use among U.S. racial/ethnic minority groups (US National Center for Chronic Disease Prevention and Health Promotion, , 1998). The Report cites culturally tailored tobacco interventions for Hispanics, such as the Programa Latino Para Dejar de Fumar (Hispanic Program to Quit Smoking) in San Francisco, (Perez-/Stable et al. 1993, Marin and Perez-Stable, 1995), which developed a self-help manual, Guia Para Dejar de Fumar), and Si Puedo (Yes, I Can) in Queens, New York; for American Indians (It's Your Life—It's Our Future); Chinese (Victory Over Smoking) and Vietnamese. Pathways to Freedom: Winning the Fight Against Tobacco is a self-help manual targeting African Americans (Robinson et al. 1992).

California has funded ethnic tobacco education networks for Hispanics, African Americans and Asian / Pacific Islanders. The Massachusetts Tobacco Control Program has developed tobacco media campaigns for minority populations. These culturally-tailored interventions have been variously described but not rigorously tested for effectiveness, except for a study of a Vietnamese intervention in Santa Clara County (Lai et al, 2000)) which found reasonable participation rates and high quit rates.

Pederson and colleagues reviewed cessation programs and self-quitting as regards to African Americans in articles from 1988-98 (Pederson, 2000). The study, which examined 56 studies, concluded that church-based cessation programs may provide an appropriate location for interventions but did not demonstrate unequivocal effectiveness. Community-based interventions showed no differences between African Americans and whites. With regard to self-quitting, both sociodemographic variables and smoking historical variables for African Americans resembled the general population. Although clinic-based programs for African Americans did not demonstrate effectiveness in this review, a double-blind, placebo-controlled, randomized trial at an inner-city hospital

outpatient program conducted by Ahluwalia et al (1998) showed 17.1% 6 month quit rates with the nicotine patch (and 11.7% with the placebo patch). More recently, Ahluwalia et al examined the effects of bupropion versus placebo along with 8 motivational counseling sessions by African American counselors, in a randomized double-blind, placebo controlled trial in 600 African American adult smokers treated at a community-based health care center over a 7 week period (Ahluwalia, et al, 2002). Biochemically confirmed 7-day point prevalence abstinence was measured at weeks 6 and 26 following the quit day and this cessation measure was significantly better for the intervention group versus the placebo group (36% vs. 19%) and the effect was maintained after 26 weeks (21% vs. 13.7%). The intervention group experienced a significantly greater mean reduction in depression symptoms at week 6 compared to the placebo group, and the intervention group also gained significantly less weight.

Fisher and colleagues examined a community intervention in low-income African American neighborhoods in St. Louis that involved cessation classes, a billboard campaign and door-to-door distribution of self-help materials (Fisher, et al. 1998). The program appeared to reduce prevalence from 34% to 27% in the intervention neighborhoods compared to a 1% reduction (from 34% to 33%) in control neighborhoods in Kansas City. Schorling and colleagues (1997) studied a church-based intervention in Virginia—consisting of individual counseling and self-help materials within the context of community activities--implemented in one rural community demonstrated changes in smokers' stages of change compared to a control county (Schorling, et al, 1997). Another stages-of-change intervention, developed and tested in Harlem by the Harlem Health Connection (involving a culturally-tailored cessation guide, a cessation video featuring African American historical figures and telephone support did not reveal a significant difference in quit rates compared to a control group which received non-tobacco specific health education materials. An intervention by Goldberg to train medical students found changes in stages of change of outpatient smokers compared to control groups, but not in quit rates (Goldberg, 1994).

One study with great salience for elder of color tobacco use is that quitting tobacco increases life extension regardless of age of quitting. This study by Taylor et al (2002)-- which analyses data compiled on 676,306 women and 508,351 men participating in Cancer Prevention II, a prospective study begun in 1982—finds that tobacco users who quit at age 65 gain 2.0 years of life expectancy among men and 3.7 years among women. Despite the gains in life extension and quality of life from smoking cessation at any age, elders may be less likely to perceive the benefits of quitting or the continued harm of smoking, according to a RAND evidence review and meta-analysis, "Interventions to Promote Smoking Cessation in the Medicare Population". The RAND study identified 488 articles (248 of which satisfied screening criteria), of which 149 related to patient education, 118 to individual counseling, 104 self-help, and 76 involving patient financial incentives. This study concluded that individual, telephone and group counseling as well as pharmacotherapy are effective in promoting smoking cessation.

One area of special interest are possible racial / ethnic differences in absorption and metabolism of nicotine and other tobacco constituents. The 1998 Surgeon General's

Report observes evidence that African Americans have higher cotinine levels per reported number of cigarettes smoked per day than whites (Wagenkneckt et al 1990; English et al 1994; Clark, 1996). Possible explanations include that African Americans absorb more nicotine from tobacco than whites and/or that African Americans smoke differently as a group, e.g. puff more deeply or hold smoke longer in the lungs (Benowitz et al. 1995)

Alcohol use reduction interventions:

No reviews or articles describing specific interventions or efforts to empirically test alcohol interventions for elders of color were identified. The lack of intervention studies with elders of color is a gap in the current literature of elder alcohol use/abuse/treatment research. Part of the reason this gap exists is a lack of understand of the extent and type of drinking patterns that exists among elders in general and elders of color specifically. Methodological limitations of existing studies have hampered theory development that would assist in the development of such intervention studies: none of the studies identified consider possible racial/ethnic group differences in elder attitudes and values concerning drinking, perceived drinking norms, symptoms of depression, or social supports as determinants of current drinking behaviors. Education and other social-economic status indicators and health status have been considered as correlates of lifetime but not current drinking in most published reports. Similarly, prior studies have not explored interactions between race/ethnicity and any of the potential correlates of lifetime or current drinking behaviors. This is certainly an area for future research.

Difficulty in engaging adults to change behavior

Although the literature on behavior change for elders of color is sparse, several studies indicated few differences between white elders and elders from traditionally underserved R/E groups. Major conclusions from systematic reviews of lifestyle interventions from studies addressing general (primarily White) populations with relevance to elders of color are described below. Dominant among these conclusions is the difficulty in engaging and maintaining engagement of older adults and others in these programs.

Physical activity interventions:

While several reviews of physical activity and multi-component interventions and individual studies with this focus were identified, no comprehensive review of nutrition and weight loss programs for older adults was identified. In a comprehensive systematic review, King identified 29 studies from 1985 to 1997 involving randomized controlled or quasi-experimental interventions to promote increases in physical activity participation by older adults (>=50 years) (King, 1998). In this review, effective strategies targeting older adults used behavioral or cognitive-behavioral strategies rather than health education, exercise prescriptions, or instruction alone. The review reported increased physical activity participation rates but a relative lack of specific behavioral or program-based strategies aimed at promoting physical activity. One randomized controlled trial in 1997 demonstrated utility of social-cognitive strategies using groups and took advantage

of the group structure to enhance physical activity levels following termination of the formal group, and only two studies systematically tested effects of specific cognitive or behavioral strategies in influencing exercise participation. A number of studies illustrated that structured group-based physical activity formats did result in short-term (6 months or less participation rates), but may not produce long-term changes in behavior. Studies of interventions using a combination of group and home-based formats found better activity adherence compared to programs that used a group format only. Ongoing telephone supervision in three studies, preceded by face-to-face counseling, and structured exercise or home-exercise was effective in improving adherence rates up to 2 years. King reported a lack of studies done in R/E elders.

Our search for controlled trials of physical activity interventions revealed that church-based culturally appropriate interventions using the social learning theory, with 20 week sessions on physical activity and nutrition and taught by lay advisors, improved physical activity at one year follow-up in African Americans (Yanek, et al, 2001). In this population, the self-help group did not show benefits as compared to the intervention group, and a spiritual component did not enhance physical activity. However, a six month culturally appropriate intervention using the social cognition theory in Mexican American women did not increase physical activity; possibly due to randomization failure (Carlos Poston, 2001). In another study, an intervention that emphasized self-directed learning and culture was more effective in Pima Indians at preventing weight gain and glucose intolerance, than a more structured lifestyle intervention that involved structured physical activity and nutritional recommendations (Narayan, et al, 1998). Both groups reported significantly improved physical activity levels but neither intervention achieved weight loss on average. Thus, an indirect approach motivated from within the culture was more effective than the lifestyle intervention. Again, literature was sparse for this population, but based on our review, adults of color may benefit from community-based, culturally appropriate interventions, which are less structured.

In a review of 38 randomized controlled studies to determine the effectiveness of physical activity interventions for older adults (average age >=50 years and minimum of 40 years; most studies had a mean age of 68 years), from 1985 to 2000, three types of interventions identified were: home-based, group-based/supervised, and educational (van der Bij, et al, 2002). In 16 of the 17 studies reporting participants' ethnicity, samples were exclusively or predominantly white. Authors reported that all three interventions can result in increased physical activity but that changes were small and short-lived without clear evidence on the effectiveness of behavioral reinforcement strategies such as reminder telephone calls, social support, and buddy groups on the initiation and maintenance of physical activity. Only two studies for the home-based interventions reported changes in physical activity and both studies reported a decline after the interventions ended, but in one study the decline was significantly larger in the control group. Participation in education interventions was much lower than for home and group-based interventions, but the clinic and group-based models were more often geared to highly motivated persons. Only a minority of studies evaluated changes in physical activity levels, with group-based and education interventions effective in increasing physical activity in the short-term. Long-term education interventions were ineffective in

improving physical activity levels and insufficient data were available on long-term effectiveness of group-based interventions.

For elders, it is important to find alternatives to formal structured group programs; data in King's review indicated that a substantial portion of older adults prefer to engage in physical activity outside of a formal group. Although King's review discussed preliminary findings of the CHAMPS II model, our review included more detail on the CHAMPS II model, a one-year lifestyle program for seniors based on social cognitive theory, where 58% of the targeted group adopted a new physical activity and 35% maintained this activity (Stewart, 2001). This study of 173 adults aged 65-90 years, is important as it is based on the personal choice model and designed to increase moderate physical activity through utilization of existing community programs, but the sample was fairly well educated and did not include elders of color. Programs like the CHAMPS II could be delivered by community agencies linked with primary care via physician referral with feedback to the physician or having the initial counseling session take place within the primary care setting.

Since persons with significant chronic disease represent the majority of the older adult population, one review included two well-designed trials on persons with arthritis and one uncontrolled trial on COPD patients and reported that long-term exercise participation can be promoted in this population to prevent disability (King, 1998). Also reviewed were studies on chronic diseases self-management in elders since growing literature exists on the effectiveness of elder chronic disease self-management programs with effective community linkages (Lorig, et al, 1999, Leveille, 1998). Lorig examined the effects of a nurse-supervised self-management program for 952 adults with chronic disease during a six-month randomized controlled trial at community-based sites such as churches, senior centers, community centers, libraries, and health care facilities. Lorig and her colleagues found that treatment subjects demonstrated significant improvement in exercise minutes per week as well as fewer hospitalizations and days in the hospital so that health care expenditure savings approximated $750 per participant, more than 10 times the cost of the intervention (Lorig, 1999). Leveille et al provided evidence that a one year senior center based randomized, controlled, chronic disease self-management and physical activity program which collaborated with primary care providers for 201 chronically ill older adults, significantly improved physical activity levels. The study also concluded that the intervention reduced hospital days in the intervention group (increased number of hospitalized participants by 69% in controls and decreased by 38% in intervention group), thus yielding a savings of at least $400 per participant per year (Leveille, 1998). The intervention consisted of a targeted health management plan developed by the participants and a geriatric nurse practitioner focusing on risk factors along with physical activity (either senior center or home based) and chronic illness programs, three follow-up visits, and 9 phone contacts by the nurse. These studies were done in predominantly white, relatively educated communities and it is unclear how these models may need to be adapted to other populations and communities.

Tobacco use reduction interventions:

The Centers for Disease Control and Prevention (CDC) has promulgated Best Practices for Comprehensive Tobacco Control Programs, which has served as a model for state tobacco control (CDC, 1999). The CDC Best Practices document recommends the creation of community programs, one of whose four goals is the "elimination of disparities in tobacco use among populations." Additionally, the Best Practices document calls for spending of $.40 to $1 per capita for statewide programs for "funding multicultural organizations and networks to collect data and develop and implement culturally appropriate interventions and for "supporting innovative demonstration and research projects to prevent youth tobacco use, promote cessation and the implementation of tobacco use counseling and treatment for young people and adults."

The National Center for Tobacco-Free Older Persons (NCTFOP) — part of The Center for Social Gerontology (TCSG) in Ann Arbor, Michigan—is an advocate for older persons harmed by tobacco use and the tobacco industry and manages a list serve and web site for issues of tobacco and older persons, including minorities. The Center for Tobacco Research and Intervention at the University of Wisconsin Medical School has developed a program to serve elder tobacco users by providing free nicotine patches for elders who enroll in the Wisconsin Quitline for counseling; but the program, which is not expected to serve significant numbers of minority elders, has not yet been evaluated.

Dietary and weight loss interventions:

Recruiting volunteers and maintaining participation for the entire course of dietary intervention studies has been identified as critical issue in the dietary intervention literature. For example, in a study by Yanek and colleagues where churches, rather than individuals were assigned to treatment and controls, the researchers encountered difficulty in getting churches to agree to have their members be in the control group (Yanek, 2001). Churches were much more willing to participate if their members would receive the intervention. The problem with maintaining volunteer participation over a study is highlighted in this same study where, at one-year follow-up, only 56% of participants completed the biological measures of the study and only 38% completed the behavioral, diet, and physical activity measures. While longer follow-up periods are more accurate in terms of assessing the long-term effects of an intervention, difficulties in keeping participants in the trial can limit the generalizability of results.

Most of the dietary intervention literature has been targeted to the general adult population and there is a wealth of information from major national interventions and smaller studies. The CDC's 5 A Day for Better Health Program is an example of a dietary intervention aimed at providing educational materials to individuals of all ages and races in order to increase their consumption of fruits and vegetables (CDC web site/Nutrition and Physical Activity). The 5 A Day educational materials have been used in a variety of settings. For example, results of a pilot study of an educational intervention to increase fruit and vegetable consumption among callers to the Cancer Information Service found that a brief educational message using materials from the "5 A Day for Better Health Program" and reinforcement with follow-up mailings led to

behavior change (Marcus et al, 1998). The study also showed that after a 4-week follow-up subjects consumed an average of 0.75 additional servings per day compared to before the intervention.

Tilley and colleagues report the results of the Next Step Trial worksite dietary intervention (Tilley et al, 1999). This randomized control trial included 5,042 employees, 66% were over age 50, and 97% were male. The intervention included classes, mailed self-help materials, and personalized dietary feedback. At one-year follow-up, there was a statistically significant 0.9% decrease in fat consumption, a 0.5g/1,000 kcal increase in fiber consumption, and a 0.2 serving/day increase in the consumption of fruits and vegetables. At two years, these results were significant for fiber only.

Miller conducted a meta-analysis of weight loss research over twenty-five years comparing the effects of diet only, exercise only, and diet plus exercise (Miller, et al, 1997). The results show that the weight loss over a 15-week period for a middle-aged population (average age of study population was 39.5) from each of these methods was 10.7 +/- 0.5, 2.9 +/- 0.4, and 11.0 +/- 0.6 kg, respectively. However, the results at one-year follow up indicate that diet plus exercise was the most effective method of weight loss. Another meta-analysis looked at effect of a low-fat diet on weight loss (Astrup, et al, 2000). The authors found that the low-fat intervention produced a mean fat reduction of 10.2% (8.1-12.3). The low-fat intervention group also had greater weight loss compared to controls.

A recent literature review of dietary intervention and disease prevention highlights the impact that diet can have on preventing cancer, heart disease, stroke, and non-insulin dependent diabetes (Bowen and Beresford, 2002). This work synthesizes the results of interventions aimed at individuals, families, and those delivered through providers and through other community channels such as worksites, churches, and grocery stores. Most of the studies reviewed did not focus on interventions for R/E groups but taken together, these studies give some indication of the effectiveness of interventions in the general population. The results of this literature review indicate that most individual intervention studies have been geared toward individuals with existing risk factors and to individuals who were motivated to change behavior in some way. Because highly motivated individuals are more likely to engage fully in the interventions, this leads to the conclusion that more intense interventions can result in larger effect sizes. For this reason, self-selection of volunteers plays an important part in the outcome of a study, and building more evidence on the determinants of engagement arises as a central concern.

A similar finding was reported in an Evidence Report from the Agency for Healthcare Research and Quality entitled "Efficacy of Interventions To Modify Dietary Behavior Related to Cancer Risk." (AHRQ, 2000) This report found that in a review of studies on fruit intake, all six studies that were conducted in high-risk populations reported significant intervention effects compared to only eight out of fourteen studies conducted among general-risk populations. This is not, however, direct evidence that fruitful intervention strategies can be effectively adapted to use by Medicare beneficiaries of color.

The most common form of dietary intervention identified in the Bowen & Beresford paper is individual or group counseling. This method is often successful in changing dietary behaviors by large amounts. Individualized interventions can involve counseling, as well as personally tailored feedback on nutrition and goals for weight loss. Other types of interventions include self-help print materials, newsletters, church based activities, fliers and signage, demonstrations, point-of-purchase labeling, and mass media efforts. Bowen & Beresford identified a study by Rhodes et al. (1996) that found that dietician led interventions produced significant decreases in dietary fat and cholesterol intake compared to videotape and other print material interventions.

In its review of 92 studies on the impact of interventions on dietary fat intake and consumption fruits and vegetables, the AHRQ Evidence Report concludes that there are several dietary interventions that appear to be effective in modifying diet (AHRQ, 2000). These include interventions involving social support, goal setting, small groups, food-related activities such as cooking, and interventions with a family component. Of seven studies reviewed that used social support as part of the intervention, all seven reported a significant intervention effect for total fat intake. This report also emphasizes the need for future dietary intervention research to follow participants for more than one year in order to learn more about the long term effects of dietary intervention, the maintenance of change, and the prevention of relapse over time.

Lifestyle interventions and multi-component interventions

Findings from a meta-analysis of randomized and non-randomized controlled trials evaluating patient education and counseling for preventive health behaviors including 39 studies on smoking/alcohol, 17 studies on nutrition/weight control, and 18 studies on other topics in patients without diagnosed disease, made a strong case for systematic delivery of these interventions by health care providers (Mullen et al, 1997). Using behavioral techniques specifically self-monitoring and using several communication channels such as media plus personal communication produced larger effects for the smoking/alcohol and nutrition/weight groups.

Our review of lifestyle physical activity interventions in adults included five randomized controlled lifestyle interventions, 1 pre-post study which included 70% minority adults, 1 randomized controlled study of minority adult women, 1 pre-post study of older adults (>65 years), and one randomized controlled study of older adults (>65 years), from 1995 to 1998 (Dunn, 1998). This review demonstrated that lifestyle physical activity interventions effectively increased and maintained levels of physical activity to levels that meet or exceed public health guidelines for physical activity using social cognitive theory, the transtheoretical model, and behavior learning. Effective interventions included those delivered via face-to-face contact. However, the randomized study of minority adult women effectively increased minutes of walking at 2, 5, and 30 months using telephone and written materials. The pre-post study that examined interventions in older adults only showed improvement in functional status and not physical activity. Dunn's 24-month randomized study of adults aged 35-60 years, reported in this review and reviewed by us in their 1999 publication. This report showed

that a behaviorally based lifestyle intervention where participants met once a week for 16 weeks and then biweekly for another 8 weeks to learn cognitive and behavioral strategies to accumulate 30 minutes of moderate intensity physical activity on most days was as effective as a traditionally structured supervised exercise sessions five days per week (Dunn, 1999). Both groups showed increased physical activity and cardiorespiratory fitness, as well as significant improvements in cholesterol/HDL ratios, blood pressure and body fat percentage from baseline to 24 months. Thus, lifestyle interventions may be essential for those with barriers such as lack of time, lack of access to facilities, dislike of vigorous exercise and structured group activity. This finding is consistent with those reported for elders of color and adults of color. A follow-up study on the Dunn project revealed that costs of the lifestyle and structured interventions were, respectively, $46.53 and $190.24 per participant per month at 6 months, and $17.15 and $49.31 per participant per month at 24 months (Sevick, Dunn, et al, 2000).

The Activity Counseling Trial (ACT), was a multiple site randomized controlled trial designed to evaluate effectiveness of interventions to promote physical activity in the primary health care setting among 874 men and women, 35-75 years of age, with 24 month follow-up using social-cognitive theory (The Writing Group for the ACT Research Group, 2001). Interventions included a recommended care/advice group consisting of physician advice and written educational materials, an assistance group which included the same as the recommended care group plus interactive mail and behavioral counseling at physician visits, and a counseling group including the same as both the groups plus regular telephone counseling and behavioral classes. The two patient counseling sessions were equally effective in improving cardiorespiratory fitness over 2 years compared with recommended care in women, while neither of the two counseling interventions were more effective in men than recommended care. Thus, this argues for more intensive physical activity counseling for women to improve fitness levels versus advice alone. In the Physician-based Assessment and Counseling for Physical Activity (PACE) five-month study, physicians were trained for 1-2 hours to give a 5 minute counseling session using social cognitive theory and the transtheoretical model. Four out of 6 precontemplators reported thinking about physical activity more, 31 out of 47 contemplators reported increased physical activity, and 35 out of 45 "actives" reported maintained or increased activity levels (Long, et al, 1996). In another study in which family physicians were trained for 15 minutes on the use of a 3 minutes protocol for physical activity advice to 396 patients, participants received the advice plus an educational handout and a 1-month telephone follow-up. 18% of patients seeing the experimental group of physicians giving advice reported regular physical activity versus just 6% of patients seeing control group physicians (Lewis and Lynch, 1993). However, the Johns Hopkins Medicare Preventive Services Demonstrations project examined the effect of preventive health examinations in elders for two years with optional counseling visits to their primary care providers, as compared to a usual care control group. They found no significant increase in physical activity in participants randomized to receive exercise counseling (Burton et al, 1995).

Another randomized controlled 6-month pilot study of disability prevention and health promotion of 100 elders was also reviewed (Wallace, 1998). This study conducted

at a senior center serving predominantly White elders, included a health promotion program with supervised exercise three times a week for 6 months, nutrition counseling, smoking and alcohol cessation interventions as needed, and telephone follow-up by a nurse at 2,4,and 16 weeks to review subjects' progress. Improved SF-36 scores and disability days demonstrated the feasibility and efficacy of providing a health-promotion program in a community senior center where physical activity improved, thus impacting health and functional status. Involvement with a health provider and social activation at the senior center could have contributed towards the improved outcomes.

Also reviewed was a report examining the effectiveness of a telephone-based health promotion program targeting 1741 high risk, ready-to-change adults using a quasi-experimental design with pre/post between-group comparisons of lifestyle-related health risks (Gold et al, 2000). Programs were offered in cholesterol control, eating habits, exercise and activities, stress management, tobacco use, weight control, and back care, and conducted by a health educator providing 3 –5 telephone counseling contacts designed to produce change over a one-year period. Participants were 1.6 to 3.5 times as likely as non-participants to reduce targeted risk in six of seven risk areas. Overall, participants significantly reduced their number of risks whereas non-participants significantly increased their risks. In this study, subjects were not randomized to either control or treatment group.

Wilcox et al conducted a quantitative literature review that examined the magnitude of the effects of 32 studies on dietary and physical activity interventions delivered in health care settings in reducing cardiovascular risk factors (Wilcox et al, 2001). Intervention effects were modest but statistically significant for physical activity, body mass index, dietary fat, blood pressure, and total and low-density cholesterol.

Roles of physicians/primary care practitioners

Physicians/other primary care practitioners and patients need to be able to prioritize the many competing demands of both preventive care and those of chronic illness in elders. Busy primary care settings cannot consistently implement disparate health behavior interventions; these interventions share common elements that can be combined under a common model (Eakin, 2001). For example, in the area of self-management of chronic illness, a common model has been identified to address health behavior change (Lorig, 1999, Leveille, 1998, Von Korff, Gruman, Schaeffer, Curry and Wagner, 1997). It appears that supervised health promotion programs with an exercise and chronic disease self-management component with primary care collaboration, covering a variety of lifestyle issues, and follow-up telephone counseling may potentially be extremely effective for elders since a large percentage have chronic disease.

Lack of time and staff support for physical activity counseling continues to be a concern of physicians. In addition, lack of reimbursement, lack of skill and confidence in counseling for behavior modification is a common concern voiced by physicians for

physical activity counseling. Lack of long-term efficacy with physician only counseling and poor ability to integrate community and other supports into the therapeutic regimen are also problems. Using data from the 1995 National Health Interview Survey, Wee and colleagues found that only 34% of participants received counseling about physical activity from their physicians. Physicians appeared to counsel as a form of secondary prevention and were less likely to counsel those patients who were moderately overweight and lower socioeconomic groups. Higher counseling rates were observed in obese patients or who had comorbid conditions (Wee, 1999).

Considerable research on physical activity counseling in adults exists. Eakin reports that successful brief physical activity counseling promoting modest, short-term increases in physical activity in adults, included 3-10 minute interventions focusing on physical activity only, as opposed to multiple health behaviors, tailoring of counseling and provision of tailored materials, and can be done by all types of health professionals (Eakin, 2001). A systematic review of the effect of physician counseling to promote physical activity in adults, identified thirteen articles in the past 30 years out of which six were randomized controlled trials and seven were quasi-experimental studies (Petrella, 2002). Most studies used strategies to address stage of change and found positive relationships between counseling and physical activity adoption, stage of change, and change in physical activity level but long-term effect of interventions was not established. Interventions that included written materials, considered behavior change strategies, and provided training and material for physicians effectively increased physical activity levels.

Physical activity counseling should be viewed as an ongoing and not an isolated event since one-time counseling is unlikely to result in long-term increases in physical activity, but brief counseling may help patients progress through stages of behavior change (Eakin, 2001). In an interview of 2507 community-dwelling Medicare beneficiaries aged 65 and over, 40% of the 301 elders who initiated activity said that their physician was a very important influence (Burton, et al, 1999).

Physicians and other primary care practitioners have the potential to counsel a significant amount of their patients about physical activity and contacts between physicians and older adults offer many opportunities to promote a healthy lifestyle, but practitioners will need training along with adjustment of office-based systems. It is unclear whether or not physician intervention would be required for initial motivation of a lifestyle change, and it may be the combination of health care system backing, culturally tailored motivational communications, and follow-up in the community. Based on a review of 77 theoretical, prospective cohort, and intervention studies on physical activity effectiveness and efficacy in the prevention and management of NIDDM among older adults and minorities, Clark (1998) comments on physician or clinic counseling in isolation from other resources. It is not likely to be the most effective approach to promoting physical activity in older adults; rather this population could benefit more from comprehensive programs drawing upon community resources (Clark, 1998). The U.S. Preventive Service Task Force found insufficient evidence to recommend for or

against behavioral counseling of physical activity by primary care physicians (Eden et al, 2002).

Cost-effectiveness studies

       Several initiatives have explored health promotion interventions for the Medicare population. Two reports discuss a demonstration health-promotion program implemented in a staff-model HMO designed to test cost-effectiveness and outcomes of the program at 24 and 48 months for 2558 Medicare beneficiaries (Patrick et al, 1999). Researchers offered intervention participants a health-risk assessment, health promotion visit, disease prevention visit, and follow-up classes compared to usual care for control group participants. At 24 and 48 months, the treatment group participated in significantly more exercise and consumed less dietary fat. But the intervention did not yield lower cost per quality-adjusted life years and total cost of care did not significantly differ between the two groups, except for the capitation amount of $186 per treatment-group enrollee per year provided by HCFA.

       Another demonstration study determined whether adding a benefit for yearly preventive visits for 2 years and optional counseling visits to their primary care provider to 4195 older Medicare beneficiaries affected costs, comparing Medicare claims data for the two years in which preventive visits occurred (Burton, et al, 1995). Authors reported no significant differences in charges between the intervention and control groups with a modest health benefit seen in the intervention group. German et al, (1995) reporting results on this same demonstration project of access to preventive services for Medicare beneficiaries reported that 63% of beneficiaries in the intervention group made a preventive clinical visit and approximately 50% made a counseling visit. The results of this study showed that those in the intervention group had a greater health benefit as measured by mortality. The death rate in the intervention group was 8.3% compared to 11.1% in the intervention group. The results also showed that for men, being married and having a solo practitioner were positively associated with making a preventive clinical visit. For women, having a mammogram, having a confidant, and a high school education, and having a female solo practitioner were related to the likelihood of making a preventive clinical visit.

A Note on Health Risk Appraisals and Motivational Interviewing

       The RAND Evidence Report on Health Risk Appraisals (HRA) and Medicare provided evidence-based recommendations regarding the use of HRA in health promotion programs for elders (Shekelle, P and Southern California Evidence-Based Practice Center, 2002). Out of a total of 267 journal articles, unpublished reports, and conference presentations, 27 were controlled trials and data indicated that the more intensive interventions, which included follow-up and feedback following HRA, are the most effective. This data agrees with the Leveille study in which follow-up telephone contact was essential after establishing the initial health promotion program (Leveille, 1998). However, out of the 27 controlled trials, 7 studies are reported to have 85% or more white persons, 18 give no data regarding race/ethnicity, one study with mean age

39-43 years had >50% white persons, and another study had >84% white. The study does conclude that these interventions are most likely to effective when feedback on health risks is combined with follow-up interventions and materials, but programs that use HRA alone or with a single follow-up contact do not appear to hold promise

Health risk appraisals that follow-through with programs using tailored print communications (TPCs) created especially for an individual based upon knowledge about that individual are particularly effective in conveying risk information in a conceptual level comprehensible by the individual. These materials provide individually relevant and appropriate information. For example, Rimer and Glassman (1999) describe the uses and effectiveness of TPC for several areas of cancer risk communication (CRC) such as dietary change, smoking cessation, mammography use, hormone replacement therapy, and genetic susceptibility to cancer. Following health risk appraisals, the use of individualized learning plans and motivational interviewing has also been proven to increase the motivation of individuals who need to change health behaviors.

Miller and Moyers (2002) describe theoretical assumptions of motivational interviewing, controversies surrounding denial and resistance and combinations of motivational interviewing with other treatments. Motivational Interviewing is a technique that has potential for successful application in effecting behavior change. Since it is by definition customized to the individual, it should be an effective method amongst elders of color as well. Dunn and colleagues conducted a systematic review of 29 randomized trials of motivational interventions (MI) for four behavioral domains: substance abuse, smoking, HIV risk and diet/exercise (Dunn et al, 2001). Out of the 29 studies, 60% yielded at least one significant behavior change effect size. Substantial evidence existed that MI techniques are effective for substance abuse when used by clinicians who are non-specialists in substance abuse treatment, but data were inadequate to judge the effect of MI for the other domains. There was no significant association between length of follow-up time and magnitude of effect size.

Stein et al, tested motivational interviewing for reducing alcohol use on 187 needle exchange clients through a randomized clinical trial (Stein, et al, 2002). The brief MI consisted of two 1-hour therapist sessions following assessments visits, one month apart, and focused on alcohol use and HIV risk-taking. Drinking days were significantly reduced in both groups, but comparisons on dichotomous outcomes showed that those in the MI group were over two times more likely than controls to report reductions of 7 days or more. Heavier drinkers appeared more suited for this intervention, but further research is needed on optimal intensity of treatments and which components of MI are most effective.

A further study reported preliminary and modest support of a MI strategy used for 269 resistant pregnant smokers (Stotts, et al, 2002). In this prospective, randomized, controlled trial, all participants received brief counseling plus a self-help booklet at their first pre-natal visit and seven booklets mailed weekly, while the intervention groups received a stage of change-based personalized feedback letter and two telephone counseling calls using MI strategies. All participants reported smoking in the past 28 days at 28 weeks. An implementation analysis suggested that 43% of women in the

intervention group were classified as not smoking compared to 34% of the control group and at 6 weeks postpartum, 27% of the experimental group reported being abstinent or light smokers, versus 14.6% of the controls.

Moyers and Rollnick apply the motivational interviewing approach to resistance, conceptualized as the product of an interaction between the client and the therapist, and review principles of motivational interviewing, therapeutic goals, sources of resistance between the therapist and client, as well as specific recommendations for responding, giving three case vignettes (Moyers and Rollnick, 2002).

Mallin discusses the importance of combining behavioral and drug combination to dramatically increase the patient's chance of quitting smoking (Mallin, 2002). Family physicians can use motivational interviewing techniques to encourage and support smoking cessation, to help patients move from the precontemplation stage through the contemplation stage and thus to the preparation stage, where plans for treatment can be made. Once the patient stops smoking, continued motivational techniques and support are needed during the action stage, and group or individual behavioral counseling can facilitate and improve chances of quitting.

D: Discussion and Conclusions

There is a growing conviction that the next paradigm shift needed to improve overall health status will emerge from extensive education about, awareness of, and adherence to healthful lifestyles and behaviors. The health care financing and delivery systems in the United States and health care practitioners are largely focused on diagnosis and treatment of acute disease. Systems and practitioners are making only slow progress towards recognizing the importance of primary prevention and maximizing the well being of persons with chronic disease. Noteworthy barriers to adherence to healthy lifestyles have been erected. Not only are interventions such as those directed towards the need for physical activity, good nutrition, and avoiding substance abuse (including tobacco) under-utilized; they are rarely, if ever, targeted towards older adults and especially older adults of color, because of three popular but largely false assumptions: 1) the benefits of prevention activities diminish rapidly in the face of "normal aging"; 2) prevention is not as effective once chronic disease processes have begun; and 3) older adults are less responsive to health education and promotion activities.

These concepts may be even more insidious in the case of racial/ethnic minorities, but in any case, recent research in gerontology, geriatrics, and chronic disease suggests that all three concepts may be somewhat remediable (Rowe, 1999; Vita et al., 1998; Russell, 1998; Ornish et al, 1998). In order to do so, recognition of a failure by public policy, health care provider organizations, and practitioners needs to be a starting place for major re-thinking of how our society cares for elders. The disconnect between current understanding of cancer prevention and health promotion and current practice in care for older adults can be addressed through efforts directed to reducing patient, provider, and program design/financing barriers.

Reducing Patient Barriers: Gaps exist in educating older adults regarding primary prevention. Elders and particularly elders of color are bombarded on a daily basis with conflicting information on behavioral and lifestyle changes and their relationships to cancer or other health outcomes. Yet they receive little support from health professionals and others in sorting through this information, distinguishing credible and actionable recommendations from commercial claims, or finding sources of support for appropriate lifestyle modification. In response to this confusing environment and the failure of the health care system to provide consistent and clear recommendations and support, elders may develop a sense that continuing existing behaviors is the best response. At the same time, many of the proposed options for adopting healthy lifestyles that have received the greatest attention and support are presented in culturally insensitive ways or seem to require extraordinary efforts. Elders may find such activities too time-consuming, report that they cause discomfort, or say that the benefits are not immediately tangible. Moreover, older adults may develop an attitude of hopelessness regarding growing older, and become seemingly resigned to the immutability of lifelong habits that are harmful to health. They may accept functional limitations as an inevitable consequence of aging and think it is too late to gain advantages from incorporating healthful practices into their daily routine.

Reducing Provider Barriers: An emerging body of evidence has demonstrated that physicians and other health practitioners are not being as effective as they might be over the long term at intervening with elders and particularly elders of color around cancer prevention and health promotion issues. Although these practitioners are not the only, or necessarily the best sources of motivation and support for lifestyle modifications, their lack of adequate involvement in supporting healthy lifestyles has emerged as a significant barrier.

Most providers are trained to treat disease. There is inadequate training and sensitivity to the need for preventive services, and inconsistency in how preventive services are prescribed. Physicians acknowledge both the importance of delivering preventive services to their patients and their responsibility, but few consider themselves successful at highlighting prevention and many do not even try (Wechsler et al., 1996). Training about prevention is not always thoroughly incorporated into clinical syllabi and does not emphasize the importance of such practices in the treatment of individuals throughout the lifespan.

Both established practitioners and trainees may be reluctant to focus on lifestyle interventions because of ongoing uncertainties in current understanding of the roles of behavior in carcinogenesis and other disease processes. As indicated in our review more and more studies seek to elucidate the multifactorial nature of carcinogenesis. For example, understanding the gradual process of the transition from adenomatous polyp to adenocarcinoma allows one to examine and modify lifestyle (reducing red meat, alcohol and tobacco, increasing physical activity, using chemoprevention) (Alberts, 2002). Similarly, since oxidative damage is increasingly recognized as an important factor in the pathogenesis of numerous diseases including cancer and cardiovascular disorders, studies are being done to learn more about the constellation of lifestyle and antioxidant capacity.

For example, non-smoking, regular activity and a nutrient-rich diet are positively associated with increased antioxidant capacity, while smoking, psychological stress, alcohol consumption, low fruit and low fish consumption were shown to be negatively associated with antioxidant capacity (Lesgards et al, 2002). The authors conclude that "the evaluation of the total human resistance against free-radical aggression, taking into account nutritional habits, lifestyle, and environmental factors, maybe useful in preventive medicine as a precocious diagnosis to identify healthy subjects" (who are at risk for cancer).

It is expected that answers to the relationship between lifestyle factors, environmental exposures, and the risk of cancer, mortality, and survival will require the conduct of large-scale, prospective cohort studies such as the Cancer Prevention Study II sponsored by the American Cancer Society, (Calle et al, 2002). This study investigates for dietary, hormonal, genetic, physical activity, medication use and other factors and association with cancer risk. Meanwhile, large gaps exist in our understanding of environmental, lifestyle and heritable causes of cancer. For example, the association between fat intake and prostate or breast cancer remains inconclusive (Moyad, 2002). However, recommendations to modify lifestyle need not await the results of prospective studies of the relationship between and among environmental, lifestyle, genetic factors, and cancer, since simple changes in behavior can result in increased longevity and improve quality of life.

While it is imperative that those charged with managing older patients (such as geriatricians, geriatric nurse practitioners) understand the ongoing benefits of prevention at any age, and even as disease advances, such understanding is equally important for practitioners trained in other specialties or serving other age populations. In particular, community-based social and supportive service and lifestyle enrichment practitioners serving elders and other older adults may play pivotal roles in supporting health promoting choices and activities. As the aging patient population grows larger, many practitioners will likely encounter older adults in their professional careers, and unless practitioners are aware of the potential, they may miss opportunities to advocate and practice prevention for older adults. Similarly, as the demographics change, and our elderly become more racially and ethnically diverse, providers will need to be more sensitive to, and capable of, delivering culturally competent care.

Reducing Programmatic Barriers: Current programs for delivering health care preferentially reimburse for acute care services, rather than for prevention and health promotion. Other than a few underutilized clinical preventive and screening procedures, this is especially true for older adults. Furthermore, once chronic conditions become apparent, we fail to make use of continuing prevention efforts that may slow progression or morbidity and improve physical or psychological functioning. This places an inordinate burden on the health care system.

Serious health insurance barriers also exist. For those without insurance, the problem is compounded by the fact that there is often no usual source of care and that even basic screening services are not available. Even when some preventive services are

covered, as through Medicare, their rate of use is erratic (Wennberg, 1999). Particularly for elders living alone, loss of mobility as one gets older, social isolation, and poverty hamper access to prevention services even if they are available in the community.

Unless these features of most delivery systems are altered, it is unlikely that several proven prevention interventions will actually become widespread. Different mechanisms for promoting their use therefore need to be encouraged. Likewise, until delivery systems allocate sufficient time for meaningful communication between health care providers and their older patients, lack of knowledge and awareness, misunderstandings, and "lack of compliance" will certainly persist. The literature shows that the best preventive care for older adults is composed of a combination of ambulatory services including patient education, life-style counseling, and clinical oversight through routine check-ups and timely screening (Waltzer, 1998), both able to be done in an efficient and cost-effective way despite resource constraints.

This review found remarkably few studies assessing the aforementioned types of interventions for elders of color. Minimal research exists on promoting physical activity, nutrition change or weight loss, smoking cessation, or alcohol use reduction among elders from traditionally underserved racial/ethnic and socio-economic groups. Based on our review, there is only very weak evidence that elders of color can be recruited to participate or would change behavior through established program models. The strongest evidence is for weight loss and nutrition change, although the existing studies with few exceptions are focused on highly motivated volunteers and clinical samples. There does appear to be evidence from two studies in this area that used motivational interviewing by paraprofessionals and one study of physician counseling that both can be beneficial in helping elders of color engage in interventions. Existing studies emphasize development of culturally sensitive physical activity programs based on social cognitive theory and or similar models, but there is insufficient data comparing alternative theoretical constructs in intervention design. The lifestyle studies reviewed here do indicate that interventions may need to vary for different racial/ethnic groups but clearly more research is needed for specific groups.

Although the evidence is somewhat sparse, it appears that known strategies for behavior change can be adapted to adults of color. There is evidence that adults of color may benefit from community-based, culturally appropriate interventions more oriented towards changes in the context of everyday life than those requiring significant additional time and effort commitments. These data provide little insight on how effective alternative strategies are in engaging persons in health risk management activities, but they do suggest that a wealth of self-help materials and materials that can be used in organized programs have been culturally and linguistically translated.

A Broader Concept of Risk and Protective Factors:

This review of potentially modifiable determinants of R/E disparities in cancer also suggests that the needed paradigm shift requires a new understanding of cancer risk and protective factors. Just as sociodemographic, lifestyle, and psychological factors such

as self-efficacy have been shown to be protective (Seeman and Chen, 2002), system of care and provider organization factors can also be protective against increased risk of cancer. For example, it has been shown that physician recommendation to stop smoking is associated with cessation. Having a usual source of care is similarly been shown to affect health positively, gaining entry to the health care system is positively associated with the use of preventive services, and low SES continues to be a barrier to the receipt of screening and early diagnosis (Merzel and Moon-Howard, 2002). Finally, the utilization of screening and preventive services by low-income and minority adults is comparable to that of other adults in a community health center (CHC) setting, a finding that is at odds with findings in other organizational settings (Frick and Regan, 2001). These authors find that CHCs appear to facilitate the use of preventive services by this population, but it does not show which characteristics of CHCs are most likely to be associated with this improved performance.

The imposition of co-payments for preventive services in managed care results in decreased utilization of preventive services and increasing deductibles results in decreasing all services. Conversely, the provision of no-cost screening interventions such as mammography increases utilization in low-income populations (Klassen et al, 2002). This may speak to how important eliminating cost barriers to such service may prove to be. Benefits coordination and integration of care in various organizational models for the provision of care to Medicare beneficiaries can affect the barriers raised by the traditional fragmentation of care in fee-for-service settings (Leutz and Capitman, 2001; Boult and Pacala, 1999). However, simply providing programs for benefits coordination across programs such as Qualified Medicare Beneficiary (QMB) and Specified Low-Income Medicare Beneficiary (SLMB) may not be an effective means of ensuring protection for low-income beneficiaries because of the complexities inherent in coordination (Lamphere and Rosenbach, 2000). The role of someone to assist in coordination and navigation thus becomes apparent.

Changing lifestyle can be facilitated by guidance, teaching, and motivation from a trained and knowledgeable health care promoter. Using an empathetic, culturally sensitive and non-judgmental approach, these personnel can assist patients to modify attitudes, goals, and behaviors. Even if Medicare beneficiaries have a usual source of health care, it may not detect health risks, and periodic health risk appraisal is a starting point for health promotion and cancer prevention efforts. Once risks are identified, this should be followed by clinical preventive services and interventions (Hornsby et al, 1997). Health risk appraisals can be specific for conditions (cardiovascular risk, cancer risk, Theis et al, 2002) and be tailored by population, for example, the Native American specific health risk appraisal Welty et al, 1993). Successful models that incorporate health risk appraisals have included program elements such as regular risk appraisals, 24-hour telephone access for advice and triage, web-based support, and audio taped educational materials (Edington et al, 2002). Annual health risk appraisals have been associated with better compliance with self-reported utilization of preventive services by persons 65 and older (Musich et al, 2001).

Summary of Findings:

The major findings from our review of reports on cancer risk factors, R/E differences in modifiable risks, and interventions to change exercise, nutrition, smoking, and drinking are summarized below.

1. There is epidemiological evidence linking one or more of the behavioral risks to each of the cancers.

2. There is some evidence that R/E differences in behavioral risk factors do explain some of the R/E differences in cancer.

3. Available epidemiological studies do not differentiate cumulative lifetime exposure to behavioral risks from current behaviors as influences on cancers.

4. There appear to be no examples of intervention studies that demonstrate a link between behavioral change and cancer incidence in elders, but studies of smoking cessation and lung cancer in younger populations are relatively conclusive and prevention of breast, cervical, and colorectal cancer recurrence through lifestyle change for general populations is receiving increasing support.

5. Participation in behavioral risk management activities, cancer control, and management of chronic health conditions are all associated with owning Medicare supplemental insurance and maintaining a usual source of care.

6. Both primary care practitioners and social/supportive service providers can be effective in motivating health risk management activities. Primary care practitioners may not be as effective as other health and human service professionals in supporting behavior change and maintenance of new behavior. Further these practitioners often miss opportunities to encourage or support elder patients in deciding to use and sticking with lifestyle change supports.

7. There are very few studies of physical activity, nutrition/weight management, and multi-component interventions with elders of color. There appear to be no published reports on health risk appraisal, smoking cessation and alcohol use reduction interventions with elders of color.

8. There is a clear need for new research focused on how to engage and maintain participation of elders of color in effective and efficacious physical activity, nutrition/weight management, smoking cessation, and multi-component interventions.

9. Available studies from both elders of color and other populations underscore the challenges associated with engaging persons in behavioral risk factor management and suggest that motivational interviewing or other techniques that individualize messages about prevention based on stages of change or similar frames.

10. For elders and elders of color, health promotion interventions seem more effective when they highlight health improvement rather than disease avoidance and that can be individualized to preferences on activities, group participation, timing, and effort.

11. There are many examples of linguistically and culturally adapted materials and programs, and methods for community and religious organizations to make them available. Cultural adaptation can be consistent with application of intervention approaches that are working in general populations.

Thus, we find strong evidence from epidemiological studies for the importance of behavioral risks in cancer etiology and severity but almost no experimental evidence that altering behaviors influence cancer rates or outcomes (because of lead time biases and other challenges for such studies). Nonetheless, because there is evidence that behavioral risks can also influence co-morbid conditions and treatment outcomes, it seems likely that increasing R/E elders' engagement in management of behavioral risks and other modifiable determinants of health can alleviate some R/E disparities in cancer and health. Further the Chapter reports almost no examples of proven behavior change strategies for R/E elders and real difficulties in engaging such persons on behavior change. But there is sufficient evidence from studies with general aged populations and R/E adults of populations to suggest that R/E elders could be engaged in a broad array of effective behavior change activities.

As with all attempts to change behavior, the problem of motivation and engagement needs to be addressed. The link with a usual source of care and access to benefits and services is well documented. Hence, we propose the need for tailored health risk management; in order to overcome issues of mistrust and barriers to basic access to primary care. Such assistance should be offered by a person with enduring connections to the community being served and armed with motivational skills, skills in benefit counseling and enrollment, and a close link to and link back to the physician, the health care system and community prevention resources. This will translate into a culturally tailored service that helps individuals to get coverage, develop more continuous relationships with a usual source of care, understand their current risks, motivate them to engage in risk management, and receive support and encouragement for these efforts.

Chapter III: Racial/Ethnic Disparities in Cancer Treatment and Outcomes

A: Introduction and Approach

This chapter examines evidence for racial/ethnic (R/E) disparities in cancer outcomes and receipt of appropriate screening, diagnostic, and treatment services. Evidence for interventions to address these gaps will also be examined. This exploration of the available literature emphasized the most prevalent cancers among elders: breast, cervical, lung, prostate, and colorectal, as well as several less common cancers that are nonetheless associated with strong R/E differences, including stomach, oral (neck and throat), pancreas cancers and leukemia. In exploring cancer outcome data, an effort was made to identify R/E differences among Medicare beneficiaries or elders. Published studies often did not focus on this population segment and thus reports on older adult populations (age 50 and above) and general adult populations were examined as well. Nonetheless, at any age, survival from cancer, discomforts of care, costs of treatment, and other outcomes are closely associated with stage of the disease at the time of diagnosis. Further, for several anatomical sites, detection and treatment of pre-cancerous lesions is possible, thus preventing the progression to invasive disease. For these reasons, the review sought evidence that R/E groups differed in detection of pre-cancerous conditions and in stage at diagnosis, and that these differences were associated with R/E differences in outcomes.

Because the cancer prevention and treatment process differs at least to some extent by type of cancer and the potential exists that disparities arise differentially by R/E group at any phase in this process, the study has sought to detail the process specifically for each cancer. It is possible that different R/E groups among the Medicare beneficiary population experience barriers to appropriate care at different phases in the process. Appendix II, the sequential model for breast cancer, exemplifies the sequential models that were developed for each cancer and used to organize our work. Each review was organized around a sequential model of cancer detection and treatment consensus: we sought to identify where there was agreement about what care an individual Medicare beneficiary should receive to detect cancer as early as possible and to treat it effectively. The potential to influence outcomes through Medicare policies and programs – as compared with options for basic research on cancer care—is notably enhanced when there is a consensus on what to do. In these cases, attention can shift from promoting innovations in treatment to ensuring equitable access to a standard of care. A central concern of the reviews was the extent to which there is consensus on detection and treatment.

The models for each cancer site were used to begin identifying at what points in the management of cancer and in what aspects of the health care system, new Medicare benefits or services might effectively influence R/E differences in cancer care and outcomes. Each review sought evidence for differences in the timeliness or completeness of diagnostic procedures, complete primary treatments (e.g. breast conserving surgery and resection of axillary lymph node dissection), secondary treatment (e.g. radiotherapy after breast conserving surgery) and adjuvant treatment (tamoxifen or other chemotherapy after radiotherapy). Each review also sought

specific evidence that these differences in treatment accounted for additional variance in outcomes beyond that associated with stage at diagnosis.

Much of the recent focus on systematic reviews and policy analyses has been on the efficacy of **cancer screening** mechanisms and interventions to increase their appropriate use. This review sought to focus attention in particular on initiatives to increase screening participation by older adults of color. But Freeman and his colleagues on the President's Cancer Panel in their 2002 report underscore the observation that **treatment** disparities by R/E and SES groups are at least as significant as disparities in cancer detection. Since our findings did demonstrate disparities in diagnostic completeness, treatment, and follow-up services, we sought evidence for interventions aimed at reducing R/E disparities at these later stages in the cancer care process. Although recently initiated research by NCI and AHRQ supported scholars in several clinical settings are addressing the reasons for such treatment differences, this review was largely unsuccessful in identifying any published reports focused on reducing R/E differences among Medicare or other populations in receipt of cancer services after screening. A handful of initiatives focused on improved follow-up subsequent to suspicious cervical cancer screens is highlighted, however.

After briefly describing the identification and selection of reports for the reviews, this Chapter describes findings on R/E group and cancer prevalence and mortality. Attention then turns to cancer detection methods. We focus first on whether or not there is a consensus on methods for detection and diagnosis, next on R/E differences in screening participation and diagnostic completeness, and then on interventions to increase participation in screening or early detection methods. Finally, cancer treatments are explored, focusing first on treatment protocol consensus, and then on R/E differences in treatment. No studies of treatment management were identified or reviewed. A final section summarizes findings and implications.

Identification and selection of reports for systematic reviews:

We conducted electronic searches of Medline and the NCI CancerLit from 1985 to 2002, supplemented by backward citation searches using Social Science Citation Index/Web of Science for selected papers. Searches were performed for breast, cervical, prostate, colorectal, lung, stomach, oral, and pancreatic cancer and leukemia. These terms and their variants (e.g. "colon", "rectal", "prostatic" etc.) were used in each search. All searches used the following key words to locate reports on cancer among persons of color, "minority elderly, race, elders of color, elders, minority, older adults, adults, African-American, Blacks, Hispanic, Latino, Spanish surname, American Indians, Native Americans, Alaskan Native, Hawaiian Native, Pacific Islanders, and Asian American." Additional key words included "prevalence, incidence, mortality, survival, screening, diagnosis, treatment, surgery, chemotherapy, radiotherapy, radiation, quality of life, relapse, monitoring, culture, intervention, RCT, community health worker, case management, quality improvement." Other sources of information were Interventions that Increase the Utilization of Medicare-Funded Preventive Services for Persons Age 65 and Older prepared for CMS by RAND and the reviews supporting the AHRQ Task Force on Clinical Preventive Services guidelines, Cochrane group reviews, other review papers. Most of the cancer topic literatures are relatively sparse with respect to reports on R/E elders and prevalence, mortality,

stage at diagnosis, screening participation, diagnostic completeness, treatment access, and treatment outcomes. In these cases, our reviews reference all published studies on these topics and R/E differences. For breast, cervical, and prostate cancer, literatures are more extensive, and additional criteria for article selection for the review are described as appropriate.

B: Cancer Incidence and Mortality Differences by R/E

Table III-1 summarizes our findings on R/E differences in cancer prevalence and mortality. The results show consistently that African Americans (AA) and other traditionally underserved groups are at greater risk for getting cancer and/or have lower potential for surviving cancer for each of the sites considered. Evidence for the role of late stage at diagnosis and R/E differences in survival was mixed. For the better-studied cancers---breast, prostate, colorectal, and lung---there was evidence that R/E differences in stage at the time of diagnosis accounted for a significant share of mortality or survival disparities. Also noted were SES gradients and age differences in stage at diagnosis that seem to have implications for survival. For the remaining cancers, there was no evidence on the role of stage at diagnosis differences in survival or mortality differences.

Specific findings for each cancer are described in detail below.

Breast Cancer

In the past two decades, breast cancer incidence has been rising, while mortality has remained relatively stable. Increased mammography and clinical breast examinations are primarily, but not solely responsible for this incidence/mortality discrepancy. SEER data shows that White, Hawaiian, and Black women have the highest incidence rates of invasive breast cancer, with Koreans, American Indians and Vietnamese among the lowest (Miller et al, 1996).

On the other hand, incidence rates for in-situ breast cancer are much lower than for invasive breast cancer for all R/E groups. However, the manifestations of in-situ breast cancer across groups are very similar. For example, White women have the highest rates, over twice the rate for Hispanic women.

Mortality rates for breast cancer range from 15% of the incidence rate for Japanese women to 33% of the incidence rate for Black women. African American women have the highest age-adjusted mortality, followed by White and Hawaiian women. Research suggests that compared to White women, the higher breast cancer mortality among African Americans is associated with later stage at diagnosis (Miller et al, 1996). The higher mortality rate among women of color is primarily due to late stage breast cancer at diagnosis (McCarthy et al, 2000).

Since stage at detection is predictive of survival and mortality, it has become a central aspect of the debate on breast cancer screening policy. The relationship of stage at diagnosis and survival, of course, is complex and depends at least upon timely access to appropriate treatment and follow-up services. Further as the debate on screening mammography has suggested, it may be difficult to distinguish lead-time biases from improved survival. A more comprehensive review of breast cancer prevalence and survival data and how these data are used in clinical and policy debates are provided in the section on screening and diagnosis.

Table III-1:
Summary of Findings on R/E Groups and Cancer Prevalence and Mortality*

	R/E Prevalence	R/E and Mortality	R/E and Stage at Diagnosis (dx)
Breast	White women have highest rates. AA and NHOPI rates also high. Lower for other groups.	AA women have highest mortality and lowest survival. White women have longer survival than all other groups.	Women of color at later stage at dx. Stage at dx associated with White/AA, White/non-White, SES, and other survival differences. Older women at greater risk of late stage at dx.
Cervix	Hispanic women have highest rates, followed by AA and API.	AA have highest mortality rates, followed by Hispanics and API. Lowest for Whites	AA women have unfavorable survival compared to White women, inferring stage differential at diagnosis, but empirical evidence mixed regarding stage at diagnosis is mixed
Prostate	AA men have much higher rates than Whites. Latino men have higher rates than Whites.	AA and Latino men have higher mortality and shorter survival than Whites	AA men at later stage at dx. Stage and grade at dx associated with White/AA and SES survival differences.
CRC	AN have highest rate. Japanese and AA men have higher rates. AI rates lower.	AA and AN have higher mortality than other groups.	Stage at dx associated with White/AA, White/non-White, and SES survival differences. Older people at greater risk for late stage at dx.
Lung	AA men have highest rate. AA rate higher. Latino rate may be lower.	AA have higher mortality and shorter survival than Whites	Stage at dx associated with White/AA and SES survival differences for person under age 65
Stomach	Asian, AI/AN and NHOPI rates are highest. AA and Latino rates are higher than Whites.	Whites have lower mortality and longer survival than other groups.	Stage at dx associated with survival. Asians more likely to receive dx at early stage. No evidence that stage at dx differences explain R/E differences
Oral	AA rates higher than Whites, particularly among men.	Whites have lower mortality and longer survival than other groups.	Stage at dx is primary predictor of survival. . No evidence that stage at dx differences explains R/E differences.
Pancreas	AA and NHOPI higher than Whites.	Little evidence. No apparent difference in survival after adjusting for age/	No evidence.
Leukemia	Whites and AA have highest rates, Asians have lowest	AA and NHOPI have worse survival	No evidence.

*AA = African American, AN = Alaskan Native, AI = American Indian, NHOPI = Native Hawaiian and Other Pacific Islanders, SES = socio-economic status, and dx = diagnosis.

Cervical Cancer

Incidence: Uterine cervix cancer is almost 100% preventable, if caught and treated at the pre-cancerous stage. Yet some women continue to die from this disease. In 2002, an estimated 1,250,000 women will develop the pre-cancerous form of cervical cancer known as cervical intra-epithelial lesion (SIL) or cervical intra-epithelial neoplasia (CIN), 13,000 women will develop invasive cervical cancer and 4,100 cervical cancer deaths are expected (ACS Cancer Facts and Figures, 2002; NCI Cancer Prevention PDQ, 2002). Older women have a higher incidence of cervical cancer. For example for the period 1995-1999, cervical cancer incidence

rates for women ages 50 and over were 2 times higher than incidence rates for younger women (6.9 vs. 14.5 per 100,000).

R/E incidence of uterine cervix cancer differs from that of other cancers, being most common for Hispanics, followed by AA women and Asians/Pacific Islanders (API) and least common for American Indians/Alaskan Natives (AI/AN). Among the top 15 cancers, it is 10th over all; but is 4th most common cancer for Hispanics, 6th for African American, 7th for API and for AI/AN and 9th most common cancer for White women (Ries et al 2001b-- Statistical Supplemental Material #1). Incidence rates vary similarly. For example, for the period 1992-1999 the age adjusted incidence rate for cervical cancer was highest for Hispanics (17.7), followed by Black (13.3), and API (11.7) and lowest for AI/AN (7.7) per 100,000

Table III-2
Cervical Cancer Incidence Rates by Race and Ethnicity: US SEER Sites; 1992-1999

	Incidence Rate [I]	EAPC (%)
Race/Ethnicity		
All Races	10.2	-2.3*
Hispanic	18.5	-4.3*
White non Hisp [q]	8	-2.0*
African American	13.3	-1.9*
Asian/Pacific Islander	11.7	-3.9
AI/Alaskan Natives	7.7	-

SOURCE: NCI/SEER (2002) Statistical review 199\2-1999 The EAPC is the estimated annual percentage change over the time interval - =Statistic not shown. Rate based on less than 25 cases for the time interval
Trend based on less than 10 cases for at least one year within the time interval. [I]=Incidence data are shown fro the 12 SEER area (San Francisco Connecticut, Detroit, Hawaii, Iowa, New Mexico, Seattle, Utah, Atlanta San Jose-Monterey, Los Angeles an Alaskan Native Registry); [q]=Hispanic is not mutually exclusive from Whites Blacks, Asian and Pacific Islanders and American Indians/Alaskan Natives. Incidence data for Hispanics does not include cased from Detroit, Hawaii and Alaskan Native Registry.).
*The EAPC is significantly different from Zero (p<05)

There are also significant ethnic variations in cervical cancer incidence within API populations. Between 1988 to 1992, for example, the distribution of cervical cancer incidence rates among API varied widely: 21.1 for Chinese, 28.2 for Filipino, 55.2 for Koreans, 181.6 for Vietnamese and 9.5 for per 100,000 for Japanese American women. (Miller et al (1996)

Mortality rates: Trends in uterine cervix cancer mortality rates for the period 1973 to 1999 show that although cervical cancer mortality rates declined rapidly, (by 44% from 6.2 to 3.5 per 100,000), declines in mortality rates have been much lower. From 1991 to 1999, for example, mortality rates declined only17 % (from 3.5 in 1991 to 3.1 per 100, 000 in 1999).

Like incidence rates, mortality rates for uterine cervix cancer also vary by age and R/E. They are highest for Blacks followed by Hispanic, API, and AN/AI and are lowest for White non-Hispanic women. From 1992 to 1998, for example, cervical cancer mortality rates were 6.7 for Blacks, 3.8 for Hispanics, 3.3 for AN/AI and 3.1 for API women compared to 2.7 per 100,000 for White women The age disparity in cervical cancer mortality is also apparent with women 50 years and older having higher mortality rates than younger women For the period

1995-1999 for example, women 50 years and older had 4.5 greater odds of dying from cervical cancer compared to younger women (1.6 vs7.2 per 100,000).

Within race comparisons, show age-race interaction in cervical cancer mortality with older AA women having the highest rates. For the period 1995 to 1999, for example, AA women 50 years and older had 6.1 times greater odds of dying from cervical cancer than were younger AA women compared to 4.4 greater odds of dying among from cervical cancer between White women 50 years and over vs. younger White women.

Survival Rates: Time trend analyses of uterine cervix cancer survival rates show disappointing changes over time. Although there have been large declines in mortality rates, (defined as number of deaths from a specific cause in the population at risk over a specific period of time, usually a year) there have been no comparable changes in survival rates (defined as number of deaths among cases). From 1974 to 1997, for example there was overall no significant improvement in uterine cervix cancer survival rates (69% in 1974/76 to 70% in 1992/97). Slight improvement in survival during this period is seen only among White women from (70% in 1974/76 to 72% for the period 1992/97). This data suggests that the improvements in mortality rates are attributed mostly to early detection efforts and not to improvement in treatment. This is better demonstrated in the next section by analyzing stage-specific survival rates.

Table III-3
Trends in Five-year Survival Rates by Race and Year of Diagnosis

	White (%)	Black(%)	ALL(%)
1974-1976	70%	74%	69%
1983-1985	71%	60%	69%
1992-1997	72%*	58%	70%

Source: ACS facts and figures, 2002; Rates adjusted for normal life expectancy and are based on cases diagnosed fro 1974 to 1976 and 1983 to 1985 and in 1992; *Significant at p <0.05

Stage and survival: Survival rates vary significantly by stage. Compared to treatment of invasive cervical cancer, treatment for pre-clinical lesions and localized cervical cancer is more effective. Treatment failure for regional disease and distant metastases seem to be common. For example according to the ACS cancer facts and figures (2002) and Ries et al (2002), the survival rate for pre-invasive lesions and carcinoma in situ is 100%; for localized disease 92%; for regional disease, 42% and for distant metastasis, 15%. Treatment for invasive cervical cancer is complicated, requiring combination of treatment modalities-- surgery, radiation therapy or both and in some cases chemotherapy that often has intolerable side effects. In contrast, treatment for pre-invasive cervical cancer is accomplished using much simpler and less costly outpatient procedures such as cryotherapy (the destruction of cells by extreme cold), by electro-coagulation (the destruction of tissue through intense heat by electric current), laser ablation, or local surgery (ACS Cancer facts and figures, 2002).

R/E patterns in stage and survival: A number of researchers have noted that AA women and other women of color generally have less favorable cancer survival than White women. It is not clear, however, whether this difference is fully explained by differences in stage of disease at diagnosis. To evaluate this both national data and analytic studies were reviewed. (In the national

data, stage specific survival by race is only available for AA and White populations). Based on the SEER data specific survival varies by age and R/E. Both AA and White women, however, experience better survival at localized stage than at advanced stages. For example, during 1973 to 1999, both AA and White women experienced better survival only for localized disease. By contrast, for regional and distant metastasis AA women had significantly worse survival (47.2% for older White vs. 44.1 % for older AA women, p<0.0000) and for distant metastasis (11.5 for older White and 3% for older AA women, p<0.0000). In older women who had localized disease there were, no significant AA/White differences in survival (85% for White and 89.3 for AA, p=0.07). Similar patterns were seen for younger women in terms of having much better survival at localized than at more advanced stages of cervical cancer. In contrast, however, younger AA women experienced significantly worse survival at every stage than younger White women. The impact of un-staged uterine cervix cancer on racial differences in survival was differentially expressed among younger women compared to older. Its significance is therefore not clear— older Black women with un-staged cancer had better survival than older White women while the reverse was true among younger women.

Table III-4
Cervical Cancer Survival Rates by Stage and by AA and White Race and Age

%Survival	Less than 50 years				50 years and Over			
	White	AA	BW diff	p-value	White	AA	BW diff	p-value
LOCALIZED	95.5	86.4	-9.1	0.0000	85	89.3	4.3	0.0746
REGIONAL	56.3	37.7	-18.6	0.0000	47.2	44.1	-3.1	0.0000
DISTANT	24.9	12.6	-12.3	0.0000	11.5	3	-8.5	0.0000
UNSTAGED	71.3	55.7	-15.6	0.0000	36.3	40.1	3.8	0.0000
ALL_STAGES	81.9	63.1	-18.8	0.0000	57.2	55.4	-1.8	0.0000

Source: ACS facts and figures2002; BW diff=AA/ White difference in rates; the AA White differences and P-values are calculated using original data; rates adjusted for normal life expectancy and are based on cases diagnosed from 1974 to 1976 and 1983 to 1985 and in 1992.

Using SEER data for the period 1974-1985 Ragland, (1991) did not find a consistent pattern in the association between stage and race among cervical cancer patients. Ragland examined R/E patterns of stage at diagnosis for seven selected sites including cervical cancer. For cervical cancer, as well as some cancers, it was not the case that African American women and other persons of color were not more likely than whites to have cancer first detected at later stages.

Similarly the associated between stage-race and survival seem to be complex. Among American Indians from the Seattle-Puget Sound Cancer Registry for example, Sugarman et al (1994) found that despite having similar stage distribution as White women, AI women experienced worse survival than White women did at similar stage. They compared site-specific survival among American Indians (n = 551) and Whites (n = 110,899) diagnosed from 1974 to

1989 for five cancer sites. After adjustment for age differences between American Indians and Whites, American Indians experienced poorer survival from cervical cancer and other cancers.

In another study Lin et al found significant variations in the association between stage and survival among the API subpopulations. Lin et al (2002) found that the Chinese experienced worse survival than did White women. They, however, also had worse survival than the Filipino and the Japanese. The Japanese in contrast experienced better survivals than White women. Lin et al (2002) used data from SEER to compare the distributions of stage at diagnosis and computed 5-year cause specific survival probabilities, overall and by stage of disease, for cancer patients whose diagnosis was in 1988-1994 and who were followed through 1997. The Chinese patients experienced worse survival even after diagnosis of early stage cervical carcinoma (Lin et al, 2002).

Prostate Cancer

African American men carry the highest burden in terms of incidence, morbidity, and mortality of prostate cancer. In fact, the incidence of prostatic cancer in African Americans is the highest among all R/E groups, followed by Whites. AA men experience a 62% higher incidence and a 137% higher mortality rate than Whites. Between 1992 and 1997, the 5-year survival rate for African Americans was 92%, five percent lower than for Whites (Jemal, 2002). For any stage category, the 5-year survival rates are poorer for AAs than for Whites (Wingo, 1995). Families with high risk of prostate cancer demonstrate linkage of a genetic marker, HPC11, which is prevalent among African American families with at least three members with prostate cancer, compared to Whites with the same family history (over 50% vs. 34%). It has been hypothesized that this could potentially explain in part the high incidence of this cancer among African Americans (Powell, 2001). Similarly, androgens influence the development of prostate cancer, and African American males have testosterone levels higher than any other ethnic group. High-grade prostatic intraepithelial neoplasia (PIN) is considered the most probable precursor of invasive prostate cancer. African American males have a higher prevalence and extensiveness of it, which could explain the development of more aggressive cancer among this group (Montironi, 1999).

Racial differences in staging at the time of prostate cancer diagnosis have been reported consistently, as demonstrated by cancer-registry data of Surveillance, Epidemiology, and Ends Results (SEER). Between 1984 and 1991, 85% of prostate cancer cases in Whites, registered in SEER and with known stage, had a local or regional stage while only 74% was available on AAs. Whites had the following prostate cancer distribution by stage: localized 50%, regional 19% and distant 15%. The staging among AA men showed localized cancer 60%, regional 14%, and distant 26% (Harlan, 1995). Similarly, based on SEER data, between 1992 and 1996, 5.9% of Whites and 9.5% of AAs had a distant stage disease (Merrill, 2000). Unknown stage can be construed as a marker for quality of care and/or co-morbidity, in that a person diagnosed with cancer was not staged.   However, some of these differences could be explained by access to care. In an equal access to care setting (VAMC), there were no racial differences in prostate cancer stage at time of diagnosis on a population of 477 men diagnosed with prostate cancer. AAs, nevertheless, had a cancer presentation with higher levels of PSA and Gleason scores than Whites. (Freedland, 2000) Some experts think that this may indicate that AAs are at increased risk for more aggressive forms of prostate cancer.

There is a broad consensus that stage and grade at diagnosis for prostate cancer is a crucial determinant of survival. For example, long-term survival in patients with clinically localized prostate cancer aged 50-79 has been analyzed for 59,876 patients from cancer-registry data of Surveillance, Epidemiology, and Ends Results (SEER). Ten-year survival depended on the cancer stage.

Colorectal Cancer

Incidence rates for colorectal cancer are higher for men than women in all racial/ethnic groups (Miller et al., 1996). Regarding mortality rates, African Americans show the highest rate of all, followed by Alaskan Natives and Whites.

Lee-Feldstein and colleagues compared disease stage at initial diagnosis of colorectal cancer as well as survival rates, by type of insurance held by 1,329 Northern California Medicare beneficiaries (Lee-Feldstein, Feldstein, & Buchmueller, 2002). Diagnosis in early stage was greater for members of non-group HMOs and fee-for-service supplements than for members of group HMOs, Medicare/Medicaid, or Medicare only. Medicare/Medicaid beneficiaries experienced higher all-cause mortality than those with private FFS supplements. The authors note that colorectal cancer screenings are not in the HEDIS quality measures. Mandelblatt and colleagues matched NYS Tumor Registry & US Census area-level social class indicators to examine the relationship of gender, race, and SES on stage of disease at diagnosis (Mandelblatt et al., 1996). Controlling for other predictors, the odds of late-stage cancer increased with lower age and for women and African Americans. Living in low SES areas was the strongest predictor of late-stage diagnosis for all groups.

A study of the tumors of 703 newly identified cases of invasive colon adenocarcinoma in the AA White Cancer Survival Study found that Blacks were less likely to have poorly differentiated tumors (OR = 0.44) and lymphoid reaction (OR=0.49) compared to Whites, adjusting for age, gender, geography, summary stage, SES, BMI, and health care access and utilization (Chen et al., 1997). More advanced stage at the time of diagnosis accounted for most of the 60% excess mortality among Blacks. Similarly, an analysis of records of 1,245 CRC patients at an urban medical center found that local patients (who were more likely to be older and people of color) were more likely to have advanced disease at the time of presentation than patients from extended and distant communities (Neugut et al., 1991).

Lung Cancer

Available research primarily has investigated the incidence of lung cancer in African Americans and Whites. One study looked at all cancers of American Indians in Montana, using Indian Health Service data and the Montana Central Tumor Registry and found that American Indians in New Mexico had lower rates of lung cancer than Whites while American Indians in Montana had lung cancer rates comparable to Whites (Bleed et al., 1992).

Polednak (1993) studied lung cancer incidence rates in Hispanics in Connecticut using Spanish surnames. Rates for women were excluded because Spanish surnames were not a good indicator of ethnicity for women. Lung cancer rates for Hispanic men were found to be lower

than for the non-Hispanic male population, except in the age range of 25-34. Small numbers may have been a factor in this finding. Puerto-Rican born Hispanics had higher lung cancer rates than other Hispanics.

The cancer statistics for Hispanics, based on Surveillance, Epidemiology, and End Results (SEER) data, show that Hispanics had a lower incidence of lung cancer, 27.1 per 100,000 as opposed to 58.4 per 100,000 for Whites (ACS, 2002b). Mortality rates were reported at 19.8 per 100,000 versus 50.3 per 100,000 for Whites. They attribute the difference to less cigarette smoking amongst Hispanics. Specifically, rates of lung cancer were 70% lower than those for non-Hispanics, but the reliability of R/E coding as well as sample representativeness have both been challenged for these data.

A review of the lung cancer literature based on SEER data shows that the prevalence rate is 73.39 per 100,000 for African Americans and 54.31 per 100,000 for Whites (Stewart, 2001). Gadgeel and colleagues (2001) analyzed temporal trends in the impact of race on lung cancer using SEER data. The authors used data on 48,318 individuals from the Metropolitan Detroit Cancer Surveillance System (MDCSS), which is part of the SEER program. The database included patients from the Detroit area diagnosed between 1973 and 1998. The analysis only included Black and White individuals, primarily age 50 or older. Lung cancer rates were found to be comparable for women but Black males had a 37% higher rate of lung cancer than White males. Incidence rates were markedly higher in Black men younger than 50 years old. Between 1973 to 1985 and 1986 to 1998 the incidence of distant stage lung cancer increased in both Blacks and Whites but the proportional increase was greater for Blacks than for Whites. In terms of survival rates, from 1973-1985 survival rates were similar for Whites and Blacks but between 1986 and 1998 Blacks had significantly lower two and five-year survival rates than Whites. This was due to the fact that while survival rates increased for White patients they remained constant for Blacks. Overall stage of lung cancer at diagnosis was the largest predictor of survival.

Wingo and colleagues (1998) analyzed data from cancer patients diagnosed from 1974-1991 through the SEER program. Once again, they found that survival rates for lung cancer were better for Whites than for Blacks. Black males had a 5-year relative survival rate of 10% as opposed to 12% for Whites at all stages. For local stage survival, rates were 31% and 37% respectively. Relative survival rates for lung cancer are better for Whites than for Blacks, with relative survival rates decreasing by age for Blacks over 45 at time of diagnosis. Relative survival with a diagnosis of metastatic lung cancer was less than 5% for all populations. They also found that individuals diagnosed at age 75 or older had lower relative survival rates (Wingo et al., 1998). A similar analysis, of the National Center for Health Statistics (NCHS) mortality rate data reported that five-year relative survival rates for lung cancer have increased for Whites from 12.5% to 14.4% but have decreased slightly for Blacks from 11.5% to 11.3%, increasing the disparity in survival rates.

Stomach Cancer

Both the ACS (2002a and b) and the NCI (2002a) reported stomach cancer incidences in non-Whites to be higher than that in Whites. Particularly, Asian Americans tend to have higher rates of stomach cancer, although they also have lower mortality rates. It has been suggested that

Asian Americans have been survival rates because they are diagnosed for stomach cancer at earlier stages and tend to receive surgery more often than other populations (Theuer, 2000).

Koreans, Vietnamese, Japanese, Alaska Natives, and Hawaiians have high age-adjusted stomach cancer rates, while African Americans, Hispanics, and Chinese are reported to have intermediate incidence rates. Korean men have an incidence rate 1.6 times higher than Japanese men, and 2.4 times that of Hawaiian males. The highest incidence of stomach cancer amongst Vietnamese women is approximately 6.6 times higher than for White women (NCI, 2002). According to recent ACS statistics (2002), the incidence rate for stomach cancer for Hispanics was 10.3 versus 5.9 for Whites per 100,000. Mortality rates were 5.8 versus 3.6 for Whites per 100,000. In New Mexico, Hispanics and American Indians have higher stomach cancer mortality rates than did Whites between 1958-1987 (Wiggins et al., 1993).

In another study of stomach cancer comparing Whites and African Americans, based on SEER data, African American women had the highest stomach cancer rates among women. Stomach cancer rates were higher by 50% or more in Southern born AAs compared to those from other regions. The authors hypothesize that this is due to diet, poverty, lack of refrigeration, and childhood gastric infections (Greenberg & Schneider, 1995).Patients with stomach cancer have a 90% survival rate if it is diagnosed at stage 0, yet most stomach cancers are diagnosed at stages III and IV when survival rates are 10-20% and 7% respectively (ACS 2002). Surgery is the therapy of choice, combined with adjunct therapies, but surgery is rarely curative at stage III and ineffective at stage IV, which is when most stomach cancers are detected.

Oral cancers

Oral cancers are more common among African Americans than among Whites. These differences may be partially attributed to slightly higher smoking rates among African Americans (Arbes et al., 1996; Roach et al., 1992). According to SEER data from 1973-96, incidence rates of oral cancer decreased for White men, while increasing for African Americans males aged 65-69 (Shiboski et al., 2000). There is consistent evidence that persons with early-stage oral cancers have a better prognosis than those diagnosed with more advanced disease. African Americans have greater odds of diagnosis at advanced stage (Arbes, et al., 1996). In the Arbes study (1996), the odds of advanced stage diagnosis were higher for males compared to females.

Earlier studies showed higher mortality a rate among African Americans, particularly males, compared to Whites (Goldberg et al., 1994). Roach and colleagues (1992) studied possible factors for this disparity and found that after controlling for stage, sub-site and quality of care oral cancer survival was comparable for both groups. More recent research seems to contradict these findings. Compared to Whites, African Americans have a significantly lower 5-year survival rate for oral and pharyngeal cancers (squamous cell carcinoma), even after adjusting for staging and treatment (Arbes et al., 1999; Moore et al., 2001). Moore and colleagues study (2001) used a retrospective design to determine predictors of survival in 909 patients diagnosed with oral and pharyngeal squamous cell carcinoma in a teaching hospital. Study findings show that the greatest racial disparities in survival were found in African

American males compared to their White counterparts (Moore et al., 2001). After adjusting for age and treatment, African Americans were more likely to die than Whites. A primary issue may be to determine whether African Americans have higher rates of per se, or higher rates of cancers of the pyriform sinus, which are more usually late stage at diagnosis.

<u>Leukemia</u>

The incidence of leukemia is highest among Whites, and lowest among Chinese, Japanese, and Koreans. The incidence is about 50% higher for men than for women in all racial/ethnic groups except Vietnamese, among whom the male rates are only slightly higher. As people grow older ethnic differences in the incidence rates increase. Between 10-30% of all forms of leukemia are secondary leukemias (Leone et al., 1999).

Mortality rates in the United States also are higher for men compared to women. When evaluated by R/E, leukemia mortality rates are highest in White and Black populations and in Hawaiian men. Rates among Asian populations are noticeably lower. The ratio of mortality-to-incidence rates is higher for adult leukemias than for childhood leukemias. Research shows a race disparity in leukemia survival rates for Whites and African Americans (Blackstock et al. 2002). Even after adjusting for treatment modality, histology and metastatic site, African Americans had a poorer outcome.

<u>Pancreatic Cancer</u>

Cancer of the pancreas is a highly lethal disease with an extremely low likelihood of survival. In the US, only 2% of all newly diagnosed cancers are cancer of the pancreas. However, this type of cancer accounts for 5% of all cancer deaths (Miller et al, 1996).

Pancreatic cancer affects more men than women in all racial/ethnic groups. However, both incidence and mortality rates are higher for African American males and females, compared to their White counterparts. Native Hawaiians show slightly higher incidence rates than Whites, whereas rates for Hispanics and the Asian-American groups are generally lower (Miller et al., 1996). A recent study using SEER data from 1973-1995 in Hawaii, San Francisco and Seattle showed no racial differences in survival after adjusting for age (Longnecker et al., 2000).

C: Cancer Screening, Diagnosis and R/E Differences

Table III-5 summarizes our findings on cancer detection methods and R/E differences. The table highlights important differences and similarities in current consensus recommendations and observed patterns by cancer site. For breast cancer, there is broad consensus that annual mammography along with breast self-exam and clinical breast exam can be efficacious in early detection of breast cancer. Although there have been recent debates on the interpretation of efficacy trial findings, the reductions in breast cancer mortality and increases in survival for groups who are most adherent to screening recommendations are viewed as conclusive. There is somewhat more debate with respect of colorectal cancer screening since there are multiple techniques and questions of timing, but both FOBT and flexible sigmoidoscopy are considered efficacious, while colonscopy has emerged as a gold standard because of the capacity to observe

Table III-5:
Summary of Findings on R/E Disparities in Cancer Screening and Diagnosis

	Consensus on Screening	R/E Differences in Screening	R/E and Dx Timing or Quality	Screening Intervention Studies
Breast	BSE, CSE and yearly mammogram are standard and probably efficacious.	Whites and AA have similar ever-screened rates, but much lower for other groups. Whites have higher adherence to yearly screen	Multiple step process. AA women have longer delays in receiving full dx, and less complete staging. Evidence that women of color less likely to complete dx process.	Meta-analysis of 17 culturally tailored interventions shows modest, significant improvements in both first screening and adherence, but study effects are heterogeneous. Programs that combine CHW and help with access are stronger. No studies on improving dx quality or timing
Prostate	NO. DRE and PSA for high-risk men. Focus on informed consent because of uncertainty.	Rates are low for Medicare. AA, AI/AN, Hispanic and Asian screening rates are lower than White.	Multiple step process. No evidence on quality. Post-surgical staging is more accurate. Evidence that AA men less likely to completed dx process.	A small number of culturally tailored studies show modest improvements in screening and informed consent. No studies on improving dx quality or timing
Cervix	Consensus on Pap smear; but debate on frequency of follow-up for older women and those with pre-cancerous lesions	Adherence rates are lower for Medicare than younger women. Rates are low for AI/AN and Hispanic women. AA women have lower ever-screen, but not recent screen.	Multiple step process. AA women are less likely to receive full follow-up services and treatment of pre-cancerous lesions. Incomplete data on AI/AN, Hispanic and Asian, and NHOPI women on follow-up rates, but mortality data suggests inadequate follow-up	Meta-analysis of 12 culturally tailored interventions shows small, significant improvements in both first screening and adherence, but study effects are heterogeneous. Programs that combine CHW and help with access are stronger. No studies on improving dx quality or timing
CRC	Consensus on FOBT, Flex. Sig. and Colonscopy but no consensus on which or how often.	Rates are low for Medicare. All R/E groups lower than Whites	Usually multiple step process. Less complete dx and staging for elders. No evidence on R/E differences	A small number of culturally tailored studies show modest improvements in screening. No studies on improving dx quality or timing.
Lung	NO. Trials with new scan methods are underway.	NA	Usually multiple step process. No evidence for dx quality disparities for Medicare.	NA. No studies on improving dx quality or timing

and remove pre-cancerous polyps. Debates rage in the case of prostate cancer, and our review indicates an emerging consensus that high-risk men (particularly African American men) may profit from screening, but for these men and all others, the focus of policy should be on encouraging men to make informed decisions in consultation with a health professional. For

lung, stomach, and other cancers there is no currently accepted screening technique, although some alternatives are being explored in clinical trials.

As Table III-5 indicates, our review found that screening rates are lower than desirable for all Medicare beneficiaries, but notably lower for persons of color. Further, we found that for each of the cancers examined, whether or not there is an accepted screening method, that the final diagnosis and staging of cancer requires a multi-step process involving multiple and sequential tests, procedures, and professional consultations. There appears to be enormous potential for individuals to be lost during this process. In fact, for breast and prostate cancer, there is evidence that women of color and African American men are less likely to complete the diagnostic process. Further, for breast cancer there is evidence that African American women are less likely to receive complete diagnostic work-ups and valid clinical staging, while for both breast and colorectal cancer there is evidence that older persons are less likely to receive complete diagnostic processes. Finally, our review found a sizable group of studies on culturally tailored interventions to increase screening for breast, cervical, prostate, and colorectal cancer that typically involved use of community health workers to conduct educational programs, culturally and linguistically adapted materials, and other interventions to decrease access barriers. There were sufficient studies to support meta-analyses for studies on increasing the use of mammography and Pap smear by women of color. These meta-analyses show that overall such intervention studies yielded modest, significant impacts on screening rates but they are extremely heterogeneous in their findings. Qualitative reviews indicated that there was at least some evidence that the same techniques used to increase mammography use by women of color could be adapted to other screening tests. Below, the specific findings on cancer detection methods, R/E differences in screening participation, and interventions to increase screening are provided for each cancer.

Breast Cancer Detection Methods

In 2002, an estimated 203, 500 women will develop breast cancer. Eighty percent of the cancers will be invasive, out of which about 40, 000 deaths were expected. About 53% of invasive breast cancers and 66% of deaths from the disease occurred among women ages 60 years and over (ACS, -2002). One major contributor to age and race disparities in breast cancer survival is a more advanced stage at the time of diagnosis. Many studies report a more advanced stage of breast cancer at diagnosis in racial/ethnic subgroups, particularly for African Americans (McCarthy et al 1998, Jones et al 1995, Bibb et al 2001, Reeves et al 1996, Hunter et al 1993, Wu et al 1999, Jacobellis et al 2002, Jones 1995, Joslyn e et al 2000), Hispanics (Bentley et al 1998), American Indian, and Native Hawaiian women (Meng et al 1997). Possible explanatory factors for advanced stage at diagnosis in some communities of color range from differences in the basic biological characteristics at the molecular and cellular levels, to more complex behavioral attributes unique to a particular multicultural population, to societal issues-such as access to care and socioeconomic conditions (Hunter et al 1999).

There are, however, significant age and R/E disparities in breast cancer screening, which make early detection efforts ineffective. This section discusses the rationale for breast cancer screening, disparities in screening and its association with late stage breast cancer; factors that explain R/E disparities in screening and emerging culturally sensitive interventions to increase participation by women of color in breast cancer screening. Although American men also

experience breast cancer, the incidence rates are too few for R/E comparisons, and this review focuses only on breast cancer in women only.

Policy Consensus: Although primary prevention of breast cancer is desirable, its utility is limited because less than 50% of breast cancer cases are attributable to well established risk factors. In addition, many of the established risk factors are not easily modifiable (NCI CancerWeb1998, Madgan1995). Screening for breast cancer, detecting it at an early more treatable stage, and ensuring access to appropriate treatments for early stage disease therefore is the only means now available for preventing deaths from breast cancer. Mammography plays a significant role in this process. Meta-analyses of randomized controlled studies indicate that screening mammography is substantially efficacious in preventing breast cancer deaths, by about 17%, in women 40-49 years of age and 25-30% in women aged 50-69 years (NCI CancerWeb 1998 update, Shapiro et al 1997, Miller et al 1992, Alexander1997, Kerlikowske et al 1994). Despite the recent controversy regarding the efficacy of mammography (Gotzsche and Olson 2000) there is still some consensus among professional organizations that mammography saves lives (NGC 2002, NCI Statement on Mammography Screening 2002, Smith 2002.).

There is also consensus among professional organizations regarding annual or biennial mammography screening for the age group 50-69 (NGC2002; NCI Statement on Mammography Screening 2002,Smith 2002,) although organizational recommendations for other age groups differ. For example, the NCI continues to recommend that: "women in their 40s should be screened every one to two years with mammography; women aged 50 and older should be screened every one to two years and women who are at higher than average risk of breast cancer should seek expert medical advice about whether they should begin screening before age 40 and the frequency of screening"(NGC2002, NCI Statement on Mammography Screening 2002). The American Cancer Society (ACS) recommends yearly mammography for all women 40 years of age and older and for women under the age of 40 if they have additional risk factors. The ACS has no upper age limit (NGC 2002, Smith 2002) For women 70 years and older, there is currently no consensus mainly because the data are lacking to recommend or withhold recommendation, screening, however is generally encouraged up to 80 years. For women, 80 years and over, the decision is left between the individual patient and their provider. Screening is encouraged as long as the woman is in good health.

Because mammography is not perfect, (about 10-20% of breast cancer will not be detected by mammography) professional organizations also recommend complementary screening modalities. The ACS, for example recommends monthly breast self-exam and clinical breast examination every three years. "Newer but more expensive imaging technologies, such as digital mammography, magnetic resonance imaging (MRI), radionuclei imaging and high resolution ultra-sonography are also available, but are still in clinical trial and have not proven to be more superior than mammography for routine monitoring "(Muss 2000, in Cecil's textbook of Medicine). The focus of this review therefore is on mammography because it is currently the best technology available for early detection of breast cancer.

Breast Cancer Screening Rationale: Age and Race/Ethnic comparisons: Female breast cancer is one of the few diseases that meets the criteria for the utility of screening: 1) having serious consequences; 2) the pre-clinical phase detected by the screening test having high

prevalence in the population screened; 3) there being treatment which is more effective when applied in the pre-clinical phase than when symptoms lead to diagnosis (Cole and Morrison, 1978; NCI, 2002, Cancer Screening Overview). Based on these criteria all five R/E groups among Medicare beneficiaries should benefit from screening. Although there are significant race/ethnic differences in tumor and breast characteristics that might influence effectiveness of mammography, race/ethnic differences in unfavorable tumor characteristics and breast tissue are more predominant among pre-menopausal women and tend to diminish with age. Based on these criteria section compares and contrasts age and race/ethnic groups with regard to the epidemiology and tumor characteristics, which have implications for disparities in early detection.

Serious consequences: Breast cancer accounts for substantial morbidly and mortality among women. It is the leading cause of non-skin cancer for all five major race/ethnic groups, the second leading cause of cancer mortality for W, AA, AN/AI and API and the leading cause of cancer mortality among Hispanics (Howe 2001). In 2002, for example 203,500 female breast cancer cases and 40,000 deaths are estimated (ACS 2002). Incidence and mortality rates vary by age, race/ethnicity. Incidence rates are highest among W and lowest among AI/AN women. For example from 1992 to 1998 for which national data are available, the age adjusted (Year 2000 standard population) incidence rates by race ethnicity of about 137, 120.7, 93 and 82.6, 59.4 per 100, 000 population were reported for White, AA, API, Hispanic, and AI/AN women, respectively. Although the incidence rates vary by R/E all women, 40 years and over have high enough risk to benefit from screening. Based on life tables and data from the California cancer registry incidence rates from 1973 to1997, Morris et al (2000) estimated 10 year risk estimates by race/ethnicity as 2.9% (1 in 34); 2.3% (1 in 43), 2.0% (1 in 63) for White, AA, API, and Hispanic women respectively. Variations in incidence rates by R/E are probably less than reported in the population based SEER data. Using data from the National Breast Cancer Early Detection Program (NBCCEDP) May et al (2000), found less variation in breast cancer detection rates among race/ethnic groups. They used mammography and diagnostic data for 573,751 women who between July 1991 and March 1998 received breast cancer screening through the NBCCEDP. They found detection rates per 1, 000 mammograms to be 7.7, 6.4, 6.2 and 4.9 for W, AA, API, AN/AI and H women respectively. Detection rates from subsequent screening rounds were lower but varied similarly (May et al 2000).

Breast cancer stage at diagnosis varies by race and ethnicity. In 1998, for example, the stage-specific prevalence of breast cancer among Black women compared to White women were: 19.7% BW vs. 18.2 WW for carcinoma in-situ; 28.8% BW Vs 39.0% WW for stage I; 31.8% BW Vs. 26.4% WW for stage II, 6.5% BW Vs/ 4.2% WW for stage III; and 4.7% BW vs. 3.2% WW for stage IV disease (Ries et al 2001). According to this data, much of the difference in stage of breast cancer between Black and White women is between stage I and stage II. Black women are less likely to be in stage I at diagnosis by 10%, but are more likely to present with stage II by 5 %. Although Black women are more likely to be diagnosed at stage III and IV than are White women differences are much smaller (2.3% and 1.5% more respectively). Slightly more Black women have carcinoma in situ (1.5%).

Table III-6
Breast Cancer Incidence and Detection Rates and Rate Ratios for Black, Hispanic, Asian
and Pacific Islander, and American Indian Women Compared to White Women

	RACE					Source
Incidence [1]	White *	Black	API	Hisp.	AN/AI	
Rate	137	120.7	93.4	82.6	59.4	[A]
Rate Ratio	1	0.88	0.68	0.60	0.43	
Incidence [2]						
Rate	115.5	101	78	68.5	50.5	[B]
Rate Ratio	1	0.87	0.68	0.59	0.44	
Detection [3]						
Rate	7.7	6.4	6.2	4.9	4.9	[C]
Rate Ratio	1	0.83	0.81	0.64	0.64	

1=Rate per 100, 000 population, year 2000 standard; 2=Rates per 100, 000 population, 1970 standard; 3=detection rates per 1,000 mammograms; *=Comparison group for ratios; API=Asian and Pacific Islanders; AN/AI=Alaskan Native/American Indians; [A] Ries et al 2002.NCI/SEER CSR, 1973-1999, Data period 1992-1999; [B] Ries et al 2001.NCI/SEER CSR, 1973-1998, Data period 1992-1998; [C] May et al 2000. NBCCDP, Data period 1991-1998

Among the API, Chinese, Filipino and Native Hawaiian are more likely to have late stage than White women. (Meng et al 1997). The exception is the Japanese who tend to have less advanced stage than White women and other APIs. American Indians (Sugarman et al 1994, Frost et al 1996, Meng et al 1997) and to extent Hispanics (Bentley 1998) present at similar stage as the White women. According to a study by Ward-Hinds, 1982 Japanese women tend to present at an early stage at diagnosis than are White women (Ward-Hinds et al 1982, Natarajan et al 1988). Among Hispanics, race/ethnic disparity in stage seems to be age-related. It seems advanced stage at diagnosis among Hispanics is more common in the younger age group than in older age group (Delgado 1995, Bentley 1998). For example, Bentley (1998) using a sample from San Diego California, found the Hispanic/White difference in stage to be significant only for younger women --aged under 50 years (2.11 vs. 1.72, p=0.01). By contrast, they found little difference in stage between older Hispanics and older White women (Incidence rate ratio (IRR) for advanced stage for Hispanic vs. White women =0.06). The sample comprised all incident cases (10,161) from San Diego County that were identified through the California Tumor Registry and stratified by early stage (in situ or localized) and late stage (regional or distant) and by race. They calculated annual age adjusted incidence rates (AAI) for early vs. late disease and the ratio of early to late stage breast cancer. They found the incidence rate ratio (IRR) for early versus late stage breast cancer to be significantly higher for non-Hispanic Whites than Hispanics, (2.11 vs. 1.72, p = 0.01).). The race difference, however, was greatest for women under 50 years old (IRR difference 0.63), and not apparent for women 65 or older (IRR difference 0.06). These finds may or may not apply to Hispanics in other regions.

Table III-7

Stage-Specific Prevalence of Breast Cancer for Black and White Women: US SEER, 1998

	Black	White	Black /White difference
Carcinoma-In-Situ (Stage0)	19.7%	18.2%	1.5
Stage I	28.8%	39.0%	-10.2
Stage II	31.8%	26.4%	5.4
Stage III	6.5%	4.2%	2.3
Stage IV	4.7%	3.2%	1.5
Unknown	8.5%	9.0%	-0.5

Data Source: Ries et al 2001.NCI/SEER Cancer statistical review, 1973-1998 fig IV-3

Mortality rates also vary by age and race/ethnicity. Black women have the highest mortality rates and API the lowest. For example mortality rates for 2002 were estimated at 29.3, 37.3,13.1, 14.8, 17.5 per 100, 000 population (Year 2000 standard) for W, AA, API, AN/AI, and for Hispanic women respectively (Ries et al 2002). Older women shoulder a disproportionate share of the breast cancer incidence and mortality. According to American Cancer society estimates for 2001-2002, 53% of invasive breast cancer cases and 66% of breast cancer deaths occur among women 60 years and older. Older Black women have highest mortality rates despite having lower incidence rates than older White women. Black women are 30 % more likely to die from breast cancer than are White women and more than 2 times more likely to die from breast cancer than are other women of color. Compared to the relative ranking in incidence rates, the mortality rated for African-Americans, Hispanic and American Indian women are disproportionately higher than White and API women.

Prevalence of pre-clinical stage and tumor growth rate: One potential area of race/ethnic differences in detection rates is the prevalence of the pre-clinical stage**.** The prevalence of the pre-clinical phase depends partly tumor growth rate, which is determined by certain molecular characteristics (such as high nuclear grade, p53 gene expression etc) and partly on the level of the underlying risk (Garfinkelet al 1994). More rapidly growing tumors are less likely to be detected by mammography and are more likely to be in advanced stage at diagnosis. Chen et al (1994) and others have argued that women in diverse social locations may experience differences in tumor growth rates, thus explaining group differences in stage at detection. Tumor characteristics that are associated with faster breast cancer growth are reported in literature for women of color, women of low social economic status and younger women. Race/ethnic differences in tumor characteristics however are inconsistent. For example using the sample of 963 participants from the Black/White survival study Chen et al (1994) evaluated nine tumor characteristics for Black and White patients. They found significant differences in tumor characteristics between Black and White breast cancer patients. After adjusting for age, stage, and metropolitan area, Blacks were significantly more likely to have high grade nuclear atypia (OR = 1.97, 95% CI = 1.27-3.04); high mitotic activity; (OR = 2.05, 95% CI = 1.34-3.14), grade 3 tumors (OR = 1.58, 95% CI = 1.02-2.45), and more necrosis (OR = 1.51, 95% CI = 1.16-1.98); and less likely to have well defined tubular formation (OR = 0.57, 95% CI = 0.42-0.77), marked fibrosis (OR = 0.65, 95% CI = 0.45-0.94), and positive estrogen receptor status (OR = 0.78, 95% CI = 0.58-1.05) (Chen et al 1994).

Others studies suggest that age rather than race is more important in determining in tumor characteristics (Diab 2000, Furberg et al 20001). For example, Furberg et al (2001) used a case control design and a population based sample from the Carolina Breast Cancer Study (CBCS). The sample included eight hundred and sixty one women with a first diagnosis of invasive breast cancer who participated in Phase I of the CBCS. Furberg et al (2001) conducted age specific analysis and found only few differences by race. They also evaluated the distributions of 11 pathological and biological variables between African-American (AA) and White patients and between three different age groups (20-39, 40-59 and 60-74 years). They evaluated if racial differences existed across levels of age. Variables examined included histologic type and grade, tumor size, lymph node status, distant metastases, stage, hormone receptor status (ER/PR) and DNA ploidy. They found that pathologically advanced tumors (large size, high grade, and high stage, ER/PR negative) were significantly more common in younger women and AA women. They also found that racial differences varied by age. Among younger women AA and White women differed only with respect to ER/PR status, while among older women AA and White women differed only with respect to stage at diagnosis. The impact of age on tumor characteristics is supported by a study by Diab et al (2000). Diab et al (2000) found that in patients 55 years old or older, there was an association between increasing age at diagnosis and the presence of more favorable molecular characteristics of the tumor, including more tumors that express steroid receptors, lower proliferate rates, DNA ploidy, normal p53, and absence of the expression of epidermal growth factor receptor and c-erbB2 (Diab et al 2000). These studies are consistent with the evidence on the interactions of R/E and age in predicting breast cancer mortality---with younger women of color more often facing more aggressive tumors, while the less aggressive tumors found among older women are found at comparable rates among elders. At the same time, they suggest the need to focus on maintaining similar patterns of mammography use and other breast cancer detection among all elders, the contribution of tumor characteristics (and thus growth rate) to Black/White differences in tumor stage at subsequent diagnosis is small or non-existent.

Differences in pre-clinical tumor types are additional potential sources of disparity in early detection rates. The pre-clinical phase of breast cancer includes various carcinoma in situ of which ductal carcinoma in situ (DCIS) and lobular carcinoma in situ (LCIS) are the major sub-types (Muss 2000). DCIS and LCIS have a number of characteristics that have implication for early identification as well as for age and R/E disparities. DCIS is detectable through mammography, while LCIS is not. LCIS is more common among women under the age of 50 and less than among older women. In contrast DCIS is more common in the older age groups (Muss 2000).

Treatment more effective for pre-clinical than for clinical stage: Major advancements in treating regional disease and systemic micro-metastasis have been made with the advent of local radiation and systemic adjuvant therapy, which have contributed to improvements in survival rates. Survival rates, however still vary by stage with best survival rates experienced for localized disease (stage 0 and I) than for advanced disease (stage II and over). For example according to the NCI SEER data for the period 1992 to 1997 (Ries et al 2001) survival rate for women with localized disease (96.4%) was 75 percentage points higher than that for women with distant metastasis (21.1%)

Compared to treatment for localized disease, treatment for advanced breast cancer is more complicated requiring a combination of treatment modalities that often have intolerable side effects. In addition it is more costly. For most women of color, particularly Black women, the influence of stage on survival is greater than for Whites. Although survival rates for both Black and White women decline with increasing stage of the disease, Black women experience less survival at every stage of the disease (Ragland et al 1991, Ries et al 2001) with the greatest differential being for regional disease (Ries et al 2001). For regional disease Black women 50 years and older experience survival rates that are about 12% lower than that for White women. For example, for the period 1992-1997 survival rates for Black women 50 years and older were 90.6, 65.8, and 12.2 compared to 97.7, 79.1 and 20.8 among White women for localized, regional and distance metastasis respectively. The stage-specific 5-year survival differentials between Black and White women may be partly be explained by differences in appropriateness of treatment received by Black and White patients (Shavers et al 2002, Mancino et al 2001). This underscores the need for early detection.

Table III-8
Influence of stage on Survival Rates among White and Black Women: 1992-1997b

Over-all and by Race			
	Both races	White	Black
1992-97b	Total	Total	Total
LOCALIZED	96.4	97	88.5
REGIONAL	77.7	79.4	65.6
DISTANT	21.1	22.4	14.7

By Race and by Age								
	< 50 years				>=50 years			
	Both	White	Black	BW diff	Both	White	Black	BW diff
LOCALIZED	93.7	94.7	84.7	-10	97.3	97.7	90.6	-7.1
REGIONAL	77.8	80.3	65.3	-15	77.7	79.1	65.8	-11.9
DISTANT	25.9	27.9	19.8	-8.1	19.6	20.8	12.2	-8.6

Source: Seer, 1973-1998 review

The impact of stage on 5- year survival in general (McCarthy 2000) and on R/E disparities in 5- year survival rates suggested by the national data is supported by analytic studies (Yood 1999, Meng 1997, LeMarchand 1995; El-Tamer 1999). El- Tamer (999) used registry data from two institutions collected for the period 1982 and 1995 on a sample of 1,745 patients, (1,297 AA and 448 White women) to evaluate whether race was a prognostic factor in breast cancer survival after taking into account other prognostic factors which included, age, income, stage, histologic findings, type of operation, and treating institution. They found that AA patients with breast cancer were 1.27 times more likely to die than were White women (p = 0.01, 95% CI= 1.03 to 1.47). They found only stage, age, and whether the patient had a therapeutic surgical treatment significantly contributed to survival and that race was no longer significant when these factors were controlled for.

The influence of stage on survival has also been reported for other R/E groups. API (with the exception of Japanese Americans), Hispanic, and AI/AN women, experience worse survival than White women. For example, LeMarchand et al (1984) examined the survival experience of 2,956 women with invasive breast carcinoma who were identified among the 5 major ethnic groups in Hawaii between 1960 and 1979. The study population consisted of 1,174 Caucasian, 972 Japanese, 458 Hawaiian, 226 Chinese and 126 Filipino women. A multivariate analysis based on the proportional hazards regression model revealed that after simultaneous adjustment for stage of disease, age, and socioeconomic status (SES), Filipino and Hawaiian patients had significantly poorer survival than Japanese and Caucasian patients. Hawaiian women also had a significantly poorer survival than Chinese women. They found among other things that survival was higher in patients with localized tumors compared to those with more advanced tumors (LeMarchand et al 1984)

 Japanese women experience survival rates higher than Whites (Pineda et al 2001). Reasons for better survival among Japanese than among Whites women are not clear. One possible explanation is earlier stage at diagnosis, (Ward-Hinds et al 1982). They analyzed the age- and stage-specific breast-cancer incidence rates of Japanese and White women in Hawaii for a 20-year period. They compared 1192 Japanese and 1531 White patients by stage at diagnosis. They found that post menopausal (aged 50 and over) Japanese women were likely to have breast cancer diagnosed at an earlier stage than were White women of the similar age, they also found that for age 50-74, the age-specific ratios of White to Japanese incidence rates were smallest for in situ breast cancer, and got successively greater for localized, regional and distant breast cancer (Ward-Hinds 1982).

Does mammography save lives in normal clinical settings? Current research has not produced a consensus that screening mammography reduces breast cancer specific or all cause mortality. Much of the controversy regarding the efficacy of mammography was centered on the integrity of the randomization and the legitimacy of disease specific mortality as the primary end-point (Strauss 2002; Olsen 2001; Black 2002). Although RCTS protect against selection bias, lead-time bias, length bias) poor randomization or randomization failure would reduce the magnitude of the effect (rather than increase the effect) due to mixing of the screened and unscreened. Despite this Goetsche and Olsen rejected studies thought to be poorly randomized and concluded that mammography was not efficacious (Smith 2002)**.** Nevertheless, the re-analysis of the randomized controlled trials by Goetsche and Olsen that led to this controversy over mammography efficacy has also been inconsistent and has attracted criticism of its own (Smith 2002, de Koning 2000). For example although the version published in the lancet reported no effect, the version published in the Cochrane library (Olsen and Goetsche 2001) shows benefit if the majority of results for the RCTs are included in the meta-analysis (Smith 2002)

Further evidence that mammography saves lives, however comes from long-term trend analysis of the Swedish two county study (Tabar et al 2000, Tabar et al 2001) which unlike the RCT provided the opportunity to measure effect of screening among women who were actually screened (versus RCTs that compared only the effect among women screened to those not screened) (Smith 2002). Tabar et al (2000 and 2001) compared change in mortality rates among women who screened compared to a baseline rate, which was when mammography had not be

introduced and compared to change among women who had not been screened over similar periods. Tabar et al (2001) used data from clinical setting and a population based sample from two counties in Sweden and demonstrated the benefit of screening. They examined breast cancer- specific mortality across three time periods: 1) 1968--1977, when no screening was taking place because mammography had not been introduced; 2) 1978--1987, the approximate period of the Two-County randomized controlled trial of screening in women ages 40--74 years; and 3) 1988--1996, when all women in the 2 counties ages 40--69 years were invited to undergo screening (service screening). The sample comprising 6,807 women age 20 to 69 years who were diagnosed with breast cancer and 1863 breast cancer deaths among women who had lived in two counties in Sweden. They found " mortality from incident breast carcinoma diagnosed in women ages 40-69 years who actually were screened during the service screening period (1988--1996) declined significantly by 63% (relative risk (RR) = 0.37; 95% CI, 0.30--0.46) compared with breast carcinoma mortality during the time period when no screening was available (1968--1977). The reduction in mortality observed during the service-screening period, adjusted for selection bias, was 48% (RR = 0.52; 95% CI, 0.43--0.63). No significant change in breast carcinoma mortality was observed over the three time periods in women who did not undergo screening."(Tabar et al 2000, Tabar et al 2001)

Yet, further evidence comes from analysis of long-term trends in mammography use breast cancer incidence rates and mortality rates in the US national data (Chu et al 1996, Howe et al 2001, Ries et al 2001, Garfinkel 1993, Chevarley 1997). The pattern of increase in breast cancer incidence suggests the role of mammography. Lobular carcinoma in situ (LCIS) is less common, accounting for about 13% of in situ breast cancer. Only about 15 to 25% of the LCIS will become invasive. Most of the invasive cases are due to DCIS. From 1994 to 1998 DCIS accounted for 51% of the in situ breast cancers (Ries et al 2001). The incidence of carcinoma in situ increased considerably over this period. Much of the increase in carcinoma in situ has been due to the mammography-detected type--DCIS, a trend, which has continued. In contrast, the increase for the non-mammography-detected type--LCIS seen between 1982 and 1988, was smaller in magnitude and has been stable since 1988. Similarly the increases in invasive breast cancer incidence rates were smaller and have remained level (ACS 2002,ACS 2002). Much of the increase in breast carcinoma in situ was seen among White women aged between 50 and 74 years (Ries et al 2001), a pattern, which is consistent with increased access to screening.

Declining breast cancer mortality rates particularly among White women has paralleled this pattern in breast cancer incidence rates. Chu et al (1996) examined mortality data from the National Center for Health Statistics (NCHS) and incidence and survival data by extent of disease from the SEER program of the NCI. They stratified data by patient age and used statistical-regression techniques to determine changes in the slope of trends over time. They found that the age-adjusted breast cancer mortality rate for U.S. White females dropped 6.8% from 1989 through 1993. A significant decrease in the slope of the mortality trend of approximately 2% per year was observed in every decade of age from 40 to 79 years of age. They also observed that localized disease rates increased rapidly from 1982 through 1987 and stabilized or increased more slowly thereafter; while regional disease rates decreased after 1987; and distant disease rates remained level. The decline in mortally rate observed among White women between 1982 and 1989 suggest contribution not only by improvements in treatment but also due to increase in mammography use and improvements in systemic adjuvant therapy

(Chuet al, 1996). From 1980 through 1989 three-year relative survival rates increased steadily and significantly for both localized and regional disease in all ages, with no evidence of an increase in slope in the late 1980s" (Chu et al, 1996).

According to analysis of long-term trends of breast incidence and mammography use done by Garfinkel et al (1993), the increase in the incidence of breast cancer parallels a sharp increase in mammography use. The pattern of increase in breast cancer incidence particularly seen in localized small tumors, suggest the role of mammography. According to this study, between 1982 and 1989 localized breast cancer grew about 52%. Much of the increase was in tumors less than 2cm with tumors 1cm or less, 1-2cm, growing four times (from 9 to 35 per 100,000) and 2 times (from 40 to 80/100,000) respectively. In contrast the incidence of tumors 2-2.9 cm remained the same and those 3 or more cm declined by 27% (from 33 in 1982 to 24 per 100,000, 1989. The increase in the detection of localized and small size tumors and the percentage of women reporting ever having a mammogram suggestions the role of mammography. The percentage of women 40 years and older who reported ever having a mammogram increased from 22% in 1979 to 63% in 1989 and 74% in 1992 (Garfinkel et al, 1993). Thus while epidemiological data and many clinicians support the value of screening mammography in increasing early detection and treatment for breast cancer with positive impacts on survival, the scientific community has not produced conclusive evidence for this view.

Can mammography be effective in early detection of breast cancer for older women of color? One potential source of age and R/E disparity in mammography effectiveness is the characteristics of the tumor and the breast tissue. Not all tumors are mammography-detected, and some are interval-detected by other means (i.e. detected within 12 months after negative mammogram). About 10 –20% of breast cancers are not routinely detected by mammography (Gilliland et al, 2000; Porter et al, 1999). Although technical errors explain some false negative mammograms, characteristics of the tumor and breast tissue (such as high density, lobular histology, and absence of microscopic calcifications, and fast growing tumors) contribute (Porter et al 1999). Although there are no data from randomized controlled studies for women 70-79, the tumor and breast characteristics among the elderly suggest that women aged 70-79 who are in good health are just as likely to benefit from screening as their younger counter parts (50-69 year olds). In addition to having a higher risk of developing breast cancer, older women tend to have tumor characteristics that are more suitable for mammography screening (Porter et al 1999), and they also tend to have less dense, breast tissue. Several observation studies demonstrate the favorable tumor and breast density among older women:(Kerlikowske et al, 1996;Van Gils et al, 1998; Hart et al, 1989).

Kerlikowske et al (1996) used a cross-sectional study to examine factors that influenced the sensitivity of first screening modern mammography. The sample comprised of 238 women diagnosed with breast cancer, out of 28,271 women aged 30 years and older from nine counties in northern California. These women, between April 1985 and March 1992, were referred for first screening mammography to the Mobile Mammography Screening Program of the University of California, San Francisco. Measures included "breast cancer risk profile, two standard mammographic views per breast, breast density, and follow-up of abnormal and normal mammography. Data were collected from physicians and linked to the regional SEER tumor

registry to determine the occurrence of any invasive cancer or ductal carcinoma in situ. They found the sensitivity of modern mammography to be highest among women aged 50 and older who had primarily fatty breast density (as opposed to dense fibroglandular tissue), but lowest among women younger than 50. It was particularly low when the time between screenings was about two years or among women who had a family history of breast cancer, (which authors attributed to possibly rapid tumor growth).

There are however, race/ethnic differences in breast density. El-Bastawissi (2001) showed that for all races, breast density reduced with age. Shift to lower density occurred first among American Indians, and American Indians have the lowest breast density (Hart 1989). El-Bastawissi (2001) conducted a study to determine if the variation in breast density is a strong predictor of breast cancer risk, by race and age. They studied women enrolled in Group Health Cooperative of Puget Sound, Seattle, WA, aged 20-79 years, who had a screening mammogram between 6/1/96 and 8/1/97. Women with increased breast density ("heterogeneously dense" and "extremely dense") (n = 14,178) were compared to those with fatty breasts ("almost entirely fat" and "scattered fibroglandular tissue") (n = 14,323). Covariates included age, parity, age at first birth, menopausal status, current use of hormone replacement therapy, and body mass index. They found that for women 65 and over, Asians had denser breasts than White women, but did not find a difference in the younger age group. Breast density for older Black women did not differ significantly from that of older White women although younger Blacks had higher density. Breast density for Hispanics did not differ from that of White women in any group.

In another study, Porter et al (1999) used a case control design to examine patient and tumor characteristics associated with screen-detected tumors versus interval-detected tumors. The sample was comprised of 576 women age 50 years and over (162 with interval detected and 576 with screen detected cancers), all members of a HMO in Washington. The study showed the risk of interval-detected cancers was smaller for the age group 70-79 than for women 60-69 when each group was compared to women 40-49 years of age. Conversely, the proportion of screen-detected tumors was highest among women aged 70-79: 31.5% for ages 70-79 compared to 8.6%, 22.2%, 30.5%, and 7.2% for women aged 40-49, 50-59, 60-69, 80, and over respectively.

Although this body of studies is somewhat inconclusive, it does suggest that the characteristics of breast tissue in diverse older women of color indicate that mammography is less likely to be effective in tumor detection, and may suggest that mammography is more likely to detect tumors in older than younger women of all ages.

Can mammography utilization differences explain Race/ethnic disparities in stage at diagnosis? In the general population, multiple factors seem to be influencing stage of breast cancer at time of diagnosis including participation in mammography screening, obesity and biologic factors. Black women and other R/E groups (except for Japanese) are more likely to be diagnosed at a later stage than are White women. Given that R/E differences in tumor characteristics tend to diminish with age, it is envisaged that the role of characteristics in explaining R/E differences in stage at the time of diagnosis is small among older women (50 and older) and smaller compared to younger women (aged 50 and less).

Few studies have explicitly analyzed the role of mammography in breast cancer stage at diagnosis. These studies show that lack of mammography use significantly contributes to R/E differences in stage (McCarthy et al 1998, Jones et al 1995, Bibb et al 2001, Reeves et al 1996, Hunter et al 1993, Wu et al 1999, Jacobellis et al, 2002). The few available studies linking stage and screening suggest that lack of routine regular screening may result in about 5-13 percentage points excess late stage diagnosis in either the Black or White sample (Jones et al 1995, McCarthy et al 1998, Jacobellis et al 2002) While lack of screening compared to screening may account for as much as 30% excess late stage among older Black women compared to older White women (McCarthy, 1998). The study by McCarthy et al (1998) examined the association between mammography and stage using an exclusively elder sample. It suggests that among the elderly mammography use can attenuate the race-stage disparity.

McCarthy et al (1998) using an exclusively elder sample aged 67 and older found mammography use to explain about 30 % of the stage difference between AA and White women. McCarthy et al (1998), used SEER data linked to Medicare mammography claims for women aged 67 years and older who were diagnosed with breast cancer between 1987 and 1989 from three states, Connecticut, Georgia and Washington. They found that Black women were less likely to use mammography, and to have late-stage disease than were White women. They also found that the Black-White difference in cancer stage occurred only among nonusers of mammography. They found similar breast cancer stage among Black and White women who were regular users of mammography.

Studies that included younger age groups also found significant associations between stage at diagnosis and mammography, but mammography use contributed much less to reducing the differential in stage between Black and White women. Jones et al (1995) used a population-based, retrospective study of 145 African-American and 177 White women with newly diagnosed breast cancer in Connecticut, between, 1987 and 1989. Cases were ascertained through active surveillance of 22 Connecticut hospitals. They found Black women to be more likely to be diagnosed at a later stage than were White women. Black women were also more likely than were Whites to report that they had not received a mammogram in the 3 years before developing symptoms or diagnosis. In race-specific analyses, they found that mammography was protective against later stage diagnosis in White women, but not in Black women. With adjustment for mammography screening, the OR for the race-stage association was reduced only minimally, and race remained a significant predictor of stage at diagnosis.

Jacobellis et al (1998) used a 1990 to 1998 mammography database (N = 5182) of metropolitan Denver, Colorado women to examine each R/E cohort's incident cancer cases (n = 1,902) and tumor stage distribution given similar patterns of routine screening use. They found that regardless of R/E, women participating in routine screenings had earlier-stage disease by 5 to 13 percentage points. After controlling for possible confounding factors, White women were more likely to have early-stage disease compared with Black and Hispanic women. Correcting for screening did not completely reduce stage differentials among Black and Hispanic women.

Although these studies may not be directly comparable because they have methodology differences such as definition of non-user and the age groups of the population studied. They however, do demonstrate that lack of mammography use contributes to the association between

late stage and race. The studies however, also show that mammography use is not the only contributor to late stage at diagnosis among women of color.

Other factors that have been associated with late stage diagnosis include obesity (Reeves 1996, Moorman et al 2001, Hunter et al 1993) structural context variables, (Mandelblatt et al 1995), socio-cultural factors (Lannin et al 1998), and delay in seeking care for breast cancer symptoms (Hunter et al 1993). Moorman et al (2001) used data from a population-based study in North Carolina comprising 791 breast cancer cases (302 AA women and 489 White women) diagnosed between 1993 and 1996 to examine the association between late stage and obesity. They found that AA women were more likely to be diagnosed at stage II or greater; OR (95%CI)= 2.2 (1.6, 2.9) and more likely to be severely obese –BMI equal or greater than 32.3; OR (95%CI)= 9.7 (6.5 -14.5) and to be in the highest tercile for waist to hip ratio (WHR); OR (95%CI)= 5.7(3.8, 8.6). Obesity accounted for 27% of the racial difference in late stage (adjusting for obesity reduced the odds ratio for racial difference in late stage by about 27% -- 20% for WHR alone and 27% for both WHR and BMI (Moorman et al 2001).

In another population-based study using a sample of 2,863 women diagnosed with invasive cancer during the period 1988-1990 in Wisconsin, Reeves et al. (1996) examined the relationship between obesity and stage at diagnosis and found a strong dose-response relationship between increased BMI and the likelihood of non-localized disease (P < 0.001), with odds ratios for non-localized cancer increasing from 1.0 for the lowest quintile of BMI to 1.3, 1.6, 1.7, and 1.8 for the second through fifth quintiles, respectively. This association, however was present only among the 55% of women (1,585 of 2,863) who self-detected their tumors (Reeves et al 1996). The Reeves et al findings are based on relatively old data and have not been confirmed in more recent initiatives as discussed below.

Hunter et al (1993) evaluated the relationship of selected demographic, lifestyle, prior medical experiences, and health care access to cancer staging at diagnosis in Black and White breast cancer patients. They used population-based cohort study of 1222 women (649 Black and 573 White) newly diagnosed for the period 1985-1986 with primary breast cancers obtained from the NCI's Black/White Cancer Survival Study. Sources of data included abstracts of hospital medical records, central review of histology slides, and patient interviews obtained from three metropolitan areas: Atlanta, New Orleans, and San Francisco-Oakland. Within each area, 70% of all Black incident cases were randomly selected, and a sample of White cases, frequency matched by age groups (20-49 years, 50-64 years, and 65-79 years), was selected for comparison. They found that factors associated with cancer staging were different in AA and White women. Among Black women, indicators of access to health care, a lack of mammograms, and obesity (increased body mass index) was significantly (p< .02) associated with stage differences, whereas income was marginally associated (P = .06) with stage for White women only. Nuclear grade, having a breast examination by a physician, and a history of patient delay explained approximately 50% of the excess risk for stage III-IV cancer versus stage I-IIN0 cancer among Black women compared with White women (OR reduced from 2.19 to 1.68).

Among rural residents, delay in seeking care due to transportation or lack of money, and psychological barriers might contribute to late stage. For example, Lannin et al (1998), used a case-control study of 540 of 743 (540 cases and 414 controls) patients matched by age, race, and area of residence who between 1985 and 1992 were diagnosed with breast cancer at a University

Medical Center in two rural counties in Eastern Carolina. They found AA to be 3 times more likely to be diagnosed with late stage; OR (95%CI= 3.0(1.9-4.7). Other factors that were associated with late stage included having low income OR (95%CI=, 3.7(2.1-6.5); never having been married (OR, 2.9; 95% CI, 1.4-5.9); having no private health insurance OR (95%CI= 2.5 (1.6-4.0); delaying seeing a physician because of money; OR (95%CI= 1.6 (.1-2.5); or lacking transportation OR (95%CI= 2.0 (1.2-3.6). In this study demographic and socioeconomic variables reduced the odds of late stage among AA women by 1.2% (from OR (95%CI)= 3.0 (1.9-4.7)) for race alone to OR (95%CI= 1.8 (1.1 -3.2). Including belief measures along with demographic and social economic reduced the OR for late stage by another 60% (from 1.8, CI 1.1-3.2 to 1.2 CI, 0.6-2.5) and eliminated the race difference (Lannin et al 1998).

Provider institutional capacity may also contribute to late stage diagnosis. Although the study by Mandelblatt et al (1995) is quite old, it does demonstrate this point very well. In a study conducted among residents of New York, Mandelblatt et al (1995), examined the impact of individual demographic characteristics (age, race/ethnicity, and type of reporting hospital), together with measures of social context, including area of residence, socioeconomic status (SES), change in SES, and access to screening (area mammography capacity), on breast cancer stage at diagnosis among New York City residents diagnosed between 1980 and 1985. They evaluated the impact of individual variables, social context variables, and both classes of variables combined on the outcome of having late-stage (regional or distant) compared to early-stage diagnosis. They found that women diagnosed in public hospitals were 44 percent more likely to have late-stage disease than those diagnosed in nonpublic settings ($p < 0.0001$). They also found that, area mammography capacity was a significant independent predictor of stage ($p = 0.016$), (Mandelblatt et al 1995).

R/E Differences in Screening Participation: Although access to mammography has been increasing, age and R/E differentials still exist for appropriate mammography utilization, and this reduces early detection opportunities for breast cancer in these sub-populations. In addition, a substantial number of women do not screen according to recommended schedules. A substantial minority of women has never been screened, and about 10-16% of those who report ever being screened do not return for repeat screening (e.g. report having had a mammogram in past 2 years) (Blackman, 1999). Further, participation and adherence to mammography screening varies by age, R/E, SES, and geographical location. According to several studies, women of color are less likely to have repeat mammograms or to adhere to recommended screening intervals (Margolis et al 1993, Lee et al 1995, Hawley et al 2000, Hegarty et al 2000). Overall, Hispanic and AI/AN women have lowest mammography screening rates. All elderly women of color are particularly vulnerable to low rates of initial or recent repeat screening especially women aged 70 and over.

Over the past two decades, the proportion of women who report lifetime use of mammography (ever using) and recent mammography (use in the past 2 years) has been increasing for all age and R/E groups (Blackman et al 1999). For example, Blackman et al (1999) used BRFFS data for the period 1989-1997 to examine trends in mammography use, and found that the percentage of women aged 40 years and over who reported ever participating in breast cancer screening and the proportion who had participated within the previous 2 years increased during 1989-1997 (Blackman et al 1999). They also, however, found that substantially fewer

women had received screening within the previous 2 years than had ever been screened. Our review of this data shows that this differential is about 11% for women 60-69 and 16% for women 70 and over. Based on these national data, Black women seem to be just as likely to have a repeat mammogram as White women.

Regional differences in Black and White screening rates that may be masked in the national aggregate data. For example, Coleman et al (2001), used data from a national survey to study racial differences in breast cancer screening and effects of Medicare funding for mammography and to examine explanatory factors. About 13,545 women, aged 65-74, from the Medicare/CMS Master Beneficiary File was examined. The study showed broad differences by location, age, and R/E. For example, significant variations in the use of mammography in the past 2 years among the elderly (ages 65 to 74) were found between Eastern Massachusetts and the comparison region, Eastern Long Island (ELI). Black women residing in EM were more than 9 times more likely to report using mammography in the past 2 years than were Black women living in ELI (OR (95% CI) =9.27(2.14 to 40.1) In other regions, other patterns of R/E and age differences in use were found. In this sample another disturbing trend was that Black women were more likely to use breast self examination than mammography compared to White women who were more likely to use mammography than breast self- examination (Coleman et al 2001).

Other race ethnic groups seem to have both lower lifetime and recent mammograms than either White or Black women. The lowest rates are found for Hispanic and AI/AN groups (Blackman et al 1999; Gilliland et al 2000). There are also significant ethno-regional differences in the prevalence of mammography among Hispanics. For example, Ramirez et al (2000) found significant ethno-regional differences in mammography use among Hispanics. Ramirez et al (2000) used baseline data from the multi-site cancer prevention demonstration project funded by the National Cancer Institute (NCI) and the National Hispanic Leadership Initiative on cancer "En Acion project." The project involved 8 locations across the US and focused on four distinct Hispanic populations: Central American, Cuban, Mexican-American and Puerto-Rican. The sample consisted 2383 women age 40 and older, including a significant group of elders. In addition to examining ethno-regional differences in mammography use, they examined predictors of lifetime mammography use and recent mammography use. Lifetime mammography use (mammography ever) ranged from 50% in Laredo, TX to 80% in Miami, FL and 86% in San Francisco, CA. Controlling for age, education, health care plan and income, Mexican Americans, in Houston, TX, Brownsville, TX and Laredo, TX, were the least likely to be screened. Recent mammograms varied from greater than 70 among Central American Women in San Francisco and Cuban women in Miami to less than 50% among Mexican Americans women on the Texas Border (Ramirez et al 2000)

Although in general mammography use has been increasing, older women of color are less likely to have ever had a mammogram and to have repeat ones (Parker et al 1999, Burns et al 1996a, Burns et al 1996b, Coleman et al 2000), (CDC MMWR 1995, Hegarty et al 2000). For example, Burns et al (1996) used Health Care Financing Administration (HCFA) data, which included sociodemographic information and part B physician bills to examine mammography use among women age 65 or older residing in one of 10 states that had part B coverage up to December 31, 1990. They found mammography use to be " lower for Black than for White

women age 65 to 74 (14% vs. 21%, P < .001) and 75 to 84 (9% vs. 12%, P < .001)". They however, found no racial difference among women aged 85 and over.

In a related study for the same population, Burns et al (1996a) examine racial differences in mammography use associated with number of primary care visits. They found the following from Georgia and similar findings in each of other states studied: "Overall, 14% of the women had had mammography; Black women had mammography less often than White women (9% compared with 15%). At each primary care visit level (1, 2, or 3 or more visits), Black women had mammography less often than were White women (1 visit, 7% for Black compared with 15% for White; 2 visits, 12% for Black compared with 21% for White; and 3 or more visits, 12% for Black compared with 20% for White women)"(Burns et al, 1996b).

Persistent Race/ethnic disparities despite increasing uptake: Medicare reimbursement for mammography and the National Cervical and Breast Cancer Demonstration projects (CDC 1994, Kelehar et al 2000) introduced since 1990 have increased overall prevalence of first time breast cancer screening. Nonetheless, these programs have had little impact on reducing race/ethnic disparities in screening adherence (Preston 1997, Kelehar et al 2000, CDC BRFSS 1997, Hegarty et al 2000) or mortality (Marbella et al 2001) among older women. Older women of color— particularly those in AI/AN, Asian, and Non-White Hispanic communities-- are less likely to have ever had a mammogram and to have repeat one (Burns 1996a, Burns et al 1996b,Parker et al 1999). These results are also confirmed by our own analysis of the 2000 NHIS. Among women, age 65 and older, 50% of Whites and 49% of African Americans report having had a mammogram in the prior 12 months. Latinas, AI/AN, and Asian women reported lower rates of 46%, 22%, and 42% respectively. These data do not offer clues on adherence, and may be confounded by larger proportions of White women in the oldest groups, but still tend to confirm the findings of prior studies.

Studies done after 1990 demonstrate persistent racial/ethnic differences in mammography use (Coleman ET al, 2001; Hegarty et al, 2000; Gornick et al 1996; Parker et al 1998; Gilliland et al 2000). Foe example, Coleman et al (2001) used a sample of 13,545 women, aged 65-74, from the HCFA's Master Beneficiary File for the period after Medicare funded screening mammography, to examine trends in mammography use. They found that "the percent reporting a mammogram increased for White women, but not for Black women"(Coleman et al2001). In another study, Hegarty et al (2000) used a "follow-up survey of a probability sample, with 4,162 at baseline in 1986-1987 and 2,846 surveyed in 1992-1993.from Piedmont area of North Carolina to measure along with other tests self-reported use of, mammography, on a regular basis within the last two years". They found older Black women were less likely to receive, mammography than were older White women (30.2% Black vs. 40.5% White, P < .001), "(Burns et al 1996a, Burns et al 1996b, Parker et al 1999).

Gornick et al (1996) in their study of the effects of race and income on mortality and use of services also found that older Black women were less likely to use mammography than were older White women (17.1% vs. 26%). They used 1993 Medicare administrative data and a sample of 26.3 million Medicare beneficiaries (24.2 million White and 2.1 million Black women) aged 65 years of age or older with).

Preston et al (2001) used Medicare Part B mammography claims and small area analysis methodology (SAA) to identify mammography rates for 23 hospital service areas (HSAs), representing all of the catchment areas for Connecticut's acute care hospitals." They found that the mean statewide annual rates among women aged 65 years and older were 23.4% (1991), 24.5% (1992), and 24.9% (1993). The mammography use rates among Black women 65 years and older were significantly lower than their White peers in 1991 (18.8% Black vs. 23.8% White, P < .001), 1992 (20.6% vs. 24.7%, P < .001), and 1993 (22.0% vs. 25.1%, P < .001)".

Kelahar et al 2000, examined the impact of Medicare decision to provide reimbursement for mammography by comparing mammography use between Medicare-eligible and ineligible women in the years before (1990) and after (1993) the policy change, using National Health Interview Survey (NHIS) data. The sample consisted 2,419 women (60-69) years and 1,872 women ages 60-64 years who were Medicare ineligible. They examined mammography in the prior 2 years and controlled for race, ethnicity, socioeconomic status, insurance status, and usual source of care. They found that although access to mammography had increased, disparities related to access to primary care and socioeconomic status persisted after the change in Medicare coverage

Disparities in repeat use and adherence to recommended mammography schedules: The increasing prevalence of lifetime and recent mammography says little about age and race differences in repeat mammography use or adherence to schedule. Epidemiologic studies designed to answer these questions indicate significant R/E differences in repeat mammography and adherence to schedule among both Black and other women of color.

Gilliland et al (2000) examined patterns of mammography use among Hispanic, American Indian, and non-Hispanic White women in New Mexico for the period, 1994-1997. They used population-based data collected by the New Mexico Mammography Project for residents of the Albuquerque, New Mexico, and metropolitan areas and examined screening rates and proportion of women who routinely used mammography. They found that only 50% of the women aged 50-74 years were screened each year and that less than one third of women 75 years and older were screened annually. The percentage of women who routinely used mammography on an annual or biennial basis was low in all age groups, especially among Hispanics and American Indians. For example among 50-74 year olds Hispanic women were 10 % less likely to routinely use mammography than were White women (Gilliland et al 2000)

Bastani et al (1995) examined initial and repeat mammography screening in a low-income multi-ethnic population in Los Angeles. The sample was comprised of 3,240 women, age 50 years and over, from two hospitals and two comprehensive health-centers operated by the Los Angeles County Department of Health Services. After review of medical records they found that only 21% had had a mammogram in the 12 months prior to the index clinic visit, and 23% had received a mammogram in the following 9 months. Approximately 5% of the total sample received a repeat mammogram in the 21-month period over which they were tracked.

Song et al (1998) evaluated breast cancer re-screening rates among low-income women and examined initial breast cancer screening and factors associated with re-screening for women enrolled in Breast and Cervical Health Program (BCHP) in King County, Washington using data

from the Washington State BCHP tracking system. They estimated the percentages that received breast cancer re-screening for women enrolled between July 1994 and December 1995 and factors associated with time to re-screening using survival analysis. They found that overall, percentages of women who re-screened at 15 and 27 months for women aged 50-69 was 25.7% and 45.0%, respectively. They also found that re-screening differed by age groups, R/E, level of education, foreign-born status, history of previous mammography, and enrollment clinic.

Zapka et al (1991) demonstrated that although mammography adoption was increasing, the goal of regular screening according to guidelines had lagged behind. They used a random digit dial telephone survey of 693 women from two geographic areas to evaluate adherence to mammography screening guidelines among women over 50 years of age and factors related to adherence. Predictor variables examined included sociodemographic features, personal breast health history, provider-related variables, and medical care utilization. They found that while 48% had had a mammogram in the last year, only 20% reported at least two recent mammograms at yearly intervals. Women who had a higher income, were White, were 51 to 64 years old and had had breast symptoms and/or a family history of breast cancer, had a regular physician, higher frequency of clinical breast examination, and a recent physician visit, enrolled in Health Maintenance Organizations (HMOs) and/or covered by commercial plans (rather than having no insurance or with entitlement coverage only) were more likely to be adherent than women who did not have these characteristics. "These relationships were generally maintained in multivariate analysis" (Zapka et al 1991).

Explaining R/E disparities in Screening: An extensive epidemiological literature has explored factors that may account for R/E disparities in mammography, emphasizing systems of care, provider and individual factors.

Systems of care: There is strong evidence that primary care use is associated with screening (Parker et al, 1999; Coleman et al, 2001; Cummings et al, 2002). Women who have a usual source of care and a regular primary provider are more likely to use mammography that those who do not. For example, Parker et al (1999) examined Medicare billing data to estimate association between screening mammography in 1992 and subsequent screening in 1993 or 1994, among Medicare beneficiaries. They found that women with a 1992 mammogram were more than twice as likely to have a mammogram in 1993 or 1994 than women without a 1992 mammogram, RR (95%CI) =2.58; (2.57-2.59) (Parker et al 1999)

O'Malley et al (2002) showed that "organizing healthcare services to promote continuity with a specific primary care clinician, a comprehensive array of services available at the primary care delivery site, coordination among providers, and better patient-practitioner relationships are likely to improve inner-city, low-income women's adherence to mammography and other cancer screening recommendations". They examined the effects of primary care, health insurance, and HMO participation on adherence to regular breast, cancer screening among low-income African American women. They used random-digit-dial and targeted household telephone survey of a population-based sample in Washington, D.C. census tracts that had 30% or more of households below 200% of federal poverty threshold. The sample comprised 1,205 women over age 40, 82% of whom were African American. They defined adherence as reporting the last 2 screening tests within recommended intervals for age. They found that 65% of women were adherent to mammography recommendations. Factors that were associated with higher rates of adherence

included continuity with a single primary care practitioner, comprehensive service delivery, and higher patient satisfaction with the relationships with primary care practitioners. Coordination of care also was associated with screening adherence for women age 65 and over, but not for the younger women. Compared with counterparts in non-HMO plans, women enrolled in health maintenance organizations were also more likely to be adherent to regular screening (OR (95% CI)=1.95 (1.15 to 3.31)(O'Malley et al 2002).

Kelahar et al (2000), examined the impact of the Medicare decision to provide reimbursement for mammography by comparing mammography use between Medicare-eligible and ineligible women in the years before (1990) and after (1993) the policy change, using National Health Interview Survey (NHIS) data. They found that having additional insurance was the only significant predictor of having a usual source of care among the Medicare population.

Older women of color, although more likely to accept recommendation for screening than older White women, are less likely to adhere to the recommendation, especially those who have Medicare only. For example, Dolan, et al (1995) examined factors predicting adherence to a health care provider's screening mammography recommendation in a general internal medicine practice using a prospective observational study for a sample of 349 women, aged 50 years and older, without prior history of breast cancer, who received a health care provider's recommendation for screening mammography at an urban academic general internal medicine practice. Independent variables included patient age, race, insurance type, educational level, and duration of affiliation with the practice and visit type as well as health care provider gender and level of training. Dependent variables were acceptance of the recommendation and adherence, defined as undergoing mammography within three months of the recommendation. In univariate analysis, they found that acceptance of the recommendation decreased significantly with increasing age (p < 0.01), and by race: more AA women (89%) vs. Whites (82%), accepted recommendation, (p = 0.05). In multivariate analysis, only age remained independently predictive of acceptance. However, among women who accepted the recommendation, adherence significantly differed by race (more White than AA women -- 70% vs. non White 59%, p = 0.05), insurance type, and health care provider training. In a logistic regression analysis, in addition to provider training, insurance type remained independently predictive of adherence

Provider factors: Burns et al (1995), in addition to determining rates of use, explored physician factors associated with, repeat mammography using administrative data for 791 women aged 50 years and older. They found (73% of women had received repeat mammography (i.e., a second mammogram was obtained within six to 18 months of the first). They found the following provider factors to be associated with repeat use: being a woman, practicing in the women's health group rather than the general internal medicine service, and being a fellow or an attending physician (p-values < 0.01). Provider characteristics that greatly influenced their patient's repeat screening included gender and level of training. Patients of women fellows had higher repeat mammography rates than did those of men fellows, men residents, and women residents (Burns et al 1995)

As described earlier, Dolan, et al 1995 examined factors predicting adherence to a health care provider's screening mammography recommendation in a general internal medicine practice

using a prospective observational study for a sample of 349 women, aged 50 years and older, without prior history of breast cancer, who received a health care provider's recommendation for screening mammography at urban academic general internal medicine practice found provider training to be independently predictive of a woman's adherence to screening in addition to insurance type (Dolan et al 1995).

Provider-Patient intercommunication: Although there is association between previous mammography use and subsequent use, older women of color experience deficits in mammography use even with similar primary care utilization patterns (Burns et al 1996). One possible explanation for this differential in mammography use despite similar primary care use is that women of color are less likely to be recommended a mammogram by providers. Provider recommendation and the enthusiasm with which it is recommended is the strongest predictor of mammography use. Older Black women are less likely than older White women to be recommended for screening mammography (Potosky et al 1998), and are less likely to request it (Marks et al 1990; Coleman et al 2001).

The literature suggests that among cues to action, provider –patient intercommunication is more important predictor of mammography use (O'Malley et al 1997; Fox et al 1994; Danigelis et al 1996; Taylor et al 1998). It is especially important for older women than younger women.. For example Danigelis et al (1996) examined the role of age in mammography use and factors associated with a recent mammogram. They found age to be "the key context for distinguishing factors associated with having a recent mammogram:" They examined the association of predisposing, reinforcing and enabling actors with recent screening mammography use for the following age groups of 40-49, 50-64 and 65 They found " Knowledge of screening guidelines and exposure to information about breast screening on radio or television were the most distinguishing factors for the youngest age group. Having health insurance and level of education were important factors for the middle age group. The most noteworthy differences were found in the oldest group for who physician recommendation for mammography and confidence in being able to get a mammogram were the only significant factors associated with having a recent mammogram."

In a study conducted by O'Malley et al (1996) in North Carolina, physician recommendation accounted for 60 to 75% of the initial racial differences in mammography use. Less Black (25%) than White women (52%) reported physician recommendation (O'Malley et al, 1997). Fox et al (1994) found racial differences in physician recommendation as well as enthusiasm of recommendation. Non-White women were significantly less likely than were White women to have reported physician recommendation. Strong disparities occurred in the age group 50-74. Logistic regression analysis showed that "Physician discussing mammography", "physician discussing mammography with enthusiasm "and "patient asking for referral" were the strongest predictors of mammography use (Fox et al, 1994).

Solis et al (1990) evaluated use of preventive health services including breast examinations) among Mexican American, Cuban American, and Puerto Rican adults (ages 20-74) with data from the HHANES. Analyses focused on the relative importance of two predictors of recent screening: access to services (health insurance coverage, having a routine place for care, type of facility used, having a regular provider, travel time) and acculturation (spoken and

written language, ethnic identification). They found that controlling for age, education, and income indicated that utilization of the preventive services was predicted more strongly by access to care than by acculturation. For each Hispanic group, having a routine place for health care, health insurance coverage, and a regular provider were each significantly associated with more recent screening.

Individual factors among older women of color associated lower mammography use include socio-economic and socio-cultural factors.

Socioeconomic factors: Socio-economic factors associated with screening include high household income, having additional insurance to supplement Medicare insurance or being in a health plan an education beyond high school. These factors are associated with provider recommendation (Coleman et al 2001), recent use (Ramirez et al 2000, Maxwell et al 1998) as well as lifetime use--mammography ever—(Ramirez et al 2000)

Coleman et al (2001), using a national survey to study racial differences in breast cancer screening and effects of Medicare funding for mammography to examine explanatory factors for physician recommendation for a total of 13,545 women, aged 65-74, identified the Health Care Finance Administration's Master Beneficiary File found that Physicians recommended mammography more often if women were White, married, educated beyond high school and had an annual income greater than $20,000."(Coleman et al 2001)

In addition to examining ethno-regional differences in mammography use among Hispanic women, Ramirez et al (2000) examined predictors of lifetime mammography use and recent mammography use. They used baseline data for 2383 women 40-49, 50-64 and 65 and older from the multi-site cancer prevention demonstration project funded by the NCI and the National Hispanic leadership Initiative on cancer. They found that recent mammography use (past 2 years) was significantly associated with age 50-64 than 40-49 or 65 and over, OR (95% CI)=1.52 (1.17-1.97), having an income greater than $10, 000, and having a health plan.

Maxwell, 1998 assessed mammography utilization among Korean-American women and their knowledge, attitudes and barriers related to screening. They found that having health insurance and income greater than or equal to $25,000 were positively related to ever having a screening mammogram.

Tang et al (2000) found that both common and cultural barriers play a role in breast cancer screening among older Chinese-American women, with cultural factors being more influential in the initiation of cancer screening behavior". They examined screening utilization at least once and regular adherence to mammography among older Chinese-American women. The sample comprised one hundred women recruited from senior centers in two metropolitan cities. They found health insurance to be significant predictors of having had a mammogram at least once (Tang et al 2000)

Socio-cultural factors: Socio-cultural factors that have been associated with screening include attitudes towards disease or the health system, family and community contexts, limited English proficiency, (Solis et al 1990; Woloshin et al 1997; Ramirez et al 2000; Suarez et al

1997) beliefs and values—low risk perception (Tang, 2000, Austin et al 2002), perceived benefit of screening, knowledge (Sung et al 1997), modesty (Maxwell et al 1998).

Three cultural explanatory models have been used to try to understand the impact of socio-cultural factors on mammography. According to Rajaram (1998). Cultural explanatory models (CEMs) "stem from the socio-cultural context and involve <u>cultural beliefs and values</u>, personal life experiences, and both biomedical and popular explanations of health and illness (Rajaram 1998). Three popular cultural explanatory models include the 1) health beliefs model (HBM), 2) acculturation and 3) cancer models.

There is currently a dearth of quantitative studies that have used cultural concepts of cancer (in terms of folk understanding of cancer etiology, prevention and cure to predict mammography use; although knowledge scales are often tested with health beliefs. A qualitative study by Gregg, 1994 at two Atlanta clinics revealed that cancer models held by the African American patient population differed significantly from those held by clinicians. Women attending the clinics endured cancer screening tests that to them seem to serve only as heralds of a disease that will ultimately kill them. Most women doubted there was a cure for cancer, although some believed a person may live if the disease is caught in time"(Gregg et al1994).

Much of the cultural based research has focused on health beliefs using the Health Belief Model (HBM) developed in the 1950s by social psychologists (Becker et al 1994). The HBM constructs include 1) perceived susceptibility, 2) perceived severity, 3) perceived benefits, and 4) perceived barriers 5) cues to action and 6) self-efficacy. Various studies have used the constructs of the HBM especially the health beliefs to try to predict mammography use.

A study by Aiken et al (1994), done among middle class White women showed the independent contribution of psychological barriers to be about 7% (Aiken, et al 1994). Aiken and colleagues assessed the utility of the HBM for predicting compliance with the ACS recommendations for mammography screening over and above demographics, knowledge, physician input, and objective risk for breast cancer. In 1987-1989 they surveyed, 615 predominantly middle-class White women, age 35-92. A multiple indicator measurement model of the HBM constructs of perceived susceptibility, severity, benefits, and barriers was verified with confirmatory factor analysis they found that physician input alone accounted for 25% of the variance in compliance; HBM constructs alone, 16%. HBM constructs accounted for 7% additional variance in compliance beyond all other predictors.

The role of health beliefs in predicting mammography use among women of color has been least understood and produced inconsistent findings. Some studies have found some association between health beliefs and mammography use while others have found no association. No analytic model comparable to one by Aiken et al (1994) has been proposed and tested among women of color to help ascertain how much cultural belief barriers contribute to failure to engage or adhere to screening mammography. A number of studies however show those health beliefs and attitudes differ by race and ethnicity and do not consistently predict use. Although bivariate analysis tend to show association between mammography use and health beliefs, multivariate models show that most of these are not independent predictors, especially among African Americans and to some extent among some Hispanics (Laws 1998). This is

perhaps because these subjective beliefs are associated with objective socio-economic barriers. Factors that have been more consistently associated with mammography use include knowledge of screening guidelines, concern about cost (Stein et al 1991) knowledge about cancer and its prevention (Sung et al 1997), low perceived need (Tang et al 2000). The section that follows reviews some findings from a limited number of studies.

Psychological barriers (cost concerns, fear, fatalism): Stein et al (1991), assessed the relative influence of psychological barriers, SES, and ethnic differences in mammography use for a community sample of 586 White, 227 Black, and 150 Hispanic women. Confirmatory factor analyses with latent variables indicated plausible factor structures for all groups on items related to barriers to mammography. Summed indicators of SES, fear of radiation, embarrassment, pain, anxiety, and cost concerns were correlated significantly with mammography use for the pooled group. Separate analyses by ethnicity indicated a substantial relationship between mammography use and cost concerns by White and Black women, and fear of pain by Black and Hispanic women. Use of mammography was more associated with SES among Hispanic women. Pooled logistic regression analyses controlling for SES and ethnicity showed that concern about cost, remained an important independent predictor of mammography use.

Suarez et al (1997) found that older Mexican-American women with more fatalistic and fearful attitudes toward cancer were less likely to have recent mammogram (Suarez et al 1997). In another study described earlier, Tang et al (2000) found low perceived need/lack of physician recommendation to be significant predictors of not having a recent mammogram among older Chinese Americans. Similarly, Maxwell et al (1998) found that among Korean Americans, concerns about finding cancer, embarrassment, and discomfort requesting the procedure from the physician were negatively associated with use.

Knowledge: The impact of knowledge on mammography use was found to be fairly consistent with three out of 4 studies reviewed showing association with appropriate screening (Sung et al 1997) or recent use (Suarez et al 1997; Ramirez et al 2000).

Sung et al (1997) found that in general, women who were more knowledgeable about cancer and its prevention were more likely to have been appropriately screened and that various attitudes and beliefs regarding cancer generally were not associated with history of screening. They interviewed 321 inner-city **African-American women** to determine their knowledge, attitudes, and beliefs regarding cancer and cancer screening, and their history of cancer screening. The women were recruited from a variety of sources in Atlanta and were interviewed in their homes by trained lay health workers. Half of the subjects had an annual household income of < $15,000. 35% had received a mammogram within the recommended interval.

The second study by Suarez, et al (1997), examined "knowledge, behavior, and fears" concerning breast cancer among older low-income Mexican-American women They used data from baseline surveys conducted before the start of a community cancer awareness and prevention program. 923 Mexican-American women were interviewed in-person about their knowledge, attitudes, and mammogram screening practices, their knowledge and attitudes about cancer varied with age, education, type of health insurance, ability to speak English, and place of birth. Women 65 years of age and older were least knowledgeable of cancer-detection methods

and screening guidelines. Those with only Medicare or Medicaid knew far less even compared to uninsured women. Women who did not speak English well were more likely not to know the cancer signs and symptoms, risk factors, and screening guidelines. Women who had knowledge of guidelines and detection methods were more likely to have had a <u>recent screening</u>

The third study by Ramirez et al (2000) examined breast and cervical cancer knowledge, attitudes, and screening behaviors among different Hispanic populations in the United States using data collected via a random digit dial telephone survey of 8903 Hispanic adults from eight U.S. which were collected as part of the baseline assessment in a national Hispanic cancer control and prevention intervention study. They restricted the analysis to 2239 Hispanic women aged 40 and older that were self-identified as Central American (n = 174), Cuban (n = 279), Mexican American (n = 1550), or Puerto Rican (n = 236). Variables analyzed included age, education, income, health insurance coverage, language use, U.S.-born status, and knowledge of screening guidelines, attitudes toward cancer, and screening participation. They found that the level of knowledge of guidelines varied by ethnic group ranging from 58.3% (Mexican Americans) to 71.8% (Cubans) for mammography, They also found that attitudes also varied, with Mexican Americans and Puerto Ricans having more negative or fatalistic views of cancer than Cuban or Central Americans. Knowledge was significantly related to age, education, income, language preference, and <u>recent screening</u> history. Attitudes however were not predictive of mammography behavior.

The final study however found knowledge not to be an independent predictor (Hubbell et al 1997). They conducted a telephone survey of randomly selected Latinas (n = 208) and Anglo women (n = 222) to determine predictors of mammography use. The cooperation rate was 78.5%. Relatively high proportions of Latinas (61%) and Anglo women (79%) reported mammography use within the past 2 years. A logistic regression analysis revealed that knowledge and attitudes did not independently predict use. On the other hand, having health insurance, being married, and being Latino were consistent independent predictors.

Acculturation is another measure that has been used to evaluate the impact of culture on mammography use. Acculturation has been defined as the "Psychological adaptation of persons from their culture of origin to new host cultural environment" (Burnam et al 1987, O'Malley et al 1999). This measure includes measures of English proficiency, cultural identity and norms, and length of residency in the host country (Suarez et al 1994, O'Malley et al 1999). Acculturation variables such as English use length of residency in the US and group norms are associated with ever having a mammogram or lifetime use. The most consistent of the three, however is English use.

Suarez et al (1997) examined "Knowledge, behavior, and fears concerning breast cancer among older low-income Mexican-American women. They used data from baseline surveys conducted before the start of a community cancer awareness and prevention program. 923 Mexican-American women were interviewed in-person about their knowledge, attitudes, and mammogram screening practices, found that older Mexican-American women who <u>did not speak English well</u> were more likely not to know the cancer signs and symptoms, risk factors, and screening guidelines. Women who had knowledge of guidelines and detection methods were more likely to have had a recent screening.

Solis et al (1990) evaluated use of preventive health services including breast examinations) among Mexican American, Cuban American, and Puerto Rican adults (ages 20-74) was investigated with data from the HHANES. Analyses focused on the relative importance of two predictors of recent screening: access to services (health insurance coverage, having a routine place for care, type of facility used, having a regular provider, travel time) and acculturation (spoken and written language, ethnic identification). They found that controlling for age, education, and income indicated that utilization of the preventive services was predicted more strongly by access to care than by acculturation. Of the acculturation variables, *language* but not ethnic identification (which was measured only for the Mexican Americans) predicted use Solis, 1990). Ramirez et al (2000), in a study of ethnic differences in mammography use also found that English use significantly predicted lifetime mammography use.

Maxwell et al (1998) assessed mammography utilization among Korean-American women and their knowledge, attitudes and barriers related to screening. They found the following acculturation variables to be positively related to lifetime mammography use: holding positive group norms; longer duration of residency in the U.S.; and greater acculturation. Tang et al (2000), found that both common and cultural barriers play a role in breast cancer screening among older Chinese-American women, with cultural factors being "…more influential in the initiation of cancer screening behavior". They examined screening utilization at least once and regular adherence to mammography among older Chinese-American women. They found acculturation to be a significant predictor of lifetime mammography use (Tang et al 2000)

Logistical barriers: Maxwell et al. (1998) found transportation to be a significant barrier to mammography use for a sample of Korean Americans (Tang et al. 2000, Solis et al. (1990) using data from the HHANES, found that among Mexican American, Cuban American, and Puerto Rican adults (ages 20-74) the type of facility used and travel time to, produced less consistent effects on mammography use.

Barriers to completion of the diagnostic work up: Women of color not only face barriers to screening but also to timely confirmation of diagnosis and diagnostic work up which may have impact on late stage as well as on quality of treatment. A number of procedures for definitive diagnosis of breast cancer have been identified which may include additional screening, needle or excisional biopsy, histological examination to confirm the tumor and identify prognostic pathologic characteristics, identifying other tumor markers that have treatment and prognostic significance such as ER/PR status. The choice of treatment for breast cancer depends primarily on the clinical and tumor characteristics, particularly stage, and hormonal receptor status (progesterone and estrogen positive or negative) and co-morbidities. Breast cancer clinical and tumor status determines primary treatment choice; while positive estrogen/progesterone receptor status (as opposed to negative) determines the decision to use tamoxifen for systemic treatment. Women who have incomplete diagnostic work-up are therefore likely to have incomplete treatment. As, noted earlier, two studies were found that explicitly examined factors that influenced race/ethnic disparities to diagnostic work-up (Caplan et al 1996; Rojas et al 1996). Caplan et al (1996) examined provider and health care system barriers associated with delay in diagnostic work-up among 367 breast cancer cases that were part of the NCI's-Black-White survival study. They found that 45% of the delay was due to provider and health care system, through difficulties in scheduling or physician inaction, 25% was due patient factors and 17 due to both patient and provider factors (Caplan et al 1996).

Rojas et al (1996) performed a cross-sectional survey of three cancer- screening clinics at an inner city Hospital. They found high rates of non-compliance with follow-up after abnormal screening—about 50%. Overall, in comparison to those who adhered to recommendations, non-compliers were less likely to report being told to follow-up (65% vs. 100%), less likely to have suspicious mammography interpretations, and more likely to report barriers to follow-up such as cost of lost wages, medical care system barriers and fears than compliers. (Rojas et al 1996)

Interventions to Reduce R/E Disparities in Mammography: *Review of previous meta-analyses:* There is currently great interest in determining interventions to increase mammography screening. This area has also been subject to intensive reviews and meta-analysis (Legg et al 2000; Mandelblatt et al 1995; Mandelblatt et al 1999; Wagner et al 1998; Yabroff 1999; Skekelle et al 2001). Interventions to increase mammography use range from simple low cost computer generated reminders to interventions that involve human intermediaries. Both simple and more complex interventions seem effective in increasing uptake and adherence to screening, although only few studies have tested the sustainability over long periods. Interventions directed at the provider (e.g. reminders to providers, audit, and feedback, organizational change, such as information systems to enhance follow up, or scheduling changes) and those directed at the client (e.g. mailed reminders using automated reminder systems, telephone counseling, or customized reminders, or lay health workers) seem to be equally effective. But provider directed interventions seem optimal especially when at least two strategies are used, according to these reviews. For example, according to Mandelblatt and Yabroff (1999) behavioral interventions for providers increased mammography screening rates from usual care of 65 percent by 13.2 percentage points (95% CI, 7.8-18.4) compared with usual care, and by 6.8% (95% CI, 4.8-8.7) compared to active controls (such as provision of educational materials). Similarly, behavioral interventions aimed at the individual client increased mammography screening by 13.2% (95% CI, 4.7-21.2) compared with usual care, and by 13.0% (95% CI, 8.7-17.4) for multiple strategies and 5.6% (95% CI, 0.6-10.6) and for single intervention compared to active controls. The setting of the intervention also seems to matter. For example, according to Mandelblatt et al (1995) in academic medical settings, physician reminders and audit with feedback each increased use of mammography and clinical breast examination by approximately 5% to 20%, while in community settings, the effect of physician education were slightly less ranging from 6% to 14%.

Although these interventions have been found effective in the general population, their ability to increase screening among R/E groups who are Medicare beneficiaries as well as the costs of these strategies, are unknown, according to all of these reviews. Different strategies may be required for hard to reach populations such as the rural and low-income women and low education women. These women experience additional sociocultural barriers beyond the access and provider barriers. These include generally low perceived risk for breast cancer, lack of knowledge or appreciation for prevention as medical care approach and fear of discovering breast cancer, (Gregg et al 1994, Suarez et al 1997, Austin et al 2002) which is generally believed as a fatal disease. These women also face geographical access barriers such as lack of transportation (Lannin et al 1998, Maxwell et al 1998, Kiefe et al 1994) and opportunity costs (Hardy et al 2000, Burns et al 1996, Pearlman et al 1996, McCarthy et al 1996). Use of social net

models such as faith based organizations and lay health workers seems to be an emerging effective intervention for the hard to reach (Andersen et al 2000)

None of: prior meta-analyses focused on the set of breast cancer projects or studies that explore the use of explicitly culturally adapted intervention strategies to improve adherence by older women of color to screening guidelines. To fill this gap, our review focuses on interventions that are culturally tailored to women of color. Culturally tailored studies were defined as ones using any of the following interventions: 1) Language appropriate education materials or role model media education; 2) use of lay health workers chosen from the respondents' community and either of the same ethnicity as the participant or with deep roots in the community and competence in its language as the participant; and 3) use of social networks such as church or other cultural based community based organizations. Articles were searched from various sources, including Medline. Publications were also sought from prior reviews and the CDC database. Key words for this search included "interventions and breast cancer screening", patient support and breast cancer screening, breast cancer screening and lay health worker, breast cancer screening and lay health advisor, breast cancer screening and volunteers, breast cancer screening and lay educators, breast cancer screening and lay advisor, breast cancer screening and community interventions." The database was also searched using leading author names to identify prior studies on same subject by these authors. Additional article sources were recommendations by expert consultant, review of bibliographies in prior reviews, and the CMS report on Reducing Disparities in Health Outcomes: Effective and Promising Outpatient Interventions with Underserved Populations.

More than 28 reports met cultural tailoring criteria, but some of these were multiple reports on a single intervention, while other studies did not meet minimal methodological standards. To be included, studies needed to report on: 1) an experimental (randomized clinical trials and randomized community trials); or 2) quasi-experimental project (controlled community clinical trial without randomization or controlled community trial without randomization). Acceptable control strategies were: 1) Pre-test and posttest (paired control) design with independent concurrent control at each point in time; or 2) independent concurrent controls. Also, studies had to have both baseline and follow-up data to be included. Thirteen studies, yielding 18 comparisons between intervention and comparison groups out of 28 met these criteria and were included in the meta-analysis. Appendix III includes Evidence Tables for these projects.

Because of the small number of final interventions included, only three control variables were coded and tested. First, all sites either used an out-reach approach to recruitment of participants, holding screening education events and distributing materials, or an in-reach approach where participants were recruited from a clinic population. Second, sites either focused their interventions and measurement on screening uptake or screening adherence. Thus, though all out come measures were in form of mammography rates. Programs and their outcomes measures were coded as (1) measure of adherence—mammography changes among women who had some prior use, and (2) mammography uptake –measures of mammography change among women who had no or little prior use. Third, while some studies reported on the use of a single strategy for cultural tailoring, others drew on multiple strategies including operational enhancements (materials translation, management information systems, leadership and

practitioner education) and social network features (lay health workers and group meetings), while other sites only included social network components. The absolute rate difference was the Effect size measure used in this study. We use comprehensive meta-analysis software developed by Biostat, Inc. to compute fixed effects point and variance measures. This software uses a two-by-two table of measures of actual events to calculate effect sizes. For both the control and the intervention group, the change in number of screened women was calculated by subtracting the follow-up number from the baseline number. Thus, the effect measure included in the meta-analysis reflects a so-called difference-in-differences approach. Table III-9 summarizes the meta-analysis findings.

Table III-9
Meta-analysis of Interventions to Increase Mammography Screening
Among Older Women of Color

	Citation	OutcomeType	RecruitMeth	StrategyIntensity	Effect	Lower	Upper	PValue
	Margolis, 1998	Adherence	InReach/or Both	MultipleOrSocioNet	-.027	-.084	.031	.364
	Bird, 1998	Adherence	Outreach only	MultipleOrSocioNet	.220	.179	.261	.000
	Duan, 2000	Adherence	Outreach only	MultipleOrSocioNet	.073	.006	.141	.034
	Earp, 2002 High Income	Adherence	Outreach only	Single	-.057	-.119	.006	.134
	Earp, 2002 Low Income	Adherence	Outreach only	Single	.108	.045	.171	.001
	Gotay, 2000	Adherence	Outreach only	Single	-.002	-.026	.023	.896
	Zhu, 2002	Adherence	Outreach only	Single	.000	-.053	.052	.989
	Navarro, 1998	Adherence	Outreach only	MultipleOrSocioNet	.070	-.016	.156	.116
	Paskett, 1999	Adherence	Outreach only	MultipleOrSocioNet	.151	.064	.238	.001
	Sung, 1997	Adherence	Outreach only	Single	.091	-.020	.202	.123
	Webber, 1997	Adherence	InReach/or Both	MultipleOrSocioNet	.132	.072	.192	.000
	Margolis, 1998	Uptake	InReach/or Both	MultipleOrSocioNet	.096	.029	.163	.005
	Bird, 1998	Uptake	Outreach only	MultipleOrSocioNet	.111	.070	.152	.000
	Erwin, 1999	Uptake	Outreach only	MultipleOrSocioNet	.090	.032	.148	.004
	Slater, 1998	Uptake	Outreach only	MultipleOrSocioNet	.063	.026	.100	.001
	Duan, 2000	Uptake	Outreach only	MultipleOrSocioNet	.025	-.085	.136	.652
	Gotay, 2000	Uptake	Outreach only	Single	.003	-.047	.053	.911
Fixe	Combined (17)				.058	.046	.071	.000

Negative Effect   Positive Effect
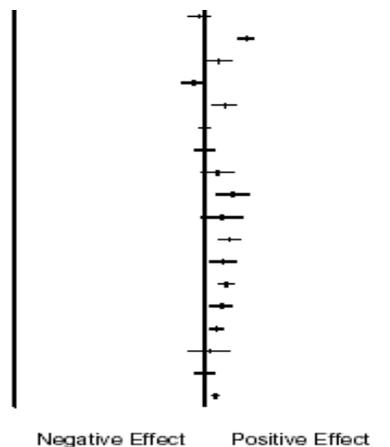
Effect=Absolute rate difference

The meta-analysis showed that as a group, these programs achieved modest impacts on screening rates, rate difference (RD) of about 8% (RD=0.0864; 95%CI =0.071, 0.103, Z=10.37 p<. 0000). Nonetheless, the program findings were remarkably heterogeneous (Q=154 p<. 0000). That is, it cannot be said that programs produced consistent findings, but rather there are differences in their designs and populations that influence outcomes. Our analysis identified only one such difference. Programs that utilized multiple social network and operational enhancements produced a larger effect of about 10 percentage points higher than the control groups (RD=0.107, 95% CI=0 .0.096, 0.121, Z=12.92, p<. 00000 than did those focused on screening uptake who had 7 percentage points higher than the controls (RD=0.007, 95% CI – 0.012,0.024, Z=0.71, ns), a significant difference (Q=59.95, p<. 0001). Considering screening uptake vs. adherence was unrelated to program effect. Similarly, focusing on outreach vs. in-reach was unrelated to program effect. These findings provide some fair level of confidence that a culturally tailored strategy for improving screening uptake and adherence that includes use of community health workers, culturally and linguistically adapted materials, and community-based small group and/or personalized interventions can be effective. Findings also suggest that what community health workers are asked to do makes an important difference for outcomes: programs that recruit participants from an established clinic populations and those that focus on screening adherence are more likely to be effective.

Cervical Cancer

There is currently no effective primary prevention for cervical cancer. Two possible primary intervention methods are immuno-prevention (vaccination) against Human Papilloma Virus (HPV) and modification of sexual behavior. The potential for immuno-prevention has been recognized and there are currently studies into developing vaccines for certain types of HPV (such as 16 and 18) which would make this possible, (NCI Cancer facts 2001). Modification of sexual behavior is often advised, though its effectiveness and relevance to Medicare populations are unclear. There is also some evidence to show that incorporating a focus on sexual behavior under cervical cancer preventive policy would stigmatize the disease and thus potentially reduce participation in screening and treatment. For example in one study among Hispanic women, Hubbell et al (1996), found that women who associated cervical cancer with sexual conduct were less likely to report ever having had a Pap smear (Hubell et al 1996).

Cervical cancer, however, is one cancer that best meets the criteria for mass screening to detect disease (Cole and Morrison 1978, NCI 2001). It is characterized by a long lead time with pre-cancerous lesions progressing through a succession of identifiable stages from least severe to most severe (termed as atypical squamous cell of undetermined significance (ASCUS) through low grade squamous intraepithelial lesion (LSIL) or Cervical intraepithelial neoplasia (CIN 1), to high grade squamous intraepithelial lesion (HSIL) or cervical intraepithelial neoplasia 2-3 (CIN 2-3) --prior to invasive disease (Smith 2000, NCI Cancer facts 2001). If detected in the pre-clinical phase there are options to treat the pre-cancerous lesions and cure is almost 100% (Smith 2000). Although there have been no formal randomized trials to test the efficacy of Pap smear in preventing mortality the test is widely accepted as an effective screening tool and its effectiveness is supported by several observational studies. Introduced in 1940 by Dr. George Papanicolaou, the Pap smear is now recognized as a major contributor to reduced cervical cancer incidence and mortality. There is broad consensus among professional organizations regarding screening policy. For example, the American Cancer Society recommend that women who are

sexually active or those who are 18 years and over be screened with Pap smear test annually. After 3 or more consecutive satisfactory screenings with normal findings the Pap test may be done less frequently (ACS Cancer facts and figures 2002, Smith 2001). To increase screening among the elderly, Medicare, in 1998 introduced coverage for cervical cancer screening.

Because Pap smear is a screening test and not diagnostic, further tests are needed after an abnormal Pap smear. There is general consensus that women whose Pap test indicate high-grade abnormal cell changes should have follow-up with more definitive diagnostic tests such as colposcopy and cone biopsy of any abnormal areas (Franco and Monsonego, 1997; NCI Cancer facts, 2001). Management of low grade ASCUS and SIL lesions to cost-effectively prevent unnecessary colposcopies and cone biopsies, however, present a challenge, potentially giving rise to disparities in invasive cervical cancer incidence and prevalence. Two options are available for management of patients with mild cervical abnormality such as ASCUS or LSIL. One option is to recommend colposcopy only for those women who present with persistent low-grade abnormalities such as two positive Pap smears within a two-year follow-up period. The other option is to have immediate colposcopy for women with a single abnormal cytology suggestive of LSIL. Additional assessment criteria focus on whether or not a patient is at low or high risk for developing cervical cancer or HSILL). According to Ferecnzy (1997), high-risk patients (women aged, 25 years and older, those who have low reliability for follow-up, have past abnormal cytology or therapy, are not known to the physician, who have had multiple sexual partners, have cytology with low rates of false positives or have a clinically suspicious cervix) should be followed-up with immediate colposcopy. If appropriate, they should be treated immediately to prevent the development of invasive cervical cancer. If repeat Pap test is positive for LSIL, low risk patients should be followed up with Pap tests at 6-month intervals for up to two years to determine whether the lesion will become persistent or will regress. When the ASCUS or LSIL finding is not supported by repeat test and the cervix is clinically normal, the patient is followed up with annual Pap tests. Any patient with clinically suspicious cervical finding should be referred for immediate colposcopy, even if the cytology test is negative (Ferecnzy 1997).

Once completed, the ASCUS/LSIL Triage Study (ALTS), a major study organized and funded by the National Cancer Institute (NCI), will help providers decide what course of action to take when mild abnormalities are found on Pap tests. The Preliminary findings from the ALTS study suggest that testing cervical samples for HPV is an option to help direct follow-up for women with an ASCUS Pap test result. The final study results are expected in about 3 years (NCI Cancer facts 2001).

Although incidence rates for cervical cancer vary widely, R/E variation in abnormal Pap smear and rates of findings associated with high risk of invasive disease seem to be much narrower. The same may not be true for follow-up. For example Benard et al (2001) used the National Breast and Cervical Cancer Early Detection Program data collected for the period, 1991-1998 to describe cervical screening and biopsy results by R/E. They examined the percentage of abnormalities detected by Pap tests and the rate of biopsy-diagnosed high-grade pre-cancerous or cancerous lesions by R/E group. The sample included 628,085 women of which about 50% were persons of color. They found that AI/AN women had the highest proportion of abnormal Pap tests for first program screens (4.4%), followed by AA (3.2%), Whites (3.0%), Hispanics (2.7%), and API (1.9%) women. The R/E pattern for high-grade lesions or high-risk cytology was different. White women had the highest biopsy detection rate of high-grade lesions

for first program screens (9.9 per 1000 Pap tests), followed by Hispanic (7.6%), Blacks (7.1%), AI/AN (6.7%), and API (5.4%) women.

Although these findings suggest that age-appropriate women in all racial/ethnic groups would benefit from cervical cancer screening, Benard et al. (2001) found that American Indian or Alaska Native women were more likely than others to report never having had a prior Pap test. They also found that Black women with a high-grade Pap test were less likely to get complete diagnostic testing or preventive treatment of pre-cancerous conditions.

The Potential to Benefit from cervical cancer screening by older women: The lead time and prevalence of pre-cancerous phase of uterine cervix cancer lesions suggests that older women would benefit from at least one screening and ensuring that abnormal screens are followed up and properly evaluated and treated. The pre-cancerous lesions form a continuum of increasing abnormal changes and patterns and timing of persistence, regression, and progression to invasive cervical cancer vary. For example, the average time for progression of CIN 3 to invasive cancer is 10 to 15 years without treatment, but there is a small subset of rapidly progressive cervical cancers, which are diagnosed within 3 years of a confirmed negative Pap test (NCI Cancer prevention PDQ 2002).

However, repeat screening is necessary because of the high possibility of false negatives. Like other screening tests, Pap test is not perfect. It is highly liable to technical and interpretive errors with both false positive and false negatives being common. The Pap test has a high sensitivity and specificity for pre-cancerous lesions when the most techniques are used to obtain the cytological specimen. Nonetheless, given variability in the adequacy of cytologists' review of the findings, pap test failure rate in diagnosing invasive cancer can be as high as 50% (NCI Cancer prevention (PDQ) 2002). This necessitates repeat screening.

The Bethesda system of reporting Pap tests introduced in 1988 minimizes reporting errors and demands accountability in reporting in that it requires evaluation of adequacy and a descriptive diagnosis of the specimen. Under this system, the Pap test is reported as LSIL, HSIL, or ASCUS. The LSIL and HSIL correspond to carcinoma in situ 1 (CIN 1) and carcinoma-in-situ 2-3(CIN 2-3), respectively while the ASCUS does not fulfill any of these criteria (NCI Cancer prevention (PDQ) 2002).

R/E Patterns of Uterine Cervical Cancer Screening and Follow-up Compared to other cancer screening tests, the Pap test is the most highly utilized both in terms of women who have ever had a test and women who have had recent test. Like other cancer tests, however, there are significant age and R/E differences in the utilization of Pap test. Older women of color are significantly less likely to have ever had Pap test (Mandelblatt et al 1999, Hegarty et al 2000, Zambrana et al 1999, Kagawa-Singer et al 2000, Blackman et al 1999) or to have a recent test (Mandelblatt et al 1999, Blackman et al 1999). As for some other cancer sites, cervical cancer can be prevented through interventions to treat pre-cancerous lesions, while treatment for early stage cervical cancers can also be effective as described in subsequent sections. Available, limited research indicates however, that for elders in general and women in under-served R/E groups, there are greater gaps in the adequacy of follow-up after abnormal screening (Mandelblatt et al 1993, Fox et al 1997).

General Adult Populations: Among all women age 18 and over, trends in the past two decades show major gains in access to Pap smear tests but R/E disparities persist. For example,

for the period 1991-1997, considering all ages and all five R/E groups represented in the national compilation of BRFFS data, Blackman et al (1999 found that 80-90% of women had ever received a Pap smear. But API and Hispanic women were less likely to have ever used a Pap smear (79.5, 84.8 respectively) than AA, White or AI/AN were (92.2,93.1 and 90.4 respectively). The proportion of women reporting recent use for the period 1991-1997 was lower than women reporting ever use--ranging from 67.8 for API to 81% for AA. Again, Hispanic and API women were less likely to report recent use.

Other studies also support the finding that API and Hispanic women have much lower lifetime and recent Pap tests than either White or Black women (Gilliland et al 2000. Kagawa-Singer & Pourat (2000) used the National Health Interview Survey (NHIS data for 1993 and 1994) to evaluated major socioeconomic and access variables associated with screening practices among APIs as a group and among subgroups. They used the Healthy People 2000 (HP2000) criteria to evaluate the most recent NHIS screening rates for APIs as one group and for six distinct subgroups compared with HP2000 criteria. The sample comprised 2756 non-Hispanic API and 64,196 non-Hispanic White women age 18 years or older in the 1993 and 1994 NHIS. They found that cervical cancer screening rates for APIs were below those for White women and well below national goals and guidelines (Kagawa-Singer & Pourat 2000).

Elders and R/E differences: Blackman et al. (1999) also examined trends in Pap use by age and R/E group and showed that older women, age 70 and over, followed by women aged 60 and 69 are less likely to ever use or to have recent use than the younger women. Older AA women seem to be less likely to ever use although they are just as likely as White women to have recently used (CDC 1995, Blackman et al 1999). More recently, Hegarty et al. (2000) used a follow-up survey design and a stratified probability sample" to evaluate rates of Pap test utilization among women from the Piedmont area of North Carolina-- 4, 162 surveyed at baseline in 1986-1987 and 2,846 surveyed in 1992-1993. At time of follow-up survey in 1992-1993 there were 1,486 women aged; 70 years and over, 1,246 of these were Black and 966 were White. They found that: compared with older Whites, older Black persons were 8.5 % less likely to receive Pap test (48.1% Black vs. 56.6% White, P <; .001).

Mandelblatt & Yarboff (1999) used a structured telephone survey of a quota sample of 1,420 New York City women from four Hispanic groups (Columbian, Dominican, Puerto Rican, Ecuadorian) and three groups of African descent (U.S., Caribbean, and Haitian) to evaluate R/E patterns of "ever" and "recent" self-reported use of Pap smears. The sample included both elders and non-elder women. They found that women age 65 and older were significantly less likely to have ever had a Pap test by 21% (OR (95%CI) 0.79(0.65-0. 96) and 33 % less likely to have recently Pap test (OR (95% CI) = 0.67, (0.57 -0.79)) than younger women.

Follow-up on abnormal Pap tests and women of color: Women of color are also less likely to be followed up after abnormal Pap smear. For example, Mandelblatt et al. (1993) found that nearly 1/3 of older AA women with abnormal Pap smear failed to complete follow-up with further evaluation. This cross-sectional study examined clinical findings from a nurse-practitioner-based breast and cervical cancer-screening program at an urban public clinic for poor, elderly, AA women. The sample comprised 491 women aged 65 years and over. They

measured rates of participation, abnormal tests, and cervical cancer. They found that nearly one-third of women with abnormal Pap smears failed to complete follow-up.

In another study, Fox et al (1997) found significant differences in follow-up on cervical cancer screening by R/E and urban /rural residence. About 1738 women in the California Breast and Cervical Cancer Control Program who received an abnormal cervical screening result comprised the sample. They found significant differences by age, R/E, initial screening results, and urban/rural residence. They also found severity of diagnosis to be a highly significant predictor of follow-up

Racial/Ethnic Group Differences in l Screening, Abnormal Screening Findings, Cancer Incidence and Mortality Rates: Benard et al (2001) used national breast and cervical cancer demonstration project data for period 1991-1998 to examine R/E patterns in pre-cervical cancer lesions. The table below presents a comparison of these screening outcomes with screening rates, incidence and mortality. To get a sense of the area of cervical cancer prevention in which each R/E group is lagging, Tables III-10 provides a quantitative summary of relative rates of screening abnormal and high-risk cytology rates, incidence and mortality to help ascertain possible policy implications.

Table III-10
R/E Patterns of Pap Smear Tests, Abnormal and High-Risk Pap Tests,
and Uterine Cancer Incidence and Mortality: 1991-1998

	Ever had a Pap smear [A]	Pap smear in past 2 yrs [A]	Abnormal Pap Screens [B]	High risk Pap (biopsy detected) rates [B]	Incidence[C]	Mortality [C]
White	93.1	78.1	3.0	9.9	9.6	2.8
Black	92.2	81.	3.2	7.1	13.3	6.7
Hispanic	84.8	71.5	2.7	7.6	17.5	3.8
API	79.5	67.8	1.9	5.4	11.7	3.1
AN/AI	90.4	74.0	4.4	6.7	7.7	3.3

The data are from difference sources: [A] Source: Black (1999), data source BRFFS 1991-1997, data covers 1991-1997; [B] Source: Benard et al. (2001) National Breast and Cervical Cancer Demonstration Project (NBCCDP) data, N=628,085, data is for 1991-1998, rates are per 1000 Pap tests; [C] (Source=NCI/: SEER Statistical review 1973-1999, data is for a the period 1992-1998. API=Asian and Pacific Islander, Alaskan Native/ AN/AI=American Indian

The tables show that:
- African-American and White women have comparable Pap screening rates (both lifetime and recent) and abnormal cytology rates but different high-risk cervical cytology, incidence and mortality rates.
- Although African -American women have lower rates of high-risk cervical cytology, the incidence of cervical cancer is higher among African-American compared to White women. In addition African-American women experience higher mortality rates than White women. Although this data might be consistent with differences by R/E group in underlying incidence of any cervical cancer, similar screening and abnormal screen rates among White and Black

women, but differences in biopsy detected rates suggests a different explanation. Lower rates of follow-up and treatment of pre-cancerous conditions and early stage cancer. African - American women could probably benefit from more aggressive follow-up of abnormal screens.

- Hispanic women have moderate to low Pap screening rates; relatively low abnormal screening rates but moderate levels of high-risk cytology findings and high incidence of cervical cancer and moderate mortality rates.
- API have low levels of Pap screening as well as abnormal/high risk cytology detection rates, but have moderate incidence and mortality rates;
- AN/AI have high to moderate screening rates, high abnormal cytology rates and low high-risk cytology rates, low incidence of cervical cancer but moderate mortality rate.

Explaining R/E Differences in Pap screening: Factors associated with R/E disparities in cervical cancer screening and follow-up include provider factors, systems of care/access barriers, and individual factors –both economic and socio-cultural factors. Some of the evidence for each of these potential determinants of R/E disparities is described below. In general, these studies provide compelling support for the roles of provider, system of care, and individual economic status/insurance in receipt of Pap smear, but less consistent findings for the effects of attitudes and beliefs. Women with more adequate insurance coverage, income and education and a usual source of care were more likely to adhere to Pap smear testing and to receive complete follow-up services.

Provider factors: Mckee et al 2001) used an historical cohort and collected data by chart abstraction to examine the level of adherence to recommended follow-up after Pap test screening for a sample of women attending 7 urban community health centers who had an initial ASCUS or atypical Pap test**.** They found that health care providers recommended colposcopy after an initial atypical Pap test results in 12% of cases and repeat cytology in 67%. Failure to document a plan for management was found in 19% of cases, complete adherence to screening and treatment guidelines was achieved for 27% of subjects, moderate adherence for 28%, and low adherence for 45%. The factors associated with complete versus moderate or low adherence included site of care, description of the abnormality (ASCUS vs. atypia), availability of on-site colposcopy, and discussing the plan with the patient at a visit. Benard et al (2001) found that Black women were less likely to be followed up after abnormal screening than White.

Systems of care and Access: Zambrana et al. (1999) compared the use of Pap smear, 3 years prior to interview among five subgroups of Hispanic women, and examined whether sociodemographic; access; health behavior, perception, and knowledge; and acculturation factors predict screening practices for any subgroup. They used data 1990 and 1992 National Health Interview Surveys on women who reported that they were Hispanic. The study sample included 2,391 women. They found differences in education, health insurance, use of English language, and screening use. Mexican women were the least likely to be screened with any procedure. Logistic regression results for each screening practice showed that having a usual source of care was a positive predictor for obtaining Pap test in the last 3 years. Being married, being more than 50 years of age, were all predictors of having a Pap smear.

O'Malley et al (1997) examined R/E patterns of cancer screening for 7 groups: US-born Blacks, English-speaking Caribbean-born Blacks, Haitian Blacks, and Puerto Rican, Dominican, Colombian, and Ecuadorian Hispanics. They found that women with usual source of care and regular provider were more likely to have ever had a Pap smear or to have recently had a Pap smear. Compared with women without a usual site of care, those with a usual site, but no regular clinician, were 1.56 times as likely ever to have received a Pap smear, and 1.84 as likely to report receiving a recent Pap smear.

Hiatt et al (2001) using a multi-ethnic sample of 1599 women aged 40-75–Latina, Chinese and AA—found significant R/E variations in the use of Pap smears. They examined patterns and predictors of Pap smear use. They used baseline data from a Breast and Cervical Cancer Intervention Study – conducted in the in the San Francisco Bay Area from 1993 to 1996. They found about 89% had ever had a Pap test. Pap smear screening in the past 3 years was low among non-English-speaking Latinas (72%) and markedly lower among non-English-speaking Chinese women (24%). They found that the strongest predictors of screening behavior were having private health insurance and frequent use of medical services. Having a regular clinic was also important predictor of having a Pap smear in the past 3 years.

Juon, et al (2000) evaluated breast and cervical cancer screening tests and factors associated with cancer screening behaviors among Korean-Americans. They used a face-to-face cross-sectional survey of 438 Korean-American women residing in Maryland. About 50% of women age 18 and older had had a Pap smear in the past 2 years. In multiple logistic regression analyses, the strongest correlate of screening behaviors was having a regular medical check-up (Juon et al. 2000).

Economic factors: Hubbell et al (1996) found health insurance significantly predicted reports of using Pap smear within the past 3 years. They conducted a telephone survey using the computer-assisted telephone interview system, random digit dialing, and an instrument adapted from national surveys and a previous ethnographic study. The sample comprised, 1225 non-institutionalized Spanish- or English-speaking respondents 18 years or older-803 Latinas (533 immigrants and 270 US born) and 422 White women.

Socio-cultural Beliefs--attitudes, fears, and fatalism: Ramirez et al (2000) used a bilingual survey instrument to collect information on, attitudes toward cancer, and screening participation. They assessed differences in knowledge and attitudes across Hispanic groups using either chi-square tests or analysis of variance and they used. Logistic regression models to assess the influence of knowledge and attitudes on screening participation. They found that attitudes were not predictive of Pap smear behavior. Attitudes varied, across Hispanic subgroups with Mexican Americans and Puerto Ricans having more negative or fatalistic views of cancer than Cuban or Central Americans. Knowledge was significantly related to age, education, income, language preference, and recent screening history. Overall, attitudes were not predictive of Pap smear behavior.

In contrast, Suarez et al (1997) found that for older Mexican American women with more fatalistic views were less likely to have a recent Pap smear. They used data collected from a baseline surveys conducted before the start of a community cancer awareness and prevention

program. They interviewed 923 Mexican-American women were about their knowledge, attitudes, and Pap smear and mammogram screening practices

In another study, Chavez et al. (1997) found that Latina women who had more fatalistic views were less likely to report having a Pap smear in the previous 3 years. They used ethnographic interviews and a cross-sectional telephone survey in Orange County, California. The sample comprised 94 Latinas and 27 White women selected through organization-based network sampling for the ethnographic interviews and 803 Latinas and 422 White women randomly selected for the telephone survey.

Acculturation: Wu et al (2001), examined patterns of mammogram and Pap screenings among Mexican American women ages 67 and over. They used on 1,403 Mexican American women from the Hispanic Established Population for the Epidemiological Study of the Elderly, a cohort study of community-dwelling Mexican Americans ages 65 years or over from the southwestern United States. They found that Mexican American women, age 75 or older were less likely to ever have had cervical screening than women ages 67 to 74, even controlling for sociodemographic, cultural, and selected health factor. They found that among older Mexican Americans, women who were less acculturated and had lower education were less likely to have ever had a Pap smear.

Hubbell et al. (1996) also examined role of acculturation along with other factors. They conducted a telephone survey using the computer-assisted telephone interview system, random digit dialing, and an instrument adapted from national surveys and a previous ethnographic study. The sample comprised, 1225 non-institutionalized Spanish- or English-speaking respondents 18 years or older-803 Latinas (533 immigrants and 270 US born) and 422 White women. They found acculturation to be negatively associated with receiving a Pap smear in the past 3 years.

Juon et al. (2000) evaluated breast and cervical cancer screening tests and factors associated with cancer screening behaviors among Korean-Americans. They used a face-to-face cross-sectional survey of 438 Korean-American women residing in Maryland. About 50% of women age 18 and older had had a Pap smear in the past 2 years. In multiple logistic regression analyses, the strongest correlate of screening behaviors was having a regular medical checkup. Although the strongest predictor was having regular medical checkup, age and acculturation were also found to be important predictors of cancer screening tests: Women less than 50 years of age were more likely to have cancer screening tests than those 50 years and older. They found length of stay in the US, employment status and marital status to be associated with having a Pap smear. Those who had spent substantial amount of time in the US, those who were both married and employed were more likely to have had a Pap smear than those who did not have these characteristics.

Knowledge: Kim et al. (1999) examined cervical cancer screening knowledge and practices of Korean-American women.159 Korean-American women, 40 to 69 years of age comprised the sample. They used the 1987 Cancer Control Supplement questionnaire---which they translated into Korean -- to collect data. Twenty-six percent of the respondents never heard of the Pap smear test. Only 34% of respondents reported having had a Pap smear test for

screening. The most frequently cited reason for not having had a Pap smear test was absence of disease.

Beliefs: Hubbell et al. (1996) found that Hispanic women who believed that cervical cancer had a connection with sexual behavior were less likely to report Pap smear within the past 3 years. They conducted a telephone survey using the computer-assisted telephone interview system, random digit dialing, and an instrument adapted from national surveys and a previous ethnographic study. The sample comprised, 1225 non-institutionalized Spanish- or English-speaking respondents 18 years or older-803 Latinas (533 immigrants and 270 US born) and 422 White women. They found that Latina immigrants were more likely than US-born Latinas or White women to believe that a variety of behaviors were risk factors for cervical cancer. Logistic regression analysis revealed that Latinas who held such beliefs were significantly less likely, to report receiving a Pap smear within the past 3 years than women who did not hold these views. Other independent predictors of Pap smear use included health insurance status, martial status, and acculturation.

Interventions to Reduce R/E Disparities in Cervical Cancer Screening: *Review of prior meta-analyses:* There is currently great interest in determining interventions to increase Pap screening. This area has also been subject to previous reviews and meta-analysis (Yabroff et al 2000; Marcus and Crane 1998; Shekelle et al 2001). Prior reviews have focused on increasing screening participation and adherence for general populations. Further, prior reviews have not sought to assess the impacts of interventions for elders of color in particular.

Interventions to increase cervical cancer screening are similar to ones used to increase mammography screening and can be broadly classified as directed at changing 1) patients, 2) practitioner, 3) both patients and practitioners, 4) provider organizations, and 5) systems of care/financing. Strategies for engaging patients range from simple low cost computer-generated letters and leaflets/pamphlets to more complex interventions involving human intermediaries. In general, these interventions can be further classified into 1) promotional/educational efforts (i.e. mass media campaign through print, audio/visual media, individual counseling using professional staff or volunteer lay health workers (using individualized in-person; group; telephone counseling methods) 2) invitations to participate in screening (either through personalized or mass letter mailings or use of human intermediaries) 3) reminders (e.g. computer generated mail reminders, personalized letters or telephone reminders).

Examples of provider directed strategies include computer-generated prompts/reminders regarding patients due for screening, report cards and feedback, as well as cultural competence training. Financial and systems of care and access barrier directed include coverage for screening test, reimbursement through vouchers, transportation provision/vouchers. Provider organization directed strategies includes re-organizing delivery methods (scheduling, setting up management information systems and involving non-traditional staff).

Table III-11 summarizes findings from several of the prior reviews and individual studies about the relative effectiveness of these approaches.

Table III-11
Interventions that Increase Participation in Pap Smear Screening:
Summary of Prior Reviews and Selected Studies [REFORMATED]

TARGET	RECRUITMENT STRATEGY	DESCRIPTION	INTERMEDIARY	IMPACT*
Client	Out reach			
		Media campaigns	General Mass media Print, Audio/visual	(+)(-)
			Mass media multiple or targeted to remove access barriers	(+)
			Mass media with other strategies	(+)
		Cultural /social net based	Lay health worker (CHW)	(+)
			CHW with Community intermediary	(++)
		Individual Mailing	Personalized letter	(+)
			Letter with other strategies	(+)
			Mass mailing	(-)
Patient and Provider	In reach Outpatient	Recruitment and reminders	Patient prompts/checklists	(+)
			Patient and provider prompt	(++)
Provider		Reminders (Cognitive)	Physician prompts	(+) (-)
			Combined with other strategies	(+)
Patient	In Patient	Recruitment	Inpatient recruitment	(+)

SOURCE: Marcus et al. (1998) and Shekelle et al. (2001) Table is re-organized to suit objectives for this study.
(+)= Positive impact=improves screening rates; (-)=Negative impact; does not elevate screening rates; (-) (+)=Mixed
effects=some studies show no impact others studies show that it elevates screening; (++)=Impact is greatly
elevated=combining the strategies increases impact above what is noted for singles strategy. Outreach activities
target a community population, while In-reach activities target existing clinic or health plan participants.

According to each of the systemic reviews, both simple and more complex interventions
seem effective in increasing uptake and adherence to screening, although some strategies seem
more effective than others, while yet other strategies seem to work better in combination with
others (Marcus and Crane. 1998, Shekelle et al 2001).

- The impact of media campaign on increasing Pap screening are mixed (Marcus and
  Crane 1998). Some studies have found little or no effect (Suarez et al 1993; Byles et al
  1994; Alexander et al 1981; Dignan et al 1994) while others have found some effect
  (Shelley et al .1991; Mitchell et al 1991). However, they tend to work better when
  multiple media are used (Dietrich et al 1989; Holland et al 1993) or when tailored to a
  specific screening program that reduces access barriers (Dietrich et al 1989; Holland et al
  1993); or in combination with other strategies (Byles et al. 1994).

- Use of lay health workers as community intermediaries has been reported to have some
  positive impact on Pap use in previous reviews.(Marcus and Crane 1998) It has also been
  observed that the impact of the Lay health workers is enhanced if they are coordinated
  with existing community intermediaries (Hulka 1966; Hulka 1967; Evans et al 1980;
  Dunn 1993; Dignan et al 1996; Davis, 1994)

- Other community outreach programs include use of outreach clinics and mobile examination rooms (MacGregor et al 1963; Osborn et al 1966; Dignan et al 1996; White et al 1993; Satarariano et al 1982; Holland et al 1993; Hirst et al 1990; Marcus and Crane 1998). Although mobile clinics are effective in increasing screening participation, one potential problem with use of mobile clinics among population without a regular provider is continuity of care and thus access to appropriate screening follow-up.
- Patient mailings are among the most successful low cost outreach interventions, especially if they are personalized (Laara 1987; Bowman et al 1995; Prichard 1995; Lancester et al 1992; McDowell et al 1989; Mitchell et al 1990; Lantz et al 1995; Hulka et al 1966; Hulka et al 1967; Fulghum et al 1962) or if they are used conjunction with other strategies Mitchell 1991; Byles et al 1994). However, mass mailings without personalized messages tend to be ineffective (Hulka et al 1966; Hulka et al 1967; White et al 1993; Marcus and Crane 1998).

- Personalized prompts to patients regarding screening done before an encounter with a provider have been found effective (Dickey 1992; Dietrich et al 1989; Yancy et al 1995; McPhee et al 1991; Turner et al 1989; Becker et al 1989; McPhee et al 1993) especially if they are combined with physician prompts (McPhee et al 1991; Turner 1989; Becker et al 1989; McPhee 1993; Marcus and Crane 1998).

- In-reach within the health facility's in-patient and outpatient departments appear to represent under-utilized opportunities for increasing participation in Pap screening particularly for older women. According to the review by Marcus and Crane (1998), the impact of physician prompts in the outpatient department is mixed. Some studies have shown positive effects on Pap screening (Pierce et al 1989; McPhee et al 1991; McDonald et al 1984; Robie 1988) while others have shown no impact (McDowell et al 1989; Turner et al 1989; Cheney et al 1987; Schreiner et al 1988; Dietrich et al 1992; Hahn et al 1990; Harris et al 1990; Tape et al 1990; Tierney et al 1986; Clementz et al 1990). By contrast, studies have shown consistent positive effects of recruiting patients from the inpatient department especially the elderly (Mandelblatt et al. 1993; Byles et al 1994; McDowell et al. 1989; Marcus and Crane. 1998).

Although these interventions have been found effective in the general population, their ability to increase screening among R/E groups who are Medicare beneficiaries and improve rates of screening adherence and complete follow-up, are unknown, according to all of these reviews. In addition, the long term impact of these interventions is not known, because few have tested the sustainability over long periods Different strategies and greater effort may be required for hard-to -reach populations such as the rural, low-income, and low education women. These women experience additional socio-cultural barriers beyond the access and provider barriers. These include generally low perceived risk for cervical cancer, lack of knowledge or appreciation for prevention as medical care approach and fear of discovering cancer (Gregg et al 1994; Suarez et al 1997; Austin et al 2002), which is generally believed as a fatal disease. These women also face geographical access barriers such as lack of transportation (Lannin et al 1998; Maxwell et all 1998; Kiefe et al 1994) and opportunity costs (Hardy et al 2000; Burns et al. 1996b; Pearlman et al 1996; McCarthy et al 1996). Use of social net models such as faith based organizations, and lay health workers seems to be an emerging effective intervention for

increasing mammography among the hard to reach (Andersen et al. 2000) it is not clear whether or not it is equally effective for increasing cervical cancer screening.

Meta-analysis of culturally tailored cervical cancer screening interventions: None of prior meta-analyses focused on the set of cervical cancer projects or studies that explore the use of explicitly culturally adapted intervention strategies to improve adherence by older women of color to screening guidelines. This review focuses on interventions that are culturally tailored to women of color. As for mammography screening, culturally tailored studies were defined as ones using any of the following interventions: 1) Language appropriate education materials or role model media education; 2) use of lay health workers chosen from the respondents' community and was of the same ethnicity as the participant or spoke same language as the participant; and 3) use of social networks such as church or other cultural based community organizations. Articles were searched from various sources, Medline search using Endnote and without limit on period. Publications were also sought from prior reviews and the CDC database. Key words for this search included "interventions and cervical cancer screening, patient support and cervical cancer screening, cervical cancer screening and lay health worker, cervical cancer screening and lay health advisor, cervical cancer screening and volunteers, cervical cancer screening and lay educators, cervical cancer screening and lay advisor, cervical cancer screening and community interventions." The database was also searched using leading author names to identify prior studies on same subject by these authors. Additional article sources were recommendations by expert consultants, review of bibliographies in prior reviews, and the CMS report on Reducing Disparities in Health Outcomes: Effective and Promising Outpatient Interventions with Underserved Populations.

Twenty-five reports met cultural tailoring criteria, but some of these were multiple papers on a single intervention, while other studies did not meet minimal methodological standards. To be included, studies needed to report on 1) an experimental (randomized clinical trials or randomized community trials); or 2) quasi-experimental project (controlled clinical trial without randomization or controlled community trial without randomization). Acceptable control strategies were: 1) Pre-test and post-test (paired control) design with independent concurrent control at each point in time; or 2) independent concurrent controls. In addition, studies had to have both baseline and follow-up data to be included. 8 programs, yielding 12 comparisons between intervention and comparison groups met these criteria and were included in the meta-analysis. Appendix III includes Evidence Tables for these projects.

Because of the small number of final interventions included, only three control variables were coded and tested. First, all sites either used out-reach activities for recruitment of participants such as screening education events and distributing materials, or used only in-reach activities to recruit participants from an established clinic population. (Only one study, yielding two comparisons, however used an in-reach strategy). Second, programs either used a single strategy (i.e. lay health workers as health educators) or combined multiple strategies (i.e. lay health worker, personalized letter, adapted materials). Third, programs either focused their interventions and measurement on screening uptake or screening adherence. Thus, though all outcome measures were in form of Pap rates, programs and their outcomes measures were coded as (1) measure of adherence—Pap smear rate changes among women who had some prior use, and (2) Pap uptake –measures of Pap test change among women who had no or little prior use.

The absolute rate difference was the Effect size measure used in this study. We use comprehensive meta-analysis software developed by Biostat, Inc. to compute fixed effects point and variance measures. This software uses a two-by-two table of measures of actual events to calculate effect sizes. For both the control and the intervention group, the change in number of screened women was calculated by subtracting the follow-up number from the baseline number. Thus, the effect measure included in the meta-analysis reflects a so-called difference-in-differences approach. Table III-12 provides a summary of the meta-analysis

The meta-analysis showed that as a group, these programs achieved small but significant impacts on screening rates, rate difference (RD) of about 10% (RD= 0.096; 95% CI =0. 08, 0.11); Z=10.4, p<. 0000). Nonetheless, the program findings were remarkably heterogeneous (Q=167.18, p< .000). That is, it cannot be said that programs produced consistent findings, but rather there are differences in their designs and populations that influenced outcomes. Our analysis identified two such differences: single vs. multiple strategies and uptake/adherences. Programs that utilized a single strategy produced smaller effects of about 3% higher than the control groups (RD=0. 030; 95% CI=0.01, 0.04; Z=3.5, p< .0005). Those that combined multiple strategies had on average a 14% improvement in Pap smear rates compared to the control groups (RD=0.140 CI=0.109, 0.162; Z= 12.76, p< .0000), a significant difference (Q=73.53, p< .0000). Programs that emphasized screening adherence and follow-up produced a greater effect, with an average rate difference about 10% points higher for treatment than control groups (RD=0.099; 95% CI= 0.079, .12; Z=9.82, p< .000.) than did those focused on screening uptake where treatment subjects had rate differences about 4% higher than the controls (RD=0.040; 95% CI =0 .025, 0.056); Z=5.11, p< .0000), a significant difference (Q =21.02 p<0.01). Although in-reach and outreach strategies were also compared, the small number of in-reach strategies makes it difficult to make any conclusions about the difference in impact of these two strategies.

Table III-12
Meta-analysis of Interventions to Increase Pap Screening
Among Women for Older Women of Color

	Citation	OutcomeType	RecruitmentType	StrategyIntensity	Effect	Lower	Upper	PValue
	Sung, 1997	Adherence	OutReachOnly	Single	-.015	-.079	.048	.636
	Ramirez, 1999	Adherence	OutReachOnly	MultipleOrSocioNet	.065	.015	.114	.013
	Paskett, 1999	Adherence	OutReachOnly	MultipleOrSocioNet	.209	.142	.276	.000
	Navarro, 1998	Adherence	OutReachOnly	MultipleOrSocioNet	.093	.023	.163	.012
	Margolis, 1998	Adherence	InReachOrBoth	MultipleOrSocioNet	-.038	-.115	.039	.335
	Gotay, 2000	Adherence	OutReachOnly	Single	.071	.032	.111	.000
	Dignan, 1996	Adherence	OutReachOnly	Single	.098	.021	.174	.013
	Bird, 1998	Adherence	OutReachOnly	MultipleOrSocioNet	.214	.170	.258	.000
	Margolis, 1998	Uptake	InReachOrBoth	MultipleOrSocioNet	.128	.049	.208	.002
	Gotay, 2000	Uptake	OutReachOnly	Single	.020	.003	.037	.014
	Dignan, 1996	Uptake	OutReachOnly	Single	-.128	-.258	.001	.066
	Bird, 1998	Uptake	OutReachOnly	MultipleOrSocioNet	.180	.134	.226	.000
Fixe	Combined (12)				.062	.050	.074	.000

Negative Effect   Positive Effect
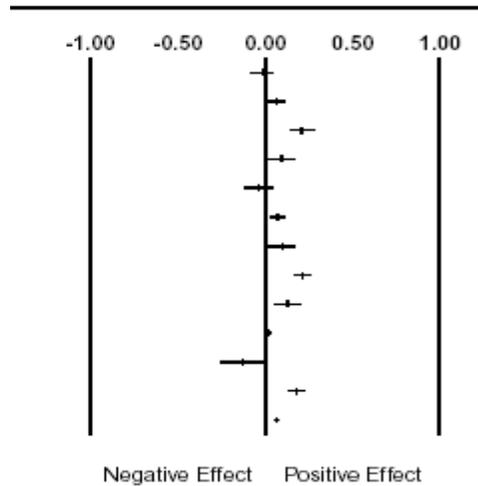
Effect=Absolute rate difference

One study (Margolis et al 1998) that had some component of in-reach was over all not significantly different from the control –particularly in the Pap adherence arm (RD=-0.27 (CI=-0.084, 0.031), p=0.364). However, this intervention was significantly more effective than control when used to increase Pap uptake (RD=0.09, CI=0.029, 0.163, P=0.005).

These findings provide some confidence that a culturally tailored strategy for improving cervical cancer screening uptake and adherencerates can be effective. Important cultural tailoring strategies include use of community health workers, culturally and linguistically adapted materials, and community-based small group and/or personalized interventions. Findings also suggest that what community health workers are asked to do makes an important difference for outcomes. Programs that recruit participants from both an established clinic populations and the general community (that is using both outreach and in-reach strategies), and programs that use cultural tailored approaches appear to have more influence.

Prostate cancer detection methods

The first-line tests commonly used for early detection of prostate cancer are digital rectal examination (DRE) and prostate-specific antigen (PSA). Their combined use increases the positive predictive value of an abnormal result (Crawford, 1997). The effectiveness of DRE in detecting clinically significant intracapsular tumors is questionable, as is its ability to reduce prostate cancer mortality rates. The presence of an abnormal DRE (induration, nodule or asymmetry) increases the chances of having the disease spread outside the prostate. Nonetheless, patients with metastatic disease do not seem to be different from controls in terms of having had a prior DRE (Coley, 1997). In a study of 2,425 men without history of prostate cancer aged 55 –70 years, overall sensitivity and specificity of DRE were 57.9% and 96.3% respectively (Mettlin, 1991). The positive predictive value of a digital rectal examination at the first screening is about 31. This value decreases with subsequent screenings (Crawford, 1997).

The PSA is the most reliable non-invasive test available for the early detection of prostate cancer. The PSA is a serine protease only found in the prostate gland. Its serum levels are associated with prostatic volume (age-dependent), and benign pathology (such as hyperplasia or prostatitis) as well as with malignance, so it is non cancer-specific. (Miller, 2001). The introduction and diffusion of the use of the Prostatic Specific Antigen (PSA test) have played a major role in the detection of this cancer. Incidence of prostate cancer has followed a parallel trend with first-time use of PSA testing, with a rise and a decline shape during 1990s (Legler, 1998). It has higher sensitivity but lower specificity than DRE. Positive predictive value depends on the levels of PSA: the higher the level the larger the positive predictive value, but the higher the level, the higher the chance of advance disease. The usual PSA threshold for further diagnostic evaluation (prostatic biopsies) is 4 ng/mL, but this cutoff point is controversial. For instance, among 2,526 volunteer men aged 40 or older with a PSA value between 2.6 and 4 ng/mL, 28% of the men had cancer detected by biopsy. However, when the PSA level was greater than 4.0ng/mL, cancer was detected in 30% of the men (Roehl, 2002). The first year of the Finnish arm of the European Randomized Study of Prostate Cancer recruited 5053 volunteers aged 55-67 years. Eight percent of them had a PSA level higher or equal to 4.0 ng/mL. Cancer was detected in 27% of those with abnormal PSA level.). The cancer detection rate among

participants was 2.1% (Maattanen, 1999). In another study of 91,000 men first time screened with PSA as part of the Prostate Cancer Awareness Week project (PCAW), the positive predictive value of the PSA was, however, a little higher than that recently reported for the PSA by Roehl and Maattanen (42%). The combined first screening with DRE and PSA testing can be associated with a positive predictive value close to 60% (Crawford, 1997).

PSA levels tend to be higher in Blacks than in Whites among men without clinical evidence of prostate cancer and among men at the time of prostate cancer diagnosis, although these studies may not adequately control for stage at diagnosis (Abdalla, 1998; Moul, 1995).

In order to increase specificity and positive predictive value of the PSA test, additional measurements have been used including PSA age-adjusted reference measurements (as PSA level increases with age); and measurement of free and total PSA (a free fraction lower than 25% is in favor of cancer). Also, rate of PSA level can change over time (the faster and the larger the change, the riskier) and PSA density -PSA value divided by the prostatic volume- have been used (Crawford, 1997; DeAntoni, 1997). The sensitivity of free PSA level using a cutoff of 25% for men over 60 years of age is similar for Blacks and Whites (94%)(Catalona, 2000).

Other tests such as transrectal ultrasonography and transrectal needle biopsy are not considered as first-line tests for early detection of prostate cancer, but they are used as follow-up tests when first-line tests provide suspicious results. Diagnosis of prostate cancer is made by needle biopsy and histologic confirmation. Transrectal ultrasound is often used to guide needle biopsies.

Needle biopsy is the standard for diagnosis of prostate cancer. However, among patients with a suspicious PSA and/or DRE, one time biopsy can miss up to 23% of clinically significant prostate cancer cases. A serial biopsy study of 2,526 volunteer men aged 40 or older with abnormal PSA and/or DRE demonstrates the following cumulative cancer detection rate: one biopsy 77%, two biopsies 91%, three biopsies 97%, and four biopsies 99% (Roehl, 2002).

Screening for Prostate Cancer: Debated Efficacy: The goal of screening is to diagnose prostate cancer at an early, localized and clinically unrecognized stage, with the goal of potential cure, thus reducing or eliminating the morbidity and mortality associated with it. The classical principles of screening are: the disease has a natural history which is well understood, should represent a serious public health problem and be able to be detected in an early stage, a simple, valid, harmless and acceptable test must be available, diagnosis and treatment in an early stage must be more beneficial than in an late stage, the program must be cost-effective (Wilson, 1968; Moffat, 2000). Only randomized trials can conclusively demonstrate that early prostate cancer diagnosis by PSA testing and subsequent aggressive treatment reduce mortality. The underlying assumption is that cancers detected at lower PSA levels are associated with a better likelihood of cure. Until information from those randomized trials is available, population-based mass screening will continue to be very controversial.

Currently, there are two prospective randomized trials underway to test the efficacy of PSA screening for reducing prostate cancer mortality (Maattanen, 1999;Gohagan, 1994). Quality of life associated with treatment is another key endpoint that will be considered. In total,

about 180,000 men have been randomized. In one of these trials, the European Randomized Study Screening for Prostate Cancer (ERSPC), which targets men aged 54-74 years, researchers decided not to use DRE when PSA levels were normal (Maattanen, 1999; Candas, 2000).

Many major professional organizations have published guidelines on screening for prostate cancer. They are: American College of Physicians-American Society of Internal Medicine (ACP-ASIM)(American College of Physicians, 1997), American College of Preventive Medicine (ACPM, 1998), American Cancer Society (ACS: Smith, 2000;Smith, 2002), American Urological Association (AUA, 1999), Canadian Task Force on Preventive Health Care (CTFPHC, 1994), and U.S. Preventive Services Task Force (USPSTF, 1996).

Among them, the ACP-ASIM, the ACPM, the CTFPHC and the USPSTF do not recommend routine population screening for prostate cancer. The main reasons stated against routine screening include low specificity of DRE and or PSA, leading to a relatively high biopsy rate; biopsies are not free of complications; the known and significant risk of adverse effects associated with prostate cancer treatment; and the lack of conclusive evidence of effectiveness of treatments on survival rates. In a synthesis review, 18% to 26% of the men screened (and in whom biopsies were performed) had an abnormal DRE and/or PSA test. Biopsies were positive for cancer only in 15% to 21% of men with any or both abnormal tests, implying that four out of five subjects who undergo biopsy do not have the disease. The cancer detection rate among the population screened is close to 4% (Coley, 1997).

Autopsy studies have shown that latent prostate cancer is very common among men who are 50 years old and above, and its prevalence increases with age. There is an overall 30% histologic prevalence of latent cancer among this age group (Coley, 1997). However, the lifetime risk of clinical prostate cancer is only 17% (Jemal, 2002). Screening leads to over-diagnosis that can be as high as 275% of those cancers that might be diagnosed without screening (Ciatto, 2000). Indolent cancers have better prognosis. When these types of biases are not taken into account, comparison of survival rates between screened and unscreened groups can erroneously suggest a benefit of cancer screening in survival rates (Coley, 1997). Over-diagnosis is associated with over-treatment. There is no conclusive evidence about what the best treatments are and how they might effectively prevent or delay mortality. Treatment is associated with very frequent adverse effects: such as incontinence and impotence or even death. This sequence of facts implies that patients with indolent cancer can end up receiving unnecessary treatments that are not only ineffective, but also both deleterious to their quality of life and costly (Alexander, 2000).

Despite this absence of definite evidence for screening, both the ACS and the AUA nevertheless recommend the routine use of DRE and PSA testing among men 50 and older who have a life expectancy of at least 10 years. They also recommend earlier screenings for higher risk men such as AA men and other men with a first-degree relative diagnosed with PC at a younger age. For these groups, the ACS guidelines suggest that screening should begin at age 45 (Smith, 2002). Their recommendations are based on the fact that prostate cancer mortality among White men has declined to levels below those existing before the PSA measurement that started in 1986. Moreover, populations that undergo annual PSA testing have higher rates of organ-confined diseases (Catalona, 1994; Etzioni, 1999). Early-stage disease is associated with

better survival than late-stage disease. (Coley, 1997; Jemal, 2002), and metastasic disease at the time of diagnosis is almost eliminated (Labrie, 1996). A population-based screening in Quebec, with 11,811 first visits and 46,751 annual follow-up visits showed that about 16% of the men screened had PSA greater than 3.0 ng/mL. Among those screened during their first visit, 2.9% were diagnosed with prostate cancer. However, prostate cancer was found in only 0.4 % of those who returned for their annual followed-up visit. These findings reveal a positive predictive value of the PSA of 17% and 27% for first and follow-up testing (Candas, 2000). Some authors, even when in favor of routine screening, doubt the benefit of an annual screening without targeting only those with a higher risk of prostate cancer. Those men with low PSA levels are expected to have a very slow progression to higher levels, making them an unnecessary target for annual screening (Carter, 2001; Fang, 2001; Brawer, 2000).

Considerations about screening on Medicare population: Screening for prostate cancer among Medicare beneficiaries deserves some consideration. About two thirds of all prostate cancer cases are diagnosed in men over 65 years. PSA testing has lower specificity and thus a lower positive predictive value among this population. Thus, the proportion of suspicious tests that demand further investigation with biopsy rises in this age group. About 19% of men at age 65 would require prostatic biopsy and as many as 27% would need the procedure at age 75. Elements to be considered for screening or curative treatment among the Medicare population include a higher risk of having metastatic cancer, more comorbidities, and shorter life expectancy (Office of Technology Assessment, 1995).

Complication rates from radical prostatectomy appear to be significant among Medicare beneficiaries. A survey of 1,237 randomly selected patients who received a radical prostatectomy was conducted. All men interviewed were 65 years of age or older at the time of the surgery. The age distribution of the surgical procedures was the following: 50% were performed on men between 65 to 69 years old, 39% on men between 70 and 74 years old, and the rest on men 75 or older. The rates of complications from surgery reported included: currently suffering from any incontinence, 63%; using pads or clamps for wetness, 32%; dripping urine every day and more than a few drops, 23%; currently having no, or partial erection, 61% (while some erection prior to the surgery was reported in 91% of the patients). Regarding cancer recurrence, among patients whose surgery was at least 4 years prior to the survey, 28% reported radiotherapy and/or androgen deprivation therapy (Fowler, 1993) subsequent to recurrence.

Importance of knowledge, perception and informed consent: One of the most important factors that influence the use of screening test is the recommendation from a health care provider. There is general consensus that given the uncertainties related to prostate cancer screening, patients should participate actively in that decision and provide informed consent. It might be argued that having informed consent around prostate cancer screening, rather than receipt of the test is the best measure of appropriate services, and thus studies of informed consent issues take on special importance. Informed consent requires that patients be knowledgeable about risks and benefits from testing and potential treatment. Primary care providers play a key role in both educating and getting patient consent. Many information aids have been developed and tested for men to foster informed decisions about prostate cancer

screening such as videotapes, scripted verbal information, pamphlets, written information, group presentation, etc (Chan, 2001; Schapira, 2000).

A survey of men, who had a PSA test ordered by their primary care physician and had no suspicion of prostate cancer, was conducted three months after the PSA test was done. Among the respondents (46% response rate), only 69% knew that their physician had ordered a test. Among those who knew they had been tested, fewer than half recalled speaking with their physician about risks and benefits of taking the test. Sixty-eight percent of those aware of being tested, pointed out their physician as the person who recommended it, 22% reported taking the initiative, and only 7% reported having made the decision with their physician (Federman, 1999). This study raises two considerations. First, PSA utilization estimates can be biased if they are based on recall information, and secondly, lack of active patient participation in their testing decision is common.

A longitudinal survey analyzed practices and beliefs of primary care physicians of a health maintenance organization regarding screening for prostate cancer across time. Responses from a total of 108 physicians who participated in a survey in 1993 and 1998 were analyzed. These physicians reported an increase in the number of PSA tests performed as part of men's maintenance health visits from 1993 to 1998. In 1993, they reported ordering PSA testing 73% of the times. In 1998, the same physicians reported ordering PSA testing for their patients in 80% of the instances. This increase in the number of tests ordered occurred in parallel to a change in physicians' beliefs about screening and treatment. While in 1993, only 30% of the physicians believed that radical prostatectomy for early prostate cancer reduced mortality; in 1998 this belief was shared by 44% of them. However, more physicians in 1998 (47%) than in 1993 (35%) believed that morbidity of treatment could outweigh its benefits. The main reason that physicians changed their behaviors regarding PSA screening could be explained by the fact that by 1998 as many as 53% believed that providers could be sued if PSA testing were not performed and cancer were detected later, whereas in 1993 only 36% of them held that belief (Voss, 2001). These beliefs may create a barrier for physicians' participation in ensuring informed consent with respect to prostate cancer screening.

When men receive information about PSA screening, they usually show less interest in having a PSA test. The usual information provided was: probability of developing or dying from prostate cancer; risk factors for developing it, chances of having a suspicious PSA test; implications of such a result; types of treatment available when early diagnosis occurs; potential but uncertain benefit from treatment; and type and likelihood of complications from treatment. A study compared the effect of educational videotape on short-term knowledge and attitude toward prostate cancer and screening. About half of 372 men seeking a free PSA testing were assigned to watch the educational videotape, while the other half watched a non-educational video. Both groups were comparable at baseline in terms of age, education, marital status and prior PSA testing. Those in the intervention group reported a better knowledge of the natural history of prostate cancer, efficacy of treatment, and PSA predictive value. The differences between the intervention and control groups were statistically significant. Men in the intervention group also showed significantly less interest in having another PSA test within the next two years, and were more in favor of receiving a conservative treatment if they were

diagnosed with prostate cancer than the control group. Indeed, some men in the intervention group opted for not receiving the PSA testing at that time (Flood, 1996).

The effect of an educational videotape intervention on prostate cancer knowledge and attitude to screening was also analyzed in a randomized trial of 160 men aged 45-70 without history of prostate cancer in a family doctor environment. Intervention (video) and control (no video) groups were assessed in the variables of interest before and two-weeks after watching the video. Men in both groups were comparable in terms of age, race/ethnicity, education, income, family history of prostate cancer, marital status and previous PSA testing. At baseline, men in both groups answered about 30% of the questions related to knowledge of prostate cancer correctly. While the control group did not experience any change in knowledge in the follow-up phone questionnaire, the intervention group however, had a 77% improvement in the number of questions answered correctly (from 30% to 48%). About 78% of the men in both groups at baseline expressed their preference for having a PSA test. Men in the intervention group changed that preference significantly in the follow-up interview when 62% responded in favor of such a test. This represents a 22% reduction in the number of men in favor of screening. The study demonstrates the lack of information about prostate cancer many men have, which might make active involvement in the screening decision difficult. This study did not include comparisons between different races and ethnicities despite the fact that about 35% of the participants were non-White (Volk, 1999).

In another study, 204 men over the age of 65 who visited their primary care physician for routine visits were randomized to receive either verbal detailed information about PSA prostate cancer (intervention) or just a brief verbal message (control). Men in the intervention group reported a 20% statistically significant reduction in the mean interest in screening measured in a 5-point Likert scale in comparison with the control group. The main reason for that reduction was that they perceived PSA testing as less efficacious than the men in the control group. There were no differences in perception of susceptibility, seriousness, or attitude to treatment risks (Wolf, 1998). Previously, the same author reported similar behavior after this educational intervention for men over 50 in a randomized study that included 205 men, one third of whom were non-White. Those who received verbal education were 66% less likely to show high interest in PSA screening. Although almost 40% of the participants were non-White, the study did not report comparisons by race, which could have shown the role race and ethnic group play in the selection of screening (Wolf, 1996). In the intervention group, the main predictors of interest in PSA testing were younger age, and had a family history of prostate cancer and perception of being at risk for cancer (Wolf, 1997).

PSA testing is associated with anxiety and decision conflict. However, being informed reduces this anxiety. To evaluate the effect of information about prostate screening, 100 men were randomized in two groups before visiting their family doctor. Men in the intervention group received verbal and written information regarding the controversies of screening and were encouraged to discuss the screening decision with their physician. In addition, the control group received an interview of the same length of time but did not receive either information or encouragement. Patients in the intervention group reported a more active role in decision-making and a significantly lower decisional conflict score than the control group. No differences in anxiety score levels were observed between groups (Davison, 1999).

The perception of being vulnerable to prostate cancer among high-risk men can be absent or not affect their screening behavior. A study compared perceived vulnerability, expectations for prevention and screening behavior between 50 men first-degree male relatives of prostate cancer patients and 100 men without family history of prostate cancer. All men were over 40 years of age. A mail survey was sent to them. As many as 43% of the first-degree relatives of prostate cancer patients perceived their risk as equal or somewhat lower than average men of their age. Indeed, men in this group did not report higher PSA frequency rates than those men without first-degree family history of prostate cancer (Miller, 2001).

R/E difference in prostate cancer screening attitudes: A community based screening program in Michigan, the Prostate Disease Early Detection Program, recruited 944 men 40 years of age and older for DRE and PSA testing. Screening was offered by appointment at a geriatric clinic or performed as mass screening in community centers, senior apartments and public housing. About 39% of the men screened were African Americans and 49% were Whites. Twenty-one percent of African Americans reported being uninsured in comparison with only 9% of Whites. African Americans had a lower knowledge of prostate cancer related issues than Whites before their involvement in the program. They were significantly less likely to be aware of PSA screening and interpretation. They were also less likely to know the components of a prostate checkup, the PSA level interpretation, or symptoms of prostate cancer. For instance, they identified incorrectly "pain" as the first symptom of cancer. The gap in knowledge about prostate cancer between African American and Whites was statistically significant prior to the intervention, but disappeared after it. This study also provided information about preferences for screening settings. African Americans were twice as likely as Whites to arrange for private appointment than to attend a mass screening. Radio was the most effective means of reaching Blacks, while newspaper ads reached Whites more. African Americans' lower level of knowledge, and in particular their inability to recognize the early symptoms of prostate cancer, could explain why they usually delay their screening (Barber KR, 1998).

R/E differences in Prostate Cancer Screening: No published data on PSA utilization for men of all ages at the national level appear to be available to date (Smith, 2002). Although analyses of self-reported screening participation using large national surveys such as the NHIS and BRFSS could address this gap, one study suggests that as many as 31% of PSA recipients do not recall having had the test (Federman, 1999). In New York, in 1996, a random-digit-dial phone survey on 273 men at least 50 year old without history of prostate cancer showed that 33% of men interviewed never heard about PSA testing. Among those who heard about it as many as 92% reported being screened at least once. There were no significant differences in PSA testing between Black and White men (McDavid, 2000). However, analysis of data from the same survey system but for 1994 and 1995, revealed that when controlling for education, income, self-perception of risk and testing advice from their physician, Black non-Hispanics were 0.3 times as likely as Whites to report ever having had a PSA test (Steele, 2000).

Among Medicare beneficiaries, Blacks have been tested at a lower and slower rate than Whites. Among Medicare beneficiaries, based on analysis of claims, in 1992, about 19% of Whites and 15% of Black men had ever received PSA testing, while 34% of Whites and only 25% of Blacks received a PSA test in that year (Legler, 1998). In 1998, an analysis of Medicare

claims found that 38% of Whites and 31% of Blacks received at least one PSA test. Among those who received the test, about 80% of them had received a PSA test in the past. The use of PSA among Blacks was 20% lower than among Whites in 1998. Our analysis of self-reported data from the NCHS National Health Interview Survey found broad R/E differences in recent PSA use among elders. While 55% of White elders reported receipt of a PSA in the last two years, the comparable proportions were 42%, 43%, 42%, and 46% for African Americans, AI/AN, Asian, and Hispanics respectively. Rates for "others" were even lower at 33%. Further, utilization rates and race differences in rates are very heterogeneous across regions (Etzioni, 2002). These data show not only the overall low testing rate among Medicare beneficiaries, but also the lower use of PSA among Blacks. Medicare differences by race may be more the result of unequal access since racial utilization rates appear to be similar in equal access settings (Freedland, 2000).

Type of primary health care facility and insurance status seem to influence screening rates. A small survey study of 142 men over 40 years of age showed differences in DRE and PSA testing rates depending on the setting in which patients were seen. Patients seen in an internal medicine clinic were compared to those seen in a private practice. Seventy two percent of men from each of the setting studied received a DRE. However, only 10% of patients seen in the clinic received a PSA testing alone or combined with DRE in comparison with 68% of patients in the private setting. While most of the patients in the clinic were Medicare/Medicaid beneficiaries (91%), the majority of the patients in the private setting were private (82%) (Perez, 1995).

Interventions to increase PSA Use by African Americans: Several studies demonstrate that educational programming about prostate cancer conducted in work sites, churches, and housing projects can recruit large numbers of men for Prostate Cancer education and screening. But large-scale general prostate cancer screening programs have failed in recruiting African Americans. The Washington University Study recruited 22,000 men but only 4% Blacks. The American Cancer Society National Prostate Cancer Detection Project recruited 2,999 men, but only 7.2 % were African Americans. The Prostate Cancer Awareness Week is arguably the largest cancer-screening program focused on men. Since 1989, this program has reached more than 3 million men, yet less than 6% were Blacks (Crawford, 1997; DeAntoni, 1997). By contrast, smaller initiatives have targeted mainly African-Americans with the objective of promoting early diagnosis and subsequent treatment for prostate cancer. Many of these studies do not report the number of persons who might have participated in programs and thus it is impossible to assess the success of these interventions in reaching men. Reports that could support the estimate of effect sizes are included in the Evidence Tables in Appendix 3.

The Detroit Education and Early Diagnosis program was initiated in 1993. Churches have played a key role in this program. An outreach coordinator tried to get support from ministers, who announced the educational session weeks in advance during services. The target population was Black men, between 40 and 70 years of age. The educational component, provided in churches at the conclusion of the Sunday service, used an African American team, a physician and a prostate cancer survivor, to reach participants. Participants completed a brief questionnaire and informed consent. The session included information regarding prostate cancer natural history, staging, diagnostic methods, and treatment options. After the session,

participants had the chance to get tested with PSA. The lab result was mailed two weeks later; if the test result was suspicious, a nurse would call the patient to coordinate a follow-up physician visit at a nearby hospital or arrange for the patient to see his own physician. More than 1,000 men participated in the program in its first 17 months. Of the 647 men who received a PSA screening, 8% had a suspicious result. The cancer detection rate was 2.5% among men tested (average age was 55 years) (Powell, 1995). In another report on the same intervention program, 1,105 Black men over 40 years were educated, PSA tested and followed. Eight percent of them had a suspicious PSA test and 3.3% of those tested resulted in being diagnosed with prostate cancer. The program lost about 12 % of the participants to follow-up (Powell, 1997).

A quasi-experimental design was used in South Carolina to analyze the effect of four educational interventions on free prostate cancer screening among 1,717 men aged 40-70 years old without history or current diagnostic evaluation for prostate cancer. For Whites the lower limit age was 50 years. Seventy-one percent of the participants were Blacks. Men were recruited from a variety of sites such as work sites, churches, housing projects or barbershops. Participants were randomly assigned to receive one of four interventions: traditional, peer-educator only, client navigator only, or a combined intervention. All of the interventions included an educational session about prostate cancer given by a nurse. The peer-educator intervention presented a testimony on the importance of screening, and was conducted by a man whose race was the same as the race most represented in the program. The client-navigator consisted of a follow-up phone call by a social worker to help the man overcome potential barriers to screening and navigate the health care system. After completion of the educational session, each man received a voucher for a free prostate cancer screening including a DRE and PSA test, to be used with his primary care physician. The physicians were reimbursed for their services. Participants' prior screening behavior was reported, and differences between races were significant. Among Blacks, 37% did not have a prior DRE and 77% did not have a prior PSA test. Among Whites, the proportions were 23% and 33% respectively. Screening participation rates depended on the race and the type of interventions. Despite the educational intervention and access to free prostate cancer screening, 39% of Blacks and 25% of Whites who participated in the educational interventions chose not to get screened. African Americans were 50% less likely to be screened than Whites. Regarding type of interventions, Blacks were 90% more likely to receive screening under the client navigator intervention than after receiving the traditional intervention. In this ethnic group, the other types of interventions did not have different screening rates than those observed with the traditional approach. Among Whites, none of the interventions produced higher screening rates than the traditional approach (Weinrich, 1998). Researchers in this study also tested the hypothesis that prior exposure to prostate cancer information was a predictor for being screened. Thirty-eight of the participants reported that they had not heard or read anything about prostate cancer within the prior year. Among those who did have access to information about prostate cancer, radio and television were reported as the most frequent source of information (37%). Only 14 % of men said they had received the information from a health care provider. However, getting information from a health care provider increased the likelihood of being tested by 69% after controlling for race, family history, level of formal education, and prior screening behavior (Nivens, 2001).

Even very simple interventions are useful in increasing screening participation. For example, 413 Black men between 40-70 years old without a history of prostate cancer who

attended a university health service were randomized in two groups after completion of a phone survey. One group received a reminder letter inviting them to a urology clinic for education and screening. The other group received a letter, plus printed informational material about prostate cancer as well as a phone call. A lay health worker performed the personal phone call. Twenty-nine percent of the men in the reduced intervention group accepted the invitation. However, 51% of men in the enhanced intervention responded (Myers, 1999).

Colorectal Cancer Detection Methods

The CRC screening regimen recommended by the American Cancer Society (ACS) and The American Gastroenterological (AGA) Association includes:

- Annual digital rectal exam at 40
- Annual Fecal Occult Blood Testing (FOBT) beginning at age 50
- Sigmoidoscopy every 5 years beginning at 50 or
- Colonoscopy every 10 years beginning at 50

As noted below, several other professional and research organizations are recommending similar multi-pronged approaches to screening. Experimental evidence, which shows the benefit of FOBT, and evidence from observational studies support these recommendations and simulation models suggest that flexible sigmoidoscopy and colonoscopy reduce CRC mortality. However, because of the relative costs, risks, and effectiveness of the various screens, and because of low rates of population participation in any screening, which colon cancer screening test(s) should be used and the frequency of testing are still being reviewed and debated.

One study used a Markov decision model to examine alternative screening strategies: FOBT alone and in combination with flexible sigmoidoscopy, flexible sigmoidoscopy alone, and colonoscopy alone (Vijan et al, 2001). Data used were colonoscopic screening studies for prevalence of polyps and the SEER data for the incidence and mortality rates of CRC. Mortality rates for the general population were derived from National Center for Health Statistics publications. The modeling varied the timing and frequency of screenings to assess optimal screening intervals, and sensitivity analyses were conducted to assess the factors that have the greatest effect on the cost-effectiveness of screening. The authors conclude that all strategies are cost-effective versus no screening, at less than $20,000 per life-year saved, but colonoscopy is the preferred test because of its greater effectiveness and because it obviates the need for follow-up testing.

Colonoscopy alone is by no means the consensus approach to screening, however. Pesce (2001) notes that the US Preventive Services Task Force states, "there is fair evidence that annual FOBT and/or flexible sigmoidoscopy every 3-5 years be considered in a periodic health exam." The guide suggests that colonoscopy may have greater risks than potential benefits when screening average-risk adults. Screening with colonoscopy receives a "C" recommendation (defined as: "there is insufficient evidence to recommend for or against the inclusion of the condition in a periodic health exam, but recommendations may be made on other grounds"). Pesce concludes that there is reliable data from randomized controlled trials to recommend the effectiveness of FOBT. Flexible sigmoidoscopy has also been shown to be effective, safer, less

expensive, and more convenient. Colonoscopy on the other hand, is more sensitive in detecting colonic neoplasia, and the indications for a full colonic exam following a flexible sigmoidoscopy still remain unclear. Studies do show that advancing age increases one's risk for CRC, hence, the attractiveness of colonoscopy as a screen for Medicare beneficiaries.

Pesce's support for FOBT rests in part on a study that showed a statistically significant reduction in death from CRC with biennial testing over an 18-year follow-up period (Mandel et al., 1999). Their 1993 study of 46,000 men and women aged 50-80 documented a 33% reduction in deaths from CRC with annual FOBT and a 6% reduction with biennial screening (the latter not statistically significant). A study of the same participants found that the screening regimen in the trial also reduced incidence compared to controls and that annual screening did so more than biennial screening. The effectiveness of flexible sigmoidoscopy as a screen has been questioned since follow-ups with full colonscopies show that cancer in the rest of the colon can be missed. One cross-sectional study of asymptomatic adults over 50 who underwent colonoscopy in a university setting in Indianapolis, Indiana from 1995-1998 (Imperiale et al., 2000) found that depending on the criteria for referring (type of polyps in the distal colon) either 61% or 79% of those with cancer in the proximate colon would have been referred with a Flex. Sig. Similarly, a study of 1,321 asymptomatic persons, at VA medical facilities, who underwent screening colonoscopy (Lieberman et al., 2000) found that 10.5% had advanced neoplasms, and 52% of those with advanced proximal neoplasms had no distal adenomas.

In summary, although FOBT has been studied the most, recommending large-scale application of FOBT is still problematic. FOBT is not effective in detecting polyps which can be precursors to CRC (colonoscopy is a better choice), adherence rate is about 50%, and the predictive value of a positive test is no more than 10% (Lowenfels, 2002). Colonoscopy is the gold standard for visualizing the entire colon and is used when abnormal findings are noted on FOBT and flexible sigmoidoscopy (Inger, 1999). However, even if the literature does not support one screening test over another, Pesce notes that the real issue is the low screening rates for CRC and that "physicians, the media, and educators, must be more diligent in recommending screening for early detection of colorectal cancer" (Pesce, 2001). Deciding which test makes the most sense continues to be debated but the low screening rates for CRC, using any modality, is considered a huge problem. One expert concludes that screening rates are so low that the test the patient wants is the best one (Barry, 2002).

Screening and follow-up for Medicare: An additional challenge for Medicare in supporting appropriate screening was identified in an analysis of follow-up testing among 24,246 aged Medicare beneficiaries receiving FOBT testing in 1995 (Lurie & Welch, 1999). Only 34% received the follow-up testing recommended by the American College of Physicians (colonoscopy or flexible sigmoidoscopy with an air-contrast barium enema). Older beneficiaries were somewhat less likely to get appropriate follow-up testing. No differences were reported by race. The conclusion is that without the recommended follow-up, covering FOBT screening is likely to be less cost-effective for Medicare than patterns identified in colonoscopies.

Factors that hold back screening for clinic patients: Many of the differences in CRC morbidity and mortality are due to differences in screening rates, which of course affect early diagnosis and treatment. A number of variables have been found to affect screening rates,

including place of treatment, knowledge among providers, and resistance to the screening procedures. First, individuals with public insurance, Medicaid and Medicare, are seen in larger numbers at ambulatory clinics in teaching hospitals. Patients receiving care at teaching facilities see residents in training for the bulk of their medical care. Residents in training rotate during their residency program, so patients seldom have continuity of care with a single provider. Further, patients seen in teaching clinics wait longer to see health care providers and specialists. Arranging a colonoscopy or flexible sigmoidoscopy becomes a more arduous process because the patients must be scheduled for the GI clinic before receiving the procedure. Getting an appointment in many GI clinics can be a 3-6 month wait, and then the appointment for the procedure can be another long wait.

Several studies have examined if residents are knowledgeable about CRC screening guidelines. Sharma et al. found that internal medicine residents had an "imperfect understanding" of current CRC guidelines (Sharma et al., 2000a). The most serious shortcoming was that only 29% recommended colonoscopy to evaluate a positive FOBT. Zack and colleagues conducted a retrospective analysis of 108 medical charts of patients who received primary care at University of Nebraska Medical Center and found that residents overstated their actual screening rates for FOBT (88%) and flexible sigmoidoscopy (78%). Actual rates for FOBT and flexible sigmoidoscopy were 13% and 16% respectively. Another study also found that resident physicians adhered poorly to CRC screening recommendations in both Black and White patients (Borum, 1999). Among 129 African-Americans (54 men; 75 women) and 52 Whites (26 men; 27 women) over aged 50, rectal exams, FOBT, and flexible sigmoidoscopy were performed on less than half. Sharma et al. mailed a 2-page structured interview about CRC and use of FOBT to 8,000 randomly selected gastroenterologists in the US (Sharma et al., 2000b). Sharma and colleagues (2000b) conclude that GEs give appropriate CRC screening advice but misuse FOBT, which may give rise to high false positive screening rates and lead to unnecessary diagnostic testing. A survey found that primary care physicians, in general, often do not recommend complete diagnostic evaluation (CDE) for patients with positive FOBT results (Myers, Hyslop, et al., 1999. In their random telephone survey of 518 primary care physicians in southeastern Pennsylvania and southern New Jersey, many physicians' reported intent to refer patients for CDE didn't match actual referral rates. Experienced physicians and those in smaller practices were more likely to favor CDE.

R/E differences in Colorectal Cancer Screening: There is extensive evidence for differences by R/E, gender, and age in CRC screening. A study of Medicare billing records in Michigan found racial, age, and gender differences in colorectal cancer screening (McMahon et al., 1999). During 1986-1989, for those receiving entire colon examinations, White males were more likely to receive colonoscopy, while African Americans, females, and the elderly were more likely to receive isolated barium enemas. Sigmoidoscopy use declined at the highest ages and was highest in urban and high-education communities.

An examination of data from the National Health Interview Survey Cancer Control Supplements (1987-1992) found that higher income and education were positively associated with screening for colorectal cancer across race/ethnicity, but older Blacks reported less screening than similar Whites, controlling for age and gender (Hoffman-Goetz et al., 1998). Our analysis of unweighted 2000 NHIS data found that while 44% of persons age 65 and older recall

ever having had a colorectal cancer screen, rates for African Americans and Hispanics were notably lower at 31% and 30% respectively. AI/AN and Asian self-reported CRC screening was intermediate between Whites and African Americans.

Zapka et al. assessed provider recommendations on utilization of CRC screening tests using a cross-sectional random-digit dial survey of 1,002 Massachusetts residents aged ≥50 (interviews in English and Spanish) (Zapka et al., 2002). The authors found that even when broad criteria are used to define CRC screening status, a substantial proportion of the age-eligible population was under-screened. The uninsured had the lowest screening rates. Among insured patients, type of insurance had little impact on CRC testing, except that HMO members had marginally higher rates. Increased screening was associated with increased health maintenance visits and a physician's recommendation. Differences by race/ethnicity were not significant.

Another study shows that physician recommendations play a role in CRC screening participation by older women (Mandelson et al., 2000). A total of 1,520 women aged 50-80 was invited to participate in a telephone survey about factors related to CRC screening. Each woman had an identified primary care provider and was a member of Group Health Cooperative of Puget Sound for at least 2 years. Only 58% of the women reported that their physicians encouraged CRC screening, but this factor was strongly related to participation (OR=12.7; 95% CI 6.6-24.4). There were no significant differences in screening rates by R/E in this managed care setting, but women age 60-69 and 70-80 were more likely to have been screened than women aged 50-59 (OR 2.76 and 4.47 respectively).

Interventions to Reduce R/E Disparities in CRC Screening: The recent meta-analysis of approaches to increasing immunizations and cancer screening conducted for CMS found that organizational changes (e.g. prevention clinics, using a care visit for prevention, or using non-physician staff to promote prevention) were most effective in increasing screening, including FOBT for CRC (adjusted OR 17.6) (Stone et al., 2002). Provider education (OR 3.01), patient reminders (OR 2.75), and patient financial incentives were also effective – more effective than provider reminders (OR 1.46), patient education (OR 1.38), or feedback (OR 1.18). Combining approaches was found even better than single changes. Few of the studies included in their analysis were focused on elders of color.

Beyond what was covered in the earlier CMS meta-analysis, there are additional and newer studies that report results of efforts to enhance screening. Initiatives focused on elders of color are reflected in the Evidence Tables in Appendix 3. Several of these studies explored system level interventions and/or reminders in settings that served persons of color. For example, researchers worked with a Chicago HMO to train and support primary care physicians in 47 practices serving low-income - largely African American and Latino - areas to increase cancer screening rates (Manfredi et al., 1998). Reviews of patient charts before (N=2,316) and after (N=2,238) the intervention showed increases in the proportion of patients with a FOBT among both HMO (14.1%) and FFS panels (20.2%). Another study randomized 49 physicians (and their 7,397 adult patients) in a university-based clinic setting for a one-year test of computer-generated reminders for preventive services (four groups: no reminder, physician reminder, patient reminder, patient and physician reminder) (Ornstein, Garr, Jenkins, Rust, &

Arnon, 1991).   Increases were highest in the patient and physician reminder group for FOBT (from 19.5% to 38.1%), and increases were greater for Blacks and for patients with insurance.

Other studies adopted more culturally tailored intervention strategies. Cargill and colleagues report on an effort to use nurse clinicians having in-person contact with patients to increase FOBT screening among a largely African American patient population (n=359) served by a medical clinic at a university hospital (Cargill et al., 1991). The percent of patients given FOBT kits increased from 4.1% to 46.6% in the experimental (nurse) group compared to 9.9% to 13.0% in the control (resident physician) group, who were reminded through a letter to promote screenings. The experimental group patients were also much more likely to return their kit (69.8% vs. 20.0%).

Powe has been involved in a series of culturally tailored efforts to increase CRC screening.   The latest is a pre/post experiment to test the effectiveness of a culturally relevant intervention to increase the rates of FOBT use in a population of elderly, rural African American females attending senior centers (Powe, 2002). One intervention group received a 5-phase self-empowerment intervention over the course of a year, another group received only Phase I, and the control received only traditional senior services. Phase I was a video entitled "Telling the story…. To live is God's will," which was designed to counteract the high rates of "cancer fatalism" among female African American elders (Powe & Weinrich, 1999) (Powe, 1995). The first intervention group had significantly higher rates of use of FOBT than the single intervention group, which in turn had higher rates of use than the control (see table below). Weinrich and colleagues report on an aging-adapted intervention to increase FOBT with a similar rural elderly senior center population (n=135 in a pre/post design) (Weinrich, Weinrich, Boyd, Atwood, & Cervenka, 1994). There was a substantial increase in screening after the education sessions (OR=6.2).

Lung Cancer Detection Methods and R/E Differences:

There is no consensus on the efficacy of screening for lung cancer. The American Cancer Society, in their Guidelines for Early Detection of Cancer, does not recommend general screening for early detection of lung cancer (Smith et al., 2002). However, they do allow that physicians and patients may make decisions for screening on an individual basis. (Aberle, Gamsu, Henschke, Naidich, & Swenson, 2001), in a consensus statement of the Society of Thoracic Radiology concurred that routine screening is not appropriate at this time. They suggested that interested individuals enroll in controlled trials of CT scanning.

Screening has not been recommended because randomized controlled trials conducted in the 1970's failed to show reduced mortality rates. Strauss (2002) reexamined data using Cox proportional hazards regression for 9192 individuals who participated in the Mayo Lung Cohort in the 1970s. The Mayo Lung Project had concluded that screening with chest x-ray and sputum cytology was ineffective. Reanalysis, taking into account lead-time bias, length bias, and over diagnosis bias, showed that screening did significantly reduce mortality rates.

There have been several advances in screening technology over the past few years, specifically in the use of low-dose helical CT. Randomized controlled trials of low dose helical

CT are only now underway. Henschke et al. (1999) described the design and baseline results from the Early Lung Cancer Action Project (ELCAP), an effort aimed at assessing the use of low-dose CT in screening for lung cancer. In their study, 1000 symptom-free volunteers, over age 60, and who had a history of smoking and no previous cancer, were given chest radiographs and low-dose CT. Malignant nodules were detected in 2.7% of individuals through use of CT scan versus .7% by chest radiography. CT scans and chest radiographs were both read separately by two board certified chest radiologists.

Marshall et al. (2001) created a decision analysis model for no screening versus baseline screening using helical CT, based on estimates from (SEER) data, baseline results from the ELCAP and estimates of program cost based on Medicare payment data. They found one time screening of high-risk and low-risk patients aged 60-74 years of age to be cost-effective. However, ongoing screening was not modeled as cost-effective. In another study based on the same modeling, (Marshall et al., 2001), attempted to assess the costs of annual lung cancer screening using Helical CT. They found that for high-risk individuals between the ages of 60 and 74 annual helical CT scanning was cost-effective at $18,968 per life year saved. Both the Marshall studies were observational and non-randomized.

In an attempt to respond to concern about over diagnosis of lung cancer through screening (Dammas et al., 2001) reviewed CT records of 187 patients who had been autopsied between 1994 and 1998 at Duke University Medical Center and who had received a CT within two months of post-mortem examination. Of those 187 patients 28 had nodules of interest. They did find 19 patients who had nodules that were found on autopsy, two of which were unsuspected tumors. They authors concluded that CT screening would be a source of over-diagnosis as they found 19 patients with nodules that were not the cause of death. However, the authors point out the issue of selection bias as they only reviewed the charts of patients who had had a chest CT. In a randomized controlled trial of 57 high-risk patients (Hirsch et al., 2001) studied the use of laser-induced fluorescence bronchoscopy (LIFE) versus conventional White-light bronchoscopy (WLB) in the detection of early stage lung cancer. The study design involved each patient receiving both a WLB and LIFE screen, with the order of procedure randomized and the patients and bronchoscopists blinded to the order and bronchoscopists blinded to the results of the previous test. The only difference in the bronchoscopes was the attached light source, either White, or fluorescence. Biopsies were then taken to confirm positive or negative findings. LIFE detected 75% of lesions with angiogenic squamous dysplasia as compared to 15% with WLB. LIFE detected 69% of patients with high-grade dysplasia or worse compared with 22% by WLB.

PET scans may detect smaller tumors than CT scan. They can also determine whether or not the tumor is malignant because malignant tumors take up glucose faster than non-malignant tumors and this shows up on the PET scan. However there are only 75 PET scanners in the United States at this time (Coleman, 2002; McCann, 1998).

Blacks get diagnosed at later stages than Whites (Graham et al., 1992). Shavers & Brown (2002), found that Blacks were more likely than Whites to have metastases by the time they are diagnosed. None of the studies reviewed explored or described why the disparities in stage at

diagnosis occur. Authors simply hypothesized that the discrepancy was due to access to care and low income and education.

Bradley and colleagues (2000) analyzed disparities in lung and other cancer diagnoses and survival based on three linked statewide Michigan databases, The Cancer Registry, Medicaid Enrollment files, and the Death Certificate Registry in the years 1996-1998. Total sample size was 51,296. The majority of the participants with lung cancer were >65 years of age. The mean age group of cancer diagnosis was 65-69 for both Blacks and Whites. The authors found that seniors with Medicare had an odds ratio of .81 for risk of late stage diagnosis as compared with elders who were >65 with Medicaid, who had an odds ratio of 1.19 for late stage diagnosis. The odds of late stage diagnosis for Blacks as compared to Whites were 1.05. Risk of death from lung cancer was highest in the Medicaid population under age 65. The authors concluded that the disparities in diagnosis and mortality rates found in the study were primarily due to poverty.

Stomach Cancer Detection and R/E Differences

There are no guidelines for screening because screening has not been found to be cost-effective. Mass screening is done in Japan, where stomach cancer rates are higher than in the U.S. (NCI, 2002a). However, early detection is key to successful treatment. The overall survival rate for stomach cancer in the United States is 21%, mostly due to the fact that most patients are diagnosed at an advanced stage of the disease. The survival rate for stomach cancer is 90% if diagnosed at stage 0. However, only 10-20% of stomach cancers are diagnosed at the early stages (NCI, 2002a).

A definitive diagnosis protocol was not found. NCI, (2002a) lists the diagnostic procedures for stomach cancer as fecal occult blood tests, upper GI series, endoscopy, and biopsy. ACS (2001) adds CT scanning and MRI to this list.

There is little available research on racial/ethnic differences in the use of CT scan or other procedures to detect stomach cancers. Dominitz and colleagues (2002) found that Blacks were less likely than Whites to receive a CT scan for diagnosis and staging than were Whites.

Oral Cancer Detection

Inspection and palpation of the oral cavity is the recommended form of head and neck/oral cancer screening. Many believe that this screening should be part of every physical exam by a dentist or a doctor, especially for individuals who are 50 years of age and older, and who are/were heavy tobacco and alcohol users (Smart, 1993). This procedure enables the provider to recognize abnormalities or lesions, and then provide the proper follow-up (i.e., diagnosis, treatment, surveillance) (Marder, 1998). The recommended examination involves a careful visual examination of the oral cavity and extraoral areas using a dental mirror, retracting the tongue with a gauze pad to visualize hard-to-see areas. It is suggested that the examination is conducted in conjunction with a screening form to assess the risk factors, such as tobacco and alcohol use, and symptoms (Prout et al., 1992), and that includes digital palpation with a gloved hand for masses. However, this standard procedure is subjective to the clinical eye and many providers, principally primary care physicians, are somewhat reluctant to perform this test (McCunniff et al., 2000). Furthermore, studies indicate that many oral cancers occur on

anatomic sites that may be inaccessible to routine visual inspection. Thus, some researchers believe that early detection of cancers of the larynx and esophagus should be based upon early symptoms rather than on screening (Smart, 1993). Finally, its usefulness has been called into question because of the low incidence and prevalence of the disease (Hawkins et al., 1999). No consensus statements or guidelines recommend mass screening for oral cancers.

It has been argued that dentists are more effective than are physicians in routinely performing a complete mouth examination and detecting early-stage oral cancers (Kerr, 2000; Marder, 1998; Smart, 1993). However, several studies show that there are a number of issues with oral cancer screening in dental practice (Horowitz et al., 2000; Horowitz et al., 2001; Yellowitz et al. 2000). These issues include, inaccurate knowledge about oral cancer among dentists; inconsistencies in oral cancer examination; lack of confidence in when and how to palpate abnormalities; and lack of time for routine provision of oral cancer examination. Eighty-one percent of the dentists surveyed in the Maryland study reported conducting oral cancer examinations in all patients over 40 years of age in their first visit (Horowitz et al., 2000).

A recent study shows that most dental hygienists (DH), who are often the providers obtaining medical history information from the patients, know that smoking and alcohol use are risk factors of oral cancer (Syme et al., 2001a). Most of them probed patients for present use of tobacco, but fewer evaluated past use and type or amount of tobacco used (Syme et al., 2001b). Similarly, though in fewer numbers compared to tobacco probing, DHs probed patients for present use of alcohol. Of those who probe for current use, only a few assessed past alcohol use (Syme et al., 2001b).

Only 7% of primary care physicians reported screening patients for oral/pharyngeal cancer (McCunniff et al., 2000). This group of doctors also felt that their knowledge about these cancers was not up to date with current evidence.

More recent studies have evaluated new tools for screening and diagnosis of oral cancers. A tolonium chloride rinse (to stain suspicious lesions) has been proposed as a screening test for oral cancers. But more research is needed to evaluate the accuracy and acceptability of this technique (Feaver et al., 1999). There are no reported studies on the sensitivity and specificity of this screening for oral cancer by physicians or dentists.

Another screening and diagnostic technique is the OralCDx analysis. The procedure consists of an oral brush biopsy that permits the dental practitioner to determine which "lesions contain atypical or dysplastic epithelial cells" (Drinnan, 2000). Recent research on this screening technique suggests that its use is a valuable addition to the basic oral screening examination (Christian, 2002).

R/E Differences in Oral Cancer Screening and Diagnosis: Studies show that the US adult population (over 40 years old) has poor knowledge of the signs, symptoms and risk factors of oral cancer, including elders of color (Horowitz et al., 1996; Yellowitz, 1997). Poor oral cancer knowledge, or lack thereof, may impact relative risk, as individuals may not ask their health care providers about their risk and about proper screening (Hay et al., 2002; Ostroff et al., 1999; Rubright et al. 1996). Hay and colleagues (2000) found that current smokers or individuals who

had a high lifetime exposure to tobacco history, and males have a higher perceived risk of developing oral cancers. However, individuals with a history of alcohol use/abuse felt less at risk of developing this type of cancer. Similarly, Asians in the study felt less at risk than other racial groups (Hay et al., 2002). In another study, Ostroff and colleagues (1999) found that women and those who perceived a higher risk of developing cancer were interested in receiving biomarker testing for tobacco-related cancer susceptibility.

The literature on oral cancers highlights the importance of knowledge of risk factors and symptoms as a steppingstone for proper screening, diagnosis and screening. Overall, studies show that the population's oral cancer knowledge in these areas is lacking. There are reportedly differences in knowledge between racial and ethnic groups. For example, Yellowitz and colleagues (1997) observed that Korean elders were less likely to correctly identify risk factors (i.e., tobacco and alcohol) associated with oral cancers, particularly regular alcohol drinking, than White and African American elders. Furthermore, Korean elders were less likely to correctly identify the warning signs of oral cancers (e.g., a sore or ulcer that does not go away). These disparities in knowledge may potentially affect screening participation and stage at diagnosis of the disease.

In the past, there have been several interventions to address oral cancers screening. One intervention addressed the educational components of oral cancers screening (Prout et al., 1992). This program attempted to increase education of oral cancers to primary care physicians and to promote screening among this group of health providers. The evaluation of the intervention showed an increased number of screening for high-risk patients (Prout et al., 1992). This intervention also provided documentation on the range of pathologic conditions in these patients (Prout et al., 1997).

D: Cancer Treatment and R/E Differences

Table III-13 summarizes the results of our review of reports on cancer treatment consensus, R/E differences in treatment. The table indicates that with the exception of prostate cancer and small-cell lung cancer, there is relative strong consensus on treatment procedures. In the case of prostate cancer, there is the option for many men of taking a conservative or "watchful waiting" approach because of the indolent quality of many of these tumors. While some combination of surgery, radiotherapy, and other treatments appears helpful for some men, there are troublesome side effects that reduce quality of life and small improvements in survival with treatment. Having noted these debates, much more striking is the observation that across all cancers, recommended treatment regimens require multiple interventions over an extended time frame. This quality of cancer care provides opportunities for system failure in managing patient adherence to complicated regimens and challenges in ensuring continuity of treatment.

Table III-13 also indicates that there are consistent patterns of less than complete treatment across all of the cancers studied. AA elders and other persons of color are less likely to receive complete primary treatments and less likely to receive secondary radiation or chemotherapy. Further, there is evidence that elders in general may be less likely to receive a full course of treatment. While the small body of available studies does not adequately address

this question for stomach cancer, it appears that at least within the VA system, that R/E groups have similar access to secondary/adjuvant treatments. Lung cancer studies may suggest that co-morbid conditions and other clinical features explain differences in treatment. While this question has been debated with respect to breast, colorectal, and prostate cancer, findings for these conditions appear to indicate that clinical factors do not account for R/E differences in treatment.

Our reviews also explored to what extent, differences in the period of survival or overall mortality existed. This has most often been examined in comparisons of Whites and AA populations. Building on the findings of Bach et al (2002) and Shavers and Brown (2002), we compared mortality and survival differences by R/E group in descriptive and experimental (so-called, "equal disease/equal treatment") studies. Our review found evidence for all conditions that R/E survival differences do not occur in the equal disease/equal treatment studies. In many studies that control for treatment difference—particularly for breast, colorectal, lung, and stomach cancers---differences in treatment explain R/E differences in mortality. For prostate cancer, White/AA mortality differences remained after accounting for treatment differences, but did not occur in the equal disease/equal treatment contexts. A more extensive review may be valuable in elucidating several key issues that might give rise to disparities, including the extent to which staging is performed according to guidelines, therapy is administered appropriately to the stage, multiple disciplines are consulted and therapy options presented, therapies re provided at adequate dosage levels, and therapies are completed in a timely fashion.

Breast Cancer: Treatment Consensus and R/E Disparities

Although poorer breast cancer survival among women of color is primarily attributed to stage at the time of diagnosis, the racial/ethnic disparity in survival is not fully explained by stage (Eley 1994, Simon 1997). Alternative explanations for this residual disparity that have been explored include 1) differences in treatment efficacy due to differences in tumor pathology and 2) differences in treatment effectiveness. It has been hypothesized that differences in molecular tumor characteristics, which are associated with faster breast cancer growth, could be responsible for residual disparity. Although younger women who have more aggressive breast tumor characteristics (such as high nuclear grade, p53 gene alteration, and HER-2/neu expression, negative estrogen and progesterone receptors) and worse survival, R/E differences in these factors are not consistent and contribute little to survival disparities among the elderly. R/E differences in unfavorable tumor characteristics among the elderly are small (Furberg 2001) because these features tend to diminish with age (Diab 2000). For example Furberg (2001) found that "among younger women, African American and White women differed only with respect to ER/PR status, while among older women African Americans and Whites differed only with respect to stage at diagnosis." In addition, although observational studies report disparities in survival, randomized controlled trials show little or no difference in breast cancer survival by R/E group (Dignam 1997, Roach 1997, Dignam 2001). This suggests a R/E difference in treatment efficacy is not the major factor accounting for residual disparity in breast cancer survival once difference in stage at diagnosis and treatment quality are accounted for.

Table III-3:
Summary of Findings on R/E Differences in Cancer Treatment

	Treatment Consensus	R/E differences in Treatment	R/E treatment differences explain survival
Breast	Multi-component Primary/ Secondary and Adjuvant	AA elders receive less complete primary and less secondary after BCS. AI/AN, Latino, Asian, NHOPI receive less (RT) after primary. AA receive less breast reconstruction. No evidence on adjuvant, but low for all elders.	White/AA differences in survival are explained by treatment differences, don't occur in equal disease/equal care studies.
Cervix	Stage based consensus; Primary/Secondary and Adjuvant	Evidence unclear; AA may receive less RT, may be linked to histology or co-morbid conditions	AA show poorer survival
Prostate	Not clear. Waiting or Multi-component Primary/ Secondary and Adjuvant	AA elders less likely to receive surgery or RT	White/AA differences remain after considering treatment, but don't occur in equal disease/equal care studies
Colorectal	Multi-component Primary/ Secondary and Adjuvant	Elders and elders of color less likely to receive complete primary, secondary, and adjuvant care. Most research on White/AA or White/non-White samples	White/AA differences in survival are explained by treatment differences, don't occur in equal disease/equal care studies.
Lung	Non-small cell: Multi-component Primary/ Secondary and Adjuvant. Small cell: Not clear	Elders and elders of color less likely to receive complete primary, secondary, and adjuvant care, but comorbid conditions may account for treatment differences	White/AA differences are explained by treatment in most studies. In some equal disease/equal care studies, White/AA differences linked with comorbid conditions
Stomach	Surgery and/or chemotherapy. Multi-component regimens being explored	Very little available evidence. In VA, AA less likely to received surgery, but no differences for RT or chemotherapy. Asians more likely to receive surgery.	Very little evidence. White/AA differences in surgery in VA explained mortality differences. Higher surgery rates for Asians associated with better survival

R/E group differences in treatment were the subject to a recent review (Shavers and Brown, 2002) although the study was not focused on elders/Medicare beneficiaries or interventions to reduce these disparities. For the following, we sought epidemiological and experimental evidence for R/E group and receipt of appropriate treatment by elder women. Our emerging sequential model of breast cancer treatment (based on consensus guidelines and recent clinical reports) indicates the potential for less adequate care for women of color in terms of primary treatment and secondary treatment. Given current consensus on treatment strategies for breast cancer, two potential sources of treatment effectiveness differences include: 1) inappropriate primary treatment in terms of breast conserving surgery or mastectomy, and 2) omission of systemic adjuvant therapy.

Inappropriate primary treatment: In 1990 the National Institutes of Health Consensus Panel recommended breast conserving surgery (BCS) with radiation therapy (RT) for stage I and II cancer as a preferable method of primary treatment than mastectomy because survival outcomes for these two treatment modalities are equivalent and in addition BCS provides better quality of life (QOL) because it preserves breast tissue. Appropriate BCS now includes complete tumor resection, axillary lymph node dissection (LND) and RT to the local area. Appropriate mastectomy is also accompanied by axillary LND and breast reconstruction. Although breast reconstruction is not essential to survival, it improves quality of life. The omission of radiation therapy is not always inappropriate. Many doctors would argue that if a BCS procedure were done with good margins and a complete LND is also done with all nodes returning negative, RT may not be needed. Although the use of BCS has been increasing since 1990 even for women of color, the proportion of women receiving appropriate therapy has also declined. For example according to Nattinger (2000), the proportion of women receiving appropriate care fell from 88% (1983-89 to 78% by 1995 (Nattinger 2000). Is this all women, minority women, old women, young women etc? Present the data so that its validity can be assessed objectively.

Omission of systemic adjuvant therapy following BCS or mastectomy, in terms of either chemotherapy or tamoxifen is another potential source of treatment disparity that has important implications for survival differences. Much of the difference in survival between African Americans and White women is attributed to failure to become disease free among AA than White women. The likelihood is greater for women in later stage than for those in early stage (Mancino 2001). For example, Mancino et al (2001) performed a retrospective review of 1345 women who were entered in the local tumor registry from October 1980 to December 1998 with invasive breast cancer ranging from stages I-IV. This data revealed no difference in survival between Black and White women who had presented with either Stage I or Stage II breast cancer. They however, found significant differences between Blacks and Whites that had presented with either stage III or IV. They also found a significantly lower percentage of Black women who became disease free after initial therapy compared to White women particularly in the stage III and IV sample. This difference in ability to achieve disease free status is not explained by differences in stage, but rather by differences in the use of adjuvant therapy. Women of color who have access to adjuvant therapy have similar disease free rates as White women (Dignam, 2001)

Evidence for R/E Disparity in Treatment: To determine whether or not there were R/E disparities in treatment for breast cancer, a systematic search and qualitative review of published literature was performed. At first, we sought primarily intervention studies addressing reducing

and R/E differences in patterns of appropriate service delivery, but the search did not yield sufficient experimental evidence to support meta-analysis. In order to see if we could further clarify options for Medicare, we also sought two additional types of studies: 1) R/E patterns in survival and treatment 2) R/E differences among elders and adult women in receipt of appropriate treatment. Unlimited Medline data base searches were performed using Endnote software. Search words included "breast cancer treatment and race"; "breast cancer treatment and African American", "breast cancer treatment and Asian" and "US, breast cancer treatment and Hispanic", "breast cancer treatment and American Indian"; "breast cancer survival and African American", "breast cancer survival and Hispanic", "breast cancer survival and American Indian", and "breast cancer survival and Asian and US". Sought were any articles that examined treatment patterns for breast cancer for the period before and after 1990. Although studies that did not combine data for the periods before and after 1990 were sought to get a clearer picture of both historical and current trends, it was not possible to have this restriction because few studies have examined race disparities in treatment and most of them combine data for the two periods.

The studies examined provided evidence for race ethnic disparity in treatment as a contributory factor to survival differences, both before and after 1990. These studies suggest that the primary contributory factors to survival differences are regional and systemic failure, i.e. failure to eliminate breast cancer cells that spread to the regional and distant sites. Studies also show that women of color are more likely to receive incomplete treatment (incomplete) than are their counterparts. Patterns in treatment and outcomes that demonstrate these findings are discussed below.

R/E Group Members Get Less Appropriate Care: Four studies reviewed demonstrate that disparities in treatment are the major contributing factor to survival differences (Bain 1986, Bradley 2002, Mancino 2001, McWhorter 1987). All these studies found (1) disparities in primary treatment, which was associated with poorer survival among Black women, (2) that Black women were less likely to have surgery or breast cancer directed treatment, and (3) when they did, they were likely to be treated less aggressively. This disparity seems to have implications for achieving disease free status among women with more advanced stage. Mancino and colleagues (2001) found no significant difference in survival among women who had stage I or II disease. But they found that among women with stage III and IV at diagnosis, Black women were less likely to become disease free (Mancino 2001). Mancino's study found evidence for differences in dosing, intensity, the use of multiple modalities, and the co-existence of co-morbidities, but could not adequately determine the impacts of each of these factors in explaining mortality differences.

Equal treatments yield equal outcomes: Further evidence in support of treatment disparity as a contributory factor to R/E survival differences is demonstrated by examining both randomized controlled trials (efficacy studies) in which patients have equal disease and equal treatment and observational of prognostic factors in which patients are either equally treated or have equal disease. The strongest indirect evidence that perhaps disparities in treatment could be responsible for the residual disparity in survival comes from randomized controlled trials of treatment efficacy by race. For example the National Surgical Adjuvant Breast and Bowel Project (NSABP) compared Black and White women on impact of treatment on survival. There was no Black/White difference in survival in this "equal disease/Equal treatment trial". This

study demonstrated that when R/E groups have similar stage and disease characteristics and are equally treated, there is little or no racial in breast cancer treatment or survival (Dignam 2000, Dignam 2001, Dignam 1997). There are no equivalent studies comparing White women to Hispanics, Asians/Pacific Islanders, and American Indian/Alaskan Natives.

Breast Conserving Therapy Versus Mastectomy: The evidence shows that up to 1990, women of color who had invasive breast cancer were less likely to receive minimal expected therapy (Breen 1999, Diehr 1989, Farrow 1992, Michalski 1997,McWhorter 1987, Muss 1992, Satariana 1992). There were, however no R/E differences in the use of BCS among women who had ductal carcinoma-in-situ (Adams-Cameron 1999). In contrast, after 1990, use of BCS increased even among women of color especially Black women (Bradley 2002, Morris 2000, Polednak 2002). However, although the use of BCS has increased, variations in use still persist (Gilligan 2002, Polednak 1997, Polednak 2002, Legorreta 2000). There is consistent evidence of R/E disparities in the receipt of BCS particularly for American Indians, Hispanics, and Asians, who are less likely to receive BCS (Legorreta 2000, Morris 2000, Shavers 2002). Although R/E disparity in receipt of BCS is less consistent for African Americans in general than in the period prior to 1990, elderly Black are still less likely to receive BCS (Morris 2000). This disparity in choice of primary surgery has potential quality of life implications. For example Deutsch (2001) found significant racial differences development of shoulder and arm problems after radiotherapy, primarily in Black women who had been treated with mastectomy and not in White women who received similar treatment or in those who had lumpectomy and radiotherapy, although the reasons for such outcomes were not fully explored and they have not been replicated in other settings or with other measures (Deutsch 2001).

Radiation therapy after Breast Conserving Surgery: Reviewers have concluded that all women of color and the elderly are less likely to receive radiation therapy after breast conservative surgery (Ballard-Barbash et al 1996, Shavers 2002). The differential is greater for the elderly 65 year of age and older than for younger women. For example, they found marked age declines in the use of radiation therapy after BCS regardless of co-morbidity status. "For ages of 65-69 years and 80 years or older, radiation therapy declined from 77% to 24% among women with no co morbid conditions and from 50% to 12% among women with two or more co morbid conditions.

Systemic adjuvant therapy: Statistically significant benefits have been observed with systemic adjuvant therapy (Aapro 2001). Use of chemotherapy in general reduces with age. No studies were found that address R/E disparities in systemic adjuvant therapy.

Breast reconstruction: One study was found that addressed the issue of R/E disparities in breast reconstruction surgery after mastectomy. Polednak (1999) used Connecticut cancer registry data to examine among 10, 756 cases (diagnosed with breast cancer between 1988-1995) trends and predictors of breast reconstruction after mastectomy. Women of color and the elderly are less likely to have breast reconstruction after mastectomy. They found breast reconstruction surgery to be negatively associated with Black race, age and poverty (Polednak 1999).

Limitations to identifying race/ethnic disparities in treatment include, limited number of studies that are based exclusively on more recent data (post 1990), and the fact that some studies

combine data from different periods –ie.1980s and 1990s periods--despite the major shift in breast treatment modalities over time.

Non-Clinical Factors explaining disparities in breast cancer treatment: A number of observational studies explore race/ethnic disparities in breast cancer treatment. Non-clinical factors suspected to influence race/ethnic disparities in receipt of treatment could be classified as individual, provider, provider organizational factors and systems of care. To determine which of these factors were associated with R/E disparities in breast cancer treatment, we examined both the crude differences and adjusted differences in treatment rates. Factors that modified the relative difference in treatment in a multivariate model were noted. According to studies that were reviewed, four factors contribute to disparities in primary surgical treatment: Provider organization characteristics, patient characteristics, and systems of care and geographical location of treatment or patient residence. Provider organization factors that seem to influence disparities in choice of primary surgical treatment include size of the practice (large versus small) (Satariano 1992). Non-clinical factors at individual patient level that are associated with disparity in primary breast cancer treatment choice include age, race/ethnicity, insurance status and social economic status, geographical location of residence differences including urban rural, high or low education census tract of neighborhood and high or low income census tract (Michalski 1997, Morris 2000, Velanovich 1999, Bradley 2002, Diehr 1989, Muss 1992).

Barriers to systemic therapy: Two of the studies reviewed suggest that transportation and distance to treatment sites are potential barriers to systemic adjuvant therapy among women of color and the elderly. For example, Guidry (1997) compared distance and mode of transportation to radiation therapy and chemotherapy and perceptions of transportation as a barrier to care among 593 multi-ethnic group of breast cancer patients (White, Black, Hispanic and Asian) who were receiving cancer treatment from a consortium of treatment facilities in Texas. In this study, women of color reported barriers such as distance, access to automobile and availability of someone to drive them to the treatment center. In this setting patients had to travel further for chemotherapy than for radiation therapy (Guidry 1997). In a related study of the same group of women Guidry found significant insurance barriers among Hispanic and Black women (Guidry 1998).

Barriers to diagnostic work up: The choice of treatment for breast cancer depends primarily on the clinical and tumor characteristics, particularly stage, and hormonal receptor status (progesterone and estrogen positive or negative) and co-morbidities. The stage and histology of the primary breast cancer determines primary treatment recommendations, while positive estrogen/progesterone receptor status (as opposed to negative) determines the recommendation for using tamoxifen or other systemic therapy. Women who have incomplete diagnostic workup are therefore likely to have inappropriate treatment. As noted earlier, two studies were found that explicitly examined factors that influenced race/ethnic disparities to diagnostic workup (Caplan 1996, Rojas 1996). Caplan (1996) examined provider and health care system barriers associated with delay in diagnostic workup among 367 breast cancer cases that were part of the NCI's-Black-White survival study. They found that 45% of the delay was due to provider and health care system, through difficulties in scheduling or physician inaction, 25% was due patient factors and 17 due to both patient and provider factors (Caplan 1996). Rojas (1996) performed a cross-sectional survey of three cancer screening clinics at an inner city

hospital and found high rates of non compliance with follow-up after abnormal screening (about 50%). Over all non-compliers were less likely to "report being told to follow-up (65% vs. 100%, p< .008), they were less likely to have suspicious mammography interpretations (p< 0.05), more likely to report barriers to follow-up such as cost of lost wages, medical care system barriers or fears than compliers (61% vs. 9%, p< 0.01) (Rojas 1996).

Interventions to reduce race-ethnic disparities in cancer treatment: Interventions aimed either at the individual level or at reducing race ethnic disparities in cancer treatment were sought from the Medline database using endnote software. Consultants and other review papers were other potential sources for these. There are currently no intervention studies in these areas that we could identify. The few observational studies on barriers to treatment by R/E women of color suggest interventions aimed at reduction in out-of pocket expenses related to treatment, help with navigating the care system and education regarding treatment options and reducing transportation barriers might be useful in reducing non-clinical barriers to radiation therapy and systemic adjuvant therapy.

Cervical Cancer: Treatment Consensus and R/E Disparities

To determine whether or not there were R/E disparities in treatment for cervical cancer, a systematic search and qualitative review of published literature was performed. Like for the other cancers we at first sought primarily intervention studies addressing reducing R/E differences in patterns of appropriate service delivery, but the search did not yield sufficient experimental evidence to support meta-analysis. In order to see if we could further clarify options for Medicare, we also sought two additional types of studies: 1) R/E patterns in survival and treatment 2) R/E differences among elders and adult women in receipt of appropriate treatment. Unlimited Medline data base searches were performed using Endnote software. Search words included "Cervical; cancer treatment and race"; "cervical cancer treatment and African American", "Cervical cancer Treatment and Asian" and "US, Cervical cancer Treatment and Hispanic", "Cervical cancer treatment and American Indian"; "Cervical cancer survival and African American", "Cervical cancer survival and Hispanic", "Cervical cancer survival and American Indian", and "breast cancer survival and Asian and US".

Table III-13 presents standard treatment options for cervical cancer. It must be emphasized from the outset that for cervical cancer the role of treatment beyond the localized stage seems limited at the moment. And as such the role of treatment in causing R/E disparities in survival is anticipated to be small for stages beyond local involvement. Nevertheless some evidence for R/E disparities was found. The race differential seems to be greater for stage II disease than for other stages—with almost equally positive prognoses for stage I disease and almost equally negative prognoses for Stages III and IV. The studies that provide this evidence are discussed below

Inability to receive radiation therapy: Mundt et al (1998) examined factors underlying the differences in outcome between African-American and White women undergoing radiation therapy (RT). They compared patient, tumor, treatment characteristics, and the outcome for 316 African American and 94 White women with cervical cancer who had had radiation therapy for a median follow-up of about 72.4 months.

They found that overall Black patients showed a non-statistically significant trend to a poorer 8-year cause-specific survival overall (47.9 versus 60.6%, p = 0.10) for African American and White women respectively). They however found a significant difference in survival for IIB-IVA disease (34.3 vs. 59.5%, p = 0.04 for Black and White women respectively). They also found that several factors were associated with poor outcome in the African American group---"lower mean hemoglobin levels during RT and lower median income. Although not significant, they also observed less frequent intracavity radiation therapy. In addition they found that these factors were major reasons for treatment protraction (prolonged treatment) and inability to undergo intra-cavity radiation therapy. These factors were not common among White women. After controlling for differences in patient, tumor, and treatment factors R/E was not a significant predictor (Mundt et al, 1998).

In another study, Han et al (1999) examined the role of duration of treatment in survival differences in 216 patients treated radically with external beam radiation (EBRT) and low-dose-rate brachytherapy for cervical cancer between 1980 and 1991 at Wayne State University. The stage distribution for the sample was: IB, 20.8%; IIA, 7.4%; IIB, 26.9%; IIIA, 1.8%; IIIB, 40.7%; and IVA, 2.3 %. They analyzed survival curves using Kaplan-Meier methods and tested differences between groups using the log-rank test and performed multivariate analysis using the Cox proportional hazards model. They found that with a median follow-up of 114 months, the actuarial disease-free survival for all patients was 60% at 5 years and 55% at 10 years. They also found stage specific 5-year survival to be 79% for Stage lB, 59% for Stage II, 53%. Racial comparisons showed significant difference in survival with White women having better survival than African American women. They also found that "survival for patients treated in shorter overall time was significantly higher ($P<;0. 001$), especially with treatment completion in under 58 days". In a stepwise Cox multivariate analysis they found the following factors to be significantly associated with survival: R/E (60% worse survival for African American than White women, stage (Stage II 2.6 times worse than stage I and Stage III 2.5 times worse than stage I), and treatment time (with 1.62 times worse survival for every unit increase in time) (Han, et al, 1999).

Lack of adherence to radiation therapy: A study by Formenti (1995) found inadequate adherence to radiotherapy among Latina immigrants to be significantly associated with poor survival for cervical cancer. They examined records of 69 consecutive Latina patients with cervical cancer who received radiation therapy at Los Angeles County Hospital. They conducted semi-structured interviews in a successive group of 30 similar patients to acquire preliminary information about their psychosocial characteristics. They found much lower rates of adherence to radiation treatment among Latina immigrant patients when compared with the rates reported in the literature for the general population of cervical cancer patients in United States (16 vs. 63%). They also found that a large subset of patients (20%) in the series elected to discontinue treatment without a medical reason. (Formenti, 1995). "When they interviewed a comparable group of Latina patients, they found, potential practical, psychological, and cultural barriers to optimal care …"

Table III-13
Stage and Standard Treatment Options for Cervical Cancer

STAGE	Standard Options per stage
0 Carcinoma in situ (pre-cancerous Lesions	1.Loop electrosurgical excision procedure (LEEP) 2.Laser therapy 3.Conization 4.Cryotherapy
Stage I Localized to the cervix	
IA Microscopic lesions	Total hysterectomy 1. Conization 2. Radical hysterectomy 3. Intracavity radiation alone
IB Clinical lesions	1.Radiation therapy: external beam pelvic irradiation plus two or more intracavity implants 2. Radical hysterectomy and bilateral lymphadenectomy 3. Postoperative total pelvic irradiation plus chemotherapy -4. Radiation therapy plus chemotherapy for bulky tumors
II Extends to beyond the Cervix but not to pelvic wall	
IIA	1.Radiation therapy—intracavitary combined with external beam pelvic radiation 2.Radical hysterectomy and pelvic lymphadenectomy 3. Post operative total pelvic irradiation plus chemotherapy after radical hysterectomy and bilateral pelvic lymphadenectomy 4. Radiation therapy plus chemotherapy
IIB	Radiation therapy plus chemotherapy (intracavity and external beam0
III Extends to the pelvic wall	Radiation therapy (intracavity and external) plus chemotherapy
IV Extend beyond the true pelvis, involves adjacent organs such as the bladder, rectum and distant metastasis	Radiation therapy (intracavity and external) plus chemotherapy

Source NCI Cancer treatment, cervical cancer PDQ (2002) http//cancer.gov/cancerinfo/pdq/cervical cancer healthprofessional /

Some evidence of equal treatments for similar disease yielding equal outcomes: Further evidence in support of treatment disparity as a contributory factor to R/E survival differences is demonstrated by two observational studies (Grisby 2000; Farley 2001). These studies demonstrated that when Black and White women have similar stage and disease characteristics and are equally treated, there is little or no racial difference survival. Grisby (2000) showed that "in a cancer treatment system where Black and White women with clinical Stage II and III cancer of the uterine cervix are all treated with radiotherapy alone, following standard treatment policies, no significant difference in cancer-specific survival outcome is shown". In this study, the sample was comprised of 922 women diagnosed with cancer and treated with radiotherapy. Patients were treated at the Mallinckrodt Institute of Radiology from 1959 through 1993. There were 576 women with clinical Stage II cancer and 346 women with clinical Stage III cancer. All women were treated following standard medical care treatment policies according to the stage of their disease. Data were analyzed by race and known treatment-related prognostic factors. Overall and cancer-specific survivals were evaluated.). They found no significant difference

between Black and White women in the 5-year cancer-specific survivals for clinical Stage II and Stage III. But, significant differences among Black and White women were found in the overall 5-year survivals rates (60 and 51% (P = 0.02))—suggesting that this was due to more AA women in Stage IV.

Another study conducted in among younger women who were treated in the military health care system also shows no statistically significant differences in survival among Black and White women who were equally treated. Farley (2001) showed that when Black and White women receive equal treatment for equal disease, they are likely to have similar survival rates. Farley et al used records for patients who were diagnosed with invasive cervical cancer from 1988 to 1999. They obtained records from the Automated Central Tumor Registry for the United States Military Health Care System. The variables examined included race, age at diagnosis, histology, grade, stage, socioeconomic status, treatment modality, and survival. They examined survival using Kaplan-Meier survival curves. The sample comprised 1553 were patients—out of which 63% were White, and 35% were non-White 29% of the non-White patients were African Americans. Black and White patients were similar on age (mean age =44 and 42 years, respectively), stage, grade, or histology 46% treated with surgery and 56% with radiation therapy, and there was no difference in type of treatment between the Caucasian and AA groups. They found that 5- and 10-year survival rates for White and African Americans to be comparable. (Five year survival was 75% for African American women and 76%, for White women and 10 year survival was 64% for African American women and 65% for White women (p = 0.59)).

Other explanatory factors for Survival differences:
Access barriers: Morgan (1996) African Americans 65 and older had worse survival than White women of similar age. Only stage and insurance predicted survival to determine whether survival from gynecological cancer was different between African-American and White patients Morgan et al (1996) analyzed data for 538 patients (89 African American, 449 White) diagnosed with cervical, uterine, or ovarian cancer at a single institution from January 1, 1989 through December 31, 1993. They found that African Americans had a significantly worse survival for cervical cancer than Whites, and African-American patients older than 65 years had a worse survival than White women of similar age. Only stage and insurance were significantly associated with survival. They found no significant difference when they stratified patients by stage or insurance.

In another study involving a younger cohort, however, Brooks (2000) found persistently worse survival by African Americans after adjusting for stage especially for stage I-II disease. Brooks et al (2000) evaluated the association of race, co- morbid illness, insurance status, and other prognostic factors on treatment and survival of patients with invasive carcinoma of the cervix. They used a retrospective cohort design to study 153 patients with invasive carcinoma of the cervix treated from 1991 to 1998 at the University of Maryland. Of the 153 women 83 (54%) were African Americans and 70 (46%) were White. African American were slightly older than White women (mean (+/- SE) age of African American women = 52 +/- 1.8 years vs. mean (+/-) White women was 50 +/- 1.8 years They found that African American women were more likely to present with stages II-IV disease (P = 0.01) and, and as a result were more likely to receive radiation therapy that surgery (P = 0.04). However the survival differences between African

American and White women seemed to be greater for stage I-II disease, After adjusting for stage, co-morbidities and other factors survival differential between African American and White women persisted. They found survival differential to be greatest for stage I-II disease.

Persistent differences in survival for American Indians: For a sample of American Indians from the Seattle-Puget Sound Cancer Registry, Washington state, however, Sugarman, (1994) found that that America Indians experience worse survival as compared to White women despite having similar stage distribution. Sugarman (1994) compared site-specific survival among American Indians (n = 551) and Whites (n = 110,899) diagnosed from 1974 to 1989 for five cancer sites. (Only cervical cancer findings are discussed here). American Indians experienced poorer survival cervical, which persisted after adjustment for differences in cancer stage at diagnosis, lack of cancer treatment, and residence in a non-urban county. After adjustment for age differences between American Indians and Whites, American Indians experienced poorer survival cervical. They also found that poorer survival among American Indians persisted after adjustment for differences in cancer stage at diagnosis, lack of cancer treatment, and residence in a non-urban county. Interestingly the authors observed that the " survival experience among American Indians who were recorded as non-American Indians in the cancer registry but who were listed as American Indians in Indian Health Service records was more favorable than that among persons initially coded as American Indians in the cancer registry

Three studies show a possible interaction between stage and tumor histology type and these may have an impact on R/E differences in survival. Thoms et al (1995) examined factors associated with cervical cancer survival. The sample was comprised of 158 women (80% African American,) diagnosed and treated for invasive cervical cancer from January 1, 1986, through December 31, 1992, at the Grady Memorial Hospital and Clinics (Atlanta, GA). They abstracted medical records to determine age at diagnosis, race, clinical stage, treatment, and survival. They reviewed pathologic material to confirm the diagnosis. They found that sixty-six (42%) had FIGO Stage I disease; 50%, Stage II or III; and 8%, Stage IV. They found no stage distribution difference between African American and White women. They however, found that the four-year actuarial survival differed significantly according to clinical stage (Ia = 94%, Ib = 79%, II = 39%, III = 26%, IV = 0%). The also found a non-significant trend towards lower survival for patients who had glandular carcinomas (adenocarcinoma) than for those with squamous cell carcinomas (26% versus 55%, P = 0.09). They however found a significant difference among patients who had stage IB adenocarcinoma versus stage IB squamous cell carcinoma (53% for adenocarcinoma vs. 88% for squamous cell carcinoma, Stage Ib, P = 0.03). This almost entirely accounted for observed trend in the overall sample. In this study the impact of stage/histology interaction on survival on racial difference was not clarified.

Differences in histology or tumor type have a potential to influence R/E differences. Anton-Culver et al (1992) looked at the role of tumor type on survival differences. Compared to White women, Asian Americans have a higher risk for adenocarcinoma while Hispanic Americans have higher risk for squamous cell carcinoma. They used a population based epidemiological study to compare epidemiologic and clinical characteristics of adenocarcinoma with those of squamous cell carcinoma of the cervix, with respect to risk by ethnic group, age at diagnosis, stage of disease at diagnosis, and survival. They found no survival differences between the two histological types of cervical cancer. The sample comprised 152 cases of

adenocarcinoma and 457 cases of squamous cell carcinoma of the uterine cervix. The data were obtained from the Cancer Surveillance Program of Orange County, California, from 1984 through 1989. They found that sixty-six (42%) had Stage I disease; 50% were in Stages II or III; and 8%, Stage IV. They found no stage distribution difference between African American and White women. They however, found that the four-year actuarial survival differed significantly according to clinical stage (Ia = 94%, Ib = 79%, II = 39%, III = 26%, IV = 0%). The also found a non-siginificant trend towards lower survival for patients who had glandular carcinomas (adenocarcinoma) than for those with squamous cell carcinomas (26% vs. 55%, p <. 09). They however found a significant difference among patients who had stage IB adenocarcinoma versus stage IB squamous cell carcinoma (53% for adenocarcinoma versus 88% for squamous cell carcinoma, Stage Ib, p <. 03). This almost entirely accounted for observed trend in the overall sample. In this study the impact of stage/histology interaction on survival on racial difference was not clarified.

Interaction of stage with treatment choice: In another study, Howell (1999) used data obtained from the Surveillance, Epidemiology, and End Results (SEER) Program for 1988-1994, to determine the associations between race and stage, and race and treatment. Racial differences in survival for up to 7 years of follow-up were adjusted for age, marital status, SEER location, and International Federation of Gynecology and Obstetrics (FIGO) stage of disease, lymph node status, grade, histology, and treatment. They found that Black women experienced worse survival than White women. Black women had more advanced stage (43.8% Black vs. 34.8% White) and were less likely to receive surgery than were White women (33.5% Black vs.48.2%, for White women) and were more likely to receive radiation therapy (35.3% vs. 25.2%,) than White women were. There was about 30 % residual disparity in mortality after adjusting for demographic factors, FIGO stage, other tumor characteristics, and treatment; the adjusted hazard ratio for mortality remained high for Black women at 1.30 (95% CI 1.14, 1.48). The role of racial differences in severity of disease, comorbidity, and socioeconomic status were not evaluated in this study.

Prostate Treatment: Consensus Views on Treatment

Currently there are three classical approaches for the treatment of clinically localized prostate cancer: radical prostatectomy, radiotherapy and conservative or expectant management (watchful waiting). Until data from randomized trials becomes available, what the most efficacious treatment is will remain unknown. Both, radical prostatectomy and radiotherapy are not free of complications. Radical prostatectomy is associated with mortality (1.1%), incontinence (any 26.6%, and complete 6.8%), impotence (85%) bowel injury (any 2.7%, and injury requiring long-term treatment or colostomy 1.3%), and urethral stricture requiring long-term treatment (12.4%). External beam radiation is also associated with similar complications but occurring at different rates: mortality (0.2%), incontinence (any 6.1%, and complete 1.2%), impotence (42%) bowel injury (any 11%, and injury requiring long-term treatment or colostomy 2.3%), and urethral stricture requiring long-term treatment (4.5%)(Office of Technology Assessment, 1995).

Long-term survival in patients with clinically localized prostate cancer aged 50-79 has been analyzed for 59,876 patients from cancer-registry data of Surveillance, Epidemiology, and Ends Results (SEER). Ten-year survival depended on the cancer grade. Patients with Stage I

disease had better survival and those with Stage III had the worst. There was not any statistically significant difference in survival by treatment among men with Stage I cancer. In this study, men with Stages II or III who underwent surgery had a statistically significant better survival than those who received radiotherapy or expectant management. The authors emphasized the possibility of selection bias, given the fact that those patients who are healthier are more likely to receive an aggressive treatment. Further, the authors found that the benefits of surgery were substantially improved when patients for whom post-surgical histological staging indicated metastatic cancer were dropped from the estimation of survival. When all recipients of surgery were considered, however, the 10-year disease specific survival for those with radical prostatectomy was substantially lower (Lu-Yao, 1997). Because patients who receive surgery are more accurately staged than those who do not, this analysis suggests that other comparisons of prostatectomy with conservative treatments may have over-stated the value of surgery by dropping cases or re-staging prior to analysis.

Prostrate Cancer and R/E Differences in Treatment: Racial differences in treatment have been repeatedly observed. For instance, a study of all invasive prostate cancer diagnosed in Connecticut between 1988 and 1992 observed that when the cancer was at a local/regional stage, radical prostatectomy was performed less frequently in Blacks than in Whites. Among men younger than 66 years, 42% of Blacks and 50% of Whites received a radical prostatectomy. When patients were between 65-74 years, the proportion of patients who receive this surgical procedure was 19% and 23% for Blacks and Whites respectively. No significant racial differences in surgery were observed among patients 75 years and above (Polednak, 1998). Interestingly, in a multivariate analysis controlling for age and levels of poverty rate from census tract as a proxy for socioeconomic status, only age and poverty levels were significant predictors of prostatectomy in patients with local/regional prostate cancer.

In an analysis of 98,377 patients diagnosed with prostate cancer between 1992 and 1996 and registered in SEER, 87.5% of them were Whites and 12.5% were Blacks. The proportion of African Americans that received conservative treatment was 46% compare to 40% for Whites. When controlling for age at diagnosis, stage and grade, Blacks were 1.3 times more likely than Caucasians to receive conservative treatment (Merrill, 2000). Between 1984 and 1991, Blacks also received conservative treatment more frequently than Whites. These racial differences in treatment were not explained by histologic differences (Gleason score) within local and regional disease (Harlan, 1995).

Similarly, a recent literature review showed differences in treatment between African American and Whites. White men with prostate cancer were more likely than non-Whites to receive more expensive or innovative treatments. Whites were also more likely than African Americans to receive radical prostatectomy. Blacks, however, were more likely than Whites to receive conservative treatment for localized cancer, or orchiectomy rather than hormonal drug treatment for advanced disease. Any of these racial differences in treatment could not be explain by racial clinical differences of the disease. Racial differences in treatment disappear when men have equal access opportunities to treatment facilities as observed among patients in the Department of Defense (Shavers, 2002).

R/E differences in treatment and survival: Many authors suggest that the relative roles of socioeconomic class versus other correlates of R/E such as treatment have not been successfully disentangled (Dale, 1996; Robbins, 2000). But a multivariate analysis of 146,979 prostate cancer patients diagnosed from 1973 to 1990 and registered in the Surveillance, Epidemiology and End Results (SEER) program showed that Blacks have a 35% higher risk of cancer specific mortality among patients with non-distant prostate cancer after controlling for age and type of treatment. Nevertheless, a recent meta-analysis has estimated the overall and cancer-specific survival differences for prostate cancers between Blacks and Whites when receiving comparable treatment for similar stage cancer. To calculate the overall survival and the cancer specific survival, a total of 30 cohort studies for average survival and 27 cohort studies for cancer specific survival were included respectively. Blacks were at a significant excess risk of death due to a greater burden of comorbidities, but there were no differences in the risk of prostate cancer specific death after controlling for population mortality (Bach, 2002).

Colorectal Cancer: Consensus Views on Treatment

Patients diagnosed with CRC typically are treated through surgery plus one or more follow-up therapies, including adjuvant chemotherapy with 5-fluorouracil (5-FU). One meta-analysis to determine the impact of compliance with the NIH standard of adjuvant chemotherapy with 5-FU for post-surgery care examined 39 RCTs (Dube, Heyen, & Jenicek, 1997). They included 1,673 people with Dukes' C colon cancer & 695 people with Dukes' B or C rectal cancer. It was found that adjuvant treatment with chemotherapy reduced mortality for both groups (OR 0.81 and 0.64 respectively). Similarly, the British Medical Journal's Clinical Evidence Issue 6 (Scholefield, 2001) reports that 5-FU improves survival by at least 5% of patients with Dukes' B and C tumors. The U.K.'s liver infusion meta-analysis group ("Portal vein chemotherapy for colorectal cancer: a meta-analysis of 4000 patients in 10 studies. Liver Infusion Meta-analysis Group," 1997) performed a meta-analysis of 4,000 people in 10 studies to determine the mortality effect of portal-vein infusion of 5-FU. They concluded that about one week of administration after surgery increased 5–year survival by a few percent.

R/E disparities in treatment: Shavers and Brown reviewed published literature regarding access/use of specific cancer treatments (Shavers & Brown, 2002), and located 7 studies on R/E and colorectal cancer treatments. They found evidence that racial disparities exist in receipt of definitive primary therapy, conservative therapy, and adjuvant therapy in larger studies and that these differences in treatment in part explain differences in survival, except in apparently equal-access systems. Reviewed below are studies included in the Shavers and Brown review and some additional reports.

Cooper and colleagues examined rates and types of surgery among Medicare beneficiaries 65 and older who had an initial diagnosis of colorectal cancer in 1987 (N = 81,579) (Cooper, Yuan, Landefeld, & Rimm, 1996). Blacks were less likely than Whites to undergo surgical resection (68% vs. 78%) even after controlling for age, comorbidity, and location and extent of tumors. Two-year mortality among Blacks was also higher (40.0% vs. 33.5%), and disparities existed in public & private hospitals and teaching & non-teaching hospitals. Neugut and colleagues identified 1,807 Medicare beneficiaries age 65 and over in the SEER database who had surgical resection for Stage II or III rectal cancer between 1992 and 1996 (Neugut et al.,

1991). Only 37% received combined adjuvant 5-FU-based chemotherapy with radiation (the study's standard), while 11% received 5-FU alone, and 14% radiation alone. Combined therapy improved survival for Stage III (RR 0.71). Receiving the standard was associated with lower age, increasing lymph node positivity, comorbid conditions, and non-Black race. Another analysis of elders identified 4,998 Medicare beneficiaries age 65 and over in the SEER database with surgically resected node-positive colon cancer between 1992 and 1996 (Sundararajan, Grann, Jacobson, Ahsan, & Neugut, 2001). The recommended adjuvant therapy for patients with this diagnosis is 5-FU plus leucovorin or levamisole. Compared to patients aged 65-69, odds ratios fell using the recommended therapy with each succeeding 5-year age group (0.82, 0.47, 0.17, and 0.04 respectively) and for Non-Hispanic Blacks compared to non-Hispanic Whites (OR 0.46).

Potosky and colleagues collected population-based random samples of patients diagnosed with colorectal cancer in 1987, 1991, and 1995 (N=4,706) (Potosky, Harlan, Kaplan, Johnson, & Lynch, 2002). Medical records showed that rates of use of efficacious adjuvant therapies were 78% for those under age 55 and 24% for those over 80. Whites received standard therapy more often than Blacks (OR 1.75). Risk ratios for 9-year mortality were lower for those receiving standard therapy both for all causes (RR 0.73) and cancer (RR 0.87). Ball and Elixhauser examined racial variations in treatment for colorectal cancer patients (N=20,000+) in a national sample of hospitals classified by subgroups in an analysis that controlled for patient demographics, insurance, and clinical and provider factors (Ball & Elixhauser, 1996). Blacks were more likely to have oncologic sequelae and advanced disease, and the odds for inpatient mortality were 59% to 98% higher for Blacks, except for the most severely ill. Treatment, also, was equivalent only for the most severely ill, with less sick Blacks less likely than Whites to receive major therapeutic procedures.

Lung Cancer Treatment

Shavers and Brown (2000b) described that SCLC can seldom be surgically resected because the disease has usually disseminated by the time the person is diagnosed. While surgery and radiation therapy do not achieve long-term survival, adding chemotherapy to the treatment regimen does increase the median survival rate. Prophylactic cranial irradiation is often recommended because SCLS often metastasizes to the brain. They also described that one third of NSCLCs can be surgically resected at the time of diagnosis.

Disparities in Lung Cancer Treatment: Shavers and Brown reviewed five studies of R/E differences in treatment for lung cancer and three studies of lung cancer treatment effectiveness. They conclude that no significant differences in treatment responses were found between Black and White patients in the VA Cooperative 188 Chemotherapy Trial. They also reported on two other studies that found Blacks and Whites had similar five-year survival rates after receiving surgical resection and radiation therapy. But, Shavers and Brown report that five population studies show that Blacks were less likely to receive surgical resection, radiation therapy, chemotherapy, or any other treatment. Median family income was also a predictor of whether or not individuals received surgical resection, even when Medicare was the payer. One study found that even with the same insurance Blacks were 30% less likely to receive chemotherapy. In a study based on SEER data Whites were 20% more likely to receive surgical resection for lung

cancer. All of these studies utilized population databases with large sample sizes. Stewart also reviewed literature that leads to the hypothesis that excess mortality of lung carcinoma in Blacks was due to inadequate access to care. Blacks undergo surgery for Stage I non-small cell lung carcinoma at lower rates than Whites.

Blackstock et al., (2002) investigated survival rates for 504 patients with advanced non-small cell lung cancer. Subjects included 458 White and 46 Black patients who were receiving chemotherapy for advanced NSCLC between 1989 and 1998 who were part of the Cancer and Leukemia Group B studies. 59% of the subjects were older than age 60. Their aim was to see if disparities in survival would persist if patients were receiving the same treatments. They found a significantly different unadjusted one-year survival rate of 22% for Blacks and 30% for Whites. However, difference in survival rates narrowed when controlling for performance status and weight loss, signifying that the Black patients were sicker when diagnosed. Black patients were more likely to be unemployed, unmarried, disabled, present with poor performance status and weight loss, and more likely to be on Medicaid. They suggest that poor social circumstances lead to poor prognosis. In a review of the literature, Shavers and Brown (2000) cite Ackerly et al. (1993), who found that Black and White males showed no significant differences in tumor response or disease progression in the VA Cooperative Study 188 Chemotherapy Trial

Bach, Cramer, Warren, & Begg (1999), using SEER data from 1985-1993, studied survival rates of 10,984 individuals with stage I or II NSCLC who were over 65 years of age. They found that rates of surgery were 12.7% lower in Black than Whites, controlling for type of Medicare and co-morbid conditions, and disease stage. 76.7% of Whites received surgery while 64% of Blacks received surgery. Survival rates were accordingly lower for Blacks, but not if they received surgery. Blacks who underwent surgical resection had similar survival rates to Whites that underwent surgery. They concluded that lower early stage NSCLC survival rates amongst Blacks is due to lower rates of surgery. (Earle, Neumann, Gelber, Weinstein, & Weeks, 2002), using SEER data, undertook a retrospective cohort study of 12,015 individuals over age 65 who were diagnosed with lung cancer between 1991 and 1996. The authors used linked Medicare data to track referral to oncologists and treatment with chemotherapy. They found that 36% of individuals who did not receive chemotherapy were never assessed by a physician who could provide chemotherapy. Factors that increased the chances of seeing a specialist were living location, treatment in a teaching hospital, and diagnosis in more recent years. Being Black was associated with decreased likelihood of seeing a specialist and decreased likelihood of receiving chemotherapy. Lower SES was also related to decreased likelihood of seeing a specialist or receiving chemotherapy.

Stewart (2001), in his review of the literature, commented that Blacks undergo surgery for Stage I non-small cell lung carcinoma at lower rates than Whites. He reported that (Bach et al., 1999) found that if Blacks underwent resection at rates similar to Whites the excess mortality in Blacks with non-small cell lung cancer would be lowered by 57%. In the Bach study Whites and Blacks had similar 5-year survival when treated with surgical resection for NSCLC. (Earle et al., 2000) conducted a retrospective study using Medicare data to determine the sociodemographic and disease characteristics of individuals who received chemotherapy for lung cancer. All individuals were greater than 65 years of age. They found that younger, healthier patients were more likely to receive chemotherapy. Non-Blacks, those of higher socioeconomic

status, those treated at teaching hospitals, and those treated at Puget Sound were more likely to receive chemotherapy.

Silvestri, Handy, Lackland, Corley, & Reed (1998) used a South Carolina severity-adjusted hospital discharge database to analyze outcomes of 1,583 resections performed by thoracic specialists and general surgeons between 1991 and 1995. The average patient age for both groups was approximately 65 years of age for those receiving lobectomies and 62 years of age for those receiving pneumonectomies. The authors found lower mortality rates for individuals who underwent surgery performed by specialists. Specifically, those undergoing lobectomy from a general surgeon had a mortality rate of 5.3% as opposed to 3% when a thoracic surgeon performed the lobectomy. Mortality rates for those undergoing pneumonectomy from a general surgeon were 20.2% versus 11.8% with a thoracic surgeon but this was not a statistically significant difference.

The most recent study reviewed here, (Jazieh, Kyasa, Sethuraman, & Howington, 2002), covered 551 individuals over aged 65 who had early stage non-small cell lung cancer. The authors retrospectively reviewed medical records, tumor registry records, and diagnostic reports and procedures. The median age of subjects was 67 years. 455 patients received surgery, 26 patients received alternate therapies, including chemotherapy, and 70 received no treatment. They found Black males were significantly less likely than Whites to receive surgery, as were those over age 65. The authors reported that the main reasons for not proceeding with surgical resection were poor pulmonary function tests, patient refusal, and confounding medical problems. The authors stressed that surgical resection is the gold standard of treatment for stage I and II NSCLC and that individuals who do not undergo resection have worse outcomes. They concluded that racial discrimination did not play a role in their results because treatment disparities might have been due to co-morbidities. They did conclude that older individuals receive surgery less often.

Stomach Cancer and Treatment Consensus and R/E Disparities

The NCI (2002a) lists the treatment for stomach cancer as surgery and chemotherapy or a combination of the two. They state that radiation therapy and biological therapy are used in clinical trials.

Dominitz et al., (2002), using the Patient Treatment File national database, studied 1290 White and 231 Black veterans with cancer of the distal esophagus between 1993-1997. They found that Blacks with adenocarcinoma were less likely than Whites to undergo surgery but had similar rates of chemotherapy and radiation therapy. Blacks with squamous cell carcinoma were less likely to undergo surgical resection but were more likely to receive radiation and chemotherapy. Survival rates were similar between Blacks and Whites when surgery was performed. There was an increased mortality rate for Blacks with squamous cell carcinoma (ACS, 2002). The authors hypothesized that the reasons why fewer Blacks received surgery for squamous cell carcinoma might be due to attitudes toward surgery, differences in disease severity, racial bias, issues of access to care, or differences in hospital use for cancer management. They were not able to analyze whether or not the veterans were offered but declined treatment. They were also unable to adjust their results for severity of disease. Theuer

(2000) found that Asians were more likely to receive surgery for stomach cancers compared to other racial groups. Dominitz et al., (2002) found mortality rates between Blacks and Whites to be similar when surgery was performed.

D: Conclusions

This review of R/E differences in cancer outcomes, detection, and treatment suggested several major findings.

1. African Americans and other traditionally underserved groups are at greater risk for getting cancer and/or have lower potential for surviving cancer.
2. Evidence for the role of late stage at diagnosis and R/E differences in survival was mixed. For the better-studied cancers---breast, prostate, colorectal, and lung---there was evidence that R/E differences in stage at the time of diagnosis accounted for a significant share of mortality or survival disparities.
3. Consensus recommendations for use of screening methods were found for breast, cervical, and colorectal cancer and consensus recommendations on timing of screening were found for breast cancer.
4. Prostate cancer screening remains controversial and there is evidence for targeted screening for some groups and a focus on informed decision-making as appropriate goals.
5. Screening rates – for breast, cervix, colon, and prostate-- are lower than desirable for all Medicare beneficiaries, but notably lower for persons of color.
6. For each of the cancers examined, final diagnosis and staging of cancer requires a multi-step process involving multiple tests, procedures, and professional consultations.
7. For breast, cervical, and prostate cancer, there is evidence that women of color and AA men are less likely to complete the diagnostic process.
8. For breast and cervical cancer there is evidence that AA women are less likely to receive complete diagnostic work-ups and valid clinical staging. For breast, cervical and colorectal cancer there is evidence that older persons are less likely to receive complete diagnostic processes.
9. For breast, cervical, prostate, and colorectal cancer, there are reports of culturally-tailored interventions to increase screening that typically involve use of community health workers to conduct educational programs using culturally and linguistically adapted materials. Some programs used multiple strategies that included assistance in overcoming barriers to access.
10. Our meta-analysis of these studies shows that overall both breast and cervical cancer screening interventions aimed at women of color and employing lay health workers and other cultural tailoring components produce modest significant impacts on screening rates, but they are extremely heterogeneous in their findings. For breast and cervical cancer screening, the combination of lay health workers and operational enhancements aimed at overcoming access barriers, rather than a single method strategy produced stronger findings.
11. There were insufficient culturally tailored prostate and colorectal screening interventions to support meta-analysis, but qualitative reviews indicated that there was at least some evidence that the same techniques used to increase mammography use by women of color could be adapted to other screening tests.

These findings suggest that interventions aimed at both reducing R/E disparities in cancer detection and R/E disparities in cancer treatment have the potential to influence overall differences in outcomes. The available research shows that both differences in stage at diagnosis and differences in treatment influence cancer and health outcomes. Improving screening participation and adherence for R/E elders are clearly worthwhile goals in light of these findings. Although the evidence could be stronger, it appears that culturally tailored screening interventions that focus on adherence and interventions based on in-reach have somewhat greater potential to influence R/E differences. Unlike prior efforts, new demonstrations might focus on programming that specifically targets screening adherence across the range of cancer screens, and such a model could also be extended to adherence to other recommended and Medicare-reimbursed screening and preventive services.

For cancers without accepted screening mechanisms, however, it appears that addressing the stage at diagnosis differences requires ensuring medical care use and attention on the part of both patients and practitioners to health risk management. The interventions proposed in Chapter II involved elders of color in health risk management with the dual goals of increasing engagement in lifestyle modification and increasing appropriate primary care utilization would also be beneficial in addressing these cancers.

Further, some of the differences in survival and treatment appear to occur because of failure to complete diagnostic work-ups, thus missing full staging of disease and potentially making incorrect treatment planning choices. This is not surprising since diagnosis for most cancers was found to be a multi-step process involving multiple practitioners and procedures with ample opportunities for failures in care continuity. Interventions that increase the likelihood that patients and practitioners follow-up on suspicious screening findings and perform complete diagnostic work-ups can reduce this differential

No less important than complete diagnosis is timely completion of all recommended primary and adjuvant treatments. These findings underscore the potential to improve cancer survivorship by ensuring that patient and practitioners complete the process. A treatment management intervention that draws upon a community health worker serving as a patient navigator holds the potential to increase the share of elders of color who receive the current standard of care. Although demonstrations and evaluations of cancer treatment management services were not identified in the literature, this review highlights treatment management as a potential area for important and cost-effective reductions in cancer care disparities.

Chapter IV: Emerging Interventions to Reduce Racial/Ethnic Disparities in Cancer and Health

A: Introduction

Because many efforts to reduce racial/ethnic (R/E) cancer and health disparities are ongoing and not yet reflected in the current literature, a series of case studies were completed on emerging models and programs that had not yet been fully described or evaluated in the published literature. The goal was to identify model programs and perform case studies of models that (1) have a high probability of reducing cancer risk factors, increasing the use of Medicare-covered services, and improving health related outcomes for R/E groups or (2) could offer insights into the design and operations of such programs. The case studies had four related goals:

1. To describe the emerging program's perspectives about the magnitude and causes of R/E disparities in cancer prevention, treatment, and outcomes in the community.
2. To describe each initiative's organization, goals, operations, outcomes and costs to the extent of data availability.
3. To understand the program's perspectives on the evidence that the program is achieving its goals or preventing or reducing the burden of cancer for communities of color.
4. To understand the program's perspective of the key problem areas and success factors for this project and similar projects/initiatives.

After describing our approach to identifying potential case study sites, the screening sample from which case study were selected, and the case study data collection and analysis approach, findings relevant to these goals are described.

B: Study Methods

In order to identify emerging models for inclusion in case studies, we first identified an inclusive and diverse list of programs, organizations, and contacts with potential relevance to our study, either as a model of care or as a source of referrals across the United States. Next, telephone contacts were established with all programs, leading to a list of referrals for more in depth telephone screens. Through ongoing review and analysis, criteria were defined for a final selection of case study programs for onsite visits, and a comprehensive examination into the replication potential, sustainability, effectiveness, and resource allocation of the selected sites.

<u>Identification of sites</u>

The process of identifying sites consisted of three steps: multiple nationwide out-reach (including Alaska, Hawaii, and Guam), selective screening for purposes of eliminating duplication, and finally, targeted screening to ensure that our sample was both representative and inclusive. Multiple out-reach incorporated following up referrals generated by word-of-mouth, phone contacts, and other sources identified by the team. To ensure comprehensive networking

at this stage, a list of organizations and contacts was generated and conference proceedings were screened for relevant contacts. This list included:

1. **Federal Agencies and Federally-Sponsored Programs**, such as the CDC REACH 2010 initiative, CMS' DASPRO initiatives, NIH/NCI Ongoing studies, and the Administration on Aging, among others.
2. **Health Payer/Delivery System Organizations**, such as Blue Cross/Blue Shield, and the National Association of Community Health Centers, among others.
3. **R/E Identity and Professional Organizations**, for example, National Indian Council on Aging, National Hispanic Council on Aging, National Association for the Advancement of Colored People, National Council of La Raza, and others.
4. **Conference Proceedings Since 1997**, including the American Public Health Association, Gerontological Society of America, Association of Health Services Research, cancer conferences, health disparities conferences, and others.
5. **Foundation Initiated Programs**, like the Robert Wood Johnson Foundation's Last Acts Campaign, etc.
6. **Cancer Centers**, such as the Moffitt Center in Tampa FL, and the Dana-Farber Cancer Institute in Boston, MA.

In addition, letters and emails were distributed through relevant networks such as the Robert Wood Johnson Foundation's Last Act Campaign diversity working group, the American Society on Aging network on minority aging, and the regional Health and Human Services women's health networks. The letters introduced the project and included a project notice. As researchers continued their work on developing a comprehensive literature review, additional referrals were identified in the literature. The project PI and Co-PI participated in the Inter-Cultural Cancer Council meetings Feb 6-10, 2002 and made several useful contacts for follow-up there. Ongoing telephone contacts with CMS project leaders and leaders of NCI, AHRQ, and CDC race and cancer relevant initiatives were additional sources of emerging model identification. Ongoing initiatives such as the CMS disparity projects with PROs, the CDC REACH 2010 and BCCP replication projects, and the NCI special populations networks were additional sources of leads. The project Co-PI also attended the Massachusetts Community Health Worker (CHW) Network day-long meeting to obtain an understanding of the definition, mission, scope of work, and governance of CHWs.

The emerging programs screening team and the literature review team met on an ongoing basis to brainstorm and to discuss and compare findings. Drawing on the resources available through the SIHP, referrals arose out of existing projects (such as the CMS sponsored evaluation of Lifestyle Modification, and collaboration in the Robert Wood Johnson Foundation's Access Project and Addressing Tobacco in Managed Care project). Additional team members were brought onboard as a need for specific areas of expertise were identified.

Over time, this open networking process resulted in recurring referrals, indicating out-reach saturation and the reduced potential of missed programs. At this point, the team began eliminating duplicate programs from the list of potential screens and began the process of identifying criteria for selection of onsite visits. Our final step was a more focused screening, to

ensure that all the targeted populations, cancers, risk factors, regional locations, organizational types, and interventions had received thorough review and consideration.

Screening Calls

The telephone screening process consisted of a systematic three-tier approach. First, out-reach mail, electronic mail and telephone contacts were made to emerging programs and referral sources (e.g., federal agencies and federally-sponsored program, health delivery organizations, national R/E organizations, medical schools, foundations and cancer centers) to identify initiatives focused on cancer-related interventions for R/E elders (as described above). In most cases, programs were sought that: (1) specifically targeted reduction in risk factors or in health care access disparities by race/ethnicity and/or socio-economic status, (2) had not been extensively reviewed in published reports, (3) were currently operational, and (4) either actively collect data on activities and outcomes or had determined some method of evidence-based practice. Telephone contact logs were completed for each screening site, recording demographic, contact, and initial program information to help determine study relevance (see a copy of this form in Appendix II). This information was later entered into a database. The goal of this phase was to identify as many relevant programs nationwide as possible.

The second phase of the screening process was to do a more in depth screening phone call. We sought to complete 100 screening interviews. In fact, we completed screening on over 100 programs and organizations nationwide (n=115). At this juncture, the focus was on four primary areas: program description (host, setting, target group, intervention, funding), program effectiveness and achievements, program costs, and program sustainability. Team members made calls and shared findings at weekly team meetings where we began to formulate a sense of actual program activity "in practice."

Screening Sample

The goal of the screening process was to be both comprehensive and inclusive in scope and to inform our study about innovative interventions and programs that may not yet be well known. Programs were each examined for and classified by organization type, region / location, urban versus rural, targeted population, targeted cancer, targeted behavior (risk factor), and intervention (innovation, feasibility, replication potential, sustainability, and evidence of effectiveness). The screening questions form used to gather this preliminary data is included in Appendix II. Building on the foundation of explanatory factors for R/E disparities, we looked for interventions that addressed at least one or more factors at one of five levels – individual / cultural level, practitioner level, provider-organization level, system of care/ financing level, or community level.

We focused on primary (cancer risk factors), secondary prevention (screening, detection, and prevention through treatment of pre-cancerous disease), and treatment targeted interventions at the following five levels of care. At the individual level, the focus included such factors as information, attitudes, and behavior. The practitioner level directed our attention to issues of cultural competency, counseling / brief intervention, and referral to intensive programs. The provider-organization level includes such factors as integrated delivery systems, and the use of

guidelines and protocols. Systems of care and financing focused on interventions directed towards innovations in resource attainment and utilization, collaborative efforts (such as university or health system collaborations), and other cost-effective efforts. Factors at the community level extended our view to programs that were based in churches, senior centers, tribal organizations, and other socially oriented bottom-up approaches. Furthermore, we looked at programs that incorporated such interventions as health care extenders, whole person approaches, and innovative and collaborative mass media efforts.

We screened a total of 115 programs addressing the areas mentioned above. Table 4.1 provides a description of the programs contacted and screened by type of cancer and R/E group. Approximately one-third of all screened programs targeted African Americans, followed by programs targeting multiple R/E groups. Slightly over one-fourth of the programs targeted Latinos, 10% American Indians/Alaskan Natives, and 10% Asian American/Pacific Islander groups. When separated by type of cancer program, 64% (n=74) addressed breast and cervical cancer among populations of color. Those breast and cervical cancer programs were evenly distributed among African American and Latina groups (27% for each group). One-third of the breast and cervical cancer programs targeted multiple R/E groups. Less that 10% of the sites targeted elders exclusively (data not shown), and these tended to focus on primary prevention and/or multiple cancers. Fewer programs addressed other types of cancer and primary prevention interventions among populations of color.

Table 4.1. Distribution of Screened Cancer Programs by Population Group

Population Group	Total n=115	Breast and Cervical Cancer n=74	Prostate, Lung, Colorectal, n=24	Primary Prevention, n=10	Other Cancers and Multiple n=7
African Americans	33%	27%	58%	40%	10%
Latino	21%	27%	11%	20%	10%
Asian American/Pacific Islander	10%	4%	0%	0%	10%
American Indian/Alaskan Native	10%	9%	11%	13%	30%
Multiple	26%	33%	20%	27%	40%

In our inclusive identification and screening process, the research team made a concerted effort to identify programs across different regions of the country and by different types of organizations. Table 4.2 presents the distribution of screened programs by region and by the type of organization where the program was housed. Of the 115 screened programs, one-third (33%) were located in the Southeast and in Texas, followed by programs in the West part of the country (23%), the Midwest/Mid-South (23%), and the Northeast/Mid-Atlantic region (21%). This distribution of screened programs seems to reflect high-density, concentration areas of R/E populations, according to the 2000 US Census. Most of the programs were housed or located at community-based organizations (36%), or at community health centers and public health organizations, including state departments of health (30%). Fewer programs were hospital, university or church based.

Table 4.2. Distribution of Regions by Organization Type

Organization Type	Total, n=115	Northeast/ Mid-Atlantic, n=24	Southeast and Texas n=38	Midwest/ Mid-South, n=26	West, n=27
Hospital	14%	6%	28%	6%	11%
Clinic/Public Health	30%	44%	20%	29%	33%
Church	5%	0%	4%	18%	0%
Community Coalition	36%	38%	36%	29%	39%
University-Initiated	12%	6%	12%	12%	17%
Private Initiative	3%	6%	0%	6%	0%

Selection of Case Study Sites

The third phase of the screening process unfolded as the team identified trends in program activity. Working criteria were developed for a diverse and inclusive selection of sites to visit and explore further. The resulting sample of 25 sites is best viewed as a convenience sample reflecting an intentional heterogeneity model (Blankertz, 1998). The selected case study sites reflect variability in R/E target population, cancer type or primary prevention addressed, cancer experience phase addressed (e.g. prevention, screening adherence, service management), organizational host, region and urban/rural status. In addition, we sought primarily programs that included or specially targeted elders, and this is the largest difference between the study site selected and the screening sample. Several programs that did not include elders were visited because they offered unique possibilities to learn about cultural tailoring, primary prevention, or other central research concerns. We also sought multiple exemplars of apparently popular strategies and unique models, as well as both premier, historically significant hosts and less well-known providers.

An additional site visit was conducted to the Aberdeen Area Indian Health Service, which serves the Indian tribes in North Dakota, South Dakota, Nebraska and Iowa. The area office is in Aberdeen, SD, and serves as the administrative office for eight hospitals and five health centers. This site visit was instrumental in informing project members about the functioning of the Indian Health Service, as we attended the Medical Directors' meeting, and visited the Area Administrative Office. Particularly, this gave us insights into how complex the coordination of benefits and services through the Indian Health Service, other payors, and contracted service vendors can be, and how residential requirements can lead to profound disruptions in service. Because of the exploratory and informational nature of the visit, the site was not included in our final list of case studies.

One of the hospitals within the Aberdeen Indian Health System unit that was visited by our team, the Sisseton-Waupeton Hospital, operates 18 beds and has 5 physicians. Included in its services are community health outreach through Community Health Representatives (CHRs); the focus is on maternal and child health and family planning issues. It also has a freestanding alcohol treatment residential facility. Historically, the Indian people have suffered from endemic health problems such as alcoholism, mental health problems, poor dental health, lack of pre-natal

care and high infant mortality. Programs available at this unit reflect this reality. Chronic illnesses are highly prevalent as well, such as diabetes, cardiovascular disease, and cancer. Therefore, recently, an initiative to target patients with diabetes has been initiated; this involves a self-management program, and CHRs are instrumental in recruiting patients into this program.

Conducting Case Studies

The selected programs were contacted by phone again to confirm willingness to participate and to determine availability for a site visit. Follow-up letters were sent that reviewed the goals and objectives of our visit. Case study teams were then selected for each site, with one designated researcher responsible for advance preparations, document collection, follow-up evidence collection, and case report writing. The case study teams were composed of two members with expertise in program implementation, outcome measurement, and cost-effectiveness analysis.

Prior to each site visit, teams reviewed with the PI or Co-PI any screening forms, all documents obtained from the site, and areas of special interest in order to tailor information requests to the extent possible. Based on this review, a tailored interview guide was developed. In general, the interview guides addressed questions in the following areas:

- Program context and theory of intervention, such as perceptions of the magnitudes and causes of R/E disparities in cancer in cancer prevention, treatment and outcomes in study community, sponsors and collaborators, program development, overall program goals and objectives, cancer type, phase or risk factors addressed, and target population.
- Program operations, such as recruitment, training, and supervision of community health workers or volunteers, recruitment and engagement of potential service recipients, delivery of interventions, coordination of service use, and use of management information.
- Cultural tailoring, including use of community members as mediators, efforts to engage elders of color, educational and informational adjustments, cultural competence training with professionals, development and use of culturally-appropriate materials and protocols, roles of churches/ other community groups, and other responses to unique needs of elders of color.
- Organizational and financing issues, such as staffing and volunteer issues, effects of funding sources on operations, focus on training rather than service delivery, research influences on operations, management information systems, and relationships with other community organizations.
- Assessment of program impacts and costs including detailed information on program budgets, service costs, staff payments, in-kind services, and other measures of resource use, volume of services, program evaluation approaches and status, and measures of program impacts on participating individuals.

The case study teams generally spent 2 days with each project or combined a day of in-person visits with telephone and written exchanges with the site. While the exact set of respondents varied by site, most case studies included interviews with program developers, champions, and current leadership as well as program staff at all levels, fiscal and MIS managers, local sponsors and collaborating agencies, and program evaluators or other researchers. Case study teams developed detailed notes and then prepared draft case studies

using a standardized outline and approach. During development and review of draft reports, additional information needs were identified and supplemental data collection initiated. Draft case studies were reviewed by site leadership and amended as needed. Analysis was based on a grounded theory framework: categorization of site objectives, intervention models, and major learnings were developed and revised and case study learnings were reconsidered in an iterative process.

C: Case Study Findings

This section of the report presents both an overall description of the case studies along with an analysis of our findings. We characterized the study sites according to the type of organization hosting the intervention, the additional organizations that have partnered with the host organization to perform the intervention, the populations served by the intervention program, and the type of cancer targeted. The descriptive section of this case study findings section concludes with a description of what the programs are learning about barriers to service utilization and access to health service for R/E communities.

Our report takes a more analytic turn as we conceptualize common patterns in intervention goals and processes. We developed a classification system of the programs based on their intervention goals. Using these goal classifications as a base, we then considered the methods interventions employed to meet these goals. Our analysis extends to intervention processes and cultural tailoring, operations, and utilization of community health workers. Study sites were located all across the US, but concentrated in areas where high concentrations of R/E exist (Figure 4.1). More detailed descriptions of each of the 25 programs we studied are included in Appendix III.

Figure 4.1.
Case Study Sites Across the U.S.
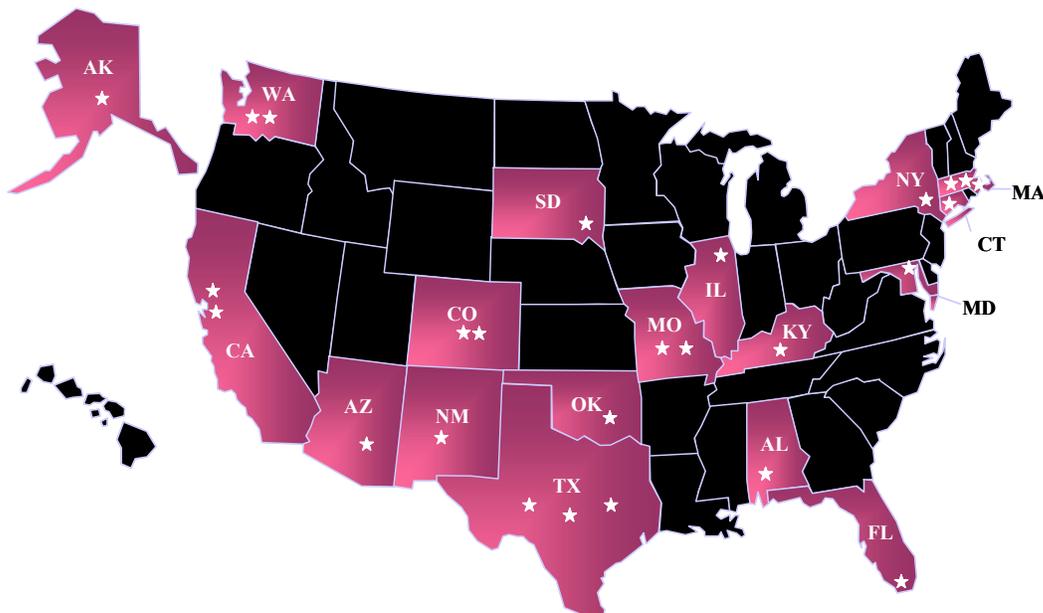
<u>Characteristics of the Study Sites</u>

A variety of different types of organizations, alone or in tandem, conducted the interventions we studied. These included 9 community health centers or networks of community health centers, 5 advocacy groups or networks, 4 government agencies including the Indian Health Service, 4 human service agencies, and 8 academic health centers or academic institutions. Many of these organizations sought formal affiliations or partnerships with other organizations in the community to help implement the interventions. Community health centers were central partners in 6 of the interventions. Faith-based organizations played a prominent role in 5 of the interventions. Hospitals or academic health centers participated in 5 of the interventions, while academic institutions assisted with two and a managed care organization was a partner in one of the interventions. A list of case study programs is provided in Table 4.3.

The sites targeted a variety of populations, with some interventions focusing on one underserved population and others on multiple underserved groups. The majority of the interventions targeted R/E groups with demonstrated disparities in cancer rates, service utilization, and/or cancer mortality: 14 served African-American communities, 11 Hispanic communities, 6 Asian communities, 2 Alaskan Native communities, and 2 Native American communities. Rural communities were targeted by 4 of the interventions, and 10 of the interventions dealt specifically with immigrant communities. Close to half of the interventions (12) targeted low-income populations. Only 7 of the interventions exclusively targeted an elder population, and none excluded persons over age 65.

The majority of the sites studied addressed breast and cervical cancer. One program addressed prostate cancer only and one lung cancer only. The 9 remaining interventions addressed multiple types of cancer.

Table 4.3: Characteristics of the Case Study Sites

Organization	Type	Program Name	Intervention Goal	Target Population	Cancer
Access Community Health Network Chicago, IL	Community health center/network	Chicago Racial Ethnic Approaches to Community Health 2010 (REACH 2010)	Screening education	African American Hispanic Immigrant	Breast and cervical
American Cancer Society Heartland Division Kansas City, MO	Human service agency	Patient Navigator Program	Treatment management	African American Hispanic Asian Caucasian Elderly Medicaid Low income Immigrant	Multiple
Asian and Pacific Islander American Health Forum (APIAHF) San Francisco, CA	Advocacy/network	The Asian American and Pacific Islander National Cancer Survivors Network (APICSN) and the Asian American and Pacific Islander Tobacco Education Network (APITEN)	Health risk management	Asian Alaskan/Pacific Islander	Multiple
Association of Asian Pacific Community Health Organizations (AAPCHO)	Advocacy/network	The Community Approach to Responding Early	Screening education	Asian Immigrant	Breast and cervical
Baltimore Cancer Coalition Baltimore, MD	Advocacy/network	Baltimore City Cancer Plan (BCC)	Health risk management Screening education Screening adherence Treatment management	African American Hispanic Asian Elderly Low income Immigrant	Prostate
Boston Public Health Commission Boston, MA	Government/HIS	Boston Racial Ethnic Approaches to Community Health 2010 (REACH 2010) Case Management Component	Screening education Screening adherence Treatment management	African American Elderly Immigrant	Breast and cervical
Clinica Tepeyac Denver, CO	Community health center/network	Reach and Teach Project	Screening education Screening adherence	Hispanic	Multiple
Community Health Services Division of the Oklahoma Department of Public Health Oklahoma City, OK	Government/HIS Human service agency	Oklahoma City Witness Project	Screening education	African American Caucasian Elderly Immigrant	Breast and cervical
Dana Farber Cancer Institute (DFCI) Boston, MA	Hospital or AHC	Cancer Prevention Through Small Business Project (CPTSBP)	Health risk management	African American Hispanic Asian Caucasian	Multiple
Deep South Network for Cancer Control Birmingham, AL	Hospital or AHC Academic institution	Deep South Network Community Health Advisors Program	Screening education	African American Rural Low income	Breast and cervical
Elder Voices, Inc. Albuquerque, NM	Advocacy/network	Public Benefits Counseling Program (PBC)	---	Native American	Multiple
Grace Hill Centers St. Louis, MO	Community health center/network	Assistance and Self-Help to End Smoking Project (Ashes) and Mammography and Pap Project (MAP)	Health risk management Screening education Screening adherence	African American Low income	Breast and cervical
Health Choice Network (HCN) Miami, FL	Community health center/network	Healthy Body, Healthy Soul -- Jessie Trice Cancer Prevention Project (JTCPP)	Health risk management Screening adherence Treatment management	African American Hispanic Caucasian Low income Immigrant	Lung cancer
Indian Health Service Alaska	Government/HIS	Community Health Representative Program (CHR)	Health risk management Screening adherence	Alaskan/Pacific Islander	Multiple
Lahey Clinic Burlington, MA	Community health center/network	Wellness for Seniors Collaborative Program	Health risk management	Caucasian Elderly	Multiple
Massachusetts General Hospital/Chelsea Health Care Center Boston/Chelsea, MA	Hospital or AHC Community health center/network	Avon Breast Cancer Project	Screening adherence Treatment management	African American Hispanic Low income Immigrant	Breast and cervical

Organization	Type	Program Name	Intervention Goal	Target Population	Cancer
National Center for Farmworkers Health Buda, TX	Advocacy/network	Culivando la salud/ Cultivating your health	Screening education Screening adherence	Hispanic Rural Immigrant	Breast and cervical
North General Hospital/ Breast Examination Center of Harlem (BECH) Harlem, NY	Hospital or AHC Community health center/network	Patient Navigator Programs	Screening Adherence Treatment management	African American Hispanic Medicaid Low income	Breast and cervical
Planned Parenthood Bridgeport, CT	Human service agency	Witness Project of Connecticut	Screening education	African American Elderly	Breast and cervical
Seattle Indian Health Board Seattle, WA	Community health center/network	Breast and Cervical Cancer Health Program and the Nutrition Program	Health risk management Screening education Screening adherence	Alaskan/Pacific Islander Native American Low income	Breast and cervical
Senior Services of Seattle/King County Seattle, WA	Human service agency	Senior Wellness Program (SWP)	Health risk management	African American Hispanic Asian Caucasian Elderly Medicaid Low income Immigrant	Multiple
Texas Cancer Council Houston, Dallas, and Tyler, TX	Government/HIS	African American Breast Cancer Outreach Program (AABCO)	Screening education Screening adherence	African American	Breast and cervical
University of Arizona at Tucson/Mariposa Community Health Center Nogales, AZ	Hospital or AHC Community health center/network	Juntos Contra el Cáncer Prevention Program	Screening education Screening adherence	Hispanic Rural Immigrant	Breast and cervical
University of Colorado Denver, CO	Academic institution	Native American Women's Wellness Through Awareness (NAWWA)	Screening education Screening adherence	Native American	Breast and cervical
University of Kentucky Center for Rural Health Hazard, KY	Community health center/network Academic institution	Kentucky Homeplace and Southeast Kentucky Community Access Program (SKYCAP)	Health risk management Screening adherence Treatment management	Caucasian Rural Low income	Multiple

Barriers to Service Utilization and Access: What the Programs are Learning.

In trying to address R/E disparities in cancer, programs learned a great deal about the nature and extent of barriers that prevent underserved communities from accessing and utilizing services. As displayed in Table 4.4, the program sites consistently identified several barriers to service utilization and access that their target populations faced. As we listened to the programs describe the barriers they had observed for R/E communities in obtaining appropriate cancer care, it became apparent that each barrier could be understood as both a process embedded in the system of care and as a process of individual experiences with the system of care. This section describes the barriers most commonly discussed by the programs at our site visits.

Culture and Attitudes: The vast majority of programs perceived a disconnection between the target populations' cultural beliefs and attitudes about cancer and health services and current health care practice. They viewed this gap as a potentially serious barrier if not addressed. **Grace Hill Centers** found that many in the African-American population they served shared a belief that cancer is a punishment for "not believing enough" and also believed that, if they had faith, "God will take care of it." Such beliefs could discourage people from undergoing treatment or screening. In another example, **The University of Colorado Native American Women's Wellness Through Awareness Program** pointed to the deficit of culturally relevant information

that would incorporate and disarm some Native American cultural beliefs, for example, that screening invites the cancer spirit into the body, or that smoking cessation activities are insulting to the tobacco spirit, which is considered good medicine. Similarly, there may be a belief that accessing the health care system is acting "white." They noted that, while the American health system has done little to engage these beliefs, the tobacco industry has gone to lengths to use Native American cultural attitudes to its advantage. For example, a cigarette that is called simply "Spirit" is advertised almost exclusively to Native American audiences.

Table 4.4: Perceived Barriers to Care for Elders of Color

Perceived Barrier to Service Access and Utilization	Number of programs
Culture and attitudes	19
Poverty	15
Lack of transportation	13
Language	12
Mistrust of medical system	12
Lack of insurance (non-aged population)	11
Lack of knowledge about cancer	10
Practitioner attitudes	9
Co-pays/deductibles/coverage	7
Intimidating system/bureaucracy	7
Service availability/distance	7
Fear of cancer	6
Lack of awareness about Medicare	3
Neighborhood violence	2

Poverty and Its Social Consequences: Poverty and unemployment constituted a separate, formidable barrier identified by more than half (15) of our 25 sites. Cancer education and screening were not high on the list of priorities for people concerned about food, shelter, and finding work. Following through on cancer detection and treatment or dealing with time-consuming medical recommendations may be particularly demanding for individuals in lower status occupations, holding multiple jobs, or taking multi-generational family responsibilities.

Lack of Transportation: Inability to get to health services due to lack of transportation posed another common barrier. Particularly in low-income communities, individuals in the target population often did not have cars, access to public transportation, or money for cab fare to get themselves to programs and services. The **Seattle's Senior Wellness Program**, moreover, found that even though its programs were within walking distance of elders' homes, there was still a transportation problem. Elders were not keen on walking in their neighborhoods, where they feared being shot or mugged.

Linguistic and Cultural Translation of Materials: Language played an important role in service access in many communities. Not being able to communicate with providers, read program materials or benefit/insurance forms, or understand educational sessions kept many in the R/E populations from participating in programs and getting effective care. In just one

instance of this problem, **APIAHF's Asian American and Pacific Islander Tobacco Education Network (APITEN)** offered striking evidence of this barrier to service access. They found that only six programs in all of California – a strikingly small number given the size of the state and the proportion of AAPI residents in its population – tailor their smoking cessation programs to AAPI groups, for example, by offering program sessions or materials in AAPI languages. Moreover, of the programs that did offer such services, including those of the American Cancer Society, APITEN judged them to be poorly matched culturally to the needs of the community or simply inaccessible to the average community member.

Mistrust of Medical System: Deep-seated mistrust of the U.S. health care system ran rampant among the R/E communities served by the programs studied and posed a real obstacle to getting target populations to utilize services. The **Chicago REACH 2010** program as well as the **Deep South Program** found that for the African-American community served by these programs, the Tuskeegee syphilis experiments, a striking example of the medical system's institutional racism and potential for abuse, still loomed large. In contrast, the program's target Hispanic population mistrusted the medical system for other reasons. Many in the community were undocumented immigrants or family members of undocumented immigrants, who worried that their illegal status would be discovered and reported if they sought medical care. **Elder Voices, Inc.** found that the Native American communities served by their **Public Benefits Counseling Program** shared a deep mistrust of government, the fruit of a history of broken agreements, betrayals, and disruptive federal policies. As a result, the population was reluctant to engage federal and state agencies for health insurance or other benefits. The **Kentucky Homeplace and SKYCAP programs**, encountered this barrier as well, and workers using state cars were supplied with special removable state decals so that recipients of care would not be immediately suspicious of them. Indeed, mistrust produced a barrier to obtaining health and social service for many R/E communities.

Lack of Insurance: Many of the programs also served non-aged and thus non-Medicare populations, and thus found lack of health insurance was a major barrier to seeking care, participating in screening, or follow-up cancer treatment. The **Chicago REACH 2010** reported that inadequate funds existed for cancer treatment for uninsured persons, while the **American Cancer Society Heartland Division's Patient Navigator Program** noted that Latino and Asian immigrants as well as Kansas residents in their metropolitan area had little access to insurance coverage and that this often complicated treatment planning. In addition, several programs serving elders noted the need to assist persons in finding sources of funding to pay for medications, co-payments, or deductibles. Some of these programs also found that elders, due to difficulties in scheduling visits as a public pay patient, had been steered to safety net providers.

Lack of knowledge about cancer: Target communities had many misconceptions about cancer and cancer screening. For example, **Planned Parenthood's Witness Project of Connecticut** discovered that older African American women are the hardest to convince that they need a mammogram or pap smear because of the widely held belief that if they are not sexually active, then they do not need these tests. The project staff also found that many older African American women do not do mammography screening because they worried that if a suspicious mass were found and a biopsy performed, then the cancer would spread once the body was "cut open".

Practitioner Attitudes: Programs identified practitioner attitudes as another barrier to health service utilization and access. In 9 of our site visits, this problem was discussed, with some of the programs claiming that community members had experienced institutional racism: health care providers did not offer cancer-related services to community members or offered different (i.e. substandard) services or treatment. Staff at the **Planned Parenthood's Witness Project of Connecticut** explained that in some instances doctors do not really encourage older African American women to utilize cancer screening tests, such as mammograms and pap tests.

Intimidating and Bureaucratic Care Systems: The U.S. health care system is difficult to navigate under the best of circumstances. **Elder Voices** staff and the other state-certified outreach workers assisting in the **PBC Program** ascertained that many Indian elders were eligible for the Medicare Savings Program, a state buy-in program that would pay for Medicare Part A, Part B, or both. Despite this auspicious start to filing for benefits, the bureaucratic nature of the system posed a formidable barrier to accessing benefits. The local office of the Social Security Administration (SSA), to which, as the lead agency, all processed eligibility screenings were to be sent, was concerned only with Social Security eligibility and did not act to pursue Medicare or Medicaid eligibility. Additionally, Elder Indians counseled by Elder Voices to apply for benefits under state-administered Medicaid programs reported that their applications were not processed by state Medicaid workers. It seems that, perhaps due to inadequate training about the eligibility status of Indian elders, the Medicaid workers incorrectly judged the elders ineligible. Adding insult to injury, in some instances the Medicaid workers reportedly treated the Native American clients curtly and inhospitably. These repeated experiences with bureaucratic red-tape and rudeness only served to make the system more intimidating and difficult to navigate for Indian elders. Such problems posed an even greater deterrent to populations struggling with the additional burdens of poverty, racism, language, and lack of knowledge about how to get services.

Difficult Service Availability: Geographic isolation is a factor for many populations in remote or rural areas. Staff at the **Deep South Network for Cancer Control** found that this isolation, coupled with inadequate public or private transportation, creates an obstacle for many in reaching necessary health care services. To obtain services some patients in that area required a 2-hour drive to the nearest hospital.

Fear of Cancer: **Oklahoma City Witness Project** representatives told us that many African Americans equated cancer with a death sentence and, therefore, preferred not to know about their own risk of cancer. Such fears were shared by many of the different R/E populations targeted by interventions. These fears, moreover, were not unwarranted given people's lack of insurance and other barriers to receiving necessary services and effective treatment and care.

Intervention Goals

Our analysis of the data collected from the sites yielded four major categories to classify the goals of the program interventions. The areas in which programs sought to address R/E cancer disparities are health risk management, screening education, screening adherence management, or treatment management, with programs often pursuing more than one of these goals at a time. Through these goals, programs attempted to address and overcome the barriers that they had

identified and that were described above. Examples of program activities related to each of these goals are presented below.

1. **Health Risk Management: Senior Services of Seattle King County's Senior Wellness Program (SWP)** and **Lahey Clinic's Wellness for Seniors Program** both engage seniors in health promotion and chronic disease management activities. Lahey's program is a replication of Seattle's successful model; both programs seek to engage senior managed care members and others in ongoing, individualized health promoting programs and group activities.

    In contrast to these two senior wellness programs**, Asian and Pacific Islander American Health Forum (APIAHF)** offers a different type of health risk management through its **Asian American and Pacific Islander National Cancer Survivors Network (APICSN)**. The network is comprised of about 40 cancer survivors, their family members, health care providers, researchers, and community members concerned about the issues of cancer in the Asian-American and Pacific-Islander communities. The network helps cancer survivors from the AAPI community manage their post-treatment issues and continuing risk by linking them with other survivors and referrals to services and providers. **APIAHF** is a particularly interesting case, since it is the only one in our study sample that dealt specifically with cancer survivors' needs and issues; it seeks to break the isolation that many cancer survivors feel. In a different vein, **Elder Voices** has worked with Native American elders at sites throughout New Mexico in establishing appropriate public or private supplements to Medicare insurance, coordinating benefits among public payers, and access to usual care.

2. **Screening Education:** In the **Connecticut Witness Project** and the **Oklahoma City Witness Project**, both part of a CDC replication initiative, community health advisors and Witness Role Models—women survivors of breast and cervical cancer—performed out-reach in African-American churches and community facilities such as senior centers. The teams sought to teach African-American women about breast and cervical cancer and to promote screening. Using a similar model, **Chicago REACH 2010** trained volunteers to provide breast and cervical cancer awareness education and information resources in their respective communities. All three of these programs strive to teach women about breast and cervical cancer, self-exams, and the importance of screening.

3. **Screening Adherence and Detection Management:** Some programs focused primarily on screening adherence. In the Texas Cancer Council's **African American Breast Cancer Outreach Program,** and in programs centered at community health centers, such as the Seattle Indian Health Board's **Breast and Cervical Health** program, efforts are made to insure that women can follow-through on a desire to participate in cancer screening by assisting in scheduling appointments and addressing coverage, co-payment, or other insurance barriers. In addition, some screening adherence and detection management efforts, such as **Breast Examination Center of Harlem** and the **MGH/Chelsea Health Center Avon Breast Cancer Project** also include setting up systems to contact persons who had missed appointments and working with persons with suspicious screening findings to schedule and attend follow-up primary care and specialty appointments. These contact systems help ensure that the patient follows through on these next step services, by contacting participants to schedule repeat screenings at appropriate intervals and facilitate

completion of the multiple steps involved in cancer detection and prevention through treatment of pre-cancerous conditions. Many of these programs also help women address other issues that might prevent them from following up suspicious screens or making it to their appointments, for example, by providing encouragement from a community health worker or case manager or by arranging transportation to appointments.

4. **Treatment Management:** The **American Cancer Society Heartland Division's Patient Navigator Program** at the Truman Medical Center in Kansas City, MO., and the hospital-based case management component of the **Boston City Health Commission REACH 2010** project and the **North General Hospital/Breast Examination Center of Harlem** are examples of treatment management programs. These initiatives work with patients from the time of referral based on a suspicious screening finding or at the time of initial confirmation of a cancer diagnosis, to assist in overcoming practical barriers to service use (transportation, grandchild care), benefits coordination, and scheduling services in a timely manner. They seek to avoid missed or rescheduled appointments and work to overcome problems in treatment completion. In addition, treatment management programs provided counseling, cultural and linguistic translation, and cancer education throughout the treatment process to encourage and support patients in advocating for their own care.

Intervention Process and Cultural Tailoring

There is overwhelming consensus among the program sites about the systemic problems contributing to R/E disparities in getting and using services and the need for interventions to combat these problems. In particular, the majority of the sites we visited seemed to have designed their interventions in response to a troubling complex of obstacles. The combination included a lack of knowledge about cancer on the part of community members, cultural ideas and myths about health service use and cancer, and a deep-seated mistrust of the medical system.

The sites reported a shared learning that established medical care provider organizations and practitioners who were not deeply engaged with—and committed to—communities of color did not typically approach elders from these communities with the same degree of enthusiastic attention and care that was offered to more affluent white health care consumers. As a result, the programs we studied were consistently convinced of the need to provide communities with a responsive, approachable, trustworthy human interface to the healthcare system. The vast majority of programs perceived that staffing the intervention with members of the community represented the most effective option for overcoming barriers created by culture and attitudes, mistrust, and lack of information. In response to this set of barriers, which programs felt contributed greatly to R/E disparities in cancer, a full 19 of the 25 programs chose to design their programs such that people in and of the community provide services and out-reach. Of the 25 sites we visited, 19 involved community members as, either volunteer or paid, community health workers, while the remaining site, among others, utilized health care professionals from the target population (see Table 4.5).

The theory of intervention driving these programs stated that community members know their communities best. Individuals from the target communities can easily identify community needs and resources. They are able meaningfully to engage the myths, symbols, and language of

their communities to disseminate information, dispel misconceptions, and influence behavior. Finally, they provide programs with much-needed credibility and access to community members.

In addition, 16 of the programs used another response to the compounded problems of culture, lack of knowledge, and mistrust. They held group events, bringing community members together to discuss cancer or other health issues or to undergo screening. Following a similar logic that the best way to reach the community was to go to the community, 14 of the programs based their activities in churches or other central community settings that inspired trust and were easily accessible to community members. The coordinator of the **Seattle Indian Health Board's Breast and Cervical Cancer Program**, for example, makes it a point to conduct out-reach campaigns at pow-wows, significant community events that brings together a large crowd from the geographically dispersed Native American community.

While there was widespread agreement among programs about the nature of the problems and the need to partner with communities to overcome them, there were divergences in program's prioritization of different barriers. For example, screening education programs and health risk management programs tend to address attitudinal barriers, such as lack of knowledge or personal motivation, that prevent people from managing their health or seeking services. In contrast, screening adherence and treatment management programs often try to tackle systemic barriers, such as lack of insurance or transportation to medical appointments, that prevent people from accessing services. In shorthand, we might say that some programs emphasized changing the individual while others emphasized changing the system. This difference in emphasis led programs to pursue different methods for culturally tailoring their programs for their target populations and for engaging community members and community health workers in these endeavors.

Table 4.5: Case Study Sites and Cultural Tailoring Methods

Methods of Culturally Tailoring Programs	Number of programs
People of community and in community providing services	20
Holds group events	18
Use of community/church settings	14
Provides/ arranges transportation	11
Meaningful ongoing relationship of worker with person	8
Provides benefits counseling	8
Address disconnect with medical establishment	7
Focus on health promotion, not disease prevention	5
Uses IT	5
Provides financial assistance	4
Reframing/negotiating meaning of health care	3
Use of ethnic media	3
Engaging the family	2
Practitioner training	2

Increasing Understanding and Motivation to Seek Services: Many of the strategies described by sites as cultural tailoring reflected a focus on increasing awareness and understanding of cancer, cancer detection, and cancer care for persons from communities of color. A second focus was on motivating individuals to advocate for themselves and seek all those health care services that they needed.

One strategy that programs used to increase awareness and motivation required a careful effort to present information about cancer in a non-threatening way that participants would understand – for example, by their peers, in their own language, and in a familiar setting or medium. A number of examples are provided below.

For example, the **Clinica Tepeyac** is located in a building next to the local church, uses staff from the community, and conducts all business in Spanish. Moreover, its **Reach and Teach** project trains Promotoras de Salud, bilingual women selected from the community and trained in out-reach and health prevention, to perform out-reach to women in the community by distributing health information, providing one-on-one education, and holding health groups. Similarly, **AAPCHO's Care Program** recruited community out-reach workers who came from the same cultural background and also spoke the language of the population served by their respective community health centers, and the six intervention sites all used the ethnic media to educate the community. In another example, the **Seattle Wellness Program** committed significant resources to translate a letter about its diabetes Health Education Promotion program for several communities in an effort to make the invitation to the program both linguistically accessible and more appealing.

The **Connecticut and Oklahoma City Witness Programs** provide an example of using participants' peers to talk about cancer in a socially appropriate and acceptable way. These programs ask community volunteers to speak in their own words to groups of women about their experiences with breast and cervical cancer. Not only do the African-American women who become Witness Role Models address groups of their peers in a non-intimidating and engaging way, but the notion of "witnessing" draws upon a familiar spiritual tradition appropriate and familiar to the church settings in which many of the education sessions occur.

In another example, the issue of providing culturally appropriate program material was tackled in a different manner by the **Baltimore Cancer Coalition**. Staff from one of the program's community sites, the Hispanic Apostolate, found the breast and cervical cancer educational materials provided in Spanish from the National Cancer Institute were not adequately tailored to the population they served. Therefore, the staff held focus groups to develop culturally appropriate educational materials for breast cancer awareness. Fotonovelas ("paper soaps") are unique to the Latino population and were selected to model educational materials. The results were that both written material and an educational tape were developed that was more realistic for the population. For example, the woman in the fotonovela asks her husband for permission to go for the screening. Similarly, the **Baltimore Cancer Coalition's** sites targeting African Americans had to be careful about cultural translation. Health educators expressed the importance in this community of promoting services as "no cost" rather than as "free," a term that connotes lack of quality and charity care.

Another strategy that programs used to increase individuals' understanding and motivation involved presenting information in a way that participants might find personally relevant. Some of the programs made an effort to provide culture-specific examples or scenarios in discussions of health risk and treatment. Some others were careful to emphasize health promotion rather than disease prevention. Promoting and improving health made for a much more acceptable topic of discussion than the gloomy topics of disease and illness. Moreover, health promotion presented a much more immediate and compelling goal than prevention of diseases that participants may not yet or may never have.

The **Dana Farber Cancer Institute's Cancer Prevention through Small Business Project**, for example, sought to generate cultural relevance and engagement for participants. The program offered a different activity addressing a particular health promotion topic (e.g. nutrition, physical activity, smoking cessation) to blue-collar and clerical employees at several small manufacturing companies. This out-reach effort involved using detailed information and hands-on activities to appraise workers' health risks, to provide education about health promotion and prevention, and to encourage participants to change their behaviors. The program uses real-life examples to emphasize simple ways in which employees can alter their lifestyle and improve their health. It customized its health messages for each of the different ethnic groups involved in the intervention – Hispanic, Cape Verdean, Brazilian, and Asian – by developing relevant activities and materials that consider the employee's social context. The nutrition component, for instance, uses examples of healthy and unhealthy choices from ethnic diets. Additionally, the program asked bilingual and bicultural employees of participating worksites to translate at the different activity sessions.

Other programs emphasized health and well-being, rather than avoidance of illness, in an effort to engage participants and increase motivation. All of the sites targeted to AI/AN, Asian, and Latino groups emphasized the importance of adopting this kind of positive message, and related learnings about the psychological and cultural barriers created by disease prevention messages. For example, the six **Association of Asian Pacific Community Health Organizations (AAPCHO) CARE** realized that women in the community might be unwilling to come to events specifically focused on breast cancer screening. Participating health centers reported that in order to share information about breast cancer screening in a culturally tolerable fashion that would draw and engage participants, they needed to held health promotion and wellness events to which they invited both women and men.

Finally, in attempting to increase personal motivation, some programs worked hard to cultivate a personal connection between participants and program workers. Developing meaningful, ongoing relationships between program staff and participants constituted an important method for overcoming motivational barriers.

For example, **Grace Hill Community Centers' Assistance and Self-Help to End Smoking (ASHES) and MAP programs** both relied upon a "neighbors helping neighbors" approach. Neighbors, working as coaches in the Grace Hill Community Centers programs encouraged their neighbors to quit smoking in the ASHES program or, in MAP, to have mammograms and pap smears. In the **Elder Voices** project, staff made multiple visits to each pueblo and AI community, held public forums and individual meetings, and extended their

process of gaining trust and familiarity with elders over a month or more before actually working with an individual to apply for additional insurance coverage or work to resolve a benefits coordination problem. In the **Native Sisters** program, community health workers are encouraged to build on existing relationships and take the time to become familiar and trusted by elders in the communities they serve.

In the **American Cancer Society's Heartland Division Patient Navigator Program**, developing relationships with patients allowed nurses to understand patients' needs and activate services to help them get care. Patients are typically referred to the program if they miss appointments, need transportation assistance, have inadequate informal support, have co-morbid psychiatric or behavioral health diagnoses, or face other barriers to service use. In the Patient Navigator Program, navigator nurses were not necessarily members of the communities served. The nurses emphasized the highly diverse clinical roles they play in minimizing the consequences of cultural disconnects and acts of disrespect. The program uses a case-by-case approach, facilitated by the ongoing relationships that nurses have with patients in the program. One of the nurses described an incident in which one of her patients, a Latino man, refused cancer treatment. Having met on several occasions with the man and his family, the nurse knew that the patient thought that undergoing treatment was a sign of weakness. Even though, in this case, the nurse was also from the Latino community, she recognized that, as a woman, she did not have the cultural power to reframe this man's view of what treatment meant. Although she could speak to the patient in Spanish, she deliberately requested that the male translator come to assist her. She asked the translator to tell the patient that refusing treatment was a sign of weakness; without treatment, the man would not be able to be strong and support his family. Within minutes, the patient requested that treatment begin.

Overcoming Systemic Barriers to Accessing Care and Receiving Adequate Attention: Other programs emphasized assisting individuals in overcoming systemic barriers to use of the health care system or in solving other life problems that may interfere with cancer prevention, screening, and treatment participation. These programs emphasized the importance of addressing issues such as transportation, distance or scheduling problems, financial assistance, and cultural/linguistic translation of materials. Some examples of each of these strategies are presented below.

Not being able to get to programs and services due to lack of transportation represented a barrier for the communities served by 13 of the programs.

In response, 11 programs began providing transportation. Community Health Advisors (CHAs) in the **Deep South Network Community Advisors Program** provide information about rideshares with others in their community and provide information about private transportation services. Additionally, the CHAs travel to rural areas to provide out-reach to residents of more remote and isolated communities. Similarly, the **Grace Hill Centers** deploy a "Health to Go Van" to the "fringes" of its catchment area. Rather than transporting community members to receive services, the van brings CHAs to underserved areas to teach health promotion and provide assistance with Medicaid eligibility sign-ups. The health centers also provide transportation, through bus and taxi vouchers and shuttles, to patients with no other means of transportation to medical appointments.

Having to travel great distances to access service due to limited service availability also creates transportation issues. The **Seattle Indian Health Board** recognizes that the Native American and Alaskan Native population that it serves are extremely mobile and may need to travel great distances for service. Its **Breast and Cervical Cancer Program's** medical assistant, who tracks all patients' mammogram/gyn appointments and makes sure they schedule their next exam, therefore, makes a concerted effort to schedule all of a patient's medical appointment on the same day of the month that the mammography machine is available. The **Indian Health Service**, as another example, designed its **Community Health Representative Program** in response to the lack of health care services in remote Alaskan villages. Instead of bringing community members to a service, it established a service near them.

Several of the programs employed translation services or sought to provide service in the population's native language in an effort to insure that participants received appropriate care. In **The Avon Breast Cancer Project**, Latina patients requiring diagnostic work-ups and treatment are aided by a Spanish-speaking Breast Health Care Coordinator from the Chelsea Health Care Center in getting referrals and making appointments for care at the **Massachusetts General Hospital**. Since their care providers at the hospital may not be bilingual, the program holds a dedicated weekly breast clinic during which a full-time Spanish interpreter is available to help surgical residents communicate with their patients and address their patients' concerns.

Attitudes of providers presented another systemic obstacle that programs felt it was necessary to overcome in order to improve access to appropriate health services and care. Two of the interventions, **AAPCHO's CARE Program and Boston REACH 2010**, directly tackled the problem of practitioner attitudes by providing cultural-sensitivity training to providers. In addition, the **Seattle Indian Health Board** implemented a family practice residency program to train Native American and Alaskan Native physicians and those committed to working with the Native American and Native Alaskan communities.

Individuals in the target populations often lacked insurance or struggled with expenses related to co-payments, deductibles, or lack of coverage for select services. Closely related to lack of insurance or an inability to pay for services were the systemic problems created by poverty and unemployment. Several programs responded to their participants' financial difficulties: Some programs used strategies that addressed participants' ability to pay for services; others assisted participants in obtaining public benefits; and still others helped participants address immediate needs for food and shelter.

The **Baltimore Cancer Coalition's** prostate cancer project and the **Clinica Tepeyac**, for example, both provided services to needy members of their communities at low or no cost. **Grace Hill Centers**, in response to difficulty recruiting volunteers from the low-income communities it serves, implemented the MORE $ program through which health center clients trade their volunteer time for services in the health center. A major element of the **North General Hospital Patient Navigator Program** is up front attention to the financial obstacles that might prevent access to services. Upon a patient's arrival at the cancer center, a "first encounter" staff person conducts a preliminary financial interview, completes an intake form, and arranges for the hospital's financial office to complete financial assessment and insurance applications. The first encounter staff also connects patients to navigators, who are particularly

important for patients who face complicated financial barriers to the diagnosis and care process, including coverage for drugs or lost income as a result of time spent getting care. Although not finance experts, navigators have developed personal connections with people in the hospital and elsewhere who can address these needs. In fact, navigators' ability to help patients solve problems related financial, in addition to clinical, aspects of care has emerged as a competitive advantage for North General Hospital in attracting African-American and Latino patients.

Elder Voices, Inc.'s Public Benefits Program reached out to Native American elders, assisting them in identifying and applying for federal and state public benefits for which they may be eligible. Staff provides several education sessions over a period of months and stay afterward to provide one-on-one counseling about eligibility for public benefits. For the participants who request assistance applying for benefits, the same staff members return to the next session with the necessary paperwork almost completely filled out. This site is particularly important in highlighting the special challenges by AI/AN elders in coordinating benefits between the Indian Health Service, tribal health programs, Medicare and state Medicaid programs. The **Asian and Pacific Islander American Health Forum**, the **AAPCHO CARE** project, and the **Juntos Contra el Cáncer** promotora program in Arizona all also emphasize the difficulties in understanding public and private health insurance and coordinating benefits faced by members of Latino, Asian and NHOPI communities. All three projects also discussed the complex benefits coordination challenges they address for participants.

The **University of Kentucky Center for Rural Health's Kentucky Homeplace and SKYCAP programs** recognized that client issues among the rural Appalachian community were complex and reached beyond the health system, and they help clients access social and economic as well as medical services. Similarly, the staff of the **Boston Public Health Commission's Boston REACH 2010 Program** found that most clients need help with housing and economic security let alone health or cancer-related issues. In addition to being cancer experts, case managers have become housing experts, adept at helping people get onto public-assistance housing waiting lists and into shelters or other interim living conditions.

Operations: Out-reach, In-reach, and Training

Differences in emphasis on addressing motivation and knowledge, or addressing systemic obstacles to receiving services were expressed, not just in terms of the barriers addressed by programs, but in the operational approaches programs took in trying to improve R/E disparities. Although composed of a variety of different types of organizations, community partners, target populations, and target cancers, the interventions in our sample may be characterized as using three types of approaches to address R/E disparities: out-reach, in-reach, and training.

Out-reach: The majority of the sites focused their operations on out-reach---identifying and recruiting members of the community who might profit from cancer prevention and control interventions. Out-reach represented a difficult undertaking for the programs. Out-reach workers sometimes had difficulty attracting community members from the target populations to attend educational activities and events. For example, **Chicago REACH 2010** held events in Black churches in the hope of attracting low-income African-American women to its programs. Recognizing that pastors hold sway in the community and can be persuasive out-reach workers,

the program asked pastors in participating churches to incorporate health messages and announce health seminars during sermons. Despite this culturally savvy approach, using the churches to perform out-reach to the community did not provide the anticipated access to the targeted low-income African-American population. Although the churches were in low-income inner city neighborhoods, their members, many of whom had moved out of the neighborhood but retained ties to the church, commuted from higher income suburbs. **AAPCHO's CARE Program** staff quickly realized that a one-size-fits-all approach to out-reach in the Asian community would not achieve desired results. They found that different populations were more or less receptive to different methods of out-reach. For example, in the Los Angeles Thai community, out-reach workers were most successful when they approached people at places of business and were careful to avoid out-reach efforts during Thai holidays, when discussion of cancer and disease would be considered bad luck. In contrast, Samoan women responded to church-based out-reach, while for Filipina women, Health Education Parties became the out-reach strategy of choice. For Chinese women, these group event approaches were off-putting, and out-reach workers had greater success when they took a one-on-one approach.

Most programs using this model reported that out-reach workers spent significant time building upon existing community relationships to engage neighbors in events or activities, rather than providing education or assistance to community members. Many of the out-reach-focused programs expressed frustration that they did not have the resources or necessary infrastructure to perform activities aimed at improving screening adherence. While one of the common goals of these screening education programs was to increase the number of individuals screened for cancer, many of the programs had no way of tracking program participants to know how many actually took this next step. Even when programs did have data on the number of individuals seeking screening as a result of out-reach activities, the results could be disappointing. For example, **The Deep South Network for Cancer Control's Community Health Advisor Program** trains volunteers as Community Health Advisor Research Partners (CHA-RPs) to provide cancer awareness messages and resources to their communities. Although in the second year of operation, CHA-RPs made approximately 3,189 contacts with women and men with the cancer prevention message, only 11% of these contacts, 365, resulted in screening referrals, and fewer actually received screening.

Compounding this problem, programs recognized that even if they sufficiently motivate people to want to get screened, program participants may lack the necessary resources to get screened. For example, in our site visit, the **Chicago REACH 2010** program staff complained that the program only had funds for out-reach and education, but not for related services. They felt that this situation put them in the uncomfortable position of educating people about their cancer risk and not offering any services or care to help them manage either their risk or disease.

In-reach: While some of the out-reach programs struggled with the problem of attracting participants and then having nowhere to send them, in-reach-only programs could face the opposite problem. The **American Cancer Society Heartland Division's Patient Navigator Program** intends to reduce the time frame between an initial suspicion of cancer (based on screening or referrals) and initiation of treatment or other case resolution, increasing adherence to recommended courses of treatment and follow-up, and improving quality of care for cancer patients. The program addressed potential barriers to screening and treatment adherence by

providing patient education and support, assistance with scheduling and coordination and services, referrals for support services, and assistance with transportation. With such a wide range of services, the Patient Navigator Program supplemented existing medical management and social services and has the capacity to become a social asset to those patients with the fewest resources to assist them. However, referrals from the affiliated community health center were irregular, and without out-reach to the community, the Patient Navigator Program staff felt that the program failed to reach a large number of people who could benefit from its services. Similarly, without an out-reach component, the **Boston Public Health Commission's Boston REACH 2010 Case Management Component** has had trouble recruiting participants in its in-reach-focused case management program and is operating well below capacity. The program had no specific marketing or out-reach for its case management component and had not established objectives or procedures to ensure that all persons non-adherent on screening and all persons with positive screenings are offered care management assistance. While the program hoped to recruit 600 women of African descent for its case management program, only 78 had been recruited at the time of our site visit.

Combining Out-reach and In-reach: Programs that combined out-reach with in-reach activities seemed successfully to overcome the difficulties faced by out-reach-only and in-reach-only programs. Combination programs managed not only to recruit participants from the community, but also to bring them into the health system for screening and, in some cases, diagnosis and treatment. For example, the **Baltimore Cancer Coalition's Baltimore City Cancer Plan Prostate Cancer Project** involved risk assessment, community-based screening and education, and referrals for diagnostic care and treatment services for those deemed at risk. The program consciously constructed its budget to accommodate expenses for screening, further work-up due to a positive screen, and treatment for uninsured participants with cancer diagnoses. In this way, the program avoided the problem that some of the other sites faced of educating people about risk but being unable to assist them further.

Combination programs that used management information systems (MIS) also overcame the problem of not being able to track individuals encouraged by the program's out-reach efforts to undergo cancer screening. Three of our study sites utilized MIS technology. The University of Kentucky Center for Rural Health's **Kentucky Homeplace** hires and trains Family Health Care Advisors to provide community-based education, advocacy, referral, and health system navigation services. The Family Health Care Advisors used pen-based computing tablets to collect data about each encounter with clients in the program. The system tracks demographic information about program participants as well as information about their needs, clinical diagnoses, and treatment. This information helps the program understand who is being served by the program, and it helps the Family Health Care Advisors to keep updated on their clients' situation and needs. **Grace Hill Centers** also used MIS in its Breast and Cervical Cancer Project, which it calls **MAP** (Mammography and Pap). Complementing the out-reach efforts of neighborhood coaches and education sessions by staff from the clinics, the clinics followed patients with a computerized tracking system so that, when necessary, program staff can provide support as well as assistance with scheduling, follow-up reminders, and transportation. In **Health Choice Network's Healthy Body, Healthy Soul -- Jessie Trice Cancer Prevention Project (JTCPP)**, as part of its out-reach efforts, Lay Health Educators (LHE) screen community members for lung cancer risk. Those at high-risk for lung cancer (i.e., family history, cigarette

smoking pack history) and who are willing to be further screened clinically, are referred to a primary care physician and case manager at the community health center, who may then send them to a collaborating hospital to receive a Spiral CT scan. HCN has a sophisticated MIS. The LHE sets up the appointment for clinical screening and enters it into the computer system, making it easy for the case manager to remind patients about upcoming appointments, to keep track of whether patients kept their appointments, and to ask the LHE to follow-up with patients who did not show. Since physicians also enter data about the patient's visit into the same computer system, case managers know the patient's test results and are better able to coordinate any care the patient might subsequently require. The **Breast Examination Center of Harlem's Patient Navigator Program** goes even further in its use of MIS to link inreach and outreach activities and promote ongoing screening adherence. Through outreach, volunteers and cancer survivors/support groups encourage individuals to go for an initial screening. Using its extensive patient navigation database, the program then endeavors to get former screening participants to return on a biannual basis. The medical records department generates a letter in anticipation of the need for screening, and, if an appointment is not scheduled, the client may receive a second or third letter, followed by a phone call from a volunteer and perhaps a call from a health educator.

Like **MAP** and **JTCPP**, many of the combination programs complemented out-reach efforts with case management programs in community health centers. These programs succeeded in assisting program participants from out-reach activities through screening and even diagnosis. However, these programs often seemed to have difficulty "passing the baton" when patients needed to move from the community health center setting to the hospital for treatment, notable exceptions being the **Baltimore Cancer Coalition's** prostate cancer project and the **University of Kentucky Center for Rural Health's Kentucky Homeplace and SKYCAP** programs and the **Breast Examination Center of Harlem**. During our observations, staff members sometimes expressed their feelings that they "were losing the patient to the hospital." Indeed, the community heath center programs, even those that utilized MIS, did not have the capability to track patients who moved to another part of the system and did not engage in follow-up with cancer survivors. Such programs successfully addressed issues of screening education and screening adherence, but they did not address disparities at the treatment and follow-up stages.

Training: Finally, our site visits identified one other type of intervention, namely those aimed at training organizations or individuals to perform interventions in their communities. Five of our case study programs emphasized training as its main focus. The **AAPCHO's CARE Program** is a breast and cervical cancer prevention program aimed at building infrastructure and organizational capacity in its six partner centers. The **CARE Program** trained staff at the six centers to enhance their existing resources and programs in the areas of funding, organizational support, coalition/partnership building, assessment of community needs, and community out-reach and in-reach. Similarly, **APIAHF's Asian American and Pacific Islander Tobacco Education Network** works with multicultural organizations, mainstream tobacco control programs, and community-based organizations to address tobacco issues in the community and to provide capacity building technical assistance and training. The intervention reflects the view that improving primary prevention and cancer services for the AAPI communities requires

focused attention on policy change and the creation of infrastructure to support policy advocacy. Alaska's CHA/CHP model is a prime example of this kind of program.

A training program of a different type, the **Indian Health Service Community Health Representative Program** trains American Indians and Native Alaskans as healthcare paraprofessionals to be the principal providers of primary care in their village. The **University of Colorado's Native American Women's Wellness Through Awareness (NAWWA) Program** offers a comprehensive and intensive academic-institution-based training for community health workers, called "native sisters," to promote mammogram adherence and general wellness in multiple health settings. The **National Center for Farmworkers Health** also provides a program, **Cultivando la salud/ Cultivating Your Health** for training community health workers, in this case called "promotoras." The emphasis of this program, however, is not only on training community health workers, but on "training the trainers." The program provides technical assistance and materials to migrant and community health centers. In participating centers, an Out-reach Director/Lay Health Worker Supervisor is trained as a trainer, who then recruits farmworker women and trains them to conduct door-to-door out-reach, small-group educational sessions, and individual assistance with screening adherence.

All of the training programs we visited, with their rigorous and demanding curricula, demonstrated the ability to export and replicate their program at multiple sites. While in most of these examples the training may have successfully developed the abilities of community health workers to provide out-reach, limited funding or project scope could prevent programs from evaluating or supporting the subsequent community work of program participants. (The **Indian Health Service Community Health Representative Program** provided a clear exception. Not only did the program place graduates in the community, it provided for their professional support from physicians in the Alaskan Area Native Health Service Units and native corporation-administered hospitals.)

<u>Community Health Worker/ Promotora de Salud</u>

Among the programs we studied, community health workers predominated as a key strategy for cultural tailoring of interventions and, often, as the principle personnel responsible for program operation. 19 of the 25 programs we studied utilized community health workers. The community health worker model has great potential to make the healthcare system more accessible to members of traditionally underserved R/E populations. However, programs have encountered a number of obstacles related to this model. Given the central importance of the community health worker role to so many of the interventions we studied, this section describes some of the lessons learned about developing effective community health worker roles.

Definition of a Community Health Worker (CHW). A number of groups are seeking to clarify the definitions and roles of CHWs. The National Rural Health Association has indicated that a CHW is a public health professional who promotes full and equal access to necessary health and social services by applying his or her unique understanding of the experiences, language and culture of the communities he or she services. This group identifies a worker such as this to be essential for the provision of "quality health promotion and disease prevention information" as well as to provide the critical link to existing health care services and facilities.

The CHW is a member and resident of a community who reaches out, educates, assists and connects individuals and families to the health delivery system. A recent CDC initiative has identified up to 60 different kinds of names for these workers and also concludes they are most effective when local and a resident of the community being served. Some title examples are: community health advisor/educator, lay health advisor/educator, outreach worker/educator, promotora, family health advisor, peer counselor, family support network, among others.

While latest figures are not available, CDC reported in 1998 that there were upwards of 600 programs nation-wide using more than 12,500 CHWs. These CHWs bring to the job a unique knowledge and understanding of the culture and the health issues, needs and challenges of that community. They also serve as a natural link between community members and the health delivery system and its providers. The role and responsibilities of the CHWs vary enormously depending on the needs of the community and the program goals. For example, some of the roles of the CHW include outreach worker, educator, advocate, translator/interpreter, community organizer, counselor and cultural mediator. Among the various responsibilities, CHWs may assess the individual's needs, coordinate care and case management, educate individual/family about health promotion and disease prevention, and educate them about access to care and eligibility for benefits.

Despite the numerous programs using the CHW model, there is no rigorous national evaluation of such programs. This is mostly due to the fact that many of these programs lack funding, resources and/or expertise to conduct an evaluation of the program. In addition, the mission of many programs focus on the individuals who need the help from the CHW, therefore, efforts to implement an evaluation process are often seen as taking time and resources away from this focus.

Traditional funding streams for health care are not designed to compensate either for this kind of worker, nor for the services they deliver. This lack of empirical evidence on program outcomes and cost-effectiveness creates problems of funding. A lack of standardization and evaluation creates a barrier to sustainability, as funders seek evidence of improved health outcomes, reduced costs, or both.
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CHW Training and Certification. Training and certification of CHWs constitute another important issue in developing, funding and sustaining these programs. Factors affecting the great diversity and variety of roles and responsibilities also effect the training and certification process of CHWs. Consequently, there is a great variation in the training these workers receive across programs. Some CHWs only receive a few hours of training, while others receive two to four weeks. This discrepancy in CHW training further hampers funding for the programs.

In recognition of the problem of training, a national movement has been taking place to develop consistent and uniform standards for training and certification of these workers. Most of this effort is spearheaded by the Center for Sustainable Health Outreach, a collaboration between the University of Southern Mississippi and Georgetown University. The mission of the Center, funded by the Health Resources and Services Administration, is to "help support the role of community health workers as an essential component of sustainable community wellness". Through annual conferences, CHW models analysis and networking between different

initiatives, including statewide training and certification programs in Texas and Virginia, CHW advocates are formulating the blueprint for a national training and certification program.

Our case studies provide important information about what content training programs need in order to successfully prepare individuals as effective CHWs. Of the 19 programs employing the community health worker model, 16 had some type of training program for community health workers, and 12 had an established, presumably standardized, curriculum. The training programs, however, tended to focus on imparting information about health, cancer, and screening, but not on motivating people to use services or to change behavior. The programs, therefore, sought to create yet another "cancer expert," whose own pre-existing skill (or lack thereof) in motivating her peers determined program success. Some examples from the program sites illustrate the shortcomings of this type of training.

Funding changes reduced the **Oklahoma City Witness Project's** budget. In response, the program found it necessary to eliminate the Outreach Coordinator position. While the program continued to train volunteers to be community health advisors and Witness Role Models, the program's effectiveness suffered. The volunteers had been trained to lead group sessions, but were not prepared to attract community members to sessions or to perform the critical function of helping people connect to the health system. Similarly, even though **Chicago REACH 2010** provides formal training for volunteers by Access Community Health Network and Northwestern University staff, this training did no seem to prepare community health workers for their role as outreach workers and advocates. Even after training, representatives of the program complained to our research team that there remained wide variation among volunteers in the their involvement with and commitment to the program, their skills in leading out-reach programs, and their level of advocacy activities. These complaints represented more than trivial grumbling, since these variations directly influenced the extent of participation among church members in the health seminars and other activities that the program sponsored. The **Clinica Tepeyac** experience with its **Reach and Teach Program** also bears on this problem. Although the Promotoras de Salud trained by the program are in charge of out-reach, program representatives confided that the promotoras seemed to do little more than advise women in the community to access services at the clinic. It is unclear whether the promotoras are any more effective at motivating women to access the clinic than simple word-of-mouth and advertising about services might be.

In many of the programs that train CHWs, training is provided by medical professionals or academics. The training programs tend to build upon the existing competencies in the healthcare system of providing information about health and disease. Only two of the programs we studied made efforts to teach CHWs about engaging community members and motivating them to adopt new behaviors. Both the **AAPCHO CARE Program**, in its effort to strengthen the organizational capacity of its six participating community centers, and the **National Center for Farmworkers Health,** in its endeavors to train the trainers, utilize a behavioral change theoretical perspective communicated in their curricula. As part of the curriculum for training CHWs, these programs taught workers to assess individuals with respect to their readiness to change and to target their motivational messages and change-oriented questioning to this stage of change.

Upon examination of the CHWs' role and task definitions in the study programs, it seems that curricula that emphasize community organizing and motivation tactics would be appropriate additions.

Integrating the CHW Role into the Health Care System. Programs active in the field universally acknowledge the utility of using CHWs. Our case studies revealed the range of activities that CHWs can perform in the context of cancer control initiatives. In our case study investigations, we repeatedly observed instances where, in keeping with the findings from the Pew report, CHWs provided "bridge" services by reducing barriers to access and increasing motivation to access preventive services.

In addition to highlighting the value of CHWs, our case studies also suggested that CHWs are an underutilized resource. We found that most programs trained CHWs to perform a very narrow scope of service—focusing on screening education without attention to ensuring individual follow-through – specific perhaps to one disease or one population. However, our study also hinted at how much more CHWs could potentially do.

The CHWs could, with very little additional training, do much more than perform screening education. With very little additional training, CHWs could provide assistance with more focused activities such as motivating individuals to manage their current health risks, as they do in the **Grace Hill Community Centers' Assistance and Self-Help to End Smoking (ASHES) and MAP programs**. CHWs may help individuals obtain coverage and benefits, as they do in the **Juntos Contra el Cáncer Prevention Program at the University of Arizona/Mariposa Community Health Center**. CHWs can also be trained to manage screening adherence across a range of cancer screening activities, or to serve as case managers as individuals move through the complex process of cancer diagnosis and treatment. For example, the **Jessie Trice Cancer Prevention Project** illustrates how effective CHWs can be in promoting screening adherence by following up with patients who miss appointments, while the **Kentucky Homeplace and SKYCAP programs** demonstrates the important role that CHWs can play in treatment management as patient navigators.

It is clear that CHWs could assist with each of the goals of health risk management, screening education, screening adherence, and treatment management. What is not clear, however, is whether an individual CHW could or should perform all of these roles. The management of diagnostic and treatment processes may require a different set of skills/knowledge, than health risk management and cancer education, and may require affiliation with different sorts of institutions. While an individual CHW does not need to serve in all of these capacities at once, it is clear that CHWs could be an important resource in meeting program's goals of addressing R/E disparities in cancer.

An important element in the success of the CHW role is its incorporation into the health care system. CHWs' capacity to act as a conduit between the community and the health care system may be severely limited if their role is not integrated into the health care system. For example, traditional health care professionals may not comprehend the role of the CHW nor value it. As a result, practitioners could fail to communicate or cooperate with the CHW in a way that might most benefit community members seeking services.

Integrating CHWs into the healthcare system requires a substantial commitment. For example, it requires leadership and advocacy. CHWs serving in a patient navigator capacity must have the respect and support of critical decision-makers and gatekeepers in order to assist patients in negotiating a complex system. For example in **the Breast Examination Center of Harlem Patient Navigator Program**, clinical staff are required to refer all cases to the patient navigators if the Memorial Sloan-Kettering Cancer Center radiologist finds suspicion of cancer upon review of a mammogram, a nurse practitioner indicates the need for additional tests based on clinical examination or Pap smear findings, or a surgeon or other physician has scheduled further clinical tests. As a result of the hands-on and detail-oriented approach of the program's founder, Dr. Harold Freeman, the patient navigators have been incorporated into the clinical protocol at the Cancer Center. At both **North General Hospital** and **MGH/Chelsea** clinical and administrative leaders receive regular feedback on the outcomes of the navigation program and work personally with navigators and others to maximize its impacts. Such institutionalized support for the CHW role is not always available, however. Nor is it easy to operationalize. As these example also illustrates, developing and enhancing the role of these valuable workers requires a solid infrastructure and organizational capacity for tracking patients and sharing information between the community center and the hospital.

Many of the programs we studied confronted problems in documenting the success of the CHW model primarily because of lack of organizational capacity to support the program and to ensure its sustainability. Therefore, a successful CHW model must take into consideration the commitment from leaders in the medical community as well as infrastructure and capacity building.

Recruitment and Retention of CHWs. The discrepancy between need and supply of CHWs constitutes a significant problem for the success of this model. Many of the programs identified problems with recruitment and retention of CHWs. Since many programs devoted considerable resources and attention to training CHWs, frequent turnover among CHWs had the potential to hurt program effectiveness and was economically costly for programs, which faced the recurrent problem of training and orienting new CHWs. Resource constraints were the primary culprits in this chronic recruitment and retention problem. In many cases, limited funding made programs dependent upon the unpaid labor of volunteers. This model has clear advantages: Structuring and delivering services through volunteers involves low cost to the healthcare system and, to the extent that volunteers belong to program's target populations, provides a convenient method for culturally tailoring services. It is unclear, however, that this volunteer-reliant model is a sustainable or responsible model for addressing R/E disparities in cancer, especially when socioeconomic inequality, namely poverty and unemployment, constitutes a primary barrier to health service access and use. It seems unreasonable and unfair to design programs around the expectation that people who are struggling with basic life needs would or should volunteer their time and effort to address issues that may be low on their lists of priorities.

Hiring CHWs did not seem to solve the recruitment and retention problem for the case study programs. For the most part, programs that hired CHWs did not have the resources to offer them good jobs – jobs with enough hours, competitive pay, and opportunities for

advancement and promotion. The tight budgets and grant-funded nature of many of the programs obstructed their ability to design attractive CHW jobs. For example, while the **National Center for Farmworkers Health's Cultivando la Salud Program** hired promotoras de salud, these CHW positions paid $8 an hour but were only slated to last six months, hardly making them attractive long-term job opportunities.

The Alaska Indian Health Services' Community Health Program is an interesting example. In this program, CHWs needed to have at least a 6th grade education, while other sites required high school graduation. Despite the lower educational requirement, the program offered CHWs a career ladder and opportunity for advancement, something that no other program did, and higher pay than any program in the sample. Nonetheless, many of the Community Health Aides and Community Health Practitioners left the program. Individuals recruited to be CHWs often had few marketable skills or training, but program training often enhanced their position in the labor market. Moreover, the stress of being the only primary health care provider and resource in remote areas was cited as a major reason for leaving the program.

Despite the issues associated with utilizing, training, integrating, and retaining CHWs, this analysis shows that their role is crucial if one is to make a difference in disparities in cancer prevention and health promotion. A model of care in which CHWs are an essential and integral part of any such program of care has a long history of success in developing countries. CHWs can be the bridge between the underserved and the health care system in the U.S. as well. Chapter V reviews our findings from the case studies with respect to economic aspects of CHW programs and details one set of proposals for how they might be included in Medicare efforts to reduce R/E cancer disparities.

Other Findings: Organizational Issues

Many of the programs we studied received funding from private foundations and state and federal agencies. While often generous grants enabled these programs to develop or to continue their important work in the community, it also created many problems for programs.

Our case studies revealed the common problem that just when many intervention programs established themselves in the community, their funding was about to run out. In communities in which mistrust represents a significant barrier to service utilization, repeated here-today-gone-tomorrow experiences may only exacerbate the problem. Intervention programs, moreover, have high start-up costs – the time, money, and effort required to build a new program and establish its trustworthy reputation in the community. In many cases, grant funding sustained intervention programs through the start-up phase, but with no plans to continue interventions, even effective ones, once the grant-cycle ended. In most cases there was no mechanism for ensuring sustainability. Grant agencies presumably moved onto the next interesting project, seeding another start-up or innovative activity, thereby repeating the cycle. Intervention programs that applied for new grants faced the task of reinventing themselves – adopting new activities or a new service focus – to make themselves attractive to new funding streams. Related to the grant cycle issue, many of the programs received funding because of their research focus. In some cases, this commitment to research undermined the program's ability to serve target communities. For example, **Dana Farber Cancer Institute's CPTSBP**

engaged 24 sites in its research project, but only provided educational and health promotion activities in 12 of those workplaces.

D: Conclusion

This chapter described our approach to identifying, collecting data and reporting findings from 25 case studies. The case study sites are based in diverse organizational settings that have often been hampered in achieving and maintaining steady-state operations by the demands of grant funding and research requirements. The programs address R/E cancer disparities by focusing on screening education, screening adherence, health risk management, and treatment management.

The processes used to pursue these goals often reflected variations among sites in what their leaders believed to be their primary learnings about R/E differences in cancer control. Sites that focused on health risk management and screening education were more likely to address attitudinal barriers that prevented R/E community members from seeking or utilizing health care services or engaging in health promotion. In contrast, programs that focused on screening adherence and treatment management were more likely to address the systemic barriers to care for their clients, such as transportation, poverty, and lack of insurance.

In all of the programs that we studied, cultural tailoring was a significant component of the interventions as a strategy for overcoming barriers, whether attitudinal or systemic. Although programs used a variety of mechanisms for cultural tailoring, perhaps the most striking finding from the case studies was the predominance of the community health worker role as the primary mechanism for cultural tailoring. The vast majority of case study sites utilize promotoras/community health workers, but they are diverse with respect to use of volunteer or staff positions for this role, experiences with recruitment and retention of these workers, training and supervision procedures/resource requirements, and relationships of CHWs to the health care team.

Programs appreciated the way CHWs, as members of the community they serve, could act as effective mediators with the health care system. Sites have come to believe that only through the mediating roles played by CHW's as cultural and linguistic translators and as vehicles for improving trust in health care system can broad barriers to care for R/E elders be addressed.

The intervention goals not only influenced the processes and cultural tailoring programs utilized to overcome barriers, but they also influenced program operation. Programs involved in health risk management and screening education tended to focus on outreach, namely educational activities in the community, while programs involved in screening adherence and treatment management tended to focus on inreach, particularly case management or patient navigation. Programs that used a combination of these operational approaches had the greatest success in motivating members of the community to seek services and then in helping them obtain those services. Among combination inreach/outreach programs, MIS seemed to play a key role in ensuring that community members, once motivated, actually received the services they required. Our findings suggest that combination interventions seem to hold the greatest promise

for addressing the disconnect between communities and the health system that programs perceived as playing a key role in R/E disparities in cancer control.

Very few of the programs we studied provided follow-up services to cancer survivors. While such efforts may not serve as the first line of defense in preventing R/E disparities in cancer control, their rarity represents an important missing link. Once individuals have received treatment for cancer, it is still crucial to maintain a link to the health care system in order to manage ongoing cancer risk and to reduce racial ethnic disparities in survival rates.

Through our case studies, we have provided a snapshot of the innovation, creativity, and commitment that programs across the country have used to address different aspects of R/E disparities in cancer control. We relate numerous shortcomings related to limited resources, narrow program focus, the need for greater infrastructure, and issues with the CHW roles that may prevent programs from reaching their full potential. At the same time, these problems are not insurmountable, and they provide important lessons about the elements required for a successful Medicare program that improves cancer prevention, diagnosis, treatment, and follow-up processes, not only for Medicare beneficiaries from R/E communities, but for all Medicare beneficiaries.

Chapter V: Medicare Demonstrations To Reduce Racial/Ethnic Cancer and Health Disparities: Recommended Models and Issues in Assessing Cost-Effectiveness

A: Introduction

This review and others have shown signficant racial/ethnic and socio-economic disparities in cancer prevention, detection, and treatment in the United States. Reducing these disparities is a goal for Medicare policy on moral and political grounds, even though their economic implications for Medicare and other payors remain unknown. In part, this reflects ongoing debates with respect to many of the most prevalent and deadly cancers about the efficacy and cost-effectiveness of current practices. As shown in Chapters II and III, there are some anatomical sites where preventive measures, including lifestyle changes, as well as detection and treatment of pre-cancerous lesions or early stage cancers (most notably, breast, colorectal, cervical, and oral diseases) is both efficacious with respect to quality of life and survival as well as notably less expensive for health care payors than less aggressive approaches. There is sufficient evidence to conclude that ensuring that elders of color participate fully in assertive prevention, detection and treatment strategies makes sense from a health outcomes perspective. For other cancer sites, the science is less developed: the potential for prevention through lifestyle modification or improved treatments on health outcomes and costs are simply not known for elders of color and other groups. In all cases, it is not yet possible to quantify the potential savings or new costs for payers in increasing access and utilization of emerging standard of care prevention, detection, and treatment measures as compared to current practices. This policy making context is made more complex because (1) there is inadequate evidence about the best targets of intervention to reduce racial/ethnic disparities in access to proven practices, and (2) the relative impacts of different strategies to address disparities in each area.

The literature reviews and case studies of emerging, promising interventions suggest that across R/E populations of Medicare beneficiaries, that opportunities exist for improving participation in lifestyles and health risk management, cancer detection, prevention and diagnostic services, and cancer treatment. The literature also highlights the central importance of both culturally-determined beliefs and attitudes as well as practitioner, provider systems, and financing barriers as determinants of less adequate health care access, treatment, and outcomes. Strategies particularly targeted to how elders of color are offered access to-- and are treated within -- the health care system appear to be required to address disparities. The available evidence, however, does not allow clear determinations of the relative importance of primary prevention, detection, and treatment oriented measures in reducing disparities. Further, the available studies ---primarily in the context of breast and cervical cancer screening participation---and experiential and anecdotal evidence from the emerging programs highlight the importance of both:

a) Introducing new workers (such as community health workers, promotoras de salud, patient navigators) with strong understanding and empathetic relationships with elders of color and the health system,

b) Focusing the efforts of community health workers on improving accessibility and continuity of cancer prevention, detection and treatment services rather than only patient education,

c) Backing up these workers with new health care system information systems and decision-making supports.

Based on these conclusions, this chapter addresses three goals: 1) Summarizing and assessing evidence from the case studies on the costs and cost-effectiveness of community health workers; 2) Proposing three new roles for community health workers and associated systemic supports that might be explored in a Medicare demonstration to reduce racial/ethnic cancer and health disparities; and 3) Developing a framework for asessing the immediate and longer-term cost-effectiveness of these three new services under Medicare.

Understanding the short and long-term costs and impacts of community health worker models is critical for efficient resource allocation and implementing cost-effective strategies for reducing R/E disparties in cancer among the Medicare population. Reliably capturing the start-up and recurring costs of the service, estimating relative cost-offsets in health care utilization, and accurately measuring changes in health-related behaviors and outcomes are vital for providing necessary cost-effectiveness evidence to decision-makers. In practice, obtaining reliable short and/or long-term cost-effectiveness estimates for these services can be complicated due to underdeveloped or varying alternative community health worker models in the field, a lack of existing data in the literature and in community-based practice settings, as well as limited existing economic modeling applied to understanding the impact of health interventions on racial and ethnic disparities.

In an attempt to investigate both program costs and impacts associated with the sites visited under this project, the site visit protocol included a specific inquiry into the cost of resources required to deliver services under each initiative along with an inquiry into currently available impact or outcome data. Initially, we had hoped to provide some preliminary cost-effectiveness analyses based on data collected from the sites, but due to overall limitations in data availablity and a high variability in the amount and reliability of cost and impact data collected from each site, we have concluded there is a lack of information upon which to build a strong cost-effectiveness model based on the case studies. Some of the sites were able to provide an aggregate financial expenditure total at most, while others were able to provide more detailed personnel and non-personnel cost data or evaluation and medical cost-offsets data regarding patient services and health care utilization. Although the availablity of resource and impact data was highly variable, many lessons can be learned from the case studies about resource use, costs, and impacts associated with different health promoter models currently used in the field.

B: Lessons from the Case Studies

The case studies provided an opportunity to investigate the type of resources (and associated costs) used in delivering a varying educational, diagnostic, and treatment management services for reducing R/E disparities throughout the United States. Critical questions for obtaining this information were included as part of each site visit protocol. Most sites were able to provide some cost data to a greater or lesser degree. Some were able to provide aggregate financial data, while others provided detailed breakdowns of personnel costs including FTEs by staffing category, hourly or annual rates of pay and fringe benefit rates. Furthermore, some sites also provided information about non-personnel costs including rent, telephone, equipment costs, and in-kind contributions. If service volume data were also available, unit cost estimates per service were either obtained directly from the site or derived by our team.

Table 5.1 summarizes cost data obtained from 12 sites that utilized some variation of the community or community health worker model in delivering cancer or primary prevention services to the community, and for which there was some cost data available. More specifically, for each of the 12 programs, the table indicates (if available) the average annual community health worker wage, the volume of services provided by each program annually (including the number of contacts made by the community health worker and subsequent diagnostic services) as well as a unit cost estimate for information dissemination and/or diagnostic services

Table 5.1 CommunityHealth Worker Wages, Service Volume and Unit Service Costs Obtained from Sites Utilizing CommunityHealth Workers			
Program Name	**Average Annual Community Health Worker Wage**	**Average Annual Volume of Services**	**Average Unit Cost Per Service**
African American Breast Cancer Outreach Program	N/A	approximately 342 mammograms per year and 5,296 receiving services and/or information	$526 per woman screened and $34 per women receiving services and/or information
Association of Asian Pacific Community Health Organizations (AAPCHO)	N/A	493 clinical breast exams, 527 Pap smears, and 680 mammograms, a total of 1,700 services per year	$141 per service
Baltimore City Cancer Plan	Community Health Worker $21,000 per year. Cancer Information Specialist $30,000 per year.	632 prostate cancer screenings at 6 sites	N/A
Deep South Network Community Health Advisors Program	Volunteer Service – $50 incentive to complete training	3,189 people contacted, 365 screening referrals	$193 per person contacted

Table 5.1   CommunityHealth Worker Wages, Service Volume and Unit Service Costs Obtained from Sites Utilizing CommunityHealth Workers (Cont.)

Program Name	Average Annual Community Health Worker Wage	Average Annual Volume of Services	Average Unit Cost Per Service
Healthy Body, Healthy Soul – Jessie Trice Cancer Prevention Program	$21,600	667 screened for lung cancer by cat scan in 10 months	$1,573 per person screened (total cost includes in-kind resources) $1,209 per person screened (total cost without in-kind resources)
Mariposa Community Health Center	$22,000	225	$203 per client served
MGH Chelsea HealthCare Center Breast Health Program	N/A	144	$623 per referral
Kentucky Homeplace (KH) and Southeast Kentucky Community Access Program (SKYCAP)	Family Health Care Advisors (FHCA) for KH salary approx. $19,390 per yr. Family Health Navigators for SKYCAP receive a salary of $18,000 per yr.	Kentucky Homeplace served over 10,400 clients in 1999	$182 per client served for Kentucky Homeplace. $293 per client when including the market value of donated meds, free health care visits and reduced health care debt.
Native American Women's Wellness Through Awareness (NAWWA)	Community Health Worker/Native Sister, approx. $30,000 per yr plus fringe benefits	N/A	N/A
North General Hospital	$45,000	750	$125 per client
Chicago Racial Ethnic Approaches to Community 2010 (REACH 2010)	$5000 stipend	500 people contacted per church	$10 per person contacted
Community Health Aide Program	$37,440	300,000 patient encounters	$135 per patient encounter
Oklahoma City Witness Project	$20 per 1 hour meeting	N/A	$21.70 per woman served
Buda	3 LHWs for 15 hours / week for 24 weeks at $8 per hour		Program costs are $12,000 per site per 6 months.
Assistance and Self-Help to End Smoking Project (ASHES) and Mammography and Pap Project (MAP)	Health Care Coach (serves both programs) $21,650 Follow-up Supervisor $27,600	N/A	N/A

The table represents a high level of variation in types of programs using a community health advisor model in the delivery of services, varying amounts of data available, as well as different measures of service volume captured at each site depending on the service rendered. For example, community health workers based in community churches in Chicago working under "Chicago Racial Ethinic Approaches to Community 2010" received a $5000 annual stipend for working through the church to disseminate information about breast and cervical cancer self-exams, screening, diagnosis, and

treatment services. These community health advisors worked between 2 and 10 hours per week. An alternative model, based in St. Louis, MO, "Assistance and Self-Help to End Smoking Project (ASHES) and Mammography and Pap Project (MAP)" hires health coaches to work full-time (40 hours per week) directly with patients through an "in-reach" process based at Grace Hill Community Health Center. These coaches are paid on average $21,650 per year. For sites utilizing a full-time community health worker, the average salary of the community health worker is approximately $24,154. Most of these full time workers received a fringe benefit rate of about 20%. Unit costs of services were obtained based on available data. Programs such as North General Hospital in New York, Mariposa Health Center in Nogales, AZ, and Kentucky Homeplace in eastern Kentucky, all providing similar services, showed unit costs per patient served between $120 and $195.

After reviewing data from the site visits, we identified nine major findings regarding current resource use and the state of cost and impact data pertaining to most sites. These findings are outlined below.

- Use of in-kind resources are significant – Most programs require resources above and beyond budgeted financial expenditures. In-kind resources such as office space, computers, and volunteer staff are acquired from various community organizations. Based on some program estimates the proportion of the value of in-kind resources to total costs ranged from 10-50%.

- Many programs are currently in development/or embedded in research efforts Not having yet reached a steady state of operation, it is difficult to project unit costs of service at full implementation. Most likely, unit costs of several service will drop as programs are brought up to full scale implementation. Because many programs are embedded in research and development projects, it was difficult to distinguish costs of these efforts from what might occur in steady-state, non-research contexts.

- Programs used the promotora role to a greater or lesser extent as part of a team approach – In some programs, the community health advisor was the only staff member working to deliver service, while in others, they worked as part of a team including case managers, social workers, and nurses. This made it difficult to compare both costs and impacts based on the activities of the community health worker alone. From additonal site visits to BECH and MGH we learned of the importance that top clinicians working with community health workers is critical to the success of the program. Furthermore, these programs are re-thinking roles of other clerical staff to address navigation issues.

- Role of the promotora varied – The role of the community health worker ranged from providing educational material or recruiting participants for group events to working with an on-going caseload for which the community health worker would provide some counseling and brief health or medical

assessments. Volume of services delivered, persons contacted, or persons whose cancer-relevant behavior was influenced varied markedly, with implications for unit costs. At BECH the navigator handled about 750 cases a year—in a screening adherence to diagnosis role.

- <u>Programs had varying funders or resources overtime</u> – Direct service costs are funded in multiple ways. Few programs maintained consistent funding from the same funders overtime. As a result, many programs were forced to change their organizational structure/strategy or staffing requirements, and community health worker functions and service costs may have been impacted.

- <u>Insufficient data</u> – Few programs were able to provide enough data to support elaborate cost or impact analyses.

- <u>Intermediate process measures</u> – Programs were unable to provide process measures such as "number of contacts made" or "number of screening referrals" and only a few programs provided any information regarding subsequent client health status or quality of life.

- <u>Costs of management information systems were difficult to allocate</u> – Many programs were beginning to use computerized information systems to track client encounters. The cost of these systems were difficult to estimate based on difficulties in allocating capital and recurring MIS costs to specific initiatives or programs.

- <u>Wide range of training resources supporting community health workers</u> – Programs in the field were found to be using a wide variety of training curriculums to develop the skills of community health advisors. The amount of time spent in training community health advisors ranged from 16-80 hours of training. The average time spent in training was approximately 60 hours. The costs of training for many programs appeared significant due to the intensity of speakers and trainers involved. We believe these costs could be significantly reduced with a more standarized approach.

From these major findings, we conclude that there is a lack of sufficient evidence upon which to construct a formal cost-effectiveness analysis from the site visit data. Alternatively, in the next section, we recommend three possible models for reducing R/E disparities in cancer among the Medicare population, and discuss cost-effectiveness assessment considerations in assessing these models.

C: Recommended Demonstration Models for Reducing Racial/Ethnic Disparities in Cancer and Health

Based on findings from the literature reviews, programmatic findings from case studies, and ongoing discussions with CMS and consultants on feasible structures for Medicare fee-for-service benefits, three possible services with the potential to reduce R/E disparities in cancer and health among elders were identified. Table 5.2 summarizes three possible Medicare demonstration services, all of which could be performed by community health workers with appropriate training, supervision, and information management/clerical supports. These models include health risk management (HRM), screening adherence and detection facilitation (SADF), and treatment and follow-up facilitation (TAFF). Each of these services would be performed as an integral component of and link to the local health care system. For this reason, in a demonstration context, a particular health system might be able to reconfigure two or more of these roles as the responsibilities of a single worker or group of workers. While the following discussion emphasizes how they are different and the importance of exploring each of these roles, community health workers in the context of a racial/ethnic cancer disparities reduction program might perform two or more distinct billable services. In each role, the community health care worker would collaborate bothwith other health care clerical, financial, and administratve staffs and with health care professionals such as physicians, nurses, social workers, and case managers on patient education, care continuity, and self-care empowerment, but also provide specific support and linkage services. Furthermore, each role would include the use of data management technology to improve the accuracy of data collection and reduce the amount of administrative time spent by each community health worker. The three separate models are described below.

- Health risk management – (HRM) is a service that targets three specific behavioral health changes and three system level changes that would be most effective in improving the health of Medicare beneficiaries from a primary care perspective. The three behavioral health improvements are weight management, increased physical activity and substance use, including smoking cessation. System level activities include linking Medicare beneficiaires to a regular source for their primary care and facilitating enrolment in all appropriate supplemental insurance.

- Screening adherence and detection facilitation – (SADF) is a service with the objective of ensuring Medicare beneficiary adherence to breast, cervical, prostate, oral and colorectal cancer screening as well as follow-up of questionable screening results, including treatment of pre-cancerous conditions and complete diagnostic work-ups, and completed referral for initiation of treatment in a timely fashion. This is accomplished by assisting the Medicare beneficiary through the screening process and

Table 5.2 - Three Possible Medicare Demonstration Services for Reducing R/E Disparities in Cancer: Service Descriptions and Recommended Requirements			
Type of Service	I. Health Risk Management (HRM)	II. Screening Adherence and Detection Facilitation (SADF)	III. Treatment and FollowUp Facilitation (TAFF)
Primary Role	Performs Health Risk Assessment (HRA), conducts motivational interviewing, tailored lifestyle counseling, assists with benefit coordination, referral to primary care and screening, referral to social and prevention services	Maintains individual record of adherence to all Medicare-reimbursed screens, sends personalized reminder letters, calls and arranges for service on schedule, follows-up on missed visits, facilitates referrals out to other providers for cancer detection, prevention, and treatment services, tracks patient till definitive resolution	Maintains individual record of progress and facilitates access to standard of care services from suspicion of cancer through definitive diagnosis, primary and secondary treatments, adjuvant care and reoccurence monitoring. Assists with benefits coordination, health and social service referrals.
Organizational Affiliation	Community Health Center, CHHA, Health Dept., group practices	Community Health Center, screening provider, cancer center	Hospital, safety net health system, cancer center
Operational Supports	Patient registry, MIS to track service referrals, actions and follow-up, computerized HRA, adapted health education materials	MIS to track use and completed referral, personalized letters, links to financial offices, interpreter services, adapted health education materials	MIS to track use and completed referrals, decision supports to track standard of care completion, interpreter services, adapted health education/discharge summary materials
Training/ Certification	40-60 hours in class plus extra training in motivational/tailoring techniques and use of computerized HRA and registries	40-60 hours in class plus extra training in screening issues and MIS use; extra clinical training re screens and benefits	40-60 hours in class plus extra training in screening issues and MIS use; extra clinical training re cancer treatment and benefits
Intensity	4-6 hours per year per eligible person	2-4 hours per year per eligible person	20-30 hours per year per eligible person
Staff Requirements	At least a High School Diploma or Equivalent, Associates Degree in human services field preferred	At least a High School Diploma or Equivalent, Associates Degree in human services field preferred	At least an Associates Degree in a human services field
Possible Maximum Reimbursement	$210 = $35 x 6 hours, estimate based on salary and loaded overhead.	$140 = $35 x 4 hours, estimate based on salary and loaded overhead.	$1050 = $35 x 30, estimate based on salary and loaded overhead.
Supervision Requirements	BA level supervisor (health educator or nurse)	BA level supervisor (nursing and administrative)	MA level or MD supervisor (nursing, medical, and administrative
Productivity Measure	HRA's performed, plans developed, plan follow-ups, referrals completed, insurance applications completed	Number of cases managed; number and types of screens arranged, insurance applications completed	Number of cases managed, number of completed referrals, insurance applications completed
Immediate Outcome Measures	% of HRAs with tailored action plans; % with supplemental insurance, % with usual source of care, % of cases engaged in weight management, smoking cessation, and physical activity programs; % adherent to overall lifestyle recommendations	% of cases adherent on all screens; % of cases brought to resolution, % of cases with standard of care detection and prevention services, reduced Screen-to-resolution lag time, patient satisfaction health-related quality of life	% of cases completing standard of care diagnosis and treatment; time to completed treatment; % of cases tracked annually, patient satisfaction and health-related quality of life

detection process, while working with multiple health care system actors to facilittate timely task completion and documentation. To accomplish this task, thecommunity health worker may notify the patient or provider regarding the need for a particular screen, follow-up for a missed screening appointment, and link the beneficiary to further preventive services and diagnostic work-ups in a timely manner and treatment as needed. To accomplish this, the navigator will perform activities such as telephone calls to beneficiaries and providers, completing referrals, setting up appointments, explaining the process to the Medicare beneficiary and providing emotional support, and linking the beneficiary to needed services such as transportation or interpreter services

- Treatment and follow-up facilitation– (TAFF) is a service that involves navigating patients from the definitive diagnosis of cancer at any anatomical site through the treatment and reoccurence monitoring process. Additional objectives of this service include tracking for cancer reoccurrence, facilitating referrals to complimentary health risk management programs, and assisting with benefits coordination, and health and social service referrals.

The table provides a service description, recommended staffing requirements, necessary training/certifications, supervision levels, possible staff reimbursement ranges, potential delivery sites and technological support, along with a description of productivity and evaluative outcomes measures. Suggested reimburement levels differ for each of the three models with SADF costing the least $140 for four hours of service, while HRM would cost approximately $210 for six hours of service, and TAFF would cost approximately $1050 for a maximum of 30 hours of service. Delivery sites would most likely also differ where HRM would be implemented in homes, health care facilities, community centers and senior center, SADF would be implemened by screening providers and TAFF would be implemented in hospitals and outpatient cancer centers. All three suggested models would approximately the same required level of supervision, amount of training, and technological support.

We recommend that CMS develop demonstrations that allow for separate assessment of each of these services. Such an approach is indicated because of real uncertainty as to their relative effectiveness in reducing R/E racial disparities and improving health as well as their impact on Medicare expenditures. As highligted in the table, the services would be based in different organizational settings, address different phases in the cancer process, and thus would be assessed against distinct intermediate outcomes. Individual and small group primary care practitioners, public health offices, community clinics, and larger multi-level health care systems may find alternative ways of organizing these new roles and their associated supports.

We recommend that CMS set forth a series of demonstrations to test each of these models in one or more R/E groups against customary care reciept for that same R/E group using a rigourous research design with random assignment. Such a design would enable a more complete and compelling evaluation of both the costs and impacts associated with each service. As for a specific research design, we recommend

comparing each of the individual services separately against a control case leading to three separate clinical trials. This type of design is important for several reasons. First, under its current structure, Medicare reimbureses for specific services. This design would inform CMS about the costs and impacts of each individual service. Secondly, the organization of the current health care delivery system allows for easier implementation of this type of design. More elaborate, hybrid models would be more complicated to implement. Lastly, it is anticipated that the immediate outcomes best measured in a demonstration context differ across these models. As the demonstration framework and implementation plans develop, it may be appropriate to reconsider the best combinations of these models for further exploration.

The outcomes associated with health risk management include specific health related behavior changes pertaining to weight reduction, increase in physical activity and smoking cessation. Additionally, outcomes associated with having a routine primary care provider and comprehensive insurance coverage based on eligibility will be measured. Outcomes associated with breast and colo-rectal screening include adherence to screening protocols, complete and timely follow-up to questionable screens, and patient satisfaction. Lastly, outcomes associated with treatment and follow-up management include treatment adherence and completion, reduced time to completion, and patient satisfaction.

The length of the demonstrations will impact the type of questions that can be addressed regarding cost-effectiveness of the interventions. Shorter term (2-3 years) clinical trials are less costly but and can yield analyses involving intermediate outcomes. Longer term community and clinical trials would provide greater evidence for the cost-effectiveness of each of the proposed interventions including more reliable estimates of cost-offsets in health care utilization, long term impacts on mortality and potential improvements in quality of life. Economic modeling of these variables is possible based on shorter term studies but are often less reliable. Estimating the potential increase in survival based on long-term data is critical but would take several years. This tradeoff should be carefully considered due to the current lack of knowledge in the field regarding potentially high cost-savings in acute care and inpatient hospitalizations and late stage cancer treatments due to these type of services. The following section addresses a framework for cost-effectiveness analysis of the three interventions assuming shorter term demonstrations of 2-3 years and is followed by a brief discussion of longer term issues.

D: Considerations for Economic Evaluation of Medicare Demonstrations to Reduce Racial/Ethnic Cancer Disparities

Cost-effectiveness analysis

(CEA) is a methodology used to assist in the decision-making process concerning health interventions. It is not meant to be the only consideration for coverage or policy decisions regarding health interventions, but when used appropriately, it can guide

policymakers in making more informed choices concerning alternative health interventions or services.

One of the fundamental considerations in any CEA is the perspective taken for the study. The perspective influences what costs and outcomes are identified and measured. The perspective can be that of a MCO, employer, government program, society, or patient (Russell, Gold et al. 1996). For this demonstration, the perspective of the Medicare Program will be taken.

The backbone of any CEA study is the C/E ratio. The ratio compares the incremental costs between an intervention and its alternative and the incremental outcomes. The numerator of the ratio represents the incremental costs and cost-offsets of the two interventions. In order to obtain this, one must define and measure the resources used to provide the health intervention as well as estimate increases or reductions in costs in other health and/or social service areas associated with the intervention. The final goal is to examine incremental cost differences, not total costs.   (Gold, Siegel et al. 1996) The denominator in a CEA reflects the incremental effectiveness between the interventions. Life years gained is measure often used in CEA but does not reflect health related quality of life improvements.

The effectiveness of the interventions must be carefully measured, both positive and negative. For the CMS demonstrations, we recommend using key interim outcomes to measure effectiveness.

Cost-effectiveness analysis can be used to evaluate the three recommended community health worker models outlined in the previous section. With regard to the three direct services and their associated control interventions, this process would entail measuring and collecting detailed, time-tracking and personnel data, as well as collecting information about direct and indirect non-personnel costs.   Moreover, cost-offset data would need to be collected on a per patient or sub-sample basis in order to capture changes in the costs assoicated with other health care and social service utilization.

<u>Costs, Cost-Offsets and Impacts of Cancer Disparity Models</u>

Conducting careful cost-effectiveness analyses of the suggested cancer disparity models under the conditions outlined in section C of this chapter will provide data regarding various direct and indirect costs of each intervention. Additionally, impacts on the adherence, timeliness and completeness of cancer screening, further work-up for suspicion of cancer and treatment will be measured as well as health-related behavior changes, evidence of an established primary care provider and supplemental insurance. Furthermore, these analyses will provide insight into vital information about potential cost-offsets or cost-savings due to each of the interventions. Figures 5.1-5.3 represent a broad framework for thinking about both the impacts and resource costs of each of the possible interventions. Each figure shows a separate flow of possible impacts on patient behavior and health care utilization as well as possible longer term impacts on survival, quality of life and R/E disparities due to implementation of one of the possible

interventions. Although the demonstrations would most likely focus on obtaining intermediate outcome measures, these figures also show possible longer term effects on health care utilization, improvements in quality of life, reductions in health disparities and potential cost-offsets. For each figure, below the flow of impacts is a description of possible changes in resource use or costs to the health system as well as changes in the costs to society. At the bottom of each figure is a list of cost-effectiveness hypotheses that could be explored through each of the demonstrations.

As a preventive service, HRM will increase patient use of weight reduction, physical exercise and smoking cessation programs. Outcomes measures include participation, attendence and/or adherence for each of these programs and reduction in weight and smoking (reduction and/or cessation). An increase in primary prevention services and care will be tracked as evidence of a routine primary care provider. Based on this ongoing engagement with the health care system, we also predict an increase in the number of cancer screenings each year among those receiving HRM. As for costs of the intervention and cost-offsets, we predict an initial increase in the cost of primary prevention and routine physician services, and outpatient services but also expect cost-savings due to reduced urgent care services such as emergency room visits and acute care and inpatient utilization.

The following hypotheses can provide guidelines for developing a cost-effectivness analysis framework pertaining to a randomized clinical trial of HRM (See Figure 5.1). It is critical to consider both short and long term evidence for cost-effectiveness as a thorough cost-effectiveness analysis will consider all costs and impacts.

C/E Hypotheses of HRM:

- HRM will have total costs equal to treatment as usual – The added costs of HRM may be offset by reductions in unnecessary health services.
- HRM will have an increase in direct service costs when compared with treatment as usual – HRM will incur costs due to the intervention itself as well as increases in other prevention activities.
- HRM will have short-term cost–offsets/cost-savings when compared with treatment as usual. – Reductions in acute and inpatient hospitalization may occur in the short run.
- HRM will be more cost-effective when compared with treatment as usual on measures of inpatient hospitalization.

As an important step in facilitating early screening and detection, SADF will increase adherence and timeliness of breast, cervical, prostate and colorectal cancer screenings, and have some, but have somewhat less than HRM, impact on the use of physician services. Most importantly, we predict an increase in dectection and treatment of pre-cancerous conditions and detection of cancer at early stages leading to an increase in survival and quality of life, and a reduction in costly cancer care due to later stage diagnoses. This intervention would be focused on a smaller population than HRM but may have significant cost-savings in both the short and long run. (See Figure 5.2.)

The following hypotheses can provide guidelines for developing a cost-effectiveness analysis framework pertaining to a randomized clinical trial of SADF.
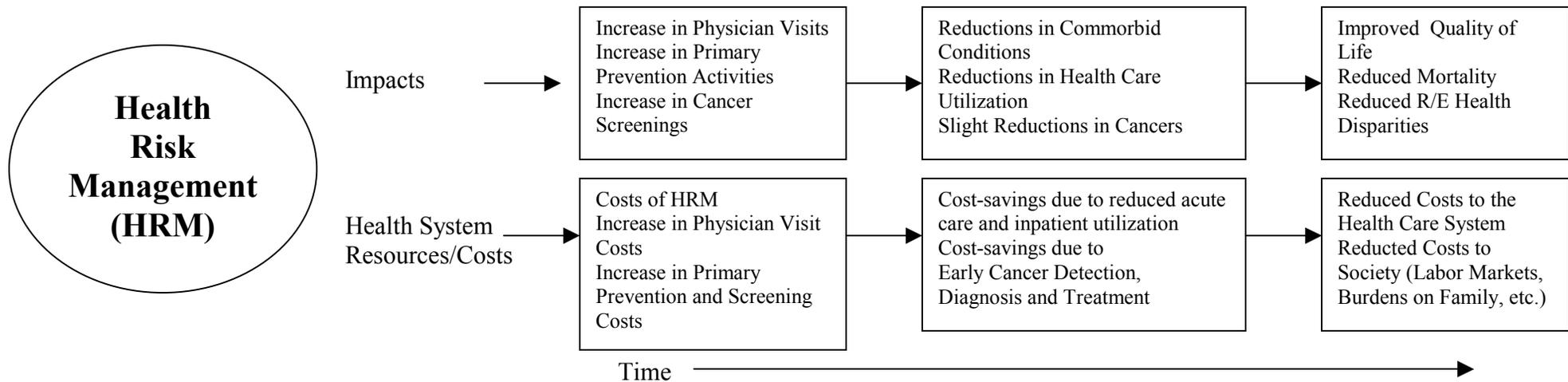
C/E Hypotheses of SADF:

- SADF will have total costs equal to treatment as usual – The added costs of SADF may be offset by reductions in unnecessary health services.
- SADF will have an increase in direct service costs when compared with treatment as usual. - SADF will incur costs due to the intervention itself as well as increases in other prevention activities.
- SADF will have short-term cost–offsets/cost-savings when compared with treatment as usual. - Reductions in acute and inpatient hospitalization may occur in the short run.
- SADF will be more cost-effective when compared with treatment as usual on measures of capturing early stage diagnoses and patient satisfaction.

As a treatment and followup facilitation protocol, TAFF will most likely increase timely initiation and adherence to complex treatment processes across a range of cancer sites, and follow-up care. TAFF will most like reduce clinical and economic inefficiencies from time of diagnosis to time of treatment. (See Figure 5.3.)

C/E Hypotheses of TAFF:

- TAFF will have total costs greater than treatment as usual. – Most cost-offsets will occur in the longer term.
- TAFF will have an increase in direct service costs when compared with treatment as usual. - TAFF will incur costs due to the intervention itself as well as increases in other prevention activities.
- TAFF will reduce inefficiencies in time from diagnosis to treatment.
- TAFF will be more cost-effective when compared with treatment as usual on R/E disparities and patient satisfaction.

Lastly, in conducting cost-effectiveness analyses of all three possible models it will be important to consider capital investments and start-up costs assoicated with each of the interventions. Furthermore, research costs will need to be extracted from an analysis of the pure costs of each of the interventions. Significant sensitivity analyses will need to be conducted to investigate the various assumptions in the analyses. Changes in cost-effectiveness ratios should also be considered when shifting implementation from a clinical trial to a real world setting.

Figure 5.1   **Cost-Effectiveness Hypotheses for Health Risk Management**

Short-term (2 years) C/E Hypotheses:
- HRM will have total costs equal to treatment as usual
- HRM will have an increase in direct service costs when compared with treatment as usual.
- HRM will have short-term cost –offsets/cost-savings when compared with treatment as usual.
- HRM will be more cost-effective when compared with treatment as usual on measures of inpatient hospitalization, quality of life, and R/E disparities.

Long-term (Greater than 2 yrs) C/E Hypotheses:
- HRM will have lower costs than treatment as usual.
- HRM will have an increase in direct service costs when compared with treatment as usual.
- HRM will have long-term cost-offsets/cost-savings when compared with treatment as usual.
- HRM will be more cost-effective when compared with treatment as usual on measures of inpatient hospitalization, racial and ethinic disparities, mortality, and quality of life.
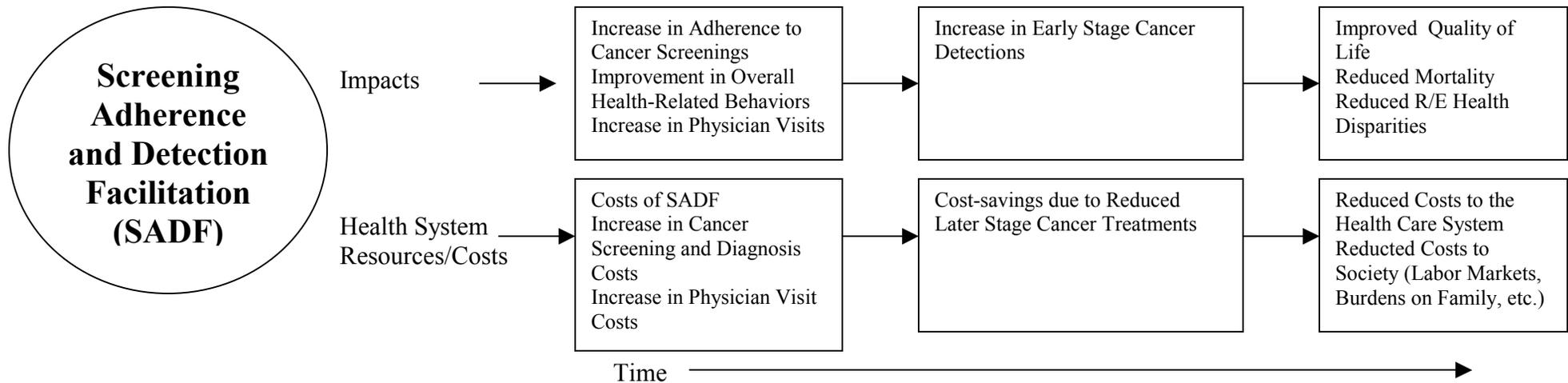
Figure 5.2   **Cost-Effectiveness Hypotheses for Screening Adherence and Detection Facilitation**

Possible C/E Hypotheses for the Demonstrations:

- SADF will have total costs equal to treatment as usual – The added costs of SADF may be offset by reductions in unnecessary health services.
- SADF will have an increase in direct service costs when compared with treatment as usual. - SADF will incur costs due to the intervention itself as well as increases in other prevention activities.
- SADF will have short-term cost–offsets/cost-savings when compared with treatment as usual. - Reductions in acute and inpatient hospitalization may occur in the short run.
- SADF will be more cost-effective when compared with treatment as usual on measures of capturing early stage diagnoses and patient satisfaction.

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                                      ┌──────────────────────┐   ┌──────────────────────┐   ┌──────────────────────┐
                                      │ Increase in Adherence │   │ Reductions in Recurring│  │ Improved  Quality of │
                                      │ to Treatment Process  │   │ Cancer                │   │ Life                 │
   ⎛  Treatment  ⎞   Impacts ────────▶│ Improvement in Overall│──▶│ Increases in Survival │──▶│ Reduced Mortality    │
   ⎜ and Follow- ⎟                    │ Health-Related Behaviors│ └──────────────────────┘   │ Reduced R/E Health   │
   ⎜     Up      ⎟                    │ Increase in Physician │                              │ Disparities          │
   ⎜Facilitation ⎟                    │ Visits                │                              └──────────────────────┘
   ⎝   (TAFF)    ⎠                    └──────────────────────┘
                    Health System     ┌──────────────────────┐   ┌──────────────────────┐   ┌──────────────────────┐
                    Resources/Costs ─▶│ Costs of TAFF         │   │ Cost-savings due to   │   │ Reduced Costs to the │
                                      │ Increased Efficiencies│──▶│ Reduced Recurring     │──▶│ Health Care System   │
                                      │ in the Treatment Process│ │ Cancer                │   │ Reducted Costs to    │
                                      │ Increase in Physician │   └──────────────────────┘   │ Society (Labor Markets,│
                                      │ Visit Costs           │                              │ Burdens on Family, etc.)│
                                      └──────────────────────┘                              └──────────────────────┘
                                        Time ─────────────────────────────────────────────────────▶
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Figure 5.3   Cost-Effectiveness Hypotheses for Treatment and Follow-Up Facilitation

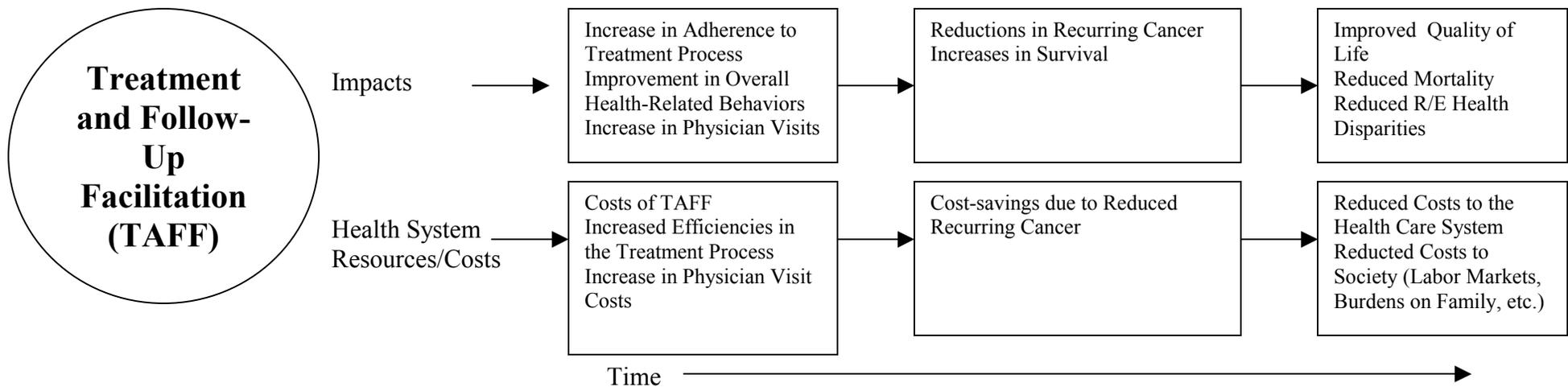Possible C/E Hypotheses for the Demonstrations:

- TAFF will have total costs greater than treatment as usual.
- TAFF will have an increase in direct service costs when compared with treatment as usual.
- TAFF will reduce inefficiencies in time from diagnosis to treatment.
- TAFF will have greater impacts on survival than treatment as usual.

E: Conclusion

Conducting cost-effectiveness evaluations of these proposed models under the conditions of randomized clinical trials will provide critical information about costs, cost-offsets, and impacts of each intervention for decision-makers seeking to reduce R/E disparities among the Medicare population. It is important to recognize that these clinical trials will yield limited information on important measures of longer term survival, cost-offsets in health care utilization, changes in quality of life, and broader impacts on racial and ethnic disparities. Although each of the interventions will incur initial start-up and on-going direct service costs, increases in survival and quality of life, reductions in racial and ethnic disparities, and cost-offsets in health care utilization will most likely be greater over a longer period. In summary, we hypothesize for each of the interventions, cost-effectiveness compared to treatment as usual will be greater over time.

Cost-effectiveness analysis is not meant to be the only consideration for coverage or policy decisions regarding health interventions, but when used appropriately, it can guide policymakers, providers, and patients in making more informed choices concerning alternative health interventions or services. Further analyses should make attempts at longer term modeling and should consider possible changes in the cost-effectiveness of these interventions when changing service implementation from a research environment to a community-based setting.

Evidence Report and Evidence-based Recommendations:
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CANCER PREVENTION AND TREATMENT DEMONSTRATION FOR ETHIC AND RACIAL MINORITIES: Evidence Report

Appendix I

Evidence Tables:

Physical Activity and Nutrition Interventions for Elders of Color

Interventions to Decrease Racial/Ethnic Disparities in Breast, Prostate, Cervical, and Colorectal Cancer Screening

Physical Activity Intervention Studies

Author	Design	Population	Intervention	Outcome Measure	Findings for Study Group	Findings for Control Group
Effects of a community-based intervention to increase physical activity in American Indian elders Kachevar, A. et al (2001)	Randomized controlled trial (small control group, n=6) Subjects serve as own controls as well	26 AI adults age range 55-75, with one or more chronic diseases taken from community clinic	Six week exercise classmodeled after "SMILE" (so much improvement with a little exercise).40 minutes twice a week – flexibility, strengthening, and aerobic exercise. Either physician recommended or client interest.	Baseline and intervention measures of emotional and physical self-assessment survey,Blood pressure, and activity log. High attrition rate.	Survey measures baseline vs. post exercise: Ability to perform chores :2.2(.92)vs.3.3(1.3)* Exercise activities: 1.8(.92)vs.2.5(1.3)* Systolic BP:141.5 (19.3) vs. 135.1 (15.6) *	No data on chores and exercise activities. Systolic BP:132.0 (12.8) vs. 131.0 (7.4)(not significant)
Predictors of older primary care patients' participation in a sub-maximal exercise test, and a supervised low-impact exercise class Damush et al. (2001)	'Prospective single group study	Non-volunteer sample, 500 primarily low income, African-Amercian women, aged 50 or over.(mean age =64), high rates of chronic disease	'Physician referred and encouraged exercise test and exercise class. Daily exercise class with stretches, aerobics/walking and resistance exercise	Percentage of class participation	'28% attendeed one exercise session and 9% attended exercise sessions through 1 year.	NA
A randomized controlled trial of weight reduction and exercise for Diabetes management in older African Americans Agurs-Collins, et al. (1997)	Randomized Control Trial Randomized to either control group with usual care (1 class and 2 informational mailings at 3 and 6 months) or intervention group	64 African American men and women aged 55-79 years, with dx.of diabetes, HbA1c levels >8%, >=120% of Metropolitan weight standards	12 weekly culturally sensitive group sessions (60 minutes of nutrition education and 30 minutes of exercise) with one diet counseling session for first 3 months based on Social Action theory. Six biweekly sessions for next 3 months. Individualized weight	HbA1c, Blood pressure, nutrition knowledge, physical activity and food frequency questionnaire, self-efficacy and attitude, behavior questionnaire, height, weight. BMI, cholesterol ration.	Baseline (SD) 6 months (SD) Net difference (CI) Weight: 90.3(18.6)90.7(20.1)-2.4(-4.3,-0.5)* BMI: 33.9(5.1)33.1(5.7)-0.9(-1.6,-0.2)*HbA1c: 11.0(1.7)9.9(2.0)-2.4(-4.2,-0.6)* Systolic BP: 144(17)146(21)-5.9(-14.3,2.4) Diastolic BP:79(10)79(9)-4.0(-7.9,-0.02)* Cholesterol:HDL: 5.3(1.4)5.2(1.6)-0.07(-0.7,0.6) Physical activity scores:92.5 (60.5)101.1 (81.7)8.6 (-30.4 , 47.6)	Baseline (SD) 6 months (SD) Weight:94.9 (20.1)96.9 (21.6) BMI: 34.9(6.8)35.8 (7.0) HbA1c: 10.0 (1.9)11.5 (4.4) Systolic BP:139 (14)147 (22) Diastolic BP:77(10)80 (10) Cholesterol:HDL: 4.8(1.5)4.8(1.5) Physical activity scores:115.1 (66.7)113.7 (76.4)

Nutrition Intervention Studies

Author	Design	Population	Intervention	Outcome Measure	Findings for Study Group	Findings for Control Group
Ard et al. (2000) Culturally-Sensitive Weight Loss Program Produces Significant Reduction in Weight, Blood Pressure, and Cholesterol in Eight Weeks	Randomized modified cross-over study. 56 African American participants, 44 completed the study	56 African Americans enrolled, 44 completed the study and 54 of those enrolled were women. The average age was 40.4.	1000-calorie/day version of the Rice Diet. Modifications to the program included decreased cost, culturally-sensitive recipes, addressing attitudes about exercise, and including family members in weight loss efforts.	Weight, BMI, cholesterol, blood pressure. Outcomes measured were assessed at enrollment, after 4 weeks, and after 8 weeks.	Participants lost an average of 14.8 +/- 6.8 pounds. BMI decreased by 2.5 +/-1.2 kg/m^2 Cholesterol decreased by an average of 13.7 +/- 27 mg/dL. Systolic BP decreased by 4.3 +/- 8.7 mmHg. Diastolic BP decreased by 2.5 +/- 7.5 mmHg.	No significant change in any outcome measures.
Coates et al. (1999) The Women's Health Trial Feasibility Study in Minority Populations: Changes in Dietary Intakes	Randomized Control Trial	2,208 women ages 50-79 from Atlanta, Birmingham, and Miami. 28% of women were black and 16% were Hispanic. 80% of women were still enrolled after 18 months.	Each participant was assigned a personal fat gram goal. Group sessions met weekly for six weeks, biweekly for six weeks, monthly for 9 months, and then quarterly. Sessions included discussion of behavioral and nutritional change strategies, such as low fat recipes, and other support group strategies. Reading materials were translated into Cuban Spanish and staff members were of varied racial/ethnic backgrounds.	Whether participants remained in the program and whether there was a reduction in total fat consumption of ten percent of energy. Outcomes were measured at 6, 12, and 18 months.	Approximately 80 percent of the women were still enrolled in the study after 18 months. At six months, fat intake was reduced from 39.7% to 26.4% of energy- a 13.3% energy reduction (95% CI 11.9-10.2). The effects of the intervention did not vary between black women and white women or by level of education. This study was less effective for Hispanic participants.	At six months the intervention group had reduced the fat intake by 2.3%.
Kumanyika et al. (1999) Outcomes of a cardiovascular nutrition counseling program in African Americans with elevated blood pressure or cholesterol level.	Randomized Control Trial	Random assignment to self-help or to full instruction intervention counseling to reduce intake of dietary fat, cholesterol, and sodium. Food nutrition guides were given to both groups. The intervention	333 AA adults ages 40-70 with elevated or high BP Of those randomly assigned, 68% (n=223) attended the 4-month visit, 59% (n=194) attended the 8-month visit, and 77% (n=255) attended the 12-month visit.	Changes in lipid levels and blood pressure after 12 months.	Total cholesterol and LDC-C level decreased by 8% overall. Blood pressure also decreased significantly in the self-help and the full instruction groups. Systolic blood pressure decreased by 7-11 mmHg and diastolic blood pressure decreased by 4 to 7 mmHg (p<0.01). Total cholesterol for women in the full instruction group	Total cholesterol for women in the self-help group decreased from the baseline level of 6.28+/-0.09. The average decrease for women was 0.43 (SE +/-0.07). Total cholesterol for men in the self-help instruction group decreased from the baseline level of 5.87+/-0.16. The average decrease for men was 0.36 (SE +/-0.13).

Author	Design	Population	Intervention	Outcome Measure	Findings for Study Group	Findings for Control Group
		group also received video and audiotape series.			decreased from the baseline level of 6.16+/- 0.09. The average decrease for women was 0.41 (SE +/-0.07). Total cholesterol for men in the full instruction group decreased from the baseline level of 5.98+/- 0.14. The average decrease for men was 0.50 (SE +/-0.12).	
Kumanyika et al. (2002) Ethnic Comparison of Weight Loss in the Trial of Nonpharmacologic Interventions in the Elderly	Randomized Control Trial	421 overweight white and 163 overweight black adults ages 60-79. All participants had blood pressure controlled on a single anti-hypertensive drug.	Randomization to counseling for weight loss, sodium reduction, both weight loss and sodium reduction, or to usual care. Usual care was defined as using an antihypertensive drug.	Weight change 15-36 months after enrollment.	For weight loss group only, net weight change was -2.7 kg in blacks and -5.9 in whites (p<0.001) at 6 months and -2.0 (p<0.05) in blacks and -4.9 (p<.0001) in whites. For the weight loss and sodium reduction group, weight change was -2.1 (p<0.01) in blacks and -2.8 (p<0.001) in whites at 6 months and -1.9 in blacks and -1.7 in whites at the end of follow up (p<0.05).	
Resnicow et al. (2001) A Motivational Interviewing Intervention to Increase Fruit and Vegetable Intake Through Black Churches: Results of the Eat for Life Trial	Randomized Control Trial	Members of 14 African American churches. Of the initial sample, 861 (85%) were assessed at the one-year follow-up. Mean age of the sample was 44.	Random assignment of churches 1) comparison, 2) self-help intervention with 1 telephone cue call, and 3) self-help with 1 cue call and 3 counseling calls. The telephone counseling in group 3 was based on motivational interviewing. The intervention included an 18 minute video, a project cookbook, printed health education materials, and several "cues" imprinted with the project logo and a 5 a Day message.	Fruit and vegetable intake assessed by 3 food-frequency questionnaires, 24-hour recalls, and serum carotenoids. Assessment at baseline and 1-year follow-up.	Number of servings of fruits and vegetables Group 2 Pretest=3.91 Group 2 Posttest=4.38 Group 3 Pretest=3.78 Group 3 Posttest=5.17	Number of servings of fruits and vegetables Pretest=3.61 Posttest=3.91
Yanek et al. (2001) Project Joy: Faith-Based Cardiovascular Health	Randomized Control Trial. Churches-not individuals were randomized to	529 Church going African American women in Baltimore over age 40. Women were	There were two intervention groups: 1.) Behavioral model based on standard group methods with weekly sessions	There were 13 measures including weight, BMI, waist, percent body fat, cholesterol,	There was no difference between the spiritual and the standard intervention, so results are reported together.	Mean weight change =0.83 (SE 0.52) Mean change in BMI=0.14 (SE 0.09) Mean change in waist

Author	Design	Population	Intervention	Outcome Measure	Findings for Study Group	Findings for Control Group
Promotion for African American Women	treatment and control.	from 16 different churches. 294 (56%) of participants completed one-year follow-up biological measures and of these (199) completed all follow-up measures including behavioral outcomes in diet and physical activity.	2.) Behavioral group model supplemented with a spiritual and church cultural component The control group was non-spiritual, self-help.	energy intake, fat intake, sodium intake, and energy expenditure. Follow-up period was one year.	Mean weight change= -1.1pounds (SE 0.042) Mean change in BMI= -0.17 (SE 0.07) Mean change in waist size = -0.66 inches (SE 0.11) Mean change in percent body fat=-0.37 (SE 0.11)	size=-0.007 (SE 0.2) Mean change in percent body fat = -0.11 (SE 0.1)
Agurs-Collins et al. (1997) A randomized controlled trial for weight reduction and exercise for diabetes management in older African-American subjects	Randomized Control Trial	'64 overweight African-Americans ages 55-79 with non-insulin dependent diabetes.	Intervention included 12 weekly group sessions, 1 individual session, and 6 biweekly group sessions. There were two "usual care" groups. The first usual care group received 1 individual session and 6 biweekly sessions. The second usual care group received 1 class and 2 informational mailings.	Weight loss with assessment at 0, 3, and 6 months	At 3 months, those in the intervention group had lost 2.0 kg on average. Statistically significant differences in change in weight, level of physical activity, dietary intake of fat, saturated fat, cholesterol, nutrition knowledge, and HbA1c were all found at 3 months. At 6 months, statistically significant differences in changes in weight and HbA1c were found between the intervention and the usual care groups.	
Smith et al. (1997) Motivational interviewing to improve adherence to a behavioral weight-control program for older obese women with NIDDM. A pilot study	Randomized Control Trial	22 older obese women. 41% were black.	Participants were randomly assigned to one of the following groups: 1)a standard 16-week group behavioral weight-control program providing instruction in diet, exercise, and behavioral modification or 2)the same group behavioral program with three individualized motivational interviewing sessions added.	Weight loss, attendance at group meetings, recording food diaries, and blood glucose levels.	Number of group meetings attended=13.3 Number of completed food diaries=15.2 Number of days recording blood glucose level=46.0 Weight loss was not statistically significantly different from the comparison group.	Number of group meetings attended=8.9 Number of completed food diaries=10.1 Number of days recording blood glucose level=32.2

Mammography Intervention Studies

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Andersen (2000)	Adherence	RPT	Population based	50-80	NONE		community activities	N: 180	N: 182	
					>10% Hispanic			BL rate: 94.4	BL rate: 95.6	1.2
								FU rate: na	FU rate: na	
					<10% Hispanic			n:687	n:673	
								91.6	94.6	3.0
Andersen (2000)		RPT	Population based	50-80	NONE		Individual counseling (IC)	n:180	n:182	
					>10% Hispanic			BL rate: 94.4	87.9	-6.5
								FU rate:na	FU rate: na	
					<10% Hispanic			n:687	n:674	
								91.6	93.2	1.6
Andersen (2000)	Adherence	RPT	Population based	50-80	NONE		Individual counseling and community activities	n:180	n:89	
					>10% Hispanic			BL rate:	BL rate:	
								94.4	87.6	-6.8
								FU rate :na	FU rate: na	
					<10% Hispanic			n:687	n:853	
								BL rate	BL rate	
								91.6	94.4	2.8
								FU rate:na	FU rate:na	
Bird (1998)	Adherence	CPT	community based	40 and over	100% Vietnamese Americans (API)	51-65% below poverty level	Lay health educators/education materials/promotional events [A]	N :306	N: 399	
								Baseline rate:	Baseline rate:	
								32	37	
								Followup rate:	Followup rate:	
								28	55	
								BA rate diff	BA rate diff	
								-4	18	22

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Bird (1998)	uptake (Mammogr am ever)	CPT	community, San Francisco, Sacramento CA	40 and over	100% Vietnamese Americans (API)		Lay health educators/educati on materials/promoti onal events [A]	N: 306	N: 399	
								Baseline rate:	Baseline rate:	
								43	54	
								Followup rate:	Followup rate:	
								47	69	
								BA rate diff:	BA rate diff:	
								4	15	11

'Footnote: A. Small group education session by lay health workers, plus education material distribution, promotional events.

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Duan (2000)	Adherence	RCT	convenience sample of churches [A]	50-80	67% Latinos + blacks [B]		Telephone counseling [C]	N: 397	N: 416	
								Baseline rate: 65.0	Baseline rate: 63.5	
								f/u rate: 23.3 (M) ,37.4 [C] [D]	f/u rate: 15.8 (M), 34.8 (C) [D]	7.5 * (M) 2.6 (C)
								f/u N: 397 [E]	f/u N: 416 [E]	

Footnotes: A. 30 churches randomized to telephone counseling and control. B. 8 mostly Latino churches, 12 mostly black churches, and 10 mostly white churches in Southern LA County were included in the study. Churches were matched into 12 blocks based on dominant race/ethnicity, size, and resources. C. Telephone counseling annually over two years. D. Rates are the 1-year NON-ADHERANCE RATES. Two year rates were not reported. Rates were broken into maintenance (M) for those adherent at baseline and conversion (C) for those who became adherent during the study. Rates were not reported for the entire control or experimental groups as a whole. The rate difference of the M group was significant at p. .029 (one-sided). D. Only those who completed the study period were included in the final analysis. 1113 subjects began the study.

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Earp (2002)	Mammogra m past 2 yrs	CPT	Population based, probabilitic sampling[A]	50 and over	100% African Americans	low income	Lay health Advisors[B]	Baseline n:235	Baseline n:279	
								Baseline rate:	Baseline rate:	
								49	37	
								followup n: 235	followup n:279	
								Followup rate:	Followup rate:	
								60	59	
								BA rate diff	BA rate diff	
								11	22	11
Earp (2002)	Mammogra m in past 2 yrs	CPT	Population based, probabilitic sampling[A]	50 and over	100% African Americans, high income	high income	volunteer lay health advisors [B]	Baseline n:138	Baseline n:66	

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
								Baseline rate:	Baseline rate:	
								73	56	
								followup n: na	followup n:na	
								Followup rate:	Followup rate:	
								82	59	
								BA rate diff	BA rate diff	
								9	3	-6

Footnotes: A. Population based probabalistic sampling in NC, 37% non-white, 5 intervention counties; B. 170 trained volunteer lay health advisors prompted awareness of mammography in the community.

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Eaker (2001)	uptake (not adherent at baseline)	CPT	Population based, probabilistic sampling [A]	40 and over	no racial break down, rural population	high and low	community allience activities, various	Baseline n:955	Baseline n:947	
								Baseline rate: [A]	Baseline rate:[A]	
								55.7	43.3	
								followup:n	followup:n	
								525	412	
								Followup rate:	Followup rate:	
								29.7	37.1	
								BA rate diff [B]	BA rate diff [B]	
								-26	-6.2	19.8
Eaker (2001)	Adherence (Mammogram in women adherent and base-line	CPT	Probabilistic sampling [A]	40 and over	no racial break down, rural population	high and low	Community allience activities, various	Baseline rate:	Baseline rate:	
								44.3	56.7	
								followup:n	followup:n	
								419	542	
								Followup rate:	Followup rate:	
								76.4	76.4	
								BA rate diff [B]	BA rate diff. [B]	
								32.1	19.7	-12.4

'Footnotes A. Population based probailistic sampling involved 4 intervention counties, 4 control counties in Wisconsin. Different intervention for each county. B. The authors' calculation did not take into account baseline differences. Baseline rates presented here were obtained by subtracting the compliant rates from 100. Beacuse the authors did not consider baseline differences in participation, the erroneous conclusion was drawn that the intervention was effective amond women who were adherent at baseline OR 1.28.

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Erwin (1999) (The Witness Project)	uptake (Ever had a Mammogram)	CBA	convenience sample of churches [A]	40 and over	100% african American	Per capita income ($13, 093), 54% with high school	Witness Project Team [B]	baseline n:150 [C]	Baseline n:160 [C]	
								Baseline rate:	Baseline rate:	
								60.4	52.4	
								f/u n: 140	f/u n: 152	
								f/u rate:	f/u rate:	
								63.3	64.4	
								BA rate diff	BA rate diff	
								2.9	12	9.1

'Footnotes: A. two intervention counties, 11 churches (28% of the churches in the community), five communities, 2 control counties, 48% blacks. B. Seven local African American women, the witness role model spoke to a group of church members about her experience and highlighted the need for early detection and taking responsibility for your own life; taught Breast Self Exam using breast model tool, discussed resources for free and reduced cost mammograms, and provided a limited number of vouchers for free mammograms. About 32 out of 84 vouchers were distributed within a 6 month f/u, women made their own appointments and transportation. There was no federal funding or systematic screening program. The Witness Project used elements of social learning theory. C. Baseline samples were not explicitly provided. We calculated baseline samples as follows: Intervention group- 75% of 216 less 2 who were not black; for the control group- 69% of 217.

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Fox (1998)	uptake (Ever had a mammogram)	Community [A]		>35 (% >60 =24%)	100% Hispanic	na, estimated at 60% less than 15K	Language appropriate Education and screening promotions [B]	baseline n:75	Baseline n:56	
								Baseline rate:	Baseline rate:	
								39	20	
								followup:n	followup:n	
								101	70	
								Followup rate:	Followup rate:	
								36	44	
								BA rate diff	BA rate diff	
								-3	24	27
Fox (1998)	Adherence	Mammogram in the last 2 years		40 and over (24% 60 and over)	100% Hispanic	NA, estimated at 60% less than 15k	Language appropriate Education and screening promotions [B]	Baseline n:75	Baseline n:56	
								Baseline rate:	Baseline rate:	
								23	12	
								f/u n: 101	f/u n: 70	
								Followup rate:	Followup rate:	
								24	27	
								BA rate diff	BA rate diff	
								1	15	14

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff

Footnotes: A. Used children in ESL classes to send brochures home to their parents; pharmacies helped and displayed messages about mammography; collaborated with Catholic church breast health day. No information about community participation in the planning process. B, Community-wide information; language appropriate information materials were used; information fairs, classes took place in community settings.

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Gotay (2000)	uptake mammogram ever	CPT	Community based:Random digit sampling[A]	40 and over (24% , 60 and over)	Native Hawaian	low and high income, 28-30% with some college	Kokua groups [C]	baseline n:158	Baseline n:129	
								Baseline rate:	Baseline rate:	
								75	75	
								f/u n: 167	f/u n: 137	
								Followup rate:	Followup rate:	
								80	80	
								BA rate diff	BA rate diff	
								5	5	0
Gotay (2000)	Adherence (complaint with guidelines)	CPT	Population based, randomn digit dial sampling[A]	40 and over (24% , 60 and over)	Native Hawaian	low and high income, 28-30% with some college	Kokua groups (Volunteer lay health advisors) [C]	baseline n:104	Baseline n:124	
								Baseline rate:	Baseline rate:	
								60	59	
								f/u n: 105	f/u n: 126	
								Followup rate:	Followup rate:	
								61	60	
								BA rate diff	BA rate diff	
								1	1	0

Footnotes: A. Random sample, telephone digit sampling/Kokua neighborhood was intervention community with neighborhood control communitites identified through census tracts. B. Lay health advisors led the kihua groups. Native Hawaiians conducted interviews. There was no information about community participation in the planning process. C. The intervention was a Kokua groups, which were composed of community women gathered by friends or collegues. The groups were led by female lay health advisors. The definition of kokua is: Healp without being requested and without expectation of payment. D. There was no difference in these unadjusted estimates between the intervention and control communitites. The authors based their conclusion of positive findings on hierachical linear regrassion in which the kokua group was a significant predictor of mammography use as compared to the control.

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Margolis , 1998	Adherence (up to date at baseline)	CCT	In reach [B]	40 yrs and over	Native Americans		Screening invitation by Lay health advisors and same day refferal by nurse practitioner[A]	baseline n:711	Baseline n:772	
								Baseline rate: [C]	Baseline rate: [C]	
								39	48	
								followup:n	followup:n	
								711	772	
								62.9	69.3	
								BA rate diff	BA rate diff	

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
								23.9	21.3	-2.6

Footnotes: Lay health advisors assessed participants breast cancer screening status and offered appointments with a female nurse practitioner at a women's cancer screening clinic (WCSC) to women who were due. Each each visit to the WCSC was linked to a pelvic exam and mammography on the same day so screening could be completed in one visit. B. Women, including American Indians, were recruited from non-primary care clinics by senior aides, female low income lay staff who were paid by a federal job retraining program. Lay aides were supervised by a study coordinator. C. Rates were calculated for the entire sample because there was no baseline data for either group. Baseline data for the entire sample was calculated by subtracting the percentage of women due at baseline from 100.

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Navarro, 1998	Recent use (mammography within the past year) 2. Social network (lay health workers) and education strategy 3. Por Lavida	RCT [D] (conjeras were unit of randomization)	social network based recruitment and random assignment of lay health advisors + recruits to exp + cont. groups	40 yrs and over [A]	low income Latino, meidan income:$12,000, 75% had less than 12 years of education	low SES [C]	Por La Vida Model [B]	baseline n:162 baseline rate: 24.6 follow up n=162	Baseline n:199 Baseline rate: 30.4 -- ------------------- follow up n= 199	
								followup rate:	Followup rate:	
								43.6	56.4	
								BA rate diff	BA rate diff	
								19	26	7
Paskett (1999)	Adherence (having a mammogram within age appropriate ACS guidelines)	CPT	Outreach [A]	40 yrs and over	Blacks (66%)	low income	Multiple out reach educational and promotional strategies with/out lay health educators [B]	baseline n:123	Baseline n: 125	
								Baseline rate:	Baseline rate:	
								30	31	
								f/u n: 134	f/u n: 168	
								Followup rate:	Followup rate:	
								40	56	
								BA rate diff	BA rate diff	
								10	25	15

Footnotes: (Navarro) A. Age range in text is 18-72 but the table for baseline showa age stratified as <40 and 40-49 yrs. B. The Por La Vida model involved 36 lay health "natural" helpers conducting educational sessions with ave. 14 members. Natural healpers are described as people who have a reputation in the community for good judgment, sound advice discretion, and caring. C. Median income 12k, median educ. 7 yrs. D. Recruited conjueras who recruited participants through social networks. Randomization was by conjueras. (Paskett) A. Education brochures to address identified barriers: eg. where to get a mammogram. B. Multifacited education and promotional intervention "...free party in the community that included educational classes and information booths, prizes, choleterol and diabetes screeening.

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Slater (1998)	Recent mammogram (past 15 months),/	RCT	personal invitations (FTF) and promotional fliers [A]	50-79	White and black women, 84% were white women, no separate analyses	low income, 84% white, 47% less than high school, 84 % with annual income less than 8,000	Friend to Friend (FTF) project --A Multistrategy intervention-[B]	Baseline n: 228 [C]	Baseline n: 199 [C]	
								Baseline rate:	Baseline rate:	
								53.5	57.3	
								f/u n: 163	f/u n: 151	
								f/u rate: 52.2	f/u rate: 62.3	
								BA rate diff	BA rate diff	
								-1.3	5	6.3
Suarez (1997)	Increase pap + mammogram screening	CPT	population based [A]	40+	Spanish speaking (Hispanics)	Low, immigrants	Mexican-American women served as role models. Role model stories were advertised. [B]	Baseline n: 473	Baseline n: 450	
								Baseline rate:	Baseline rate:	
								24.1	21.4	
								f/u rate: 43.3	f/u rate: 38.1	
								BA rate diff	BA rate diff	
								19.2	16.7	-7.5

Footnotes: (Slater) A: Community involvement was planned by ACS and a high rise resident volunteer. B. The Friend to Friend (FTF) Project involved education, limited provider and patient reminders, limited free mammograms, screening promotion, scheduling assistance small group discussions, health professional talks, opportunities to request assistance in obtaining a mammogram,and provider reminder. Recruitment involved FTF parties, fliers, posters and presentations at resident council meetings, educational newsletters sent to building residents, personal invitations. Women who attended FTF parties were encouraged to invite those who did not. (Suarez) A: Intervention community- El Paso. Comparison community- Houston. B. Low income Mexican-American women recruited to tell their stories. During the 3 -year study period presentations were made, stories were broadcast on tv and radio, in newspapers and newsletters. C. Rates reported here are for mammography screening only. Comparison community was significantly m

Weber (1997)	Mammogram	RCT	Six primary care practices	52-77 mean age 63	36% black 7% Hispanic 4%Asian	21% medicaid 31% Medicare plus another ins. 9% Medicare	Physician letter plus case management and educational materials	Physician Intervention n: 186 [A]	CHE intervention n: 190 [B]	
								Baseline Rate: 16	Baseline Rate: 23	
								f/u rate: 17	f/u rate: 41	
								f/u n: 118	f/u n: 99	9
								BA rate diff: 1	18	17

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Sung (1997)	Adherence	RCT	Community based	18-97	Black women	48% < 15,000	In home education by lay health workers [A]	n: 158	n: 163	
								Baseline rate: 34.3	Baseline rate: 35.5	
								f/u rate: 39.4	f/u rate: 50.4	
								f/u n: 102	f/u n: 93	
								BA rate diff: 5.1	BA rate diff: 14.9	4.8
Zhu (2002)	Mammogram last 12 mos.	RCT	Ten Public Housing	>65	Black Women	Low Income	Lay health workers provided education about screening	Baseline n: 161	Baseline n: 162	
								Baseline Rate: 47 [A]	Baseline Rate: 49	
								f/u rate: 53	f/u rate: 55	
								BA rate diff 6	BA rate diff 6	0

Footnote: (Weber) A. Physician intervention was a letter on practice letterhead reminding the woman she was due for a mammogram. B. CHE group received the same letter, but then a follow-up letter written in English and Spanish, telephone calls, other reminders, home visits, and assistance facing barriers. (Zhu) A. Baseline rates were calculated based on differences between control/intervention groups pre/post and ave. frequency postintervention. (Sung) A. Lay health workers visited from a community-based women's health organization.

Cervical Cancer Intervention Studies

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Bird (1998)	Pap Adherence	CPT	Community based	40 and over	100% Vietnamese Americans (API)	51-65% below poverty level	Lay health educators/ education materials/ promotional events [A]	N : 339	N: 306	
								Baseline rate:	Baseline rate:	
								25	26	
								Followup n: 372	Followup n: 345	
								Followup rate:	Followup rate:	
								22	45	
								BA rate diff	BA rate diff	
								-3	19	22
Bird (1998)	Pap Uptake (Pap smear ever)	CPT	Community Based, San Francisco, Sacramento CA	40 and over	100% Vietnamese Americans (API)		Lay health educators/ education materials/ promotional events [A]	N: 339	N: 306	
								Baseline rate:	Baseline rate:	
								40	46	
								Followup n: 372	Followup n: 345	
								Followup rate:	Followup rate:	
								42	66	
								BA rate diff:	BA rate diff:	
								2	20	18
Dignan (1996)	Pap Adherence with pre and with no pre-test [C]	RCT [A]	Cherokee tribal lands N. Carolina	18+ Ave age approx.41	100% Cherokee	63.5% >20,000	Individualized educational program given by lay health workers	N: 275 [B]	N: 282	
								Baseline rate: na	Baseline rate: na	
								Followup Rate:	Followup Rate:	

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
								63.8	73.5	9.7
Dignan (1996)	Pap Uptake with pre-test and with no pre-test	RCT [A]	Cherokee tribal lands N. Carolina	18+ Ave age approx.41	100% Cherokee	63.5% >20,000	Individualized educational program given by lay health workers	N: 147	N: 65	
								Baseline rate: na [B]	Baseline rate: na [B]	
								Followup Rate:	Followup Rate:	
								34.5	22.5	-12
Gotay (2000)	Pap Uptake (Pap ever)	CPT	Community based: Random digit sampling [A]	40 and over (24% , 60 and over)	Native Hawaiian	low and high income, 28-30% with some college	Kokua groups [C]	Baseline n: 344	Baseline n: 298	
								Baseline rate:	Baseline rate:	
								96	94	
								Followup n:	Followup n:	
								345	304	
								Followup rate:	Followup rate:	
								96	96	
								BA rate diff	BA rate diff	
								0	2	2
Gotay (2000)	Pap Adherence (complaint with guidelines)	CPT	Population based, random digit dial sampling [A]	40 and over (24% , 60 and over)	Native Hawaiian	low and high income, 28-30% with some college	Kokua groups (Volunteer lay health advisors) [C]	Baseline n: 227	Baseline n:188	
								Baseline rate: 63	Baseline rate: 59	
								followup n: 232	Followup n: 213	
								Followup rate:	Followup rate:	
								64	67 [D]	
								BA rate diff	BA rate diff	
								1	8	7

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Margolis (1998)	Pap due at baseline	CCT	In reach [B]	40 yrs and over	Native Americans		Screening invitation by Lay health advisors and same day referral by nurse practitioner [A]	Baseline n: 294	Baseline n: 296	
								Baseline rate: [C]	Baseline rate: [C]	
								n/a	n/a	
								F/U N:	F/U N:	
								299	296	
								F/U rate: 50.3	F/U rate: 63.2	12.9
								BA rate diff	BA rate diff	
								na	na	
Margolis (1998)	Pap Adherence (Up to date at baseline)	CCT	In reach [B]	40 yrs and over	Native Americans		Screening invitation by Lay health advisors and same day referral by nurse practitioner [A]	Baseline n: 172	Baseline n: 205	
								Baseline rate: [C]	Baseline rate: [C]	
								na	na	
								Followup rate	Followup rate	
								84.3	80.5	-3.8
Navarro, 1998	Recent use (Pap within the past year)	RCT [D]	social network based recruitment and random assignment of lay health advisors + recruits to exp + cont. groups	18-72 [A]	low income Latina, meidan income: $12,000, 75% had less than 12 years of education	low SES [C]	Poor La Vida Model [B]	Baseline n: 162 Baseline rate: 51.6 follow up n: 162 [E]	Baseline n: 199 Baseline rate: 46.7 follow up n: 199	
								Followup rate:	Followup rate:	
								61.1	65.3	
								BA rate	BA rate diff	

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
								diff		
								9.5	18.6	9.1
Paskett (1999)	Adherence (having a Pap smear within age appropriate ACS guidelines)	CPT	Outreach [A]	40 yrs and over	Blacks (66%)	low income	Multiple out reach educational and promotional strategies with/out lay health educators [B]	Baseline n:123	Baseline n: 125	
								Baseline rate:	Baseline rate:	
								67	73	
								Followup n: 134	Followup n: 168	
								Followup rate:	Followup rate:	
								60	87	
								BA rate diff	BA rate diff	
								-7	14	21
Ramirez (1999)	Adherence	quasi exp.	population based Texas	[A]	mostly Spanish speaking	low income low level of education	Mobilization of peer networks to promote positive health behaviors [B]	Baseline n: 105	Baseline n: 107	
								Baseline rate:	Baseline rate:	
								46.8	54.2	
								Followup rate	Followup rate	
								104	107	
								Followup rate	Followup rate	
								47.1	60.7	
								BA rate diff	BA rate diff	
								0.3	6.5	6.2

Author	Disparity type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	Abs rate Diff
Suarez (1997)	Increase Pap test(Uptake)	CPT	population based [A]	40+	Spanish speaking (Hispanics)	Low, immigrants	Mexican-American women served as role models. Role model stories were advertised. [B]	Baseline n: 473	Baseline n: 450	
								Baseline rate:	Baseline rate:	
								50.1	45.5	
								f/u n: 473	f/u n: 450	
								Followup Rate:	Followup Rate:	
								56.7	51.4	
								BA rate diff	BA rate diff	
								6.6 [C]	5.9	-.7
Sung (1997)	Adherence	RCT	Community based	18-97	Black women	48% < 15,000	In home education by lay health workers [A]	Baseline n:	Baseline n:	
								158	163	
								Baseline rate:	Baseline rate:	
								51.9	50.3	
								Followup n:158	Followup n:163	
								158	163	
								Followup rate:	Followup rate:	
								BA rate diff	BA rate diff	
								62.1	58.7	-3.4

Footnote: [A.] Lay health workers visited from a community-based women's health organization.

Colorectal Cancer and Prostate Screening Interventions

Author	Disparity Type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	ABS Rate Difference
Powe (2002)	Fecal Occult Blood Testing (FOBT)	RCT	Women at 15 senior centers in South	Aged 50-94 mean age 75	Black women	Low Income	Cultural and Self empowerment group [A]	N: 29	N: 40 [B] N: 37 [C]	
								BL rate: 10	BL rate: 65 [B] BL rate: 43 [C]	
								f/u rate: 7	f/u rate: 63[B] f/u rate: 34 [C]	
								BA rate diff: -3	BA rate diff: -2 [B] BA rate diff: -9 [C]	
Myers	Prostate cancer screening	RCT	University of Chicago	40-70	100% Black Men		Print Material and telephone contacts [A]	n: 206 [B] minimal intervention	n: 207 [B] enhanced intervention	
								Baseline rate: [C]	Baseline rate:	
								f/u rate: 29	f/u rate: 51	

Footnotes: (Powe) A. Intervention groups were broken out into cultural self-empowerment groups and modified cultural groups who only received phase 1 of the intervention. B. Cultural and self-empowerment groups. C. Modified cultural groups. Intervention groups had significantly higher rates of screening than the control groups but not within groups across time. (Myers) A. Those in the control group received screening reminder letters. Those in the experimental group received the same letters as well as other printed materials and telephone contacts. B. Estimated control and experimental group numbers. C. No baseline numbers available.

Author	Disparity Type	Design	Setting	Age	Target Group	SES	Intervention	Findings Control Group	Findings Intervention Group	ABS Rate Difference
Weinrich 1998	Prostate cancer screening	RCT	222 community sites central South Carolina	40-70	71% black men	59% below 25,020	Peer educator [B]	n: 275 traditional [A]	n: 232	
								Baseline Rate: [D]	Baseline Rate: [D]	
								f/u rate: 57.1	f/u rate: 62.5	5.4
Weinrich 1998	Prostate cancer screening	RCT	222 community sites central South Carolina	40-70	71% black men	59% below 25,020	Client navigator [C]	n: 275 traditional	n: 287	
									f/u rate: 57.1	f/u rate: 70.2	13.1
Weinrich 1998	Prostate cancer screening	RCT	222 community sites central South Carolina	40-70	71% black men	59% below 25,020	Combination peer educator + client navigator	n: 275 traditional	n: 320	
									f/u rate: 57.1	f/u rate: 70.3	13.2

'Footnotes: A. Traditonal intervention was a slide tape program, handout, and question and answer with a nurse. B. Peer educator added to the traditional with testimony for screening by a man who was the same race as participants. C. Client Navigator was modeled on American Cancer Society's demonstration project in Harlem. Men in this intervention were called by a professional a week after the educational program. Barriers to screening were then navigated. Prompts included a calender, fridge magnet, and key ring. D. Baselines only provided by race, not intervention group.

CANCER PREVENTION AND TREATMENT DEMONSTRATION FOR ETHNIC AND RACIAL MINORITIES: Evidence Report
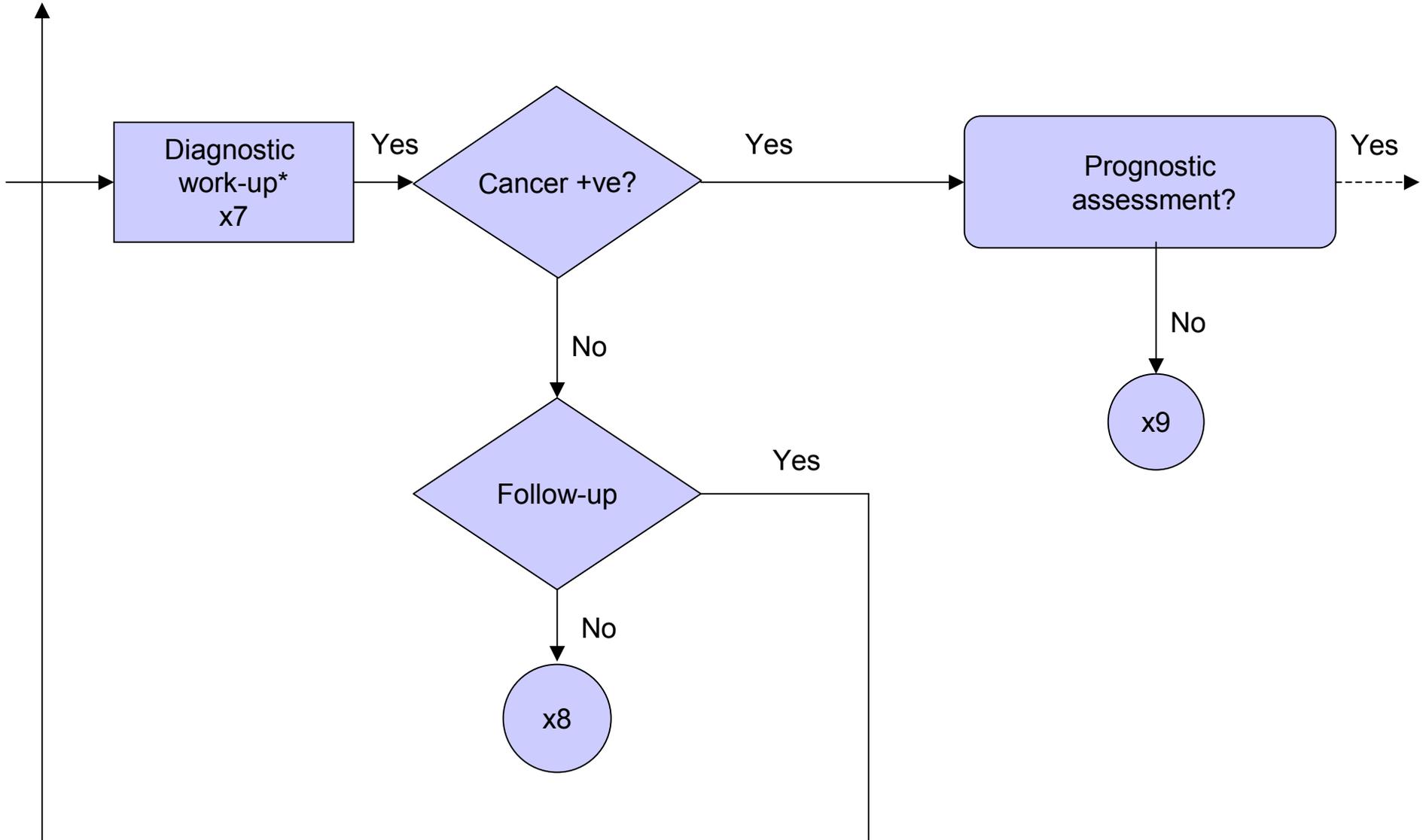
Appendix II

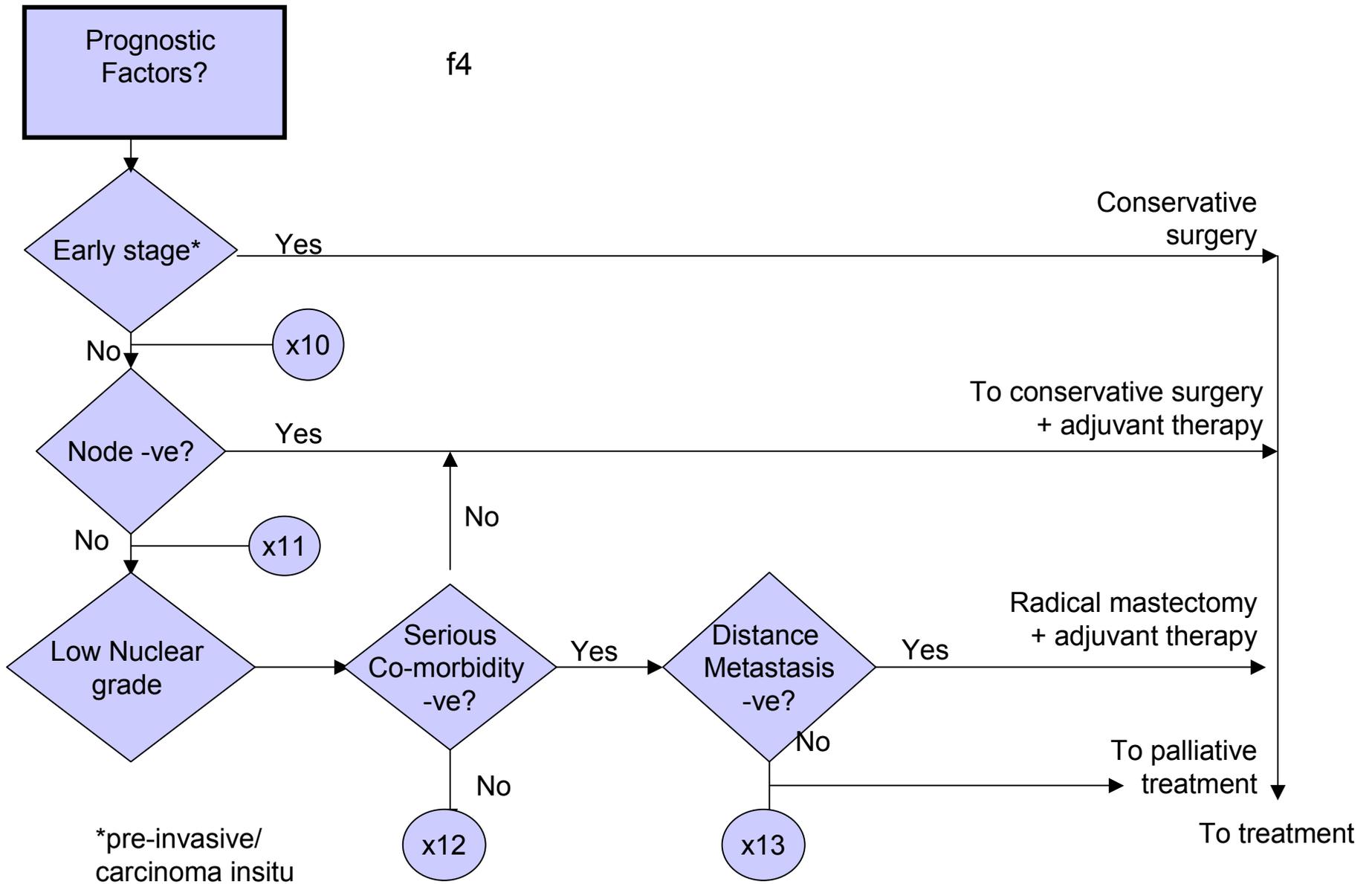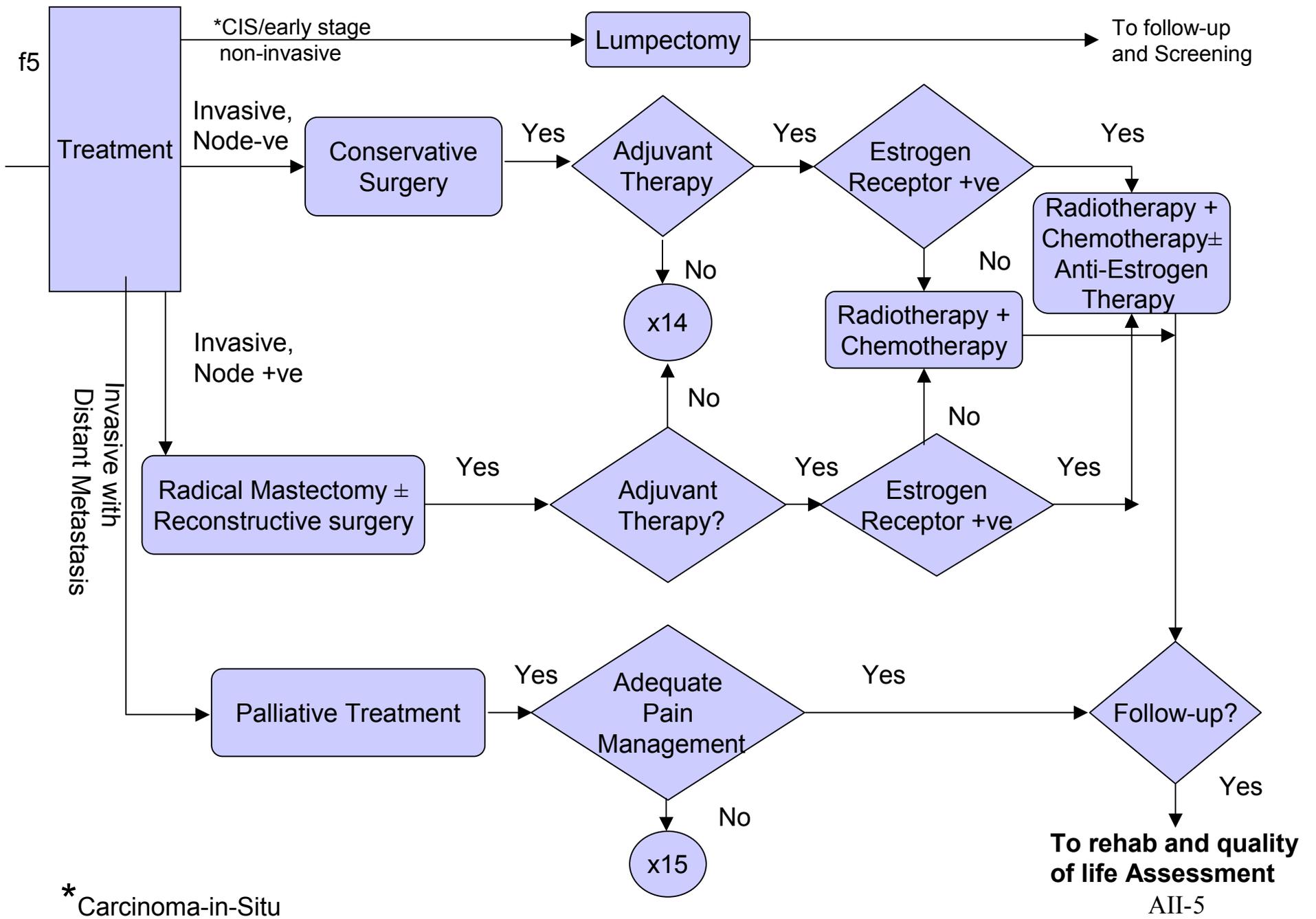## Sequential Logic Model for Breast Cancer: Identifying Potential Sources of Disparities Along Model of Care

f1

Incidental Discovery?

x2

Yes

(Population at risk) <u>Risk factors</u>

Yes

Risk Assessed /aware?

Yes

No

<u>Screening?</u> Mammography, CBE, BSE, ultrasound*

Yes

Screen +Ve?

Yes

Palpable mass?

Yes

Yes

No

x1

f2

No

Yes

Tissue biopsy

x3

No

x4

No

Ultrasound/ needle biopsy?

x5

No

Yes

Yes

Follow-up?

Yes

No

Wait and see 6 monthly follow-up

Screen +Ve?

Yes

To diagnostic work-up

Yes
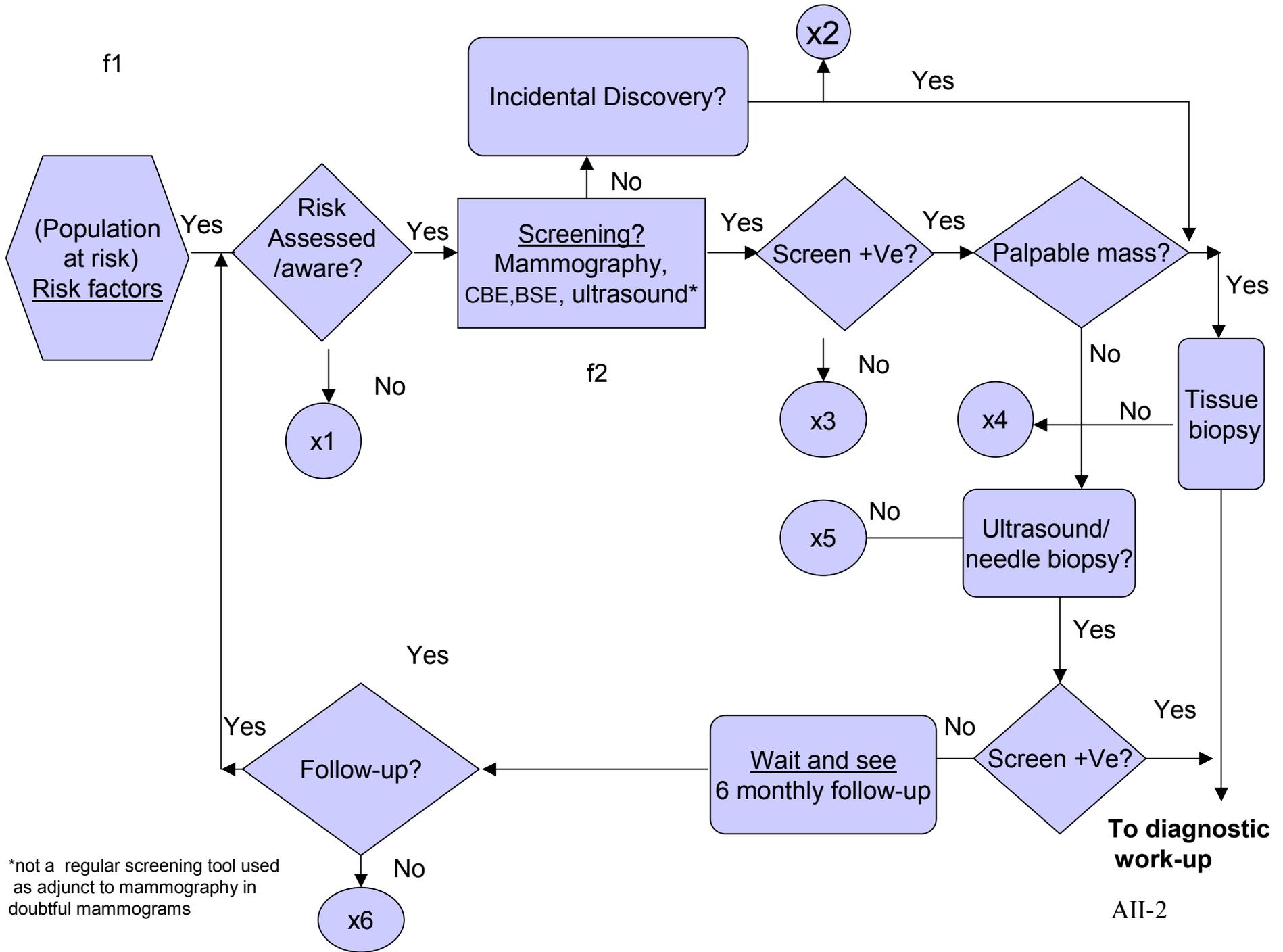
*not a regular screening tool used as adjunct to mammography in doubtful mammograms

No

x6

AII-2

To Risk assessment/
screening

f3

Diagnostic
work-up*
x7

Yes

Cancer +ve?

Yes

Prognostic
assessment?

Yes

No

Follow-up

Yes

No

x8

No

x9

AII-3

Prognostic Factors?

f4

Early stage* — Yes → Conservative surgery

No

x10

Node -ve? — Yes → To conservative surgery + adjuvant therapy

No

x11

No

Low Nuclear grade

Serious Co-morbidity -ve? — Yes → Distance Metastasis -ve? — Yes → Radical mastectomy + adjuvant therapy

No

x12

No

x13

No → To palliative treatment

To treatment

*pre-invasive/ carcinoma insitu

AII-4

f5

Treatment

*CIS/early stage non-invasive → Lumpectomy → To follow-up and Screening

Invasive, Node-ve → Conservative Surgery → Yes → Adjuvant Therapy → Yes → Estrogen Receptor +ve → Yes → Radiotherapy + Chemotherapy± Anti-Estrogen Therapy

Adjuvant Therapy → No → x14

Estrogen Receptor +ve → No → Radiotherapy + Chemotherapy

Invasive, Node +ve → Radical Mastectomy ± Reconstructive surgery → Yes → Adjuvant Therapy? → No → x14

Adjuvant Therapy? → Yes → Estrogen Receptor +ve → No → Radiotherapy + Chemotherapy

Estrogen Receptor +ve → Yes

Invasive with Distant Metastasis → Palliative Treatment → Yes → Adequate Pain Management → Yes → Follow-up?

Adequate Pain Management → No → x15

Follow-up? → Yes → **To rehab and quality of life Assessment**

AII-5

* Carcinoma-in-Situ

To risk assessment and screening

Rehabilitation
and quality of life
assessment

f6

Reconstructive
Surgery?

Yes

Survival
analysis

5 - 10 year
Survival?

Yes

Disease free
Survival?

**To quality
of life
Assessment**

No

x16

x17

No

x18

AII-6

To risk assessment and screening

Health Related Quality of Life HRQOL?

Physical Component

Yes

Mental/ Component?

Yes

Social Functioning

Yes

x19

x20

x21

Follow-up

Yes

Recurrence prevention

No

x21

AII-7

CANCER PREVENTION AND TREATMENT DEMONSTRATION FOR ETHNIC AND RACIAL MINORITIES: Evidence Report

Appendix III

Protocol Project Forms:

Telephone Contact Log

Case Study Screening Questions

Site Visit Protocol

Case Study Report Outline

Emerging Community Models
Telephone Contact Log

Organization Name: _____

CALL #	INT. INIT.	DATE (mm/dd/yy)	DAY OF WEEK	TIME	DISPO	COMMENTS
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						

Telephone Dispositions:
NA: No Answer   PNI: Phone Number Incorrect
BZ: Busy   CH: Phone # Changed
CB: Call Back   DIS: Phone Disconnected
VM: Answered by Voice Mail   POS: Phone out of Service
RF: Refused   TPOS: Phone Temporarily Not in Service
INT: Interview Completed

Complete Community Program Name: _____

Target Population(s): _____

Type of Cancer(s): _____

How Long Program in Operation: _____

Relevant Documents to be obtained: _____

Contact Person: _____

Title: _____

Address: _____

Phone Number: _____

Fax Number: _____

E-mail: _____

CMS - Case Study Screening

Program/Initiative Name:

Sponsoring/Administering Organization(s):

Starting Date of the Program:

Contact Information

Name:

Title:

Organization:

Address:

City:

State:

Zip Code:

Telephone:

Fax:

Email:

Website:

Program Description

1. Please describe your organization. What is the range of programs/services offered by your organization?

2. What are the objectives of the program (e.g., clinical trial, case controlled study, health promotion)? Please describe the specific problem it addresses.

3. What population/group does the program target (e.g., R/E group, age, gender, SES)?

4. What risk factor(s) does the program address (i.e., smoking, substance use, nutrition, exercise, sexual practices, other)?

5. What type(s) of cancer does the program address?

6. What organizations participated in the implementation of the program?

7. What other agencies (e.g., government, public or private sector, community-based organizations, etc.) do you have formal contractual relationships with?

Program Effectiveness/Achievements

1. What data do you collect to measure program success?

2. What data do you collect to measure individual success?

3. What is the major learning, or most important significant achievement of the program? Provide documentation, if possible.

Program Costs

1. Does the program have a Management Information System? If so, who manages this system? What is his/her contact information?

2. Who manages Financial Data for the program? What is his/her contact information?

3. Does each of the organizational delivery units of the program have the following data sources available?
   a) Recent Annual Financial Statements
   b) Up-to-date Full-Time, Part-Time and Contract Personnel Lists
   c) Hours Worked, Salary and Fringe Rates for Full-time and Part-Time Personnel
   d) Hours Worked and Hourly Rates for Contract Personnel
   e) Non-Personnel Resources and Costs (Ex. Phone, Building Space, Office Supplies, Computers)
   f) Depreciation and In-Kind Resources and Costs
   g) Indirect Cost Rates and Associated Resources
   h) Number of Persons Served by the Program

Program Sustainability

1. What is the funding source(s) of the program?

2. How much longer is the program funded for?

3. We will select a number of programs to learn more from through site visits. Would your program be willing and interested in participating in our series of site visits?

Brandeis Site Visit Protocol
For Cancer Programs Seeking to Reduce Racial and Ethnic Disparities

This Site Visit protocol is written in the spirit of providing a model for all site visits to selected cancer prevention/treatment access programs while, at the same time, retaining the flexibility needed to adapt to the varying characteristics and data availability among sites. Site visit team members will have reviewed as much material as possible about the site in advance, and will develop specific probe questions as follow-ups to general topics based on this preparation.

I. Site Visit Objectives

    a. To understand the program's perspectives about the magnitude and causes of racial/ethnic disparities in cancer prevention, treatment, and outcomes in the community.

    b. To understand the organization, goals, operations, outcomes and costs of the project/initiative.

    c. To understand the program's perspectives on the evidence that the program is achieving its goals or preventing or reducing the burden of cancer for communities of color.

    d. To understand the program's perspective of the key problem areas and success factors for this project and similar projects/initiatives.

    e. To learn about the program's recommendations for key elements that should be included in Medicare demonstrations addressing racial/ethnic cancer disparities.

II. Preparation for Site Visit

    a. Use telephone screening information to identify key organizational components, key contacts, and specific screening or educational interventions of the program we want to focus our attention on

    b. In some cases, a site may wish a letter in advance. If so, use the electronic pre-schedule visit and follow-up with Linda Purrini to send a hard copy.

    c. Schedule the site visit and develop a list of specific key contacts that Brandeis site visitors will meet with (schedule meeting times and locations if possible)

    d. Contact Vanessa Calderon-Rosado (vcrosado@brandeis.edu) with site visit dates after scheduling has occurred with the site

    e. Send official Brandeis letter to site via e-mail with electronic letter head and follow up with Linda Purrini to mail paper copy to the site

    f. Begin to identify, in collaboration with the program, specific types of data available on program structure, operations, outcomes and costs

g. Obtain available documentation, including proposals, mission statements, annual reports, organizational charts, process, outcome, budget, or resource cost data prior to the site visit.

h. Schedule a meeting with John Capitman and/or Sarita B and one of our cost effectiveness experts—(Stason, Shepeard, Constantine, Blaakman) to review all the materials you have collected and to formulate more detailed goals for the visit.

i. Respond to any further inquries as necessary from the program.

j. Develop an agenda and specific questions tailored to the site visit

III. Broad Questions and Specific Prompts To Achieve Site Visit Objectives

1. What is the magnitude of racial/ethnic disparities in cancer prevention, treatment and outcomes in your community?

   1a. What evidence do you have to support this?

2. What do you think are the causes of racial/ethnic disparities in cancer prevention, treatment, and outcomes in your community?

Program Services, Goals and Objectives

3. What are the goals and objectives of your program?

   3a. How you do you know that your program is achieving its goals and objectives?

4. What risk factors does your program target?

   4a. Smoking? Drinking? Exercise? Obesity?, Nutrition, etc?

5. Could you please describe in detail the various populations that you serve?

   5a. Socioeconomic Status?
   5b. Racial/Ethnic Mix?
   5c. Health Characteristics and Insurance Coverage?
   5d. Availability of Primary Care to the Population?
   5e. Do they encounter barriers to care and treatment?
   5f. What is the catchment area of the population you serve?

6. How do you deliver services?

   6a. What types of screens do you do?
   6b. What are you doing to get people screened?
   6c. What are you doing to follow-up with these clients?

6d. Could you please provide details about the Community/Health Workers Promotora (e.g. recruitment, eligibility, training, certification, payment levels, benefits, supervision, job tenure)?

6e. What steps are you taking to ensure quality of care?
6f. What steps are you taking to ensure continuity of care? (Please describe in detail the methods for followup with clients? How do you identify/flag persons for follow-up, who does this role, how often, can you connect persons to providers, do you work with insurance eligibility problems, do you contact providers directly for follow-up?)

6g. Please describe any behavioral interventions used.
6h. What would you do differently?

7. What steps do you take to culturally tailor your interventions?

7a. What are the program elements that reflect a detailed understanding of the worldview, life experiences, or current circumstances of persons in the targeted racial/ethnic groups?
7b. Has the incorporation of these elements been successful?

Program Organization

8. Could you please tell me about the history of the program?

8a. Who participated in the program design and early implementation?
8b. What community or institutional factors guided the program design?

9. What are the program's funding sources?

9a. Do you know the respective proportions to total funding?
9b. Do these funding mechanisms influence the program's operations? If yes, how so?
9c. What, if any, are the financial barriers to implementation or maximizing improvements in individual and program outcomes?

10. Is there a parent organization?

10a. If so, what is its name and structure?
10b. Do you have an organization chart?

11. Are there organizational partners?

11a. What are their names and roles?
11b. Are there any academic affiliations?

11c. Are there any field components?

11d. How does these partners work together?

12. Can you please describe any community health system linkages you might have?

12a. Do these seem to work? If not, what could be different?

13. How is your program staffed? (Including Number and Categories of Staff)

13a. Would you make any changes to the type of staff that are hired by the program?

14. How you do keep track of and share information in your program?

14a. Do you use computers?

14b. What are the computers used for?

14c. Who keeps track of financial information?

14d. Who keeps track of program or participant outcome information?

15. Has there ever been an evaluation of your program in the past?

15a. If so, by whom?

15b. Can we obtain a copy of the report?

Program Participant, Activity, and Results Data

16. Do you have data regarding the following that we might be able to obtain either by getting a copy of the data, requested reports, or analyses?

16a. Descriptive Data about Program Participants

Examples. Types of Clients Served, Ages, Racial/Ethnic Make-Up, Cancers, etc.

16b. Program Activity Data Pertaining to Interventions

Examples. Number of Participants Educated, Number of Clients Screened, Success of Follow-Up After Screening, etc.

16c. Results or Outcomes

Examples. Number of Cancers Detected, Stages of Cancer Detected, Cancer Treatments Provided (Extent to which they represent the "standard of care"

Program Resources and Costs

17. Do you have data regarding the following resource and cost data that we might be able to obtain either by getting a copy of the data, requested reports, or analyses?

    a. Program Budget for the Last Fiscal Year
    b. A List of All Paid Personnel, their hours worked per week, hourly or annual salaries, and fringe rates for the same fiscal period.
    c. A List of all Unpaid Personnel (Volunteers) and hours worked per week.

If staff contribute their time to two or more programs, could you estimate the time these staff spend working in the program of interest?

18. Do you have information about non-personnel costs, such as screening tests, laboratory studies, treatments, and other program non-personnel expenses?

19. Do you have information about other overhead costs such as space, telephone, and utilities? (Note: These will need to be allocated to the program if accounted for seperately or shared with other programs.)

20. Do you have information about capital costs, or the program's investment into equipment, furniture, or buildings?

21. Do you have information about depreciation of assets?

22. Do you have data about client borne costs such as the cost of traveling to the intervention?

23. Do you have any information about client average hourly rates of pay?

24. Do you have any information about projected savings attributable to the program?

25. What resources that are currently unavailable to you might help to increase the impacts of your program?

Recommendations for Key Elements that should be included in Medicare Demonstrations

26. We have been asked to make recommendations for new benefits (paid as reimbursements for specific services fee-for-service) or program requirements (in managed care organizations) that Medicare might explore as ways to reduce racial/ethnic disparities in cancer and health. Thinking about your experiences with the sources of disparities for older people in your community, and the successes and challenges experienced by your program, what are your recommendations about key elements from your program or others that should be included in Medicare Demonstrations addressing racial/ethnic cancer and health disparities?

CMS Project Report: An Evidence Report on Racial/Ethnic Disparities in Cancer
Case Study Report Outline

Each case write-up should address all five areas that form the basic goals of the case study. These goals are as follows:

a. To understand the program's perspectives about the magnitude and causes of racial/ethnic disparities in cancer prevention, treatment, and outcomes in the community.
b. To understand the organization, goals, operations, outcomes and costs of the project/initiative.
c. To understand the program's perspectives on the evidence that the program is achieving its goals or preventing or reducing the burden of cancer for communities of color.
d. To understand the program's perspective of the key problem areas and success factors for this project and similar projects/initiatives.
e. To learn about the program's recommendations for key elements that should be included in Medicare demonstrations addressing racial/ethnic cancer disparities.

The case study outline is intended to track closely with the specific topical areas and probes established for the case studies.

A: Overview: (1/2 page)
   1. Location (state, town, urban/rural, primary community demographics if applicable)/ Setting (ie church, clinic, hospital, community/university link).
   2. Sponsoring organization and leadership, project to organization size (e.g. small effort in larger setting, a purpose built org', etc) and major organizational partners
   3. Current status (gearing up, shutting down, steady state), funding, overall budget
   4. Target population(s) (race/ethnicity, age, gender), target cancer(s), target behavior change (e.g. prevention, screening, dx, treatment, follow-up) (The project serves _____ with the goal of reducing _____ (a cancer) by _____ (an intervention to change someone's behavior.)
   5. Principle interventions—education, screening, care management etc. …. and unique features (This site was selected for a case study because……..)
   6. Measure of outcome (proximal and/or distal) and estimated cost/unit of outcome.

B: Theory of Change and Primary Learnings (address goals a., d., and e.) (3/4 page-1page) (this section is based on what program says about its goals, rationales, learning, and recommendations---in this section we are sharing their perspective).
   1. What the program sees as biggest source of race/ethnic cancer disparities in their community
   2. How program activities are designed to/intended to address this problem?
   3. How program would measure success? What program points to as evidence for success?

4. What program sees as principle learnings about barriers and facilitators to success
5. What program would like to see in a national Medicare demo.

C: Organization and Operations (address goals b and d). (1—1.5 pages—4 paragraphs) (This section focuses on what we learned about how the program works and how organizational history, organizational context, community context, and funding shaped the program. This is the place to talk about cultural tailoring and special aspects of the design that strike us as sources of important lessons).

1. Program outreach/marketing design and targeting: More on the details on who the program does and does not serve and how they determine eligibility/appropriateness. How does the program reach out to the community and how are individuals engaged in the program. End paragraph by highlighting how the organizational/community/funding context influences targeting and outreach.
2. Details about program operations---run through a sequential description of how an individual interacts with the program—focus on how contact is made and maintained with individuals. End paragraph by highlighting how the organizational/community/funding context influences this program operation.
3. Describe how the program is culturally tailored—what is it that they do that reflects an understanding of the target population and community---what are the elements of their cultural tailoring that can be replicated elsewhere. End paragraph by highlighting how the organizational/community/funding context influences this approach to tailoring.
4. Focus more on central potential billable service components---eg, professional roles such as community health worker, navigator, chronic disease manager, care manager or specific service activities, such as classes, behavior change workshop, funding complementary service, establishing order of payment responsibility.

D: Resource Requirements, Effectiveness, Costs, and CE (CE = Cost effectiveness) (this is the part where we tell as detailed a story as we can in 1 page on measurement of costs and outputs, and any learnings/conclusions about cost-effectiveness. Also, we should detail our concerns with the accuracy of cost estimates here. Anything we learn about program elements that would increase/decrease cost-impact relationships in a replication should be highlighted here.) (1-1.5 page)

1. What measures of program output and impact are available? What do they show? How might these change were the program in a different operational phase or organizational/community context?
2. How detailed an estimate of total project costs and costs per unit of output or cost per unit of impact can we develop? What does this show? How convinced are we that that this is fair? How might these change were the program in a different operational phase or organizational/community context?
3. Does the program see and/or do we see ways that cost/output or cost/impact relationships might change in a replication? Does program have recommendations for improving CE? Have we identified other factors that might improve CE?

E: Conclusions (1/2 page)
1. What we see as the major take-away messages from this site? What did cite see as major barriers and facilitators during implementation? What else did we see as take-away messages
2. Any specific learnings about potential billable service components?
3. Any additional comments or learnings.

CANCER PREVENTION AND TREATMENT DEMONSTRATION FOR ETHNIC AND RACIAL MINORITIES: Evidence Report

Appendix IV

Case Study Reports:

Emerging Models for Cancer Disparity Reduction

Access Community Health Network

Chicago Racial Ethnic Approaches to Community Health 2010 (REACH 2010)

Overview

Chicago Racial Ethnic Approaches to Community Health 2010 (REACH 2010) (REACH 2010) is a faith-based health promotion program designed to promote early breast and cervical cancer detection among low and moderate income African American and Latino women in Chicago (IL). The lead agency is Access Community Health Network, the largest network of health centers in Chicago representing 23 different sites and serving 210,000 patients a year. Access partnered with 9 African American churches and 8 Latino Catholic parishes. The main objective of the program is to improve education about breast and cervical cancer and increase utilization of cancer screening within the target population. The principle intervention is education: health seminars (and related health messages), implemented by and within the participating churches, aimed at increasing knowledge about breast and cervical cancer. The project is in its second year. Northwestern University's Institute for Health Services Research and Policy Studies is a partner in the project and is evaluating the efficacy of the intervention. The primary measure of outcome is increased knowledge about breast and cervical cancer. The program is funded by the CDC as part of its national REACH 2010 program.

Theory of Change and Primary Learnings

When asked about what they see as the biggest source of race/ethnic cancer disparities in their community, REACH 2010 staff identified three main factors. The first is education: among the target population, the understanding that patients have some control over the likelihood that they will have cancer as well as some control over the course of the disease, should they get cancer, is not well understood. The second major factor is economic: the target population does not have the resources to get all the care they need. The largest problem here is access to mammography services and other specialty cancer care. While the health centers can provide breast exams and provide the primary care referral that is needed for a mammography, there is only a limited supply of "free" mammography services (here we are obviously talking about folks who have no insurance. The final factor is fear and related to that a basic distrust of the medical system. Tuskegee still looms large, especially among African American populations. Among the Latino population, many are undocumented, which fuels a different kind of mistrust. In addition, persistent language and cultural barriers continue to make it hard to bridge that mistrust and calm fears.

REACH 2010 is designed to address the education factor, although they also address the economic issue in so far as they work hard to obtain donated mammography services. Language and cultural barriers are also naturally addressed in so far as the target population comes to the health center for breast exams and pap smears, but it is not the focus of the intervention per se. Program activities include a series of interventions designed to educate the target population about breast and cervical cancer. "Advocates," volunteers, who are members of the church, are trained to lead these interventions. At a minimum, each Advocate leads a basic education health seminar. The Advocate participates in a training session, organized by Access and Northwestern staff, prior to running the actual seminar. Specific topics covered by the seminar include: defining cancer in general and breast and cervical cancer in particular; risk factors that can and cannot be changed; incidence, survival and mortality; early detection and screening strategies; and diagnosis, prognosis and treatment options. In addition to the basic education seminar, each Advocate (and Church) has the choice to implement other education interventions as well (considered variable interventions by the evaluators). These include testimonies, health fairs, broadcast ministries, reminders, individual education, etc.

As mentioned, Northwestern University is the evaluator for the project. They are defining and measuring success by the level of knowledge that is obtained by participants as a result of the health seminars. They have designed a pre – and post test methodology (applied to the whole congregation as well as to the sub-group who participates in the basic education seminar). Seminar participants are surveyed before and after they have sat through a health seminar. The survey queries respondents about their understanding of breast and cervical cancer. Although their survey instrument focuses on measures of knowledge and understanding about breast and cervical cancer, a recent presentation made by the evaluation team and the Annual Meeting of the American Public Health Association, suggests that they are also tracking the number of pap tests and mammograms following the implementation of the education session. There is no base line data on which to assess change in utilization, however.

What program sees as principle learnings about barriers and facilitators to success? One issue that has arisen is the limitation of outreaching the target population through Churches. This was especially true among the African-American churches. Although all 9 African-American churches are located in low-income inner-city neighborhoods, their membership is largely coming from the suburbs (families who used to live in the city, or whose parents used to live in the city and who have maintained a tie to the neighborhood church). As a result, the outreach effort targeted a higher income population than intended. This was not a problem in the Latino parishes because parish members were much more likely to come from the surrounding low-income neighborhood. As a result, program administrators feel their next phase should be to role out the model in storefronts and other venues that attract residents of the immediate neighborhood.

The program would like to see an increased role for churches and lay health advisors in reducing racial and ethnic disparities in cancer. Lay health advisors could provide a series of reimbursable services to assist clients in gaining access to knowledge about screening

and navigating the health system to received services. Churches could be one organizational component through which potential clients are acquired through outreach efforts.

Organization and Operations

Program outreach/marketing and targeting is done within the participating churches. In each church, the pastors have agreed to participate in the program and to incorporate health messages into their services. It is through the pastor that church members learn about the health seminars. The idea here is that pastors have a lot of power with church members and can thus act as relatively persuasive outreach workers. In each church, a volunteer advocate is identified: a member of the church who agrees to lead the health education seminar and in general act as the link between church members and the health care delivery system. Access staff work very closely with the advocate in all phases of the project and the advocate goes through a formal training, prior to running a seminar, organized by Access and Northwestern University.

Church members first hear about a health seminar being held in their church or parish through the pastor. As noted, an announcement would be included as part of his/her sermon. If interested, the church member would participate in the health seminar, typically held in the church during the weekend. An advocate, with assistance from Access and Northwestern staff would organize the seminar (food is usually served and advocates are encouraged to tailor the seminar to the particular character of their parish; some include prayer, others include testimonials, etc). Following the seminar, it is up to the advocates to act as agents for members of his/her church as individual issues arise (i.e., we heard a bit about advocates who are contacted by a church member who is diagnosed with cancer and needs help; the advocate then contacts Access staff who assists with access to appropriate services). There is no formal follow-up with participants, however (i.e., no one is checking up to see if participants are getting regular pap smears and breast exams and mammography's). And, there is reportedly a lot of variation among the Advocates in terms of how engaged they are with the program (and how proactively they act as "advocates") which clearly determines, in part, the level of participation among church members.

The program is culturally tailored by employing members of each church to act as Advocates. In addition, Access has assigned two staff person to lead the program, one an African-American woman and the other a Latino woman. Although they both devote time to each of the participating churches, the African-American woman takes the lead with the African-American churches and the Latino with the Latino parishes.

Potential billable service components include the role of the Advocate. Each Church is given $10,000 to participate in the program ($5000 of which is provided for the advocate).

Resource Requirements, Effectiveness, Costs, and Cost-Effectiveness

A limited amount of information was provided regarding total program costs (we are still trying to acquire these data.) Assuming a total congregation of about 1000 people, the cost of delivering the information through the church in the best case scenario is about $5 per person or $10 per female participant (since the focus is on breast and cervical cancer). However, the cost is likely to be much higher since only a small proportion of each church's members interact with the cancer advocate.

Conclusion

The major take away from this site is the challenge of implementing a church/parish-based effort and using lay workers to manage much of the intervention. Although there are clear advantages to outreaching target populations via their church/parish and in using members of the church/parish as the primary liaisons, it resulted in huge variability in the skill and commitment of the Advocates. In addition, outreaching African-Americans via churches proved to target the wrong income group and as such, a faith-based approach may not be ideal for this racial group. In addition, we heard a lot from this site about the frustration and limitation of a program that funds outreach and education activities while not funding related services. The difficulty of securing mammography services for women who have no insurance in this community is substantial. There is something almost cynical about educating populations about the risk of cancer and then providing no funds for services should they need a mammography and worse, cancer care. One is reminded about the saying that "ignorance is bliss." The program has no specific procedure or mechanism for getting a person into screening and no specific procedure or mechanism for ensuring that anyone with a positive screen actually gets to services. Although the research design does not seem adequate to draw impact conclusions, staff experience suggests that similar educational inteventions withouth a specific method for managing screening may not adequately address needs.

American Cancer Society Heartland Division

Patient Navigator Program

Overview

The Patient Navigator Program was developed as a partnership between Truman Medical Center (TMC), American Cancer Society (ACS) Heartland Division, and the Samuel Rodgers Community Health Center. Most program activities are based at the Truman Medical Center, the principle "safety net" acute care provider for Medicaid and indigent care patients in Kansas City, MO and the major teaching hospital for the University of Missouri at Kansas City Medical School. The program was initially conceptualized by the late Samuel Rodgers, MD, a prostate cancer survivor and founder of the first Federally recognized community health center in the area that now bears his name and Nancy Moylan, ACS Heartland Division Outreach Director. Cynthia Robinson of the TMC Charitable Foundation spearheaded fundraising for the project and lead development of grant applications. The program was planned as a replication of the Patient Navigator model pioneered by Dr. Harold Freeman and colleagues at Harlem Hospital in New York. In addition to initial four-year funding of about $253, 000 from the Robert Wood Johnson Foundation's Local Initiatives Program, the project has received over $500,000 in local support from the Greater Kansas City Affiliate of the Susan B Komen Breast Cancer Foundation, the John W. and Elfie E. Speas Memorial Trust, Bank of America, and other sources. Originally, funded in August 1998, the program became operational in 1999 and has sufficient funding in hand to maintain current operations through July of 2003. It is expected that sponsoring institutions and ongoing local grant support will continue the program thereafter.

The project now serves about half of the TMC cancer patients (about 150 persons/year) with the goals of reducing the time frame (latency) between an initial suspicion of cancer (based on screening findings or referral) and initiation of cancer treatment or other case resolution, increasing adherence to recommended courses of cancer treatment and followup, and improving quality of care/patient satisfaction for cancer patients served through TMC. The Patient Navigator program seeks to achieve these goals through patient education and support, assistance with the scheduling and coordination of services, referrals for supportive services, and assistance with transportation and other potential barriers to adherence. The project measures or plans to measure screening to treatment latency, completion of recommended treatment and adjuvant services, and satisfaction for participants at an estimated average cost per completed case of $700.

Theory of Change and Primary Learnings

According to Michael Penner, the Patient Navigator Project Director whose time is fully supported by the ACS Heartland Division, and Dr. William Jennings, Director of the

TMC Oncology Clinic and Principal Investigator for the Patient Navigator Program, the program is designed to address socio-economic, cultural, and care system barriers to receipt of appropriate cancer care by persons from low SES and traditionally underserved racial/ethnic groups. The racial/ethnic groupdistribution of clients served from August 2000 thru July 2001 was as follows: 47.5% African American, 36.9% European American, 10.9% Hispanic, 1.1% Native American, 1.1% Vietnamese.

Program initiators had observed an average latency of between 3 and 6 months between initial suspicion of cancer (based on screening findings or practitioner observations) and receipt of treatment. It was felt that patients were less likely to receive timely diagnosis and treatment implementation, as well as being more likely to experience subsequent difficulties in completing treatment plans, because the large publicly-focused tertiary care hospital was hard to get to, intimidating to negotiate, and inadequately responsive to the multiple social and economic challenges faced by prospective cancer patients. While these hypothesized barriers have been observed and addressed, patient navigator staff have also identified a number of specific system of care barriers for persons referred by the community health center and other primary care providers for diagnostic testing and treatment at TMC. Among these are difficulty in scheduling appointment, long wait times, failure to provide written discharge instructions in a format and language that patients can use, and cultural factors in interactions between patients, patient families, and hospital staff. The program did not identify or seek to address barriers to appropriate care for elders of color who are Medicare beneficiaries, but about 25% of program participants and TMC oncology patients are Medicare or Medicare/Medicaid dual enrollees and about 50% of program participants and TMC oncology patients are persons of color.

The Patient Navigator program seeks to address these socio-cultural, economic, and system of care barriers in several ways by targeting case management and patient education services to any TMC oncology patient who is identified as needing support. Individuals are typically referred to the patient navigator program by other providers if they miss appointments, need transportation assistance, have inadequate informal support, need of translation services, have co-morbid psychiatric or behavioral health diagnoses, or other service use barriers. There are two nurses and an administrative assistant who work with an average of 35 patients in each month. One nurse devotes about 1/3 of her time to participation in multi-institutional cancer control initiatives and outreach activities, and the remainder managing new cases referred outreach activities at the community health center and other primary care sites and the TMC clinics. The second nurse focuses primarily on managing inpatient and follow-up care for cases identified within the hospital. Both nurses coordinate with oncology service, breast cancer program, head and neck cancer program, and other clinic staff and social workers, the hospital's interpreter services, and providers of radiotherapy (not available at TMC). They also devote significant attention to answering patient questions about their treatment and providing counseling and emotional support around many of the concerns that arise throughout the cancer experience. The administrative assistant arranges for transportation to TMC for program participants, loaning out of cell phones to patients

without adequate means to telephone to their care providers, and other gap-filling benefits funded through the program.

The Patient Navigator program has found it difficult to develop and maintain a set of interventions that fit with the changing clinic structures and staff needs at both TMC and the community primary care providers. There is a belief that, although the program design has matured notably over the demonstration period, improvements are still needed. One of two major gaps have been the development of an automated patient tracking and evaluation system and identification of a mechanism to track comparable screening-to-treatment latency and treatment completion/adherence data for TMC and health center patients whether or not they receive personalized patient navigator services. Implementation of these systems would greatly support cost-effectiveness analyses of the program. Another barrier has been changes in staffing patterns and operations at the health center and difficulties in developing effective systems for identifying patients referred from the clinic or other sources to TMC for oncology diagnostic or treatment services. Over the three years for which data are available the program has received increasing numbers of referrals each month and the screening-to-treatment latency has dropped from an average of 44 days to an average of 28 days. Further, patients, TMC staff and partner agency representatives all report a high level of satisfaction with the program. Data are not currently available on treatment completion/adherence impacts of the program, the length of the total treatment process, or any measures of clinical impacts or cost-effectiveness.

Program participants and sponsors feel convinced that there is a need for an advanced professional---a registered nurse – to assist low-income persons and some members of racial/ethnic minority groups in utilizing larger tertiary care facilities and in understanding and adhering to a complex course of clinical interventions required for successful diagnosis, treatment, and follow-up of cancer. They believe that the advanced professional has the oncology and health system expertise to gain credibility from both patients and other professionals within the health system. This advanced expertise is seen as necessary to address complex questions and concerns that patients and families need help facing during the treatment process and to recognize when various levels of intervention are required to continue positive movement in the course of treatment. The project is not viewed as fully meeting its goals with respect to integrating care between the community health center, other community primary care sites, and the diagnostic and treatment service of the hospital in part because there has been much more need than anticipated for assistance supporting patient adherence during radiotherapy and chemotherapy. Although not all respondents agree with this proposition, the majority view is that a service like patient navigation is needed by low SES and minority individuals who lack strong informal supports, have specific financial and transportation difficulties in using care, have linguistic or cultural barriers to understanding care choice, or have comorbid psychiatric or behavioral conditions.

Organization and Operations

The Patient Navigator program is organized as a supplement to existing medical management and social service functions within the hospital. As an independent service, it has the capacity to interface among a number of units and programs, becoming a social asset to those patients with the fewest resources to assist them through the diagnostic and treatment process. Although this programmatic focus allows for service to an extremely diverse clientele (with respect to age, cancer diagnosis, treatment regimen, and co-morbid health, mental health, and socio-economic challenges), it also places the program as a risk management initiative that primarily serves patients in reaction to evidence of care problems rather than in a proactive and preventive role.

Program outreach/marketing design and targeting: The Patient Navigator service has been available to any TMC oncology service user. The primary referral sources for the program (see attachment)—the TMC –Mo-BCCP breast/cervical cancer screening program and the TMC oncology clinics ---are other units of the hospital. Patients are referred to the program based on missing an appointment, needing translation assistance, lack of informal support, having requested transportation assistance, having reported homeless/other social/housing crises, coordination with mental health providers also serving the individual, and clinician perception that patient needed assistance in thinking through options. There is no special targeting of elders of color, low SES, or Medicare beneficiaries. Referrals are made by physicians and nurses leading care plan implementation in multiple system of care locations. Very few cases are referred to patient navigator by the community health center at the time of scheduling diagnostic procedures at TMC. This may reflect recent change in the clinic organization and staffing pattern at the Rodgers Community Health Center and other primary care sources that have limited their capacity to collaborate in the project. One of the project nurses spends time each week at each health center, making herself known to staff and prospective TMC Oncology patients. This same nurse participates in numerous breast cancer control and health promotion for women of color initiatives around the community. Program staff and supporters within TMC believe that these activities have notably increased referrals for breast cancer care to TMC by breaking down barriers to using the facility. For the TMC Patient Navigator, developing broad community relations and securing local financial support for this quality enhancing service targeted to traditional under-utilizers was as important as developing the clinical model. The program learned that many stakeholders---health care practitioner, advocates, families, patients, potential donors---seemed to understand the idea of specific gap filling services—transportation, telephone use, child care during treatments----and would support the program to meet these needs.

In actual service delivery, although there is a special focus on breast cancer patients, the Patient Navigator seems to manage care for individuals with such complex care needs or so few resources to manage the stress of treatment that they need additional help. The client is most likely to have in-person clinic or at-home telephone contact with one of the two nurses –based on TMC referral source—because of a missed or delayed appointment

or a clinician perception that additional help will be needed to manage the individual through care. The Patient Navigator has several interactions with the individual to gain rapport and an understanding of their needs. A formal program enrollment is completed with minimal paperwork and the program obtains records and identifies areas requiring attention to ensure continuity of care. The navigator may be in touch with the client around insurance and public benefit enrollment or each session of radiotherapy and chemotherapy to assist with transportation and other issues, although the Patient Navigator Administrative Assistant actually makes transportation arrangements. The program may remain involved even after a person completes all treatment, by for example, contacting someone to assist with scheduling and coming to a post-treatment followup. The nurses emphasized the variety of methods they used to stay in touch with patients—in-person, at clinic arrival, at times of major follow-up screens, in the community---and thus the importance of training in oncological nursing and community health education issues. Each nurse had developed her own approach to keeping track of data on individual clients and thus keeping track of who needed attention on a given day and time. One nurse was using a hand-held computer while the other used tickler sheets in her calendar to manage scheduling. Clearly, a computerized program could assist in directing the patient navigator and patient to critical pathways for treatment and follow-up and in tracking where a patient is along that pathway for scheduling reminders and transportation orders.

The Patient Navigator program staff and community partners emphasized two dimensions of cultural tailoring of the program. Community partners emphasized that low income persons, persons of color, and other members of historically underserved groups lacked the personal and economic resources to manage the travails of cancer diagnosis and treatment; and that these same individuals also needed assistance in understanding and negotiating the TMC inpatient and outpatient services. Navigator nurses emphasize the important and highly diverse clinical roles they play in minimizing the consequences of cultural disconnections and acts of disrespect. By helping a latino man find dignity in fighting cancer or helping an elder African American patient to raise questions about her care options, the program uses a case by case approach to indentifying and addressing cultural barriers to a standard of care. For TMC's Patient Navigator nurses cultural tailoring can mean everything from getting the hospital's translation service to work with a discharging MD to ensure the provision of written discharge plans in the primary language of the person to working with patients to manage frustration during long delayed and interrupted treatments.

With grant funding for the Patient Navigator, the program has focused more attention on understanding the TMC systemic barriers and other system of care factors and empowering patients to advocate for their own care than on developing the most cost-effective and sustainable model of patient navigation. A Medicare demonstration might recognize care management and transportation support along with health education as a billable service component as part of a comprehensive cancer program or stand-alone service. In this adaptation of the Patient Navigator approach there would be two central elements to the intervention: all oncology patients would be tracked for progress along

key steps in their cancer experience and selected patients would be identified for clinical attention in decision making and use of support services.

Resource Requirements, Effectiveness, Costs, and Cost-Effectiveness

The Patient Navigator program has not been the subject of a systematic evaluation, although current plans call for a retrospective comparison of program patients and matched TMC oncology patients who did not participate in Patient Navigation. This model will not be able to separate the effects of program selection from program operations on latency, treatment completion, and cancer related quality of life/satisfaction with TMC oncology services. It will perhaps shed some light on how Patient Navigator patients do differ from TMC oncology patients—beyond perceptions by staff—and thus contribute to discussions of next steps for improving this program. In addition, a cost comparison could be made between the two groups in order to get further information about the economic basis for the program. The program will attempt to collect a more representative sample of patients and families for assessing program satisfaction and quality of life impacts.

Based on the opinions of program staff, a replication model might still include 2 nurses for a combined oncology service that works with about 350 persons/year from definitive diagnostic studies to surgical and adjuvant therapy with radiation and chemotherapy. At least some supervisory and management support for these persons and a full-time administrative assistant to assist with program operations, insurance issues, transportation arrangements and other direct services would be necessary. Alternatively, other staffing models could be tested using social workers and/or case managers from other human service and health backgrounds. Since most of the costs of the navigator program pertain to personnel costs, using alternative staffing may significantly reduce the costs of the program, while maintaining the effects. These alternative staff could be trained with knowledge about various cancers and navigating the Truman Medical Center and affiliate organizations for patient care. Using staff, support service, and overhead information from Michael Penner, this suggests a program cost around $700/completed case. At present, there is very little information about the variability of costs among patients in the program. Ultimately, these data could be captured if the program develops a patient and service tracking system. Furthermore, it is unclear what additional cost-offsets might be obtained from the navigator program. These cost-offsets include reductions in future hospital and outpatient service utilization, along with cost-offsets in other health and social service areas.

Conclusions

The Kansas City Patient Navigator Program at TMC in Kansas City, MO shows how a partnership between the local cancer society and other local funders and a local

community health center can induce a safety net tertiary care provider to pay new attention to improving the experiences of cancer diagnostic, treatment, and follow-up care service use. The program finds that about ½ the cancer patients at their hospital seem to need this kind of extra support to move through the health system at the desired pace and with the best possible outcomes. The partnership has shown that not only individual patients socio-economic and cultural barriers but practitioner behaviors and system of care factors influence patient adherence to plans for definitive diagnosis and treatment services; and that a relatively low cost program can not only help to reduce some of these barriers but also improve the reputation of the provider with respect to comprehensive and high quality cancer care. The project shows graphically how hard it is to move through the cancer diagnostic and treatment process with any social burdens: frailty, poverty, limited English proficiency, low informal supports and suggests that some of negative consequences of these burdens on cancer experiences can be mitigated. Project findings appear to support the idea that advanced professionals may be required to improve coordination of services throughout a cancer episode.

Asian and Pacific Islander American Health Forum (APIAHF)

The Asian American and Pacific Islander National Cancer Survivors Network (APICSN)

The Asian American and Pacific Islander Tobacco Education Network (APITEN)

Overview

The Asian and Pacific Islander American Health Forum is based in San Francisco and provides training and materials for use by health policy advocates at the national, state, and local levels concerned with the well-being of Asian American and Native Hawaiian and Pacific Island (AAPI) groups. The Forum does not provide direct services, but seeks to improve the service delivery process by offering cognitive and tactical support to individuals and groups that provide service directly or advocate on behalf of service recipient. Two programs of the Forum address issues related to cancer and AAPI groups.

- **APIAHF Cancer Program:** The cancer program, called the Asian and Pacific Islander National Cancer Survivors Network (APINCSN), was developed four years ago in 1998 by Susan M. Shinagawa. This network is comprised of about 40 cancer survivors, their family members, health care providers, researchers, and community members who are concerned about the issue of cancer in the AAPI communities. The program seeks to break the isolation that many cancer survivors feel when they are first diagnosed and going through treatment. It offers networking opportunities and links survivors with resources such as contacts with other survivors, and referrals to services and multilingual cancer materials. As a national advocacy coalition, the program is working with others to educate and advocate on the issue of cancer through speaking events, online networking, and promoting cancer survivors into national policymaking and research committees. APINCSN has limited funding from Ohio State University's NCI/SPN funded program, Asian American Network for Cancer Awareness, Research, and Treatment (AANCART).

- **APIAHF Tobacco Program:** The tobacco program, called Asian & Pacific Islander Tobacco Education Network (APITEN) mostly functions at the statewide level in California. APITEN is one of four ethnic networks established in California, which has been the leader in the tobacco control movement and includes about 600 members after being operational for almost 10 years. APITEN works with multicultural partners like the other ethnic tobacco education networks as well as the mainstream tobacco control programs, health departments, the state health department, and advocacy agencies (e.g. American Lung Association, American Heart Associate, and

American Cancer Society). Most importantly, APITEN works with the AAPI community based organizations to address tobacco issues in the community as well as provide any requested capacity building technical assistance and trainings. APITEN also has a subcontract with APPEAL (Asian Pacific Partners for Empowerment and Leadership) program as part of the stages of change model where 5 organizations are at different levels. California is at the maintenance stage due to 10 years of experience in the tobacco control movement. APITEN has not been financially affected by the tumultuous events in the governor's budget and revisions. However, this upheaval has impacted its efforts since some key regional programs were cut.

Theory of Change and Primary Learnings

APIAHF's cancer control and tobacco programs both reflect the view that improving primary prevention and cancer service outcomes for AAPI communities requires focused attention on policy change and the creation of infrastructures to support policy advocacy. APIAHF has identified several related barriers to appropriate services for their target communities, including:

- Lack of access to health care because of insurance status and/or social isolation
- Perpetuation of "model minority" myth
- Lack of translators and linguistically appropriate services and materials
- Lack of awareness and knowledge about where to get health care as well as specifics about Medicare and Medicaid Services

The Tobacco network offers some startling evidence for the third concern. Recent efforts reveal that on 6 programs in all of California target smoking cessation to AAPI groups, while the services offered by ACS, ALA and others are poorly matched culturally or simply inaccessible.

The program is primarily focused on encouraging and sustaining advocacy with respect to these issues. For example, they supported a California legislative initiative on low-English proficiency services (AB 2739) and access to health care. Similarly, a staff member in DC serves as legislative and governmental affairs coordinator. He has worked with One Voice Against Cancer and has been aware of any cancer legislation and will share that info with us. With respect to the model minority myth, Cancer Survivors Network members are from many different programs, in many communities and settings, and are able to identify and access materials and programming concepts that have been influential in other settings.

The program has not established individual-level measures of success. But staff cite outcomes such as participating in the successful effort to pass AB 2739 and is now in appropriations. Other success indicators include: participating in national cancer conferences, moving forward with the development of the CSN, working with AAPI-specific cancer support groups, developing public service announcements, and developing/implementing training programs on AAPI and cancer issues. Because the new

cancer network is inadequately funded, it has been difficult to move more quickly on these and related initiatives, but the passionate partners, parent organization's experience in advocacy, technical assistance, and community relationship building have all been important assets.

Neither the Tobacco or Cancer Survivor Networks have devoted specific attention to Medicare or elder health issues because the membership does not include persons particularly concerned with these issues. Nonetheless, program staff and members have noted severe difficulties for AAPI populations in accessing the Medicare program. They would like there to be new attention to culturally-sensitive and tailored assistance in learning about Medicare coverage and costs. They also emphasized the critical roles played by adult children of aging immigrants in care seeking and decision making about health insurance, and so recommended a focus on educating working age community members about the programs.

Organization and Operations

Both the APIAHF cancer and tobacco networks do not provide clinical services. They recruit and engage a broad range of potential advocates, including cancer survivors, family friends, researchers, professional advocates, provider organizations, and practitioners. Potential network members have learned about the programs through web-sites, mailings, and distribution of brochures by current members. Individuals or groups become members by completing a simple form and joining a mailing list or LISTSERV. In the cancer program, 16 of the 40 members are more active than this: they participate in various working groups and a steering committee, The steering committee meets by telephone and recently in person at the ICC meetings. The network provides more advocacy and educational information about cancer and cancer survivors to the AAPI community, community based organizations, and mainstream organizations. Because there is limited funding as well as staff support, the network outreach and targeting is also limited. Currently, the CSN has a .50 FTE coordinator and a .25 FTE administrative assistant, partially funded by AANCART, but primarily carried by the parent organization. The CSN steering committee members are working in other community based organizations and try to promote its services in that fashion

Both the cancer survivor network and tobacco control network at APIAHF are unique in offering a community to AAPI cancer survivors and proponents of more culturally appropriate care for AAPI groups. But the networks' agenda are determined and propelled by the AAPI community, not necessarily by the Health Forum. The network is made up of different AAPI ethnic subgroups and each member brings with them relationships with other AAPI community organizations and partners. The elements of community and family are represented in the network. Its process reflects this as well: a typical meeting includes time for members to catch up and check in: they have created an open environment where people can connect not only on a business level, but also on a personal level.

Association of Asian Pacific Community Health Organizations (AAPCHO)

The Community Approach to Responding Early (CARE)

Overview

Association of Asian Pacific Community Health Organizations (AAPCHO) is an association representing community health centers that primarily serve AAPI in the US, more specifically those who are medically underserved. Its mission is to promote advocacy, collaboration, capacity building and leadership to improve the health status and access to health care of the AAPI groups that are served at the member centers. AAPCHO's vision is "to establish a standard of excellence for community based health care that is equitable, affordable, accessible and cultural and linguistically appropriate to the people serve".

The **Community Approach to Responding Early (CARE) Program** is a breast and cervical cancer prevention program sponsored by the Association of Asian Pacific Community Health Organizations (AAPCHO). The program was implemented in six community health centers across the United States to serve Asian American/Pacific Islander (AAPI) women:
Asian Pacific Health Care Venture, Inc. (Los Angeles, CA) – Thai
Family Health Center (Worcester, MA) – Cambodian
Kalihi-Palama Health Center (Honolulu, HI) – Filipino
Kokua Kalihi Valley Comprehensive Family Services (Honolulu, HI) – Samoan
South Cove Community Health Center (Quincy, MA) – Chinese
Waianae Coast Comprehensive Health Center (Waianae, HI) – Native Hawaiian

These centers constitute community enclaves for these AAPI groups, as they have a long-standing reputation of providing culturally and linguistically appropriate care to these populations.

The CARE Program was established in 1997 with funding from the Centers for Disease Control and Prevention (CDC). The program formally ended in January of 2002. Some of the Centers that implemented the CARE program are continuing some of the activities through other funding sources. AAPCHO has submitted another proposal to CDC to expand and build upon the CARE program infrastructure.

Each community health center received $80,000 for two years to achieve the program goals (see below).

CARE served women within each AAPI subgroup targeted at health centers (i.e., Thai, Cambodian, Filipino, Samoan, Chinese, Native Hawaiian) with the goal of educating them on breast and cervical cancer.

CARE did not restrict its outreach and education activities to prior clients of community health centers. In fact, an implied goal for the program was to increase community outreach to those women who may not have been connected to the health care system.

This site was selected for a case study because it addresses breast and cervical cancer in AAPI populations. The CARE Program's major goal was to develop and enhance the organizational capacity and infrastructure of the partner centers in the areas of: 1) funding; 2) organizational support; 3) staffing; 4) coalition/partnership building; 5) ability to assess community need; 6) community outreach/inreach; 7) provider networks and screening; and 8) evaluation.

Each center carried various and different activities in each of the eight tracks tailored to their own organization. Through the community outreach track of the Program, community health workers at each partner center used and tailored different strategies to reach out and educate women in those communities about breast and cervical cancer, and to encourage them to get screened. These strategies ranged from offering interpreting services to using culturally appropriate messages, approaches and locations for each community of AAPI women.

As part of the Program activities, all partnered health centers surveyed at least 75 women 40 years of age or older in their communities about their breast and cervical cancer screening knowledge, attitudes and practices.

CARE Program proximal outcomes revolved around strengthening the health centers' breast and cervical cancer resources and programs in the eight areas listed above. The Program's distal outcomes included: 1) continued, sustainable progress for ach center along the stages of organizational capacity; 2) increased and sustained (or linkage to other sites) screening for breast and cervical cancer for AAPI women targeted in their communities; 3) identification of culturally and linguistically appropriate outreach and inreach activities; and 4) clarification of elements needed to ensure continuum of cancer care.

Theory of Change and Primary Learnings

Breast and cervical cancer rates among AAPI women are higher than national statistics show, because all subgroups are examined together in aggregate, thus, masking dramatic differences between AAPI groups. For example, breast cancer rates are extremely high for Native Hawaiian women compared to national rates. Likewise, Vietnamese American women have higher rates of cervical cancer than white women. These higher mortality rates are often a product of lack of screening among these groups.

Other sources of cancer disparities among AAPI women, according to AAPCHO staff, are the lack of disaggregated data by AAPI subgroup, the lack of affordable health care services, lack of culturally and linguistically appropriate services, lack of disease-related

knowledge in the AAPI population and the presence of other social structural factors, such as transportation.

The CARE Program framework is derived from a behavioral change theoretical perspective applied to organizational structures. The model, as applied by AAPCHO, describes the stages and areas of behavior change in an organization based on the Prochaska and DiClemente's model.

CARE aimed at assisting the six health centers in building infrastructure and organizational capacity to strengthen and enhance their existing resources and programs for breast and cervical cancer education and screening.

CARE collected qualitative data on the changes that were taking place in each organization within the eight-targeted areas of capacity building. Some other organizational data was provided by the centers through monthly reports. In addition, all six centers kept track of the number of women screened at their facilities throughout the CARE Program.

Qualitative data collected from the six sites included a set of case studies (one per center) documenting the successful strategies used to reach out and reach in to AAPI women and educate them about breast and cervical cancer screening. Based on these case studies, it appears that having a staff person who is from the cultural group targeted, who could understand and implement the appropriate approach, is one of the cornerstones of the program.

As a result of the outreach efforts, evaluation data collected revealed that approximately a total of 3,400 women age 40 and older were screened across the six CARE sites. Of these, 29% received a clinical breast examination, 31% received a Pap smear test, and 40% received a mammogram.

The CARE Program points to the credibility that many of the centers already had established in the target communities as one indicator of success. The Program fostered the development and creation of partnerships between the six CARE sites and other community-based and health care organizations. The Program also helped the centers to find temporary or permanent solutions to the problems and needs identified in the course of implementation. The sites also received direct training and technical assistance from the strong AAPCHO network and its background.

Despite the program accomplishments, many challenges and barriers were identified by the six CARE sites. A major need identified by the centers was the development of an accurate system to track the screenings performed both at the community health centers and other collaborating health organizations.

AAPCHO staff believes that the cornerstone of reducing and eliminating cancer disparities among AAPI populations is to build and support a strong infrastructure that will ensure continuity of care. They believe that Medicare can play an important role in

reducing cancer disparities among AAPI elders by crafting a benefit that will reimburse the services of a case manager based at community health centers. The role of this case manager would be to facilitate the treatment planning and referral process. In other words, this professional would be in charge of helping the elder navigate the complex health care system.

Another area that they see fit within Medicare scope of work is the coverage of a benefit and eligibility counseling service. Such benefit would enable elders of color to better understand their rights and access care.

Organization and Operations

The CARE community outreach worker at each site reaches out to the community through health and community fairs, churches/temples, community-based organizations, local businesses and markets, and through the programs and services at the health center itself. Each site varied in its outreach approach based on the targeted community. For example, the outreach to the Thai community in Los Angeles was more effectively carried on by talking to business owners and women in the business district of Thai Town, avoiding Thai holidays, as it is considered bad luck to discuss issues like cancer around those dates. Samoan women were reached out through partnerships developed with local Samoan churches. Women's Health Education Parties was the strategy that seemed effective in attracting and educating Filipinas. On the other hand, a more personal, one-on-one approach worked better with Chinese women.

All six sites recounted and stressed the importance of building trust within each community and addressing the women appropriately based on their age. All six CARE sites used different cultural/ethnic media outlets (radio, newspapers/magazines, local cable shows) to spread the word and to educate the community about breast and cervical cancer.

The community outreach worker played a very important role in reaching out to and educating AAPI women in the six communities where the CARE Program was implemented. One of the first contacts the outreach workers made with the women was to complete the breast and cervical cancer survey on knowledge, attitudes and practices. In addition, education about breast and cervical cancer was provided in different locations, based on the best approach for that AAPI subgroup (see examples above). The outreach worker also provided information about breast and cervical cancer screening and referred the women to appropriate location (community health center or collaborating hospital) to receive the screening. Thus, the outreach worker had a strong connection to the health care system.

The staffing for the CARE Program varied by center. For most sites there were two people in the CARE team, one of them being primarily in charge of the outreach efforts, and the other one of the more administrative work. This team received training on the CARE Program and its goals from AAPCHO staff. Training pertaining breast and

cervical cancer, health care resources and others was a responsibility of the community health center. The centers arranged these training through local/state health departments and organizations like the American Cancer Society.

The CARE Program uses a community outreach worker model to educate AAPI women about breast and cervical cancer using their own community resources and key people. Community outreach workers not only spoke the targeted women language, but also came form the same rich cultural background enabling to establish a connection. The workers also paid close attention to the issues of age and family-centered focus to approach the women and to establish trust.

Resource Requirements, Effectiveness, Costs, and Cost-Effectiveness

A potential billable service component of the CARE program is the referral work of the community outreach worker.

The budget for each CARE site amounted to a total of $40,000 per year, for two years (total: $480,000 for two years). This amount does not include in-kind costs. It is unclear how much money was budgeted to develop, run the program and cover the costs at AAPCHO.

The costs of the replication of the CARE model would most likely increase in other settings/organizations. A stronger, more accurate data tracking system needs to be in place to evaluate the effectiveness to the program. Furthermore, costs associated with the systematic training and certification of community health workers would increase in a replication of the CARE program.

Conclusions

The importance of culturally tailoring cancer interventions could not be more emphasized. Many interventions are designed and developed addressing the health issues of a racial/ethnic group without acknowledging the diversity within groups. The CARE Program shows that any attempt to reach out to Asian American/Pacific Islander groups have to go beyond the prescriptive formula of outreach to populations of colors. It has to be unmasked and designed keeping the cultural idiosyncrasies of each specific subgroup in mind.

Baltimore Cancer Coalition

Baltimore City Cancer Plan Prostate Cancer Project

Overview

The Maryland legislature appropriated a multi-million dollar Cigarette Restitution Fund (CRF) from the tobacco settlement. The CRF distributes money to smoking cessation programs, crop conversion assistance for tobacco farmers, and various cancer research, education, and prevention programs. In 2000, legislation was passed providing Johns Hopkins Institutions (JHI) and the University of Maryland with money from the CRF for public health initiatives and cancer research. This Cancer Research Grant is restricted to seven cancers (lung, breast, cervical, prostate, oral, colon, and skin) due to high incidence and mortality rates in Maryland. In 1998, cancer passed cardiovascular disease as the number one cause of mortality in Maryland. CRF legislation directs Johns Hopkins Institutions and the University of Maryland to conduct community-focused research and includes public health grant to provide education, screening, and treatment to low-income residents and minority neighborhoods of Baltimore. Johns Hopkins Institutions and the University of Maryland also collaborate with Sinai Hospital, Baltimore City's Health Department, and the State Department of Health and Hygiene.

From the money received through the public health grant, the Baltimore Cancer Coalition was formed and the Baltimore Cancer Plan began to develop. Dr. James Zabora, one of five associate directors of JHI's Cancer Community Programs and Research, serves as the Co-Director of the Baltimore Cancer Coalition with Dr. John Drummond of the U. of Maryland. The Baltimore Cancer Coalition consists of about 125 community organizations throughout the city. The Coalition functions as an advisory board and will meet to monitor progress of the Plan. The Coalition held town hall meetings to review drafts of the Plan and several revisions were untaken. One additional town hall meeting is scheduled to present the Plan before it is finalized. An operations manual is under development.

The goal of the Baltimore Cancer Plan is to reduce the morbidity and mortality due to seven cancers in the city by 2010. The Baltimore Cancer Plan is in its second of nine years. The basis of the Baltimore Cancer Plan is to address the following needs in order to accomplish this goal:

- form active partnerships with multiple community agencies, groups, and organizations
- provide community-based education and screening to facilitate access
- encourage community leaders to speak on behalf of screening and early detection

The Baltimore Cancer Coalition is examining the mortality rates for specific cancers by census tract and measured by standard deviation to the mean. Prostate cancer was the first cancer addressed by the Coalition due to JHIs expertise in this area (their physicians developed the guidelines for treatment in this area. Mortality rates in 1997-1999 were much higher in some areas of the city (See attachment A). These areas are poorer neighborhoods and predominantly African American. JHI contracted with eight community organizations in these high prostate cancer mortality areas. Five sites target African Americans, one focuses on the Hispanic population, another targets Korean, and Morgan State, which also targets African Americans, is now underway. The current Baltimore Cancer Coalition community sites include:

- Park Heights Community Alliance
- Morgan State University
- Urban Medical Institute
- Baltimore City Health Department's Men's Health Center
- Korean Resource Center
- The Hispanic Apostolate
- Garden of Prayer Baptist Church
- Bea Gaddy's Cancer Prevention and Education Center

For many of the sites, providing health education and screening is a new activity in their mission. For prostate cancer, the sites provide outreach education and screenings for men between the ages of 45-70, although exceptions are made to the age limitation on the basis of medical or family history. The oldest man screened was 92. The prostate cancer project includes the following components:

- Education and screening (PSA/DRE)
- Culturally appropriate educational messages
- Community-based screenings
- Risk assessment questionnaire
- Target communities based on risk
- Community based research, such as exploring attitudes/beliefs that influence participation in screening
- Referral for diagnostic care and treatment

Currently, oral, breast, and cervical cancer screenings are being conducted or implemented at the sites and development of a colon cancer screening and education program is in process. Smoking cessation education and treatment to prevent lung cancer is also underway.

This site was selected as a case study for several reasons. JHIs is an academic health center and faces the traditional challenges that all academic centers encounter in building trust in their surrounding community. Also, JHI has a strong leader in Dr. Zabora. His background in social work, relationships with community leaders, and knowledge of the city and target populations provides him with an important perspective to lead this type of effort. Furthermore, he is trusted in the community and sought out by community leaders.

Finally, the Plan addresses multiple cancers, is innovative, comprehensive, and sustainable.

Primary Learnings

Dr Zabora discussed the reasons for the high incidence of cancer is these census tract areas. First, in surveys of Baltimore residents, community priorities were ranked in the following order:

- employment
- housing
- crime
- nutrition
- education
- health

Competing priorities interfere with the community's efforts to deal with substantive health issues. For example, in East Baltimore, there are 10,000 residents with substance abuse problems, a high rate of sexually transmitted diseases, a ranking as one of the most violent cities in the United States, and the highest age-adjusted morbidity and mortality rates from heart disease and stroke. Dr. Zabora mentioned the obstacles to better health include low income; lack of insurance, education, and economic and political power; mistrust of academic institutions; and lack of continuity of care.

JHIs recognized that in order to address the issue of high cancer mortality in targeted areas of Baltimore they needed to partner with multiple community organizations, groups, and agencies. Criteria used for the selection of sites included location, credibility, commitment to health promotion, and willingness to work with academic centers. Also, JHIs recognized the need for long term partnerships to avoid past failures, citing lack of continuity and resulting distrust as a result of short-term programs. Additionally, community based education and screening was necessary to facilitate access, and community leaders needed to be willing to speak on behalf of screening and early detection. The community leaders possess four important characteristics that allow them to deliver their message: familiarity, trustworthiness, credibility, and knowledge. All of the sites perform as much of the screening process as possible outside of the hospital setting.

Dr. Zabora noted that Program Director and community leader Reverend Doug Wilson set the participative tone for the program by emphasizing the need to replace the word "outreach" with the word "partnership". Communities have diverse needs and institutions, seeking community partners to improve public health, must reorient programs to truly meet community needs. They must also assure community partners that, in the spirit of collaboration, they will play a key-role in any health related program initiatives. Dr. Zabora emphasized that the program cannot just perform screening but must also address further diagnosis and treatment. JHIs estimated in its budget not only the number of screenings performed but the number and costs of further work-up due to a

positive screen, and ultimately, the number of cancer cases diagnosed and costs of treatment.

Several key staff associated with the Baltimore Cancer Plan provided important insights for CMS:

> Reverend Doug Wilson, Program Director "You have to find out what is functioning in the community now. What is their interest ? Elderly, children etc.? You have to figure out how you can support them. You need to invest in what they are doing and be a partner; could be your presence, expertise, etc. For example, JHIs formed an advisory group. Spend time with them, learn about their organization, how you can help them. Do not take something to them; they have worth, and value,….then they will be more likely to embrace your programs, goals."

> Marcella Blinka, Health Educator, oversight of the Hispanic Apostolate and Korean Resource Center:
> "You must be in it for the long haul, not for the two years of a grant-funded project and then out".

> Sandra Briggs, Bea Gaddy Cancer Prevention and Education Center:
> "You have to meet the client's needs - whatever they are - a hug, transportation, food, money. We provide follow-up, we call people, and we pull them in. We go to them, we had a cancer screening at a mall; we screened 20 men for prostate cancer in 2 hours. Be committed for the duration. The relationship is fragile, you have to deliver. Do not say 'not eligible', meet people on their own needs. Be bold, be nosy enough, 'Holy Boldness'. Make yourself approachable".

When asked what were the key elements to include in a Medicare demonstration, Dr. Zabora emphasized the following:

- community partnership
- help communities identify their needs and respond to those needs
- it takes time to get such an effort up and running; for example a site takes about one year to really get up and running.
- The focus should be on sustainability
- Also, access to screening is vital; as an insurer, if you do not have the infrastructure, there will be no screening.

Organization and Operations

Program operations

The Baltimore Cancer Plan received $1.4 million in 2002 from the CRF. Out of that money, approximately $400,000 went to JHI and the U. of Maryland for staffing and the

remaining $1 million went towards subcontracts with the community sites. Dr. Zabora and Dr. Drummond are covered at 25% for their positions; the Educational Director at JHIs, who is responsible for curriculum development and cancer related education, is covered 20%; Rev. Doug Wilson, who is the Program Director of the Cancer Plan, is covered 25%. He is directly responsible for all the screenings performed. There is also 5% for an epidemiologist and 5% for an economist. Eventually, Dr. Zabora plans to add a fulltime data manager.

Additionally, there are four health educators (three full time and one at 70% coverage). All have a minimum of a bachelor's degree. One is a licensed social worker, one has a masters degree in public health, and two are cancer survivors. Health educators are affiliated with 2-3 sites. They are responsible for all cancer related activities provided at the site, including acting as a resource to the site, facilitating, and collecting data associated with the project. The program coordinator handles all abnormal screenings regardless of the cancer.

Each site employs a community health worker and a cancer information specialist. All of these positions receive education based on the National Cancer Institute's cancer education program a three day program provided at JHIs. The two positions are often filled by existing staff at the community centers and employment decisions are made collaboratively between the site and JHIs. For example, at the Hispanic Apostolate, two employees were hired to assume these positions. The sites also have input regarding the hiring of the health educators. The community health workers and cancer information specialists have a holistic approach to education; they do not just focus on clinical practice and screening tests, but also on nutrition, other social service needs (such as transportation), and exercise. This year the health educators and site staff began to meet together for a monthly meeting to share information. Also, quality assurance efforts will begin this year and will focus on best practices.

JHIs subcontracts with the various sites to provide staff and space dedicated to health education and screening. The cancer information specialist receives a salary of $30,000 and is typically educated at a bachelor's level. A community health worker receives a salary of $20,000-$22,000. The space rented by the Baltimore Cancer Plan typically runs 400-600 square feet and costs about $10,000 per year per site. Also, furniture, computers, and equipment are included in the subcontract. However, some sites have been totally funded by the Baltimore Cancer Coalition, including the Bea Gaddy Cancer Prevention and Education Center.

Each cancer provides unique challenges for the Baltimore Cancer Plan. For example, the health educator who is working on the colon cancer screening is addressing the need to screen both low risk and high risk individuals. High risk individuals are defined as those who have a personal or family history and those experiencing any symptoms. Low risk people will receive a FOBT and those at high risk will receive a colonoscopy. With the high risk population, there is a need to arrange for transportation to the hospital, obtain a history and physical, and ensure an effective prep for colonoscopy. Toward this goal,

JHIs is exploring the idea of having the community health worker perform a home visit the evening before the colonoscopy. The goal is to screen 100 people in the first year.

Each community center has its own history and mission. For example, the Hispanic Apostolate began as part of Catholic Charities. Founded in 1963 in response to Cuban immigration, they began providing assistance and have continued to evolve. It is located in a storefront in the heart of the community. The Hispanic population is very heterogeneous, immigrating from several countries and speaking different languages. The population includes political refugees, professionals, and people with multiple cultural differences. Also, many elderly in the community return to their country of origin, making long term follow-up and cost-effectiveness measurement difficult. The program itself provides many other services, English language, senior center, employment assistance, etc.

The Hispanic Apostolate provides primary and secondary prevention services. The prostate cancer screenings are provided by the hospital-affiliated St. Joseph's Medical Van, staffed by a physician, nurse practitioner, and nurses. The van is available each Tuesday. In addition to prostate cancer screenings, they recently began monthly cervical cancer screenings (pap smears) and providing referrals for women with abnormal screens. In order to provide these screenings, they schedule a nurse practitioner from JHIs monthly and hope to add an additional day. An exam bed was donated by a retiring physician and Dr. Zabora picked it up to deliver to the site.

Marcella Blinka, the Health Educator, calls women needing follow-up and is also in touch with staff at JHIs to set up appointments, etc. The Hispanic Apostolate follows these women and will help to fill out application for care services, arrange transportation as needed, etc. The center ensures continuity of care. For those women who have abnormal screens, they will go with them to JHIs to help navigate the system, and to help them get their questions answered. The program promotes independence; once women have been assisted they learn how to approach the system and become self-advocates. Staff go out into the community and speak with the social workers at homeless shelters and soup kitchens in the area. The Hispanic Apostolate also recently conducted an oral cancer screening and screened 104 people.

The Bea Gaddy Cancer Prevention and Education Center was founded by Bea Gaddy, a tireless advocate for the homeless who died of breast cancer late last year. The site is run by Sandra Briggs, her daughter, and is located in an African American community church less than a mile from Johns Hopkins Institutions. The Baltimore Cancer Coalition actually assisted with site selection and getting the site up and running. The site, opened unofficially in late March, and has already provided 150 prostate cancer screenings, before its official opening in May.

Dr. Kim is the director of the Korean Resource Center and his salary is currently covered at 25% as the Cancer Information Specialist for the center. According to the census, there are approximately 39,000 Koreans in Maryland; Dr. Kim's unofficial estimate is 50,000. The Korean Resource Center began in January 2001 and contracted with the Baltimore

Cancer Coalition in September of 2001. Thus far, the positive prostate cancer screening rate was higher than expected, about 30%, versus 18-20% for African American males. The reason is unknown at this time. All males with positive screens will be followed at JHIs. The Korean Resource Center is also focusing on smoking cessation due to a high smoking rate and intergenerational aspect. Thus far, oral cancer screening has not been very successful due to two sensitive questions regarding sexual practices. Also, 50-60 women have already signed up for breast and cervical cancer screenings and final arrangements are being made to provide these services.

The Garden of Prayer site is affiliated with a church and was officially opened on June 15, 2002. Rev. Dr. Melvin B. Tuggle founded the church in 1969 and has taken a personal and professional interest in public health. The site is located on church grounds and provides a number of programs including assistance with housing, unemployment, education, and health concerns. Church membership is approximately 1,000. The goal of their first year is to provide cancer information and screen men for prostate cancer; other cancer screenings will be added in time. The site already has provided educational presentations and contacted approximately 20 senior centers in the area. They have screened approximately 100 men since November and one man was diagnosed with prostate cancer.

Program outreach / marketing design

The prostate project targets uninsured men between the ages of 45-70 in areas of high prostate mortality in the city of Baltimore. However, the oldest man screened was 92 and youngest 23 with a family history. As one of the site workers offered, you cannot really turn down men who are willing to be screened and concerned they may have cancer. All sites have material from various cancer organizations such as the National Cancer Institute but also develop their own culturally specific materials and marketing plans. Marketing is dependent on the site and racial make-up of the community.

At the two African American sites visited, the community leader and social aspects of the events are promoted. For example, the Garden of Prayer features Rev Dr. Melvin B. Tuggle's name prominently on educational materials, including the flyer announcing the grand opening of the center. They also partnered with the Korean Resource Center (6 blocks away) to provide joint screenings. The staff is looking at opportunities within their radius to provide outreach, such as the senior centers and schools as well as the Church's Men's Conference. Finally, the site is trying to provide the education and screening within a social context. The grand opening will include free food, entertainment, and a clothes giveaway and this is listed prominently on the flyer.

At the Korean Resource Center, Dr. Kim uses a 2-layer approach to announcing screening, through mass media and flyers (mailed). Educational materials are written in Korean and English. He is also taking the message to the Korean American church, which includes most of the community, numbering about 1,500 members. Finally, he is a leader in the Korean community and attends almost all cultural events.

Cultural tailoring

Cultural tailoring is also site specific and the sites have been very innovative with ideas to increase screening rates. In the Korean community, Dr. Kim explained that everyone knows everyone and is aware of the need for cancer screening, they are not resistant to screening. Barriers to care/screening are that many Koreans are first generation, have no health insurance, and work long hours at small independent businesses. For example, the Korean Resource Center ran a screening targeting people who owned/worked in dry cleaners but the hours were not convenient. As a result, they try to schedule some screenings in the evenings and also at Korean community events. Another ethnic specific issue Mr. Kim addresses is discouraging reliance on "all cure" creams, diet supplements (to clean your colon) etc. advertised in the ethnic media. Smoking in the Korean community is a multi-generational and social issue. For example, Koreans may distribute cigarettes as favors at weddings.

At the Hispanic Apostolate, staff did not believe the educational materials provided in Spanish from the National Cancer Institute was tailored enough to the population they serve. Therefore, they held focus groups to develop culturally appropriate educational materials for breast cancer awareness. Fotonovelas ("paper soaps") are unique to the Latino population and were selected to model educational materials. The results were that both written material and an educational tape were developed that was more realistic for the population. For example, the woman in the fotnovela asks her husband for permission to go for the screening.

The sites targeting African Americans often have a religious focus and they provide a lot of one-to-one assistance with completing paperwork, explaining the screening, etc. The sites had a special need to allay African American fears and distrust of the health care system and to reeducate people about the purpose of research and the JHIs role in the program. They also used incentives to attract people to screenings. Health educators expressed the importance in this community of promoting services as "no cost" vs. "free", which has the connotation of lack of quality and charity care.

Potential billable services

Potential billable services are the role of the site community health, cancer information specialist, and/or health educator. Additionally, allowing the community to bill for screenings and education would increase screenings.

Resource Requirements, Effectiveness, Costs, and Cost-Effectiveness

Kevin Frick, an economist at JHIs is planning to perform cost-effectiveness analyses for all of the cancers and is currently modeling prostate cancer. The plan is to look at the societal and payor perspective using life years gained as the outcome measure. There is a data tracking instrument developed to be used by the sites to begin to collect this data.

There are two types of data being collected for individuals; patient baseline data and JHIs follow-up data. The challenge is that the patient would have to stay in the JHIs hospital system although there are discussions for cooperation and tracking of the patient at other hospitals in Baltimore. However, statistics regarding access to care in 2000 demonstrate that 40% of African Americans in Baltimore with cancer are treated at JHIs although there are five other cancer centers in the city. It is also notable that only one of the Medicaid associated PPOs cover JHI.

Proximal outcomes include the numbers of men screened for prostrate cancer.
The prostate screening effort was begun in March 2000 and as of October of 2002, 1,000 men have been screened at 20 churches and 6 community centers and the age was 55 years. The goal is to screen 2,500 men. There were 75 abnormal PSAs, 126 abnormal DREs, 25 abnormal PSAs and DREs and 45 men had a positive family history. Distal outcomes for the Baltimore Cancer Plan include decreased cancer morbidity and mortality in the targeted census tracts.

 When creating the budget specific to prostate cancer screenings, it was assumed that 20% of results would be positive and money was allocated for further diagnosis and treatment.
Dr Zabora strongly believes that there is a social responsibility to provide treatment if a positive screen, i.e. don't screen if you can't provide treatment as well.

Conclusion

The Baltimore Cancer Plan developed out of a carefully crafted, systematic plan with both short and long term goals. The plan is making significant progress towards its goals, but will take a number of years given its aggressive and comprehensive agenda. Dr. Zabora also commented that an effort such as this takes time and the focus is on sustainability. Each cancer addressed provides its particular challenges and each site is individual; there is no cookie-cutter approach. However, there are important commonalities. All sites are well established in their community and whether they have experience in healthcare is far less important then the trust of the community. Each site has strong, committed leaders who, in turn, have trust and a solid working relationship with Dr. Zabora who is the leader for the JHI effort. This has been no small accomplishment given the lack of trust the community has with this academic institution, not a situation unique to the city of Balitmore. Community residents often feel "used" by academic insititions and hospital systems and lack of long term community commitment was mentioned on several occasions during these site visits. The approach is to provide as much screening as possible at the local level.

Each site has grown in a number of ways with experience, for example the Korean Resource Center has recently been awarded a $300,000 grant from the Legacy Foundation for smoking prevention and cessation with JHIs help grant writing. Also, the sites have also begun to partner together. For example, the Korean Resource Center recently conducted a joint screening with the Garden of Prayer site.

It was very impressive to note the flexibility that the Baltimore Cancer Plan has demonstrated with the programs. Sites mold the program into their existing infrastructure, whether its hiring current staff as community health workers and cancer information specialists or planning screenings in order to be successful in their particular corner of the neighborhood.

Boston Public Health Commission

Boston Racial Ethnic Approaches to Community Health 2010 (REACH 2010) Case Management Component

Overview

In collaboration with four community health centers, the BU Center of Excellence in Women's Health at Boston Medical Center, and Brigham and Women's Hospital, the Boston Public Health Commission is in its first year of full operations of a breast and cervical cancer control demonstration as part of the US Centers for Disease Control Racial Ethnic Approaches to Community Health. The program grew from an 1-year planning process that included broad collaboration with advocates, citizens, cancer survivors and professionals from participating institutions, and was successful in winning approval for its four-year implementation phase. The project targets women of African descent (including African Americans, Haitians, and other Afro-Caribbeans) aged 40-75 through multiple interventions, including provider education, outreach through lay health educators, in-reach/patient navigation with case managers, and ongoing collaborative exploration of potential policy changes all with the goals of increasing participation in screening and appropriate utilization of treatment services. The site was selected for a case study because of the use of case management/patient navigation role at both the hospital and community health center settings. Boston REACH 2010 is also a large scale research endeavor including both annual samples of community resident women of African and other descent and engagement of case management program participants in a longitudinal study of breast cancer screening and/or treatment service use and outcomes

Theory of Change and Primary Learnings

The Boston REACH 2010 breast and cervical cancer project noted that women of African descent in the Boston area had lower prevalence but higher mortality from breast and cervical cancer than did women of European descent. They hypothesized that this was due to multiple factors, including socio-economic and attitudinal barriers to use among women, the racial attitudes and behaviors of clinicians in primary care and oncology settings, and the organization of service delivery in both health center and hospital settings. Given this broad view, the program was designed to include multiple components. Dr. Judy Bigbee of Harvard University and the Brigham and Women's hospital has not only lead ongoing research on the project but has also spearheaded cultural sensitivity and racism awareness training for practitioners in all program sites, while a set of Breast and Cervical Cancer Ambassadors have been identified and trained. These individuals function as lay health educators after receiving training. As (volunteers or paid) workers, the Ambassadors make presentations at settings around the city with the

goal of increasing awareness among women of color about the need for—and easy availability of breast cancer screens. Case management was intended to overcome both patient and provider system barriers to adherence to screening guidelines and followup/treatment of suspicious screening results.

The REACH 2010 program in Boston is in too early a stage to have generated evidence of impact or to articulate primary messages for policy. Over time, the program will assess the degree to which its interventions have influenced rates of lifetime mammography and Pap-test use and adherence to recommended levels of breast and cervical cancer screening. They are seeking population-level observable reduction in non-use and non-adherence. Among those receiving case management, the program hopes to show improved rates of follow-up and reduced lag times between diagnosis and completion of treatment, but there will be no individual level control group for the case management component. .

The program did not have recommendations for application of its model or model components to Medicare.

Organization and Operations

In this section, the focus is on the case management component only.

The case management programs at the two hospitals and the 4 health centers have been recruiting participants since around January or February of 2002. While scheduled to begin earlier, getting approval for the research protocol from all of the participating institutions proved to be a formidable barrier. Recruitment has proven difficult and is far below the 100/site (600 total) anticipated for the first operational year. Across all site, 78 women have been recruited since January, with (45%) younger than age 41, and 6% age 65 or older. Most of the women in the study self-identified as Black; 2 identified as American Indian; and 17 were born in countries other than USA.

To be eligible for case management and the research initiative, a women must be age 18-75, a Boston resident, of African descent, and either not adherent on breast or cervical cancer and/or identified by clinicians as needing assistance with follow-up services subsequent to a suspicious screening. Case managers use multiple methods to identify potential participants, including referrals from primary care practitioners, approaching individuals in the waiting rooms of the breast health clinic or other settings, and –in the case of the health centers—reviewing clinical records to find non-adherent clinic users and writing to them. (No data were available on the % of clients identified by each method). There is no specific marketing or outreach for the case management program—it is viewed as conducting "in-reach" primarily, but has not established objectives or procedures to ensure that all persons non-adherent on screening and all persons with positive screening findings are offered care management assistance.

Once a person agrees to participate, the case manager conducts a detailed interview and also identifies opportunities to be helpful. Most clients need help with housing and income security issues rather than health or cancer related issues: case managers are becoming adept at helping people get enrolled in insurance plans, on publicly-assisted housing waiting lists, and into shelters or other interim living situations. Case managers also assist in addressing questions a person may have about the diagnostic and treatment process and in making sure appointments are made at reasonable times. Case managers are also contacted if a client misses an appointment. Note that additional care management staff associated with chemotherapy and radiotherapy programs within the participating institutions and not the program case managers are responsible for helping patients complete treatment protocols, even while a program case manager may continue to stay involved to address psychosocial issues. Because relatively few cases with definitive cancer diagnoses have been served to this point, it is unclear how program case managers will interact with others to ensure care continuity and reduce lag times in care provision. Program staff were unable to articulate how program funding and context have influenced service delivery, but do note that there are multiple initiatives within each of the hospitals to ensure complete follow-up. It appears that because of the grant-funded nature of the project, there has been no specific focus on maximizing the number of persons managed by the case managers or the reach of the program into the pool of non-adherent and potentially underserved community members.

Cultural tailoring of services has been primarily addressed in other REACH 2010 components—such as the practitioner training and Ambassador aspects of the initiative. For the case management component, the use of women of and from the communities to be served has been the major element of tailoring. At Boston City Hospital for example, there are 2 ½ FTE care managers: one is bi-lingual in Haitian and English, the other African American and from one of the target communities. Both of these care managers—as well as others employed by the health centers—may be ideally suited for a "cultural translator" role because their other time and/or prior roles in the facility allows them to know many of the actors, facility systems, and informal linkages among practitioners and provider organizations.

La Clínica Tepeyac

Reach and Teach Program

Overview

This clinic is a primary health care facility located in Denver. It was founded in 1995, as a community initiative, by members of Our Lady of Guadalupe Church . A house next to the Church was turned into a health clinic to provide the uninsured Latino community with safe, modern, trusted health care conducted in Spanish. Currently, it is estimated that 28% of Denver Latinos have no health insurance. The Clinic is a vital provider since it is in a position to serve undocumented residents.

It is supported by a wide range of organizations: local hospitals and universities, local and national foundations and corporations and individuals that contribute as volunteers or donating equipment and money. It is very well-known in the Denver community and is a focus of philanthropy amongst the city's well-heeled population, and is also supported by the Catholic Church.

Theory of Change and Primary Learnings

This clinic is predicated on the belief that the low socio-economic status of Latinos is a formidable barrier to accessing health care. These Latinos would only access the health care system in the case of an emergency. Preventive care is not a priority. . Mistrust of doctors and hospitals is rampant; bad experiences become very well-known in the community. The lack of professionals from one's own community is a real barrier. In contrast, the clinic provides a welcoming environment, being right in the neighborhood, and using staff from the community, and conducting business in Spanish.

There is also not as prevalent a culture of self-care, according to some clinic staff, which makes this population different from others. The community surrounding Clínica is prone to disproportionate health disparities. There are higher rates of risk-taking behavior. The need for jobs and money requires that they work in high risk positions where the injury rate may be highand they experience higher rates of stress due to low income and class differentials. "The community gets to the point where they can't even see their self-destructive behavior." The media and tobacco industry contribute to the high rate of health disparities by targeting the young and growing Latino population. , For example, tobacco manufacturers target minority youth by placing ads on Spanish T.V.; placing cigarettes tobacco next to candy in stores, etc. This population also relies heavily on native healers (curanderos), home remedies, spiritual programs, none of them necessarily harmful per se, but a barrier if it prevents them from also accessing the health care system.

The clinic's Reach and Teach Project that targets the adult community derives its theoretical underpinnings and the Promotora Curriculum from the works of Paolo Friere's work on adult education (Pedagogy of the Oppressed). With the adult population, they want to teach that self-reliance in health care promotes dignity and is empowering.

Organization and Operations

The clinic is governed by a 16 member Board. It is an active volunteer policy-making body. It is located in a quiet, clean, working-class neighborhood next to the Church. It has two examining rooms, a verandah waiting room, supply closet and kitchen. The clinic has two major components: clinic services and outreach education services. Both type of services are in expansion in terms of quantity and type of services offered.

Clinic services
The clinic provides diagnosis and treatment for minor diseases, preventive screening tests, immunizations, lab tests, and prescription drugs. It also provides patients with referrals for emergency care, long-term chronic care or specialties to more complex health care facilities that are part of a network. The clinic does not have walk in services.

On average, four full-time clinic staff and volunteer medical and nursing providers and students provide a total of 23 hours per week of primary care visits. Volunteers number approximately 300, and are medical doctors, medical and nursing students, and clerical workers.

Most of the patients are uninsured Spanish speakers with little or no knowledge of English. The clinic reports a load of 3,000 primary care visits per year. It provides annual preventive services, baseline diagnosis and treatment for minor illnesses. It helps patients access a network of other health care providers and facilities to provide more intensive care, emergency care and long-term care. The clinic provides breast, cervical, and colorectal cancer screenings. A portable mammography unit is available at the clinic for one whole Saturday every month. In the past one year, one woman tested positive on a screening mammogram. The Promotora told us that she was "taken over by St. Joe's," the hospital with which the clinic has the connection, and did not know what the outcome was. The clinic support extends only through the screening process, although some of the Promotoras take it upon themselves to provide transportation as part of their work-day, and assistance with navigating the health system where they have been referred .

Patients are asked to pay $7 per visit, $1 for a 30 days prescription filled, and variable fees for lab test (from$2 to $60) depending on number and type of tests. The clinic also conducts regular sessions to educate the community about Medicaid, Medicare, and Social Security, and how to access it and how to determine if one is eligible. However, it doesn't provide sessions on these topics on a regular basis. They are in the process of getting an enrollment specialist from Denver Health on site during clinic hours.

Outreach Education Interventions.
The clinic also educates adults and youth on health maintenance and prevention..
Currently, there are three projects: Nuestros Milagros, Diabetes Management andReach
and Teach.

Nuestros Milagros Project brings 20-25 Latino youth every year and provides them
with weekly after-school tutoring in math and science, training in health prevention, and
community service opportunities. The project aims to expose youth to careers in the
health field, and assist the members in high school completion, as well as college
entrance and completion. The members observe and shadow medical professionals at La
Clínica Tepeyac and partnering clinics and hospitals. As peer educators, the members
share their knowledge through health presentations at elementary, middle, and high
schools, and church youth groups.

Diabetes Management Project consists of classes to diabetic patients. The classes are
monthly and last two hours each. Diabetic patients are taught by volunteer health
providers, and learn about diet, monitoring, control, and other management topics of this
chronic disease. On average, 10 patients attend each class.

Reach and Teach Project consists of Promotoras de Salud that are in charge of outreach
activities targeting the Latino community The Promotoras are bilingual women selected
from the community and trained in outreach and health prevention. Typically, the
Promotoras have 21 hours of training. Their outreach activities take place mainly at six
churches within the Hispanic community in the Denver metro area. The main activities
are: distribution of health information, one-on-one education, and health groups. They
usually distribute health information packages among church members, and they provide
one-on–one health education for those interested. They also participate in fairs,
conferences and other events. Promotoras also organize home health groups. (Door to
door outreach has since been suspended). Besides the circulation of health materials, and
the provision of education on a single or group basis, Promotoras connect interested
people with the clinic services. Through the Promotoras, those interested are signed up
for screening or other primary health services at the clinic. Outreach activities are free for
the beneficiaries. The Reach and Teach project recruits workers through ads in church
bulletins, and local newspapers in Spanish. Right now, Reach and Teach only has 2
Promotoras. Recruitment and retention are difficult. They could use 10 Promotoras.

Administrative staffing: There is an administrative staff of two and a half that supports
the clinic's activities., The administrative staff are a mixture of salaried and hourly
employees, and are housed in another leased building., The total budget is approximately
$600,000 per annum.

There are 8 staff housed in the Administrative building; that includes four direct service
employees, one project manager who does provide a great deal of programmatic work
along with administrative tasks, an accountant, a bookkeeper and the Executive Director.
The Accountant and Bookkeeper are administrative, the ED devotes about 50% of her

time to some form of programmatic work including some direct work, about 25% to Administration, and the rest to fundraising.

Resource Requirements, Effectiveness, Costs, and Cost-Effectiveness

The clinic is supported by donations, as noted earlier, and massive volunteer activity. It's annual budget is $600,000. Promotoras work 24 hours a week, at $8.50 an hour. They also receive medical and dental benefits.

Conclusion

In theory, this model should work well. In practice, there were real problems in recruiting and retaining Promotoras. Sustainability is a problem with this program, in contrast to the youth workers. The Promotoras don't seem to be doing much more than advising women in the community to access services; it is unclear whether they are reaching more women than might access the Clinic by virtue of hearing about it in the community. It is not clear that people who receive services at the Clinic are able to "wean" themselves off by learning to use the wider health care system itself, thus making room for a newer cohort of those in need.

Dana Farber Cancer Institute (DFCI)

Small Business Health Promotion Program (SBHPP)

Overview

The Small Business Health Promotion Program (SBHPP) is a workplace-based health promotion and prevention program housed at the Dana Farber Cancer Institute (DFCI) in Boston, Massachusetts. It represents the collaboration between DFCI and 12 companies in Eastern and Central Massachusetts. The program currently operates in each of the 24 work sites, targeting blue-collar workers. These sites met the criteria of being primarily manufacturing companies between 50 to 150 employees. The companies included in the study have considerable numbers of Hispanics, Cape Verdeans, Brazilians and Southeast Asians.

The DFCI is a premier cancer treatment center in Boston. The SBHPP is a research project to study the effect of a health promotion intervention in the workplace on lifestyle behaviors, with the overall goal of reducing the risk of cancer.

The SBHPP is in its final phase of intervention and data collection. Evaluation of the program data is expected to begin in the Fall of 2002. The program is funded through the National Cancer Institute (NCI).

Budget figures are not currently available for the actual cost of the intervention. This data is expected to be available also in the Fall 2002.

The project serves all workers in each of the 12 workplaces, but with a special emphasis in blue-collar workers and clerical staff. Nearly half (48%) of the employees participating in the program have a high school degree or less. Two-thirds are males, and 69% are White, followed by Hispanics (13%), Asian (7%), Black (5%), and others (6%). The mean age of the program participants is 43.6 years old.

This site was selected for a case study because it utilizes a health promotion model to reduce the risk of cancer. The project has enrolled the collaboration of 24 companies in total—12 intervention sites and 12 control sites. There are three Intervention Coordinators, and each has four worksites for which they are responsible. Activities were held at each worksite once a month for a period of 18 months. The activities at the worksites lasted between 1 to 4 hours. Workers participating in the program spent as little as 5 minutes to a maximum of 45 minutes per activity based on their time and interest. Additional staff was used to develop the activities to design and produce materials, to assist with the development of the evaluation instruments and to conduct data collection. Each monthly activity addresses a different health promotion topic (e.g., nutrition, physical activity, smoking cessation, exposure to hazardous chemicals).

Over 350 companies were initially identified in Central and Eastern Massachusetts. Of those companies, 220 met the inclusion criteria (i.e., manufacturing—laundry services and refineries, and 50-150 employees). A survey was conducted with the companies to assess the interest in participating in the intervention. Thirty-six companies were recruited for the study intervention, but only 24 participated. Twelve companies were assigned to the intervention and 12 to the control group.

The intervention sites receive detailed information and hands-on activities to appraise health risk of the worker, to provide information and education of the different health promotion and prevention topics and to encourage participants to change behaviors. The control sites receive free smoking cessation classes on-site for those who opt to participate. It is important to point out that this intervention also is offered to the intervention sites.

The primary outcomes of the SBHPP are to improve lifestyle behaviors in the workplace by assessing changes in the areas of nutrition, physical activity and chemicals exposure. Distal outcomes include: reduction of cancer risk, increase number of servings of fruits and vegetables per day, reduce servings of red meat, increase use of daily multivitamins, reduce risk of exposure of hazardous chemicals, and increase physical activity.

Theory of Change and Primary Learnings

The SBHPP attempts to work with the management of the manufacturing industry to make the workplace a safer and cleaner environment that employees will view as a motivational factor to change their own behaviors. Thus, the purpose of the program is to develop an educational cancer prevention program that is relevant to blue collar workers. The program has been working with multiethnic and multilingual workforces.

The SBHPP aims at changing lifestyle behaviors of people who are working in the manufacturing industry and who are exposed on a daily basis to harmful chemicals.

The SBHPP collected baseline data on participants' demographics and lifestyle behaviors. A second wave of data will be collected after the intervention is completed to assess changes in behavior. The intervention's unit of analysis is the workplace. Thus, data will be eventually analyzed as changes in behaviors in that site.

The SBHPP is proud of the partnerships between employers and DFCI that have evolved from this project. They are hoping to increase awareness among the group of employees participating in the program about healthy choices and make a significant change in their behaviors.

Some of the challenges of implementing a project like this one are related to the identification and recruitment of the employers. Many companies approached by the DFCI research team were reluctant or not interested in providing their employees an

opportunity for participating in such a program. To overcome some of these barriers, the DFCI developed an intervention flexible enough to accommodate employees' schedules, particularly in those industries in which there was a need for indispensable services/labor.

The DFCI team based the intervention on the framework that increasing knowledge and awareness of health facts enable the person to act positively towards their health. They believe that Medicare can play an important role in improving elders health by reimbursing for health promotion and prevention activities.

Organization and Operations

The SBHPP does not conduct outreach activities, in order to have a more controlled experimental environment. After employers were recruited, management in each of the worksites was instrumental in helping with the enrollment of employees.

The SBHPP has three Intervention Coordinators (IC) responsible for four worksites each. The IC is responsible for delivering the session topic and activity to the employees sites. Each IC received extensive training on the different areas covered by the intervention— nutrition, physical activity, smoking cessation, and exposure to chemicals. Each session is set in a non-threatening, informative fashion, where the role of the IC is to provide information and answer questions. The "pitch" provided by the IC is simple, straightforward and full of real-life examples that employees can easily follow. The sessions emphasize simple ways in which employees can alter their lifestyle and improve their health.

Some of the educational strategies used by the program are cooking demonstrations, physical measurements, physical activity challenges (e.g., team contests), and prizes as incentives, among others.

The SBHPP have made an attempt to reach out and work with multiethnic and multilingual workforces (Hispanic, Cape Verdeans, Brazilians, Blacks and Southeast Asians). They have customize health messages to each of the different ethnic groups involved in the intervention by developing relevant activities and materials that take into consideration the social context of the employee's life. For example, when talking about nutrition, the IC uses the ethnic diet background to focus on the healthy components on those diets and on the areas where appropriate ethnic substitutes can be made. The session and information is conveyed in English by the IC, and a employee of the worksite who is bilingual and bicultural provides the translation.

A potential billable service component of the SBHPP is the health promotion sessions.

Resource Requirements, Effectiveness, Costs, and Cost Effectiveness

The SBHPP currently has baseline data on participants' demographics. More data will be collected in the Fall 2002 once all intervention sites have wrapped up their activities. No budgetary information is currently available.

It is hard to estimate the costs of replicating the SBHPP model, because of its workplace focus, which might not apply to many Medicare beneficiaries, and more specifically to elders of color. However, it is possible to establish a similar program in senior centers.

Conclusions

The major message embedded in the SBHPP model is how to bring health promotion activities to people's daily routine lives and environments. Facilitating the exchange of information in one's own "world" would likely increase the positive change in behaviors.

Deep South Network for Cancer Control

Deep South Network Community Health Advisors Program

Overview

The Deep South Network for Cancer Control is a National Cancer Institute (NCI) project based at the University of Alabama's Comprehensive Cancer Center in Birmingham, Alabama. The project began in 2000 and is currently funded into 2005. The purpose of the Deep South Network for Cancer Control is to eliminate the disparity in cancer death rates between blacks and whites in the Deep South. The program targets two poor rural areas including 11 counties in the Black Belt of Alabama and 8 counties in the Delta of Mississippi, and two urban areas including Jefferson county, AL (Birmingham area) and Hattiesburg/Laurel Metro, MS. The project is a collaboration between the University of Alabama at Birmingham, University of Southern Mississippi, Jackson State University, University of Alabama and Tuskegee University.

With NCI funding, the Deep South Network uses community resources and partnerships to provide cancer awareness activities, support minority enrollment in clinical trials, and promote the development of minority junior biomedical researchers. This project was selected for a site visit because of its intensive work in promoting awareness of Breast and Cervical Cancer with the African-American communities in the Deep South. The Alabama component of the initiative was selected because the University of Alabama serves as the main implementation and investigative team for the project. The project focuses intensely on applying the "Community Health Advisor (CHA)" Model. This model trains women (and some men) who are "natural helpers" to serve as volunteers in their perspective communities to provide cancer awareness messages and resources to their communities. The CHAs are further trained as "research partners (CHA-RPs)" to enhance African American participation in clinical trials. The CHAs volunteer from a 2-20 hours per week promoting information about breast and cervical cancer at events such as church presentations, PTA meetings, neighborhood associations, and work release programs. They work to recruit women to be screened for breast and cervical cancer through the Alabama Breast and Cervical Cancer Early Detection Program, American Cancer Society's Mammography program, and the local mammography van and Medicare. During the second year of operation, the Alabama CHA-RPs made approximately 3,189 contacts with women and men with the cancer prevention message. These contacts resulted in approximately 365 (11%) screening referrals and fewer actual screens. The first two and a half years of the project have focused primarily on increasing the number of CHAs in each county. The total annual budget for the project is approximately $615,731. Assuming that the annual budget represents the total institutional costs of implementation, this results in a unit cost of $193 per person contacted. The program is still in a development stage, while recruiting and training of

volunteers just recently took place in four counties earlier this year. Therefore, the unit cost per contact appears much higher than expected when operating at full capacity.

Theory of Change and Primary Learnings

During the site visit, the Brandeis team met with Edward Partridge, Principle Investigator of the UAB-based Project, Groesbeck Parham, Avon Scholar for Cancer Control, Claudia Hardy, Project Director, and other colleagues on the project. Furthermore, the team participated in a two-hour training session provided for new CHAs in East Birmingham. The program representatives assisted us with understanding sources of health disparities in the community and provided detailed information about the program and interventions throughout the participating counties.

According to the group, there are several factors that contribute to racial and ethnic disparities in cancer and other health areas in the Deep South. These factors include a significant lack of knowledge regarding various cancers, the need for self-exams and screening, poverty and unemployment, geographic isolation in rural areas and rural transportation issues, as well as institutionalized racial discrimination within the health care system. Lack of knowledge refers to women not knowing about or recognizing the importance of monthly self-breast exams, mammography, and pap smears. One primary goal for the CHAs is to get information out to women in the community and have these women act on this information and contact friends, relatives, and co-workers about the importance of breast and cervical cancer related health issues. Furthermore, geographic isolation is a factor for many people in the Deep South. This isolation coupled with inadequate public or private transportation creates a gap for many in reaching necessary health care services. For some patients, to obtain services at the nearest hospital requires a 2-hour drive. The CHAs currently provide information about rideshares with others in their community and provide information about private transportation services. Furthermore, the CHAs go into very rural areas to meet with people in a variety of community-based settings to provide cancer awareness information.

The Deep South Network for Cancer Control works to empower members of the community to make their own health a personal priority by providing them with the necessary information and cancer services they need. The staff of the Deep South Network indicated that the health system itself is also a contributing factor to disparities in health care. Within a complicated web of services, health care providers are under pressure to move most patients through the health system efficiently, while under appropriate clinical guidance. Little resources remain to ensure that patients maintain contact with the health system in order to manage their own health. In addition, the staff indicated examples of interpersonal and institutional racism that existed in the health services community. They stated that some clinical staff make inappropriate decisions about cancer care, based on the race of the client. Under the Deep South Initiative, the CHAs also try to empower individuals in the community to advocate for themselves in their interactions with the health system.

The program does currently collect data pertaining to the training and satisfaction of the CHAs as well as baseline and follow-up information pertaining to contacts with individuals in the community. Obtaining follow-up data has proven to be somewhat complicated due to tracking problems. The program primarily attempts to obtain as much information about subsequent cancer screenings as possible.

The team discussed five primary learnings from their work:

1) Staff members should be "from the community" and ideally would have the skills to serve the community, while being able to negotiate "tensions" or barriers presented by the health system. Most staff members and administrators are from backgrounds similar to those of the clients served by the program, increasing familiarity with local conditions and barriers to facing the health care system.
2) Empowering the CHAs as volunteers is critical to improving their impact on the communities that they serve. The CHA training is essentially a means of empowering community members to take action on their own.
3) After training the CHAs, monthly meetings should focus on how to make contacts with community members and having those contacted follow through to obtain screenings.
4) Disparities in cancer occur at all levels of the system from lack of knowledge through the treatment process. Resources should be directed to where the impact will be on the largest population. This involves getting people information about prevention.
5) Community collaboration is vital to the implementation of such a project. CHAs should be well connected with the American Cancer Society and other organizations to assist community members with getting the information they need.

Program representatives advocate for the use of volunteers in the dissemination of information and connecting of individuals to the health system. They believe that structuring and delivering services through volunteers is a means of getting "neighbors to help neighbors" at a low cost to the health care system. Furthermore, the UAB team expressed that volunteers are as effective as paid staff since their primary motivation is "helping others".

Organization and Operations

The CHAs work to connect with community members in a variety of ways. They deliver information about cancer awareness at church presentations, PTA meetings, neighborhood associations, work release programs, and genealogy fairs. Some also edit and record breast and cervical cancer public service announcements for radio and video, and recruit women to be screened for breast and cervical cancer through the Alabama Breast and Cervical Cancer Early Detection Program, the American Cancer Society's Mammography program and local mammography vans. Moreover, some CHAs have

provided tours of cancer-related facilities in the Black Belt of Alabama and served on a variety of cancer and health related committees.

During the second year of operation, the Alabama CHA-RPs made approximately 3,189 contacts with women and men with the cancer prevention message. These contacts resulted in approximately 365 (11%) screening referrals and fewer actual screens. The first two and a half years of the project have focused primarily on increasing the number of CHAs in each county. It is important to note that one of the earlier trained counties in the project, Choctaw County, shifted their emphasis in year two to referrals, screenings, and planned activities. The CHA-RPs made 301 contacts during 2001 and 103 or great than 33% of these individuals obtained screenings. This was attributed to a shift in focus in a more "experienced" group of CHAs.

The CHAs undergo an eight-week (16-20 hour) training program which includes sessions on: What is Cancer?, Breast Health, Breast Cancer Treatment, Cervical Cancer, Clinical Trials, Identification and Recruitment, Cancer Awareness, and Community Resources and Action Planning. The sessions are led by UAB/Deep South Network Staff along with guest speakers that have expert knowledge in each of the above-mentioned areas. The CHAs are also encouraged share ideas and experiences about connecting with individuals in their own communities.

The CHAs will work to make themselves available to members of the community in a number of public forums as outlined earlier in this report, but they will also serve as a point of contact for individuals seeking information about cancer and necessary health care resources. When necessary, the CHAs will make referrals to points of entry in the health or social service system for individuals to receive further information or health care.

Cultural tailoring of these services consists primarily of hiring people from the local Alabama communities to work with people of the community. This model is based on the philosophy that people know their own communities best. In the African American communities of the Deep South, this includes having knowledge about myths in the African American community about cancer and how best to talk with individuals about these myths. Such interaction also includes sharing experiences with engaging with the health system and devising strategies to gain better access to services.

Resource Requirements, Effectiveness, Costs, and Cost-Effectiveness

The program was able to provide limited budgetary information regarding the delivery of services, including personnel and non-personnel costs. Paid personnel include research, administrative, and CHA training staff. The total annual budget for the Alabama portion of the Deep South Network is $617,731. This figure does not include the time contributed by volunteers to be trained as CHA-RPs and the cost of time they contribute as volunteers each week.   It is apparent that this model has focused on reducing costs by using in-

kind resources to deliver a large portion of services to the community. Given an estimated total number of contacts of 3,189, using the total budget as a denominator, this provides a unit cost of $193 per person contacted. It is important to note that the program is still in a development stage, while recruiting and training of volunteers just recently took place in four counties earlier this year. Therefore, the unit cost per contact appears much higher than expected when operating at full capacity.

One of the factors that is complex to assess on a brief visit to the site which should be further explored includes the importance of involving a university such as the University of Alabama in the delivery of this project. Many staff indicate that having UAB as a representative organization for the project significantly improves the marketing of the initiative in the community.

In order to improve cost and cost-effectiveness analyses, additional analyses would incorporate further analyses of costs and outcomes.

Conclusions

Assuming continued development and training of CHAs of the Deep South Network, the project will most likely reduce the costs of delivery cancer awareness information to the participating counties in the project. Preliminary follow-up data suggests the importance of possibly developing a second phase of CHA training to focus primarily on getting people in the community screened and connected to the health system. Furthermore, the staff show the importance of African American leadership in the delivery and credibility of the project. Hiring people from the community at all levels of the initiative is a key factor. Other key elements in the success of the project include empowering volunteers to delivery cancer awareness and encouraging people to be constantly vigilant about their own health and to maintain links within the health system.

Community Health Services Division of the Oklahoma Department of Public Health

Oklahoma City Witness Project

Overview

The Oklahoma City Witness Project is an initiative replicated after the National Witness Project Model led by Debra Erwin at the University of Arkansas in Little Rock, AR and is implemented as a collaboration between the Oklahoma Department of Health, the 12[th] District African Methodist Episcopal Church, and senior centers in the Oklahoma City area. The project began in 1998 and was first implemented through a few churches in the Oklahoma City. In 1999 more formal leadership was established through the Community Health Services division of the Oklahoma Department of Health. During this time, Patricia Hawkins, MPH, became the leader of the Witness Project in Oklahoma. After referral from Debra Erwin, Ms. Hawkins was initially contacted as part of the Brandeis telephone screening process. After speaking with her on the phone, the Brandeis team decided to conduct a site visit to the Oklahoma City project based on Ms. Hawkins knowledge about the Witness Project model and her insightfulness into racial disparities in health care in Oklahoma.

The Witness Project of Oklahoma City recruits women survivors of breast and cervical cancer and lay health advisors to team up to teach women in the community about the importance of breast and cervical cancer. Two primary goals of the program include increasing the number of African American women in breast and cervical cancer screening programs and to reduce death and sickness from breast and cervical cancers by increasing the number of women who use self-exams, mammograms, pelvic exams, and Pap tests to find cancers at an early stage. The Oklahoma Witness Project presents educational programs and events to reach underserved African American and low-income women in churches and senior centers. Approximately 50% of the 691 women that participated in the program in 2001 are over 60 years old. During this calendar year, 64% of the participants have been African American, while 26% have been white/Caucasian. All of the white participants attended the sessions held in senior centers.

In addition to the leadership provided by Patricia Hawkins, the program staff until recently included a part-time Outreach Coordinator, but the position was eliminated due to funding shortages. The role of the Outreach Coordinator appeared critical to connecting women involved with the Witness Project to the health care system. As part of the standard Witness Project implementation, needs of women enrolled as participants are assessed at the beginning of the session. Many women have expressed need for low or no cost exams, transportation, mobile mammography, schedule health exams, and more information about breast, cervical and other cancers. Since the elimination of the Outreach Coordinator position, women seeking more information or assistance now

contact Patricia Hawkins directly. Funding for the project has historically come from a grant from the Komen foundation. Since the elimination of this funding, the only funds available now for the project come from the Oklahoma Department of Health. This funding is estimated at around $15,000 per year. The total program cost per participant is around $21.

Theory of Change and Primary Learnings

During the site visit, the Brandeis team met with Patricia Hawkins, Director of the Oklahoma Witness Project, one Witness Survivor Role Model, One Lay Health Advisor, the former Outreach Coordinator, and one church minister who has participated in sponsoring the program through his church.

According to the group, there are several factors that contribute to racial/ ethnic disparities in cancer and other health areas in Oklahoma. These factors include a significant lack of knowledge regarding various cancers, the need for self-exams and screening, myths about cancer in the African American community, a lack of knowledge about Medicare benefits, geographic isolation in rural areas and rural transportation issues, other pressing social concerns, as well as institutionalized racial discrimination within the health care system and a lack of insurance. Lack of knowledge refers to women not knowing about or recognizing the importance of monthly self-breast exams, mammography, and pap smears. One primary goal for the Witness Project is to get information out to women in the community and have these women act on this information and contact friends, relatives, and co-workers about the importance of breast and cervical cancer related health issues.

Furthermore, myths about cancer in the African American community in Oklahoma are very powerful. The representatives agreed that many African Americans equated cancer with a death sentence or a sign that one who gets cancer deserves it as a punishment. They also discussed how many African Americans did not want to know if they might have cancer as they would only become more fearful. The Witness project Role Models and Lay Health Advisors work with women to discuss and manage these fears within a group setting. They also provide the opportunity for women to contact them individually to discuss such fears as needed.

According to the representatives, a lack of knowledge regarding Medicare benefits was also an important factor that contributed to racial disparities in cancer. As more women presented in the Witness sessions having questions about Medicare, the Outreach Coordinator took on more of a role in explaining and investigating the benefit structure of Medicare for women.

Geographic isolation and rural transportation issues also presented as issues for some women in the sessions. The Witness Model team would make referrals as necessary to assist with transportation.

The representatives also discussed how the complexities of other life and social issues faced by many African Americans in Oklahoma created a hierarchy of needs among the community in which cancer issues were placed somewhere below other "more pressing" needs. They indicated how the Witness Project served to try to make awareness and action about cancer and health a priority for these women.

Lastly, institutional racism and administrative "red tape" was presented as significant barriers to receiving cancer services in the Oklahoma City area. Members of the group felt that blacks were treated differently than whites in receiving services, which in turn, created a lack of trust of health services within the African American community. Furthermore, there appeared to be administrative structures that created barriers to services. With limited financial resources and a significant amount of in-kind support, the Witness project served to help individuals work through these and other barriers to receiving cancer care.

The program does currently collect data pertaining to the registration of participants in the Witness sessions, but does not conduct any follow-up at this time. Data collected at baseline includes information about participant demographics, health behaviors with regard to breast and cervical health and also needs expressed in the areas of breast and cervical exams, transportation, mobile mammography, pap tests, childcare, and other information.

The team discussed five primary learnings from their work:

6) Staff members should be "from the community" and ideally would have the skills to serve the community, while being able to negotiate "tensions" or barriers presented by the health system. Most staff members and administrators are from backgrounds similar to those of the clients served by the program, increasing familiarity with local conditions and barriers to facing the health care system.
7) Using churches and senior centers to deliver information about cancer and other health areas are cost-effective ways of delivering these services.
8) The Case Management Model delivering a holistic, "systems" approach would be most appropriate if expanding services from the Witness project into the health care system.
9) Disparities in cancer care occur at all levels of the system from lack of knowledge through the treatment process. Other stressful life issues faced by the African American population compound these disparities.
10) Individual Witness sites need greater flexibility to adjust or expand their intervention in their work with the local community.

Program representatives advocated for a Medicare benefit that would reimburse a Lay Health Advisor that would have time to promote health and provide a number of sessions to assist those that needed assistance in navigating the screening, diagnosis, and treatment process. Although, the Witness models are not salaried but do receive a stipend, the staff recommended that Medicare reimburse so that staff be paid to deliver a set of services to

reduce racial disparities in cancer diagnosis and treatment within the African American population.

Organization and Operations

After undergoing an eight-hour training program and observing three Witness Project sessions, Witness Role Models and Lay Health Advisors are then ready to conduct sessions themselves. These models and advisors work together, generally with the Lay Health Advisor introducing the one-hour session and then the Witness Role Model briefly discussing her experience with the group. The women in the group are also encouraged to discuss their experiences and feelings. Women are generally recruited in eight churches and senior centers in the Oklahoma City area, although recently the Witness project has expanded into beauty salons, public housing developments, neighborhood centers, job centers, and welfare to work centers. In 2001, 39 Witness Programs were presented with 691 participants and 18 Witness Staff members, all leading to follow-up with 111 participants on a variety of issues discussed above.

Cultural tailoring of these services consists primarily of recruiting people from the local communities to work with people of the community. These include both the Witness Role Models and the Lay Health Advisors. This model is based on the philosophy that people know their own communities best and that Witness Role models can have a significant impact on delivering the message about cancer. Cultural tailoring also includes having knowledge about myths in the African American community about cancer and how best to talk with individuals about these myths. Such interaction also includes sharing experiences with engaging with the health system and devising strategies to gain better access to services.

Resource Requirements, Effectiveness, Costs, and Cost-Effectiveness

The program has a limited budget of about $15,000 including personnel and non-personnel costs. The staff currently includes a part-time Director and the Role Models and Lay Health Advisors. Ideally, the program might re-gain the critical position of the Outreach Coordinator that seemed to play a pivotal role in helping people connect to the health system. Additional costs include a $20 stipend paid to each of the Role Models and Lay Health Advisors for preparing and conducting a one-hour session. There is little information pertaining to the effectiveness of the program, although there is data indicating a significant amount of possible improvement in health behaviors. Only 66% of the women in the sessions had conducted self-breast and cervical exams in the last month, while only 58% received a pelvic exam or Pap test. More elaborate analyses might identify cost-offsets to the health system as a whole for the delivery the Witness project.

Conclusions

The Witness Project in Oklahoma City seeks to reduce disparities among African Americans in Oklahoma. The program provides significant insight into many of the barriers faced by African Americans in gaining knowledge about and receiving health and cancer services. The project currently has limited resources to promote its message about breast and cervical cancer to women in Oklahoma. A critical component of the project, the role of the Outreach Coordinator, seemed to provide a critical link to the health system for women seeking follow-up services. The project representatives encourage taking a closer look into the role of the Outreach Coordinator as a potential reimbursable services provided by Medicare to reduce racial and ethnic disparities in cancer for the African American community.

Elder Voices, Inc.

Public Benefits Counseling Program

Overview

Elder Voices, Inc. in Albuquerque, NM is a small, woman-owned minority for-profit business, founded and directed by Rebecca Baca, which develops educational programs for elders. The Public Benefits Counseling Program ("PBC Program") has been developed for, and conducted with, American Indian elders under a contract with the National Indian Council on Aging (NICOA), with funding under an interagency agreement between the Social Security Administration, the Indian Health Services and CMS. The PBC Program serves American Indian elders in New Mexico by assisting these elders in both identifying federal and state public benefits for which they may be eligible and applying for those eligible benefits. The PBC Program, which was developed and conducted between September 2000 and August 2001, presents information about federal and state benefits programs (social security, Medicare, Medicaid, SSI and state buy-in programs) on-site to groups of American Indian elders and follows these presentations with individual counseling interviews to identify eligible benefits and put an application process into motion. The PBC program has been conducted in 11 tribal sites in New Mexico. Elder Voices has screened 557 American Indian elders and processed applications to secure eligible benefits. The Elder Voices's PBC Program has been selected because 1) this model (jointly developed by NICOA and Elder Voices) for engaging American Indian elders in benefits screening and application has been highly successful and offers the promise of wide applicability to other minority elder populations, and 2) and highlights the problems of coordination of benefits between state and federal agencies and the harmful health outcomes for American Indian/Alaskan Native elders when benefits for which they are eligible are not captured.

Theory of Change and Primary Learnings

Elder Voices identifies four factors that contribute to health disparities among Americans Indians / Alaskan Natives:

Unequal treatment for American Indian / Alaskan Natives: e.g., elder American Indians counseled by Elder Voices to apply for benefits under state-administered Medicaid programs reported that their applications were not processed by state Medicaid workers, who incorrectly judged the elders ineligible and—in some instances—treated the American Indian clients curtly and inhospitably.

Economic factors: the poverty of many American Indian elders contributes to poor health. Elders purchase foods which are less expensive but also less nutritious (eg eating

at McDonald's may be less expensive than purchasing low fat, low sodium foods). Additionally, American Indian elders may often lack transportation for the purpose of obtaining for health and social services.

Historical factors: the history of US—American Indian / Alaskan Native dealings has been a barrier to obtaining health and social services. This history—marked by broken agreements and disruptive federal policies (such as removing American Indian children from their families in favor of boarding schools)—has led to a mistrust of government and a reluctance to engage federal and state agencies. Federal and state agencies are seen as bureaucracies that are not attuned to, or reflective of, the specific needs and sensitivities of American Indian / Alaskan Native communities.

Inadequate coordination of benefits among state and federal agencies. Elder Voices views the fundamental health need of American Indians / Alaskan Natives in general, and of elders in particular, as access to treatment. IHS benefits coordinators, who may each serve 2 or 3 American Indian tribes, are often forced to address only the most acute of health problems; and preventive and non-emergent health care needs frequently go unattended. In the absence of Medicare or Medicaid enrollment, or of private health insurance, American Indian elders can not obtain referrals for treatment of diagnosed conditions. And although treatment may be eligible under the Indian Health Services, funds to provide non-acute treatment may not be available, causing elders to postpone treatment.

Elder Voices staff and the other state-certified outreach workers assisting the in the PBC Program ascertained that many American Indian elders were eligible for the Medicare Savings Program, a state buy-in program that would pay for Medicare Part A, Part B, or both. Two barriers to enrollment, however, were present. The local office of SSA, to which all processed screening were sent (SSA was the lead agency and the stipulated recipient of these screening), was concerned only with SS eligibility and did not act to pursue Medicare or Medicaid eligibility. At the same time, for reasons attributed to inadequate training on the eligibility status of American Indian elders, the county office of the state Medicaid office denied applications by American Indian elders for the Medicare Savings Program.

The PBC Program attempts to overcome this reluctance of American Indian elders to interact with federal and state agencies by "Listening to the Elders." The PBC Program involves American Indian elders, the targeted service population, in the identification of the elder community's primary needs and in plans to recruit elder participation in public benefits counseling and application for benefits. The concrete measures of success of the PBC Program are the 557 screening for benefits prepared and submitted in behalf of American Indian elders. Because of the coordination of benefits problems noted above (SSA not acting upon potential eligibility for Medicare and Medicaid; and the initial denial of Medicare Savings Program eligibility involving American Indian elders), the processing of these screenings could not be completed within the 12 month award. Elder Voices has continued to work with the screened elders beyond the NICOA award to fulfill the trust which the elders placed in the organization.) Elder Voices believes that

this model of engaging the service population in needs assessment and in recruiting members of the community to participate will be equally effective with other minority elders.

Organization and Operations

The Public Benefits Counseling Program ("PBC Program") has been developed under a contract with the National Indian Council on Aging (NICOA), with funding under an interagency agreement between the Social Security Administration (the lead agency), the Indian Health Services and CMS. The sub-contract with Elder Voices was for the period of 9/01/2000 – 8/31/2001. Program development and outreach to New Mexico American Indian elders occurred over the first 9 months. In the final 3 months, Elder Voices conducted the PBC Program in the 6 originally designated tribal sites (Zia Pueblo, Santa Ana, Jemez, Isleta, Sandia and an "urban" site) as well as additional sites (San Felipe, Santa Domingo, Cochiti, Santa Clara and Zuni).

In each of the pueblos and reservations where it has conducted the PBC Program, Elder Voices first engages elder leaders in discussions of elder needs and ways in which the PBC Program could be conducted effectively. Leaders in the local American Indian elders community assist in scheduling a series of Public Benefits Presentations and in inviting local elders. Word of mouth and direct outreach by participants of these presentations produce additional participants for subsequent presentations. Because local elders take the initiative in promoting participation, the PBC Program overcomes the reluctance of American Indian elders to participate in federal and state-sponsored programs.

American Indian elders are invited to attend one or more of a series of local presentations. The first presentation is an introduction on public benefits and screening. The subsequent presentations are on social security, Medicare, the Medicare Savings Program (a state Medicaid buy-in program), SSI and Medicaid, respectively. Following each presentation, Elder Voices staff—alone, or in conjunction with local staff, when available—conduct individual counseling sessions with American Indian elders to determine eligibility for any of the public benefits programs (not just the program presented that evening). With the permission of the elder client, Elder Voices staff will partially prepare an application for benefits to the appropriate state or federal agency which it brings to the subsequent presentation for completion and signature by the elders. Elder Voices trains local elders and/or staff to visit elders who are eligible for benefits but do not attend the next presentation. Additionally, Elder Voices will arrange to transport and assist elders to appropriate state or federal agencies to process applications for benefits.

The principal cultural tailoring of the PBC Program is the development of trust between Elder Voices and the American Indian elders. The written materials which Elder Voices distributes to American Indian elders state that the objectives of Elder Voices are to: 1) Develop trust, 2) Serve as messengers (of programs to assist elders) and 3) Make a

difference in Elders' lives. In addition to establishing the direct connection between Elder Voices and its service population, this approach re-affirms that the PBC Program (and any other Elder Voices programs) are elder-driven, and that the promotion of elder health and economic security represents a commitment of the American Indian community. The six presentations are simple, direct and very visual. Elder Voices reports that American Indian elders are often unwilling to ask questions or indicate any personal confusion about the benefits programs in front of others; and that such questions and clarifications are more apt to emerge in one-on-one discussions with Elder Voices staff, and only after a personal connection has been made between the staff and the elders. Consequently, Elder Voices staff remain on site after the presentations to make themselves available for individual discussions with elders which lead to individual benefits screenings.

With regard to billable service components, the counseling itself is labor intensive. Community health workers and navigators play an important role in identifying and enrolling American Indian elders in the benefits counseling and in assisting in the preparation and submission of applications to appropriate state and federal agencies.

Resource Requirements, Effectiveness, Costs, and Cost-Effectiveness

The cost of the Elder Voices subcontract to develop and administer the PBC Program for the 12 months of the award was $258,360.

The program costs for the PBC Program do not distinguish the substantial costs of developing the Program, including a) the 6 presentations and b) benefits screening interview computer software for entering personal data and generating applications for benefits to state and federal agencies. Developmental costs aside, the delivery of benefits screening and assistance is labor-intensive, reflecting the significant investment of time by PCB Program and local staff in developing trust with American Indian elders and working with these clients throughout the application(s) process. The cost for delivering benefits counseling and application assistance for other minority elder populations would appear to be comparable.

Conclusions

The primary lessons derived from Elder Voices's PBC Program are that 1) cultural, historical and economic barriers and 2) inadequate coordination of benefits among state and federal agencies impede full utilization of publicly-funded health and economic support services available to American Indian / Alaskan Native elders; and that this under-utilization of health and social welfare services contribute to poor health status.

The PCB Program overcomes these barriers by establishing a level of trust with American Indian elders and by engaging leaders in the American Indian elder community

in defining the goals and outreach strategies of each intervention and the technical assistance services which are most needed by the service population. The PBC Program also illustrates that the complexity of navigating among multiple state and federal agencies is an additional barrier to ending health disparities among American Indian / Alaskan Native elders—a barrier which can be overcome through paid staff which assist American Indian / Alaskan Native elders in navigating through and between public agencies and assist state and federal agencies in recognizing American Indian / Alaskan Native elders' legitimate claims for public benefits.

Grace Hill Health Centers

Assistance & Self-Help to End Smoking (ASHES)

Breast & Cervical Cancer Program (MAP)

Overview

Grace Hill Health Centers is a group of six neighborhood clinics located in downtown St. Louis, east of Grand Avenue, serving a predominantly low-income minority population. Several of the zip codes within this region (63101, 63106, and 63107) had the highest cancer mortality rates in St. Louis (1994 – 1998), with the St. Louis African-American population having a cancer mortality rate 1.5 times that of the St. Louis White population and 1.2 times the U.S. African-American population.

Grace Hill has been active in the community for almost 100 years, providing health, social, housing, and neighborhood development services as "Neighbors helping Neighbors". In a collaborative effort with Care Partners MCO and Washington University, Grace Hill adapted the AHRQ Smoking Cessation Guidelines (provider protocol) to provide ASHES – a neighborhood and peer coach, nicotine-replacement, and stage-based approach to smoking cessation. With funding from RWJF (a 3 year grant, begun in 1999) the ASHES program is now fully integrated into the health care system and is in its evaluation phase. The Breast and Cervical Cancer Project ("MAP" Project – Mammography and Pap), with partial funding from the Susan G. Komen Foundation, was also begun in 1999, utilizing health care coaches for community outreach.

This site was selected for inclusion in this study for several reasons: the Neighbors helping Neighbors Systems approach, which utilizes neighborhood peer health coaches (volunteer) and health coaches (paid) as part of a Team; the Patients Computerized Tracking System (supporting evidence-based, patient-centered care, with measurable outcomes); its collaborative approach with community resources; and several other innovative ideas, such as the MORE (Member-Organized Resource Exchange) Time Dollars Program (for bartering of services between patients and health center needs) and the Health To Go Van (for neighborhood outreach). The cancer prevention services at Grace Hill appear to be a highly sustainable and effective resource for the community, built on a solid infrastructure of community-based care.

Primary Learnings

Missouri is a major tobacco-producing state. The cancer mortality rate (for all cancers) for St. Louis is higher than both the state and US mortality rates and is even higher within the African-American community in St. Louis. Some of the reasons cited by Grace Hill Staff for this disparity include: "African-Americans do not make health care a priority" (with such competing priorities as food, shelter, safety), the hierarchy of needs (especially for mothers), lack of transportation, cultural perspectives regarding large health care institutions and academic health centers, and unintended religious messages that cancer is a punishment for "not believing enough." There is frequently a fear of "knowing" and a belief that "God will take care of it." Lack of education and information regarding how to navigate the health care system or how to complete government paperwork for eligibility, and an ongoing stigma of "being on welfare" is frequently cited as well. Elders have additional concerns and issues, including the fact that "things take more time" and there is a need for more "contact time". Additionally, elders are living longer and families are more dispersed.

Grace Hill addresses these barriers through its "Neighbor helping Neighbor approach" to providing comprehensive services in the community in which it operates. It provides both individualized and community-based support. Through teams of professionals and para-professionals, outreach is taken into the community by a neighborhood coach who is from the neighborhood and can establish a personal relationship and credibility; the knowledge worker, or professional, can then enter the home or provide care and education, with knowledge of the family's "agenda" and comprehensive physical, mental, emotional, spiritual needs. Further support is provided through "volunteers", trained neighborhood mentors, who perform health education, smoking cessation readiness surveys, and outreach and awareness for clinic programs. Volunteers function in the community as well as in clinic waiting rooms and in support groups. Because of its deep roots and current networks in this community, Grace Hill can provide the social services and other needs, such as transportation and financial assistance, to break through the barriers to health care.

Once in the clinic, every patient is followed in a patient tracking system, with adapted AHRQ guidelines, templates for selected conditions and steps, ticklers, and network links. For the ASHES Program, the clinic delivery system incorporates a multi-disciplinary provider protocol (for every provider to ask - and document - all patients at every visit about their smoking habits and determine stage of readiness to stop smoking), individualized coaches for smoking cessation, cross-trained coaches from other programs, stage-based literature, quit contacts and plans, free or low-cost nicotine replacement (supported by Care Partners MCO), and support groups. All outreach is provided by a team of four providers, 3 smoking cessation health coaches and a smoking cessation program coordinator. Though still in the evaluation phase, ASHES has achieved a 9.6% smoking cessation rate versus a 6.6% cessation rate for those not part of the comprehensive program. While this increased cessation rate is an impressive achievement, there is still much room for improvement. The preliminary finding of 9.6%

cessation rate falls short of the 15 to 18% rates achieved in prior studies in other communities.

In the MAP Program, two BCCP health coaches, one supervisor, and one program coordinator provide outreach; scheduling and coordination of mammograms, CBEs, and Pap Smears; follow-up reminders; and transportation, if necessary. Mammograms are provided onsite at one clinic, the Water Tower Health Center. It is the coach's role to work with the physician and OB-GYN nurses to encourage the patient for further diagnosis and treatment, if positive. Patients are referred to Barnes-Jewish Hospital for treatment, where assistance is provided to low income, underinsured women through programs funded with CDC, state, and philanthropic support. Though in the B-J System, patient contact is still maintained if desired by the patient.

Grace Hill employs a coaching model for outreach, i.e. one-on-one interaction in the community, small groups, mentoring, and outreach. In a program so dependent on neighborhood volunteers, the Welfare-to-work program has had the unintended affect of reducing the supply of volunteers. One means of dealing with this problem has been the MORE Program, where health center clients ("neighbors") can trade their volunteer time and efforts for services received in the health center ("MORE Time $"). All neighborhood coaches are trained by Outreach Coordinators at each Center. Volunteers are responsible for outreach and mentoring through such activities as telephone calls, follow-up, and referral to the ASHES or MAP Teams, and participation in ASHES support groups, if appropriate. Salaries for Outreach Teams are supported by the Care Partners MCO.

Other barriers include:

- A transient population makes follow-up difficult, but the patient tracking system (within the five health centers) and networking efforts with other city health providers enables some extended coordination of care.
- Need for more paid coaches.

Other facilitators include:

- Relationship of a strong executive director with other community leaders and the fact that employees live in the community as well.
- An integrated information system enables documentation and standardization of care, as well as medical case management, across all providers.
- Willingness of Care Partners MCO to provide nicotine replacement medications at no cost to clients.

When asked what Grace Hill providers would like to see addressed in a national Medicare demonstration, the following answers were given:

- Reimbursement for social/personal services and social services case management. For example, a paraprofessional could negotiate the "red tape" of paperwork and phone systems for patients rather than highly paid professionals.
- Reimbursement for Outreach Worker services.
- Reimburse women under the age of 40 years for mammography services for early detection and screening.
- An "ideal" Outreach Team would be 2 paraprofessionals (nursing or social worker assistants) / 2 professionals (knowledge workers) – 1 nurse and 1 social worker

Organization and Operations

Program outreach / marketing design
To summarize Grace Hill's outreach efforts, 5 Grace Hill Health Centers provide health services to the surrounding community. Building on a chronic care model, services are both health center-based and neighborhood-based. An Outreach Coordinator promotes all Grace Hill programs and trains (forty hours over two weeks, including 20 hours "in the field"), with Center Outreach Coordinators, all volunteers and paid health coaches. Training includes: how to do smoking surveys, review of Grace Hill programs, information on how to volunteer, and role playing. Neighborhood health coaches then work with clinic-based Outreach Teams (four members each for the ASHES and MAP Programs), to get individuals into the health center programs. There is a requirement that volunteers bring in referrals. Two significant aspects of this program are the use of paraprofessional/professional teams and the MORE $ (resource exchange) Program.

The general philosophy of Grace Hill's outreach effort is to use entry-level staff and volunteers from the neighborhoods to gain access and establish personal relationships then refer individuals to the outreach staff - from the health center – for health education. Other Outreach efforts include "bring a friend" campaigns for mammograms and CBEs, working with churches (diabetes management programs) and local businesses, and knocking on doors. A "Health to Go Van" is deployed to the "fringes" of the catchment area and underserved locations. It focuses on health promotion and assistance with Medicaid eligibility sign-ups. Transportation is provided when necessary, through bus and taxi vouchers and shuttles. Health fairs have not been a particularly good source of outreach, at least for breast cancer care, because breast health is considered a "private issue" in the community, better communicated one on one.

Program operations
Once an individual is referred into the Grace Hill system, an encounter form and patient record is created and entered into a data management system that can then be accessed by providers throughout the system. Patients are then followed by an in-house case manager. Care and treatment is multi-disciplinary and coordinated. In the MAP Program, outreach workers will accompany clients to the hospital for further tests and treatment, if desired.

Cultural tailoring
Lack of trust in the medical community has been repeatedly identified as one of the major barriers to health care for African Americans. Serving a 95% African-American population, Grace Hill's major accomplishment in the area of cultural tailoring has been to confront this issue head-on and consistently. This program is built on its long-standing reputation in the community. It is a comprehensive program addressing the holistic needs of its clients. Personal relationships and trust have been secured in its "Neighbor to Neighbor" approach. Clients, employees, and volunteers are "neighbors". Sensitive to the long-term needs of its clients, it is an empowering model that promotes self-management and neighborhood-based support. Grace Hill uses and creates community resources, through collaboration and community networking. Grace Hill's long-term success, since 1903, is primarily a result of its focused, unwavering commitment to the community it serves.

Potential billable services
Potentially billable services at Grace Hill, currently supported by funding from Care Partners MCO, are the roles of Health Care Coach, Breast and Cervical Cancer (BCC) Follow-up Supervisor, and Neighborhood Peer Coach. In St. Louis, a Health Care Coach (for both Smoking Cessation and the Breast and Cervical Cancer Programs) is paid between $18,400 and $24, 900 annually. Both positions require at least a High School Diploma and 3 years experience. The BCC Supervisor earns between $22,100 and $33,100 annually and requires either a Junior College degree or a High School Diploma and 3 years experience; Formal medical assistance training is recommended as well. (See attached position descriptions.) The Neighborhood Peer Coach is currently a volunteer position, but is compensated, indirectly, through the MORE $ Program.

Resource requirements, effectiveness, costs, and cost effectiveness
What has made the ASHES and MAP Programs so successful at Grace Hill are the existing medical infrastructure available in the 5 federally funded Health centers. If the Outreach Team can get people in the door, the health centers can provide the services, and coordinate care through its extensive computer-based organizational support system. Additionally, through its long-standing community presence and positive reputation, as well as the community connections of its leaders, Grace Hill has the support of an extensive network for collaboration, as exemplified by its ongoing research and service relationship with Washington
University and funding support through Care Partners MCO. In spite of these resources, the Clinic identifies its potential vulnerability as state funding is expected to decrease. Furthermore, it cites the need for more paid outreach workers and program coordinators to implement necessary services.

Initial results demonstrate that the ASHES Program is effective in helping smokers stop smoking. The final analysis and results are not yet complete, however. As previously mentioned, a source for further cost-effectiveness improvements is in the composition of the Outreach Team. Employing paraprofessionals to work side by side with professionals, each functioning in their appropriate role, would produce a financial benefit for the site and better outcomes for the client.

Though aspects of this program would be difficult to replicate in other sites without the urban facilities, community support, health care infrastructure, and decision support systems, there are elements that could be utilized elsewhere. For instance, the MORE $ Program has significant potential as a bartering and incentive system, where resources are limited. Using Neighborhood Peer Coaches is another element that could be replicated, with further exploration into the training program utilized by Grace Hill. Networking with health insurers to provide medications, such as nicotine replacement, creates positive paybacks to the insurer (even if long-term savings) as well as the patient.

Conclusions

A number of significant lessons can be learned and disseminated from Grace Hill. First, it is a model for what can be accomplished when community organizations and individuals work together and are committed to the betterment of their community. Second, committing to the long-term health of the community is critical to achieving the trust and relationship building that is required to overcome intractable barriers to minority health access and positive outcomes. Third, access to a health care infrastructure, such as health centers, hospital providers, and decision support systems are crucial for program sustainability. Fourth, a long-term commitment is required of organizational leaders to their employees, the community, and the population they serve in order to attain the necessary human and financial resources to implement programs. Fifth, the organization needs to be responsive - it must listen to the needs of the community it serves, and then act to empower the community. Finally, perhaps the most significant observation made at Grace Hill, and one that is replicable by other health care providers, is a "culture of care," not for "patients", but for people.

Health Choice Network

Healthy Body, Healthy Soul – Jessie Trice Cancer Prevention Project

Overview

The **Healthy Body, Healthy Soul – Jessie Trice Cancer Prevention Project** (JTCPP) is a faith-based lung cancer prevention program housed at the headquarter offices of Health Choice Network (HCN) in Miami, Florida. The program represents the collaboration between some of the community health centers affiliated with the HCN and churches in those communities.

The program currently operates in urban communities in Miami-Dade County and in Lee County, Florida. The Miami-Dade county community is culturally and ethnically diverse. Approximately 57% of the County's population is Hispanic and 20% is African American, according to the 2000 US Census. It is estimated that 20% of the county's population is uninsured, exceeding the statewide average of 16.8%. As a major entry point for immigration from the Caribbean, and Central and South America, it is difficult to estimate the actual number of racial and ethnic groups, and the number of people living in poverty and uninsured. However, it is likely that many of these immigrant groups are poor and lack health insurance. Lee County, on the west coast of Florida, has a less diverse and older population. More than three-quarters of the county's population is white. The JTCPP targets the predominantly Black community of Dunbar, where over a third of the population is uninsured.

The **JTCPP** is housed at and administered by the HCN in Miami, FL. The HCN is an integrated coalition formed and governed by six community health centers, one community mental health center and the Homeless Health Center in Florida, and six community health centers in New Mexico. The network began out of a broader coalition effort among some of these centers that coordinated clinical efforts and common fee scales among the partners. Five network-affiliated federally regulated centers in Florida used the coalition as a mechanism for strategic planning and formalized the effort into the existing integrated network. A similar coalition of centers in New Mexico learned about the integrated system established by the HCN, and agreed to become members of the network. Similar efforts are currently happening in other states, including Utah.

The CEOs of each of the network-affiliated centers serve as HCN Board Directors. Each center has to commit to the overall goals of the coalition and has to sign an affiliation agreement. The HCN provides an integrated model to ensure consistency and uniformity on the following areas: fiscal, information systems, clinical, managed care and program development. A major feature of the HCN is the integrated and highly technical effort to provide the centers with assistance in these areas. The advantages of being part of the

network include: improved quality/cost efficiency, reduced cost/better quality, increased revenue, stronger market position and stronger leverage with vendors.

The HCN has a centralized MIS that tracks information from each on the above areas and provides quarterly reports on scheduling, billing, performance, etc. The HCN MIS also manages automated appointment reminders to patients, which improves the coordination of multiple appointments.

Currently, HCN is testing an ambulatory Electronic Medical Record (EMR) system with seven physicians in the network. The EMR system will use a hand-held or Pen tablet design, so the physician can take the system with him/her. The goals of the ambulatory EMR are to: improve compliance with protocols (including patient education), reduce duplicate test orders, increase availability of patient information, improve medical outcomes, improve coding, reduce time for charting and documentation, improve reporting and improve patient self-management. The EMR will provide immediate access to a patient's chart and information. It also will generate progress reports and a standard of care features appropriate for the age and gender of the patient. This system will allow physicians to request lab tests, consultations and prescription medications and send that information directly to the appropriate department. The EMR generates a patient education sheet based on his/her health condition. The piloting of the EMR does not include the JTCPP.

The JTCPP is in its second year. The program continues to grow as more community health centers and churches have expressed interest in it. In fact, a planning stage is currently taking place in East Pasco County to establish the project, but addressing prostate cancer in African American men.

The JTCPP greatly benefits from the integrated MIS at HCN. However, much of these advanced technologies are not fully utilized within the JTCPP. For example, Lay Health Educators and Case Managers in the program do not have a similar portable EMR system. Additional funding will be needed to apply EMR to the program, once it is fully implemented within the network.

The program has numerous funding sources including private foundations, CDC and state and local government funding. The overall budget for the current fiscal year is $1,059,026. This amount includes in-kind costs from the community health centers, churches and HCN (totaling $290,833, or 27.4% of the total budget). In-kind costs, however, do not include the costs of the CT scans performed at the two collaborating hospitals—Jackson Memorial Hospital and Moffitt Cancer Center—which are estimated at $247,000 per year.

The project serves the population in which the community health center and the church are located with the goals of educating the community about lung cancer, and preventing lung cancer through prevention of smoking initiation, smoking cessation and early detection and diagnosis. Thus, they may screen all racial/ethnic groups as part of the JTCPP. However, their outreach efforts are mostly focused on two R/E groups: African

Americans and Hispanics. Between August 2001 and May 2002 a total of 667 people have been screened. Of those, 42% were African American, 37% Hispanic, and 14% white. Regarding the age of screened individuals, approximately 38% were 50 years of age and older.

The JTCPP does not restrict its screening activities to members of participating churches, or to prior clients of community health centers. In fact, the Lay Health Educators, who are the ones responsible for the screening, reach out to the communities through the church and through prevention activities conducted in local high schools. They also carry on in-reach at the community health centers.

This site was selected for a case study because it addresses lung cancer in populations of color. The JTCCP has three intervention tracks: 1) prevention of smoking initiation; 2) smoking cessation; 3) early detection and diagnosis of lung cancer. A church-based trained Lay Health Educator (LHE) is responsible for the outreach, education and referral. The LHE is hired by the participating church with direct oversight from the HCN team. This team is comprised of the Director of the Program Development Unit, the Data Manager and a part-time religious leader who advises churches in the hiring and running of the program. There is a full-time LHE per church. The annual salary for this position is $18,000, plus 20% of fringe benefits. The role of the LHE includes: running two health fairs in the church per year; organizing and setting prevention activities at local high schools; providing smoking cessation interventions; and performing lung cancer screenings at each of these venues, in addition to screening activities in other settings.

As part of the prevention track, the JTCPP addresses tobacco messages in the media and education among local high school students. The education efforts to prevent smoking initiation is comprised of a play involving high school students on the dangers and consequences of tobacco.

As part of the outreach, education and screening activities, smokers who expressed interest or willingness to quit smoking are referred to smoking cessation groups at the community health centers. The smoking cessation track uses the curriculum developed by the American Cancer Society. Ninety-two percent of those screened were current smokers, and 85% expressed interest in quitting smoking.

Finally, as individuals are screened, those at high-risk for lung cancer (i.e., family history, cigarette smoking pack history) are referred to the community health center primary care physician and Case Manager to set up an appointment with one of the two collaborating hospitals—Jackson Memorial Hospital and Moffitt Cancer Center—to have a Spiral CT scan. The Case Manager keeps track of the CT scan results and follows up with the patient, as to what needs to be done next (i.e., cancer treatment/surgery, follow-up CT scan in six months or 12 months, etc.). Nearly half (48%) of those screened were at high-risk for developing lung cancer. Overall, 62% of those screened were referred to the case manager at the community health centers.

The JTCPP outcomes are to: (a)reduce rates of illness and death from lung and other cancers; (b) improve quality of life; (c) lower rates of smoking initiation; (d) increase smoking cessation rates; and (e) early detect and diagnose lung cancer.

Theory of Change and Primary Learnings

The lung cancer rates for the Miami-Dade and Lee Counties are lower than the statewide lung cancer rate. However, the death rate from lung cancer in Lee County (94.82) is higher than the state death rate (74.12). Not surprisingly, the estimate of average years of potential life lost to lung cancer also is higher in Lee County than in the state. Lung cancer data for the Miami-Dade County (1998) shows White-Black disparities in both incidence and mortality. The program does not have conclusive data on rates by race/ethnicity in Lee County. But, they suspect the rates are much higher among R/E groups, because of the large number of uninsured and undocumented residents in these communities.

The JTCPP aims at increasing screening and early detection of lung cancer by providing community and faith-based activities, and partnering with hospitals who are willing to provide the spiral CT scan screening and treatment at no cost for those who are uninsured. Patients with private or public (i.e., Medicare, Medicaid) are responsible for paying co-payments or deductibles as applicable.

The JTCPP collects detailed data on the number of people screened and referred to the community health centers and affiliated hospitals for screening through a comprehensive number of forms that are completed by the LHE at the churches and case managers at the health centers. The data are tracked through monthly summary reports in aggregate, and for each patient through the case management module of Medical Manager, which is currently under development.

Key data tracked include: number of people screened per community; age and race/ethnicity of those screened; former versus current smokers; individuals with regular source of primary care; smoking history; lung cancer risk; desire to quit smoking; and referrals to community health centers and smoking cessation program. All these data are collected at the community-based screening stage.

The second screening stage, the clinical screening, takes place at the community health center. The data is collected at the centers through the Case Management module of the Medical Manager used by HCN. This includes the percent of patients screened who are referred to the community health centers; number of patients who kept their appointments; percent of CT scans referrals; CT scans conducted; follow-up CT scans. The data reporting aspect of the module is currently under development, and therefore there is no outcome data on these measures.

Community-based screening of smokers is the cornerstone of the early detection track of the JTCPP. Since August 2001, 667 individuals have been screened. Ninety-two percent

of screened individuals were current smokers, and of those 48% were at high risk for developing lung cancer. The program goal is to identify smokers of all ages (80% of whom are expected to be 50 years old and older) who are willing to go through the community lung cancer screening process. Currently, nearly two-fifths of those screened (38%) were 50 or older.

Of the total of smokers screened, 85% said that they wanted to quit, regardless of age. However, data showed that participation and completion rates for smoking cessation sessions are very low. Even lower was the number of people who quit smoking at the end of the program sessions.

In its short history, the JTCPP has developed strong partnerships with other organizations, particularly hospitals and academic centers. In fact, it has become a prime site in an international lung cancer study, the International Early Lung Cancer Action Program (I-ELCAP). As expressed by the program staff at the HCN, a major accomplishment of the program is to have established a comprehensive support and treatment system for underserved and underinsured patients.

Despite the program accomplishments, there still remain many challenges and barriers, such as reaching out to certain segments of the population like recent immigrants, and guaranteeing access to CT scans. In addition, the smoking cessation rates achieved by the program are much lower than expected. Another challenge faced by the LHE and Case Managers is to make sure that the first appointment at the community health center is kept by the patient. The Case Manager keeps track of the referred individuals who did not comply with the center visit, and notifies the LHE, who then follows-up with the individual. Finally, attracting, recruiting and retaining Lay Health Educators is somewhat challenging for the churches and for the program.

JTCPP staff at HCN believe that stronger outreach, education and screening efforts are important in eradicating lung cancer, or any cancer and in eliminating R/E cancer disparities. They believe that Medicare can play an important role in achieving this by creating a benefit that will enable elders of color to access information through lay health educators, and through a system that will have all the necessary components to follow up the elder patient after the screening phase.

Organization and Operations

The JTCPP reaches out to the community primarily through the church in which the LHE is located/housed. The LHE begins her/his job reaching in to the church and branching out to other churches and schools in that community. Some outreach also is done by the LHE at the community health center.

There are a total of four lay health educators (LHE) in the program. The LHE is plays a major role in three areas of the JTCPP: outreach and education, community screening, and referral. The LHE conducts and scores the screening to determine whether or not the

person wants to quit, and whether or not s/he fits the high-risk profile for lung cancer. Those who express interest in quitting are referred to the smoking cessation program offered by the LHE and a Social Worker at the community health center. Those who are not ready for quitting receive educational materials.

Individuals screened as high-risk, and who are willing to be further screened clinically, are referred to a primary care physician at the community health center. The LHE is responsible for setting up that appointment. This appointment is automatically entered in community health center's information system. At that point, the case manager follows up to make sure that the patient shows for the appointment. If this fails, the case manager checks back with the LHE, who will follow-up with the person. Several follow-ups are made throughout the process to ensure patient compliance.

The purposes of the appointment are to complete a psychosocial and health assessment of the patient, to confirm lung cancer risk, to explain the spiral CT scan screening process and to make appropriate CT scan appointment to one of the two hospitals. The case manager continues to be the key person in the continuum of care. S/he sets up CT scan appointment, in collaboration with the LHE follows up with patient after screening results are back, and after diagnosis is made. In some instances, a follow-up scan is recommended six or 12 months after baseline. The case manager also is responsible for following up on these, assisted by the automated Case Manager module.

The JTCPP uses the lay health advisor model to reach out to underserved and uninsured populations in a non-intimidating way, and through a person (LHE) who belongs to the same community where most the people approached live. The two-day program training session for LHEs and case managers includes workshops on understanding and working with diverse communities, developing successful prevention campaigns, and creating effective community partnerships.

Potential billable service components of the JTCPP are the screening and referral work of the LHE, the follow-up work of the case manager and the first primary care physician appointment.

Resource Requirements, Effectiveness, Costs, and Cost Effectiveness

The JTCPP has a very comprehensive system to collect data that will enable the evaluation of program outcomes. Some of the descriptive data regarding the composition of the population and communities served is already available. Data regarding the process at the community health centers is not currently available, as it is in the development stage.

The budget presented by the JTCPP staff at HCN provides an excellent snapshot of the program costs. This budget seems to show a detailed and accurate depiction of how much a program like this will cost on a yearly basis including an estimated value of in-kind

contributions to the program. The total annual program cost ($1,059,026) includes estimates of $290,833 in in-kind contributions, but does not include, however, CT scans the costs, estimated at $247,000. Based on the number of those screened totaling 667 for the 10 months since August 2001, and a pro-rated total budget, the total cost per person screened totals $1,573 per person screened. Reducing the total estimated costs to institutional costs only (by eliminating in-kind costs), the cost per person screened is estimated to be $1,209. These unit costs include the CT scans plus outreach, education, and overhead.

The costs of the replication of the JTCPP model would most likely increase in other settings/organizations, mostly because there would be a need for establishing an interconnected MIS, which was already in place at HCN.

Conclusions

There are two major messages embedded in the JTCPP model. First, reach out and reach in to underserved populations by utilizing the available community resources. This has been achieved by creating synergy and partnerships between community health centers, local churches, high schools and hospitals. The use and credibility of community lay health educators also ensures the success of the outreach efforts.

Second, underserved and R/E groups are better served when the delivery of care has continuity and is supported by a comprehensive network. The JTCPP staff at HCN are very clear about setting goals and program message before the implementation of any cancer screening program, meaning that there has to be an assurance that appropriate low-cost or free treatment will be provided to the individual if cancer is detected during the screening process.

Indian Health Service

Community Health Aide/Practitioner Program (CHA/P)

Overview

The Indian Health System serves the 547 federally recognized American Indian and Alaska Native tribes. Tribes have the choice of providing all of their health care, only a portion of it, or none at all – and can elect to have the Indian Health Service remain their provider of choice. Alaska is one of the Indian Health Service's twelve Administrative Area offices, located in Anchorage. It has nine service units, providing services to almost 119,000 Alaska Natives, Eskimos, Aleuts, and Indians. There are five field hospitals located in Barrow, Bethel, Dillingham, Kotzebue, and Sitka. There are seven ambulatory health care centers, in Juneau, Ketchikan, Metlakatla, Fairbanks, Tanana, Fort Yukon, and St. Paul Island.

The Community Health Aide/Practitioner (CHA/P) program uses American Indians and Alaska Natives who are trained by the Indian Health Service and tribal organizations to provide health care, health promotion, and disease prevention. In Alaska, they are employed and supervised by their tribes and communities. Since they are completely fluent in the dialects and the cultural and social aspects of their people, these paraprofessionals are very effective. In Alaska, the Community Health Aide /Practitioner (CHA/P) program trains is a selected village residents primary and emergency health care and to work in the rural isolated villages. They provide preventive health services which are coordinated with Native health corporations. They are professionally supported by physicians in the Alaskan Area Native Health Service Units and Native corporation-administered hospitals, ambulatory health centers, field hospitals, and the tertiary care facility in Anchorage, Alaska Native Medical Center.

This model came about due to a meeting in 1964 of the DHEW, the PHS, and the Alaska Native Service to find a solution to the problem of providing services in Alaska villages. A proposal was developed to provide formal training to indigenous persons, a solution soon fueled by President Johnson's initiative to improve the health of American Natives. Three primary training programs run by three separate Indian corporations became very active in training community health workers: Anchorage, Bethel, and Nome. Gradually these and other programs began sharing training programs. The first health aides worked out of their homes. Currently, most villages have a Clinic through the Village built clinic program, with lease money provided by the Indian Health Service and janitorial services and utilities provided by the village.

A shortage in resources and funding was documented in 1988 (CHA/P in Crisis), which resulted in a statewide solution that tripled funding from all sources to $15 million. This was used to increase the number of CHA/Ps trained, their salary levels, to place Clinics in

every village, to upgrade existing Clinics, and to fund regulatory Committees for oversight of training and education.

The CHA/P is the principal provider of primary health care, and is able to consult with physicians at field hospitals or clinics by telephone or radio. The CHA/P can provide first aid, examine patients, and carry out treatment recommended by the physician.

Path to Understanding Cancer, a resource guide, has been developed and serves as the basis for a continuing education course, as well as a 3-credit university audio conference distance course. As a result of course offerings, CHA/Ps reported an increase in their knowledge and understanding of cancer, a reduction in cancer lifestyle choices (quit smoking, diet change), a decrease in cancer fear, and an increase in preventive screening. CHA/Ps also expressed a sense of empowerment to provide community education about cancer.

Theory of Change and Primary Learnings

A large proportion of Alaska Natives live in 197 Alaska Native villages. Currently, upto a third of these villages have unsafe water supply, inadequate waste disposal facilities, and poor access to nutritional foods. Cancer is currently the leading cause of mortality. Other major problems include maternal and child health, heart disease, alcoholism, mental health, diabetes, and accidents. Because many of the villages are in isolated areas with no road access, one of the services that is crucial is air transport, and is variously reimbursed by whoever is paying for the health-related service, be it Medicaid, the tribal organization, or the individual 178 of these Alaska Native villages have Clinics staffed by Community Health Aides/Practitioners (CHA/Ps), a role that is therefore extremely important as not only the front-line provider, but very often, the only provider of health care that is accessible.

This program speaks to the success of using local, trusted, bilingual, culturally competent, workers, using customized, visual and learning aids such as pamphlets, booklets, and videotapes. It is best when they can be paid at competitive rates, with ample opportunities for maintaining competence and advancing professionally. But salaries vary immensely, and depending on the environment and available opportunities, may not be competitive. This has implications for recruitment and retention. They have an excellent infrastructure for maintaining contact and communication with the rest of the health care system. They provide directly or through arranging and facilitating access to the entire range of services (not targeted) that is needed by the village population. A closely-linked system (with the medical care system) is essential. If CHA/Ps do not have the support they need, they tend to resign. This supports the view of The American Nurses Association which endorses a plan that would rely on a community based system to provide long –term and other health services to the elderly (GallagherRM, How long-term care is changing. Am J Nurs. 100:65-67, 2000)

Organization and Operations

The federal government created a Certification Board to set standards and policies for CHA training and practice. CHAs are Community Health Aides who are in the process of basic training. CHPs are health aides who have completed Basic training. CHPs have completed 15 weeks of training during 4 sessions, at one of the four training sites in Alaska: Anchorage, Bethel, Nome, and Sitka. All CHA/Ps use the Alaska Community Health Aide/Practitioner Manual. It contains history questions, exam skills, assessments, and plans for the most common problems encountered in village clinics.

A recent development has been that Medicaid has begun to reimburse for services provided by CHA/Ps (Levels III, IV, P) that are supervised by Medicaid approved physicians, up to 85%. However reimbursement for CHA/P services constitutes the largest barrier to sustainability of rural outreach programs such as CHA/Ps. Currently, all the costs of training and paying CHA/Ps are borne by the tribal organizations, which may be councils, corporations, or other governing bodies. Each picks its rates, most are in the $15 to $30 an hour range. Turnover is very high; up to 20% a year, and retention has been an issue.

CHA selection requirements are: they should be known and acceptable to most of the village (typically the village makes the recommendation/selection), have a minimum of 6th grade English and math ability, and be physically able to perform functions of the job. The first thing they do is a 40 hour Emergency Trauma Technician training, (following which they may be certified as an EMT Level I or higher). They are required to obtain and maintain certification at this level. Next, they can be certified as CHA I, CHA II, CHA III and CHP IV after each of four training sessions. These encompass a total of 15 weeks of training over a period of two years. Once they also complete a preceptorship and pass a certification exam, they are called CHPs. CHA III, CHA IV, and CHP status allows them to bill Medicaid in part for their services. All CHA/Ps are required to document 48 hours of CME every two years, and CHPs must renew their CHP credential every 6 years through a re-certification exam.

Resource Requirements, Effectiveness, Costs, and Cost Effectiveness

In 2001, the Alaska Native Tribal Health Consortium received a R25 cancer education grant from NCI. The goals of the Cancer Education for CHA/Ps in Alaska project is to provide cancer education learning opportunities for CHA/Ps and Alaska Native community residents and develop culturally appropriate education resources to strengthen course offerings. A resource manual, Path to Understanding Cancer, was developed which is the basis for a 3 credit university course as well as an intensive week long continuing education course. There are eight modules which include information on what is cancer, what causes cancer, cancer diagnosis, treatment, pain management, risk factors

and prevention, screening and detection, loss and grief and self care, stress and burnout. Primary prevention, focusing on diet, alcohol, tobacco, exercise, and screening exams are emphasized. Additional course development include MammaCare training and a self directed breast health course which incorporates the Breast Health CD-ROM, developed for CHA/Ps. A breast health video, a basic cancer education CD-ROM, brochures and a flip chart are currently being developed. Understanding, a play about cancer was written as a powerful, uplifting way to explore cancer. It has been successfully performed 4 times as a readers theater and once as a play. In August 2001 it will be performed in rural Alaska.

The Alaska Native Tribal Health Consortium also utilizes resources available from the American Indian/Alaska Native Leadership Initiative on Cancer, including grant monies and educational materials for cancer training. This funding has increased awareness of cancer education resources such as the Cancer Information Service and Native CIRCLE. The 1 800-4CANCER number has proved to be a valuable resource linking rural Alaska residents to current cancer information. A current project charts the health care system in Alaska from village clinic to Alaska Native Medical Center in Anchorage in order to assist breast cancer patients and survivors navigate the health care system. The Alaska Native Tumor Registry is a population-based registry, and has a complete database of all Alaska Natives diagnosed with invasive cancer since 1969. A greater need to address cancer in Alaska is seen since cancer rates are up 50% over the last 30 years, and cancer is now the leading cause of death. The most dramatic increase has been in lung cancer, up two-fold in men and five-fold in women as a consequence of the increased use of tobacco after WW II.

Another new program is in development to address two other pressing problems: dental and behavioral health. The over 170 village clinics each have one or more CHAs and maybe a CHP as well. These CHA/Ps would be trained with additional behavioral health aide (BHA) and dental health aide (DHA) modules, that is, they would enroll in parallel educational programs in these focal areas.

Toksook Bay, the village visited by our research team, has a Clinic staffed by two CHPs, one CHA and one certified technician. The Clinic has 3 exam rooms, a waiting room, a staff room with a bathroom, a patient bathroom, and a medications and blood draw room. It is stocked with pharmaceuticals. They schedule two to three patients per day but have many drop-ins, more so in fall and winter (flus and colds). They do a lot of well-baby and prenatal visits, but not too much by way of active primary prevention in terms of counseling about tobacco, substance use, diet or exercise.

Because it was unexpectedly a clear and sunny day, the entire village was out salmon-fishing. Even the store shut down after a while. Physicians and other health professionals occasionally visit the villages. Patients can be evacuated by plane for hospitalization and needed specialty services. The initial referral center is the Yukon Kuskokwim Delta Hospital in Bethel (approximately 50 beds); then they may be referred, if necessary, to the 170-bed Alaska Native Medical Center in Anchorage. Brand-new and modern, this Center is also aesthetically pleasing, with a welcoming circular entry lobby, restful

alcoves sprinkled throughout, and remarkable Alaskan Native artwork displayed throughout the hospital. The Area Office is linked to the regional Native Alaskan health corporations, village corporations, and State and local agencies. It also works with the State's Department of Health and Social Services, the Arctic Investigations Laboratory of the Centers for Disease Control.

Conclusions

This appears to be an excellent model for meeting the health care needs of a geographically dispersed, remote rural population with major lifestyle and poverty issues. There are issues that may have been easier to overcome given the great need of the area for health care, which may not be transferable to the "lower 48". These include the scope and scale of clinical work that CHA/Ps perform, and the commensurate training and certification they receive.

Lahey Clinic

Wellness for Seniors Collaborative Program

Overview

This program is a partnership between the Lahey Clinic and the Burlington senior center. It is currently a one year structured research program to assess methods to improve the future health of seniors with chronic diseases, to prevent disabilities, and to produce a report that will impact the system of care for all seniors. This program is flexible and provides many individual choices for participants; commitment to classes is voluntary. Since it is a research study, there is no cost to participants. There are three parts to the program:

> **Well-being development program:** This is an individualized program and focuses on the personal, health, social, and physiological needs of each participant. A case manager, social worker, and exercise director coordinate the program with the program director. After a personal evaluation, this care team works with the participant to develop an individualized care plan. Issues are discussed with the client and necessary referrals made by the case manager. Action plan and follow-up calls are made by the case manager to the client and medical team as necessary.

> **Self-management chronic disease program:** Developed by Stanford University, this program is held once a week for a 2 ½ hour session for 6 weeks with 6-8 participants per class. It is designed to educate and empower seniors to effectively manage their chronic conditions. It includes topics such as appropriate use of medications, frustration, pain, fatigue, isolation, exercise, effective communication, nutrition, and identification and use of appropriate community resources.

> **Lifetime Exercise Program:** There are two exercise programs, (a) an advanced class led by a physical therapist with floor exercises, stretches, weights, balance, and aerobics, and (b) a less rigorous class with balance and stretches.

Theory of Change and Primary Learnings

The program is premised on the theory that older adults with chronic illness will benefit from an individualized program that addresses their health, social, and physiological concerns and needs. In this model, elderly patients with chronic illness have health risk appraisals performed by a clinical practitioner, who then directs them and advises them about managing their risks through an individualized care plan and facilitates access to

services needed along the continuum of care. The program is designed to empower and educate older adults so that they more effectively manage their chronic conditions. Topics covered include the use of and compliance with medications, psychosocial issues, pain, exercise, isolation, communication, nutrition, exercise and accessing the health care system as well as community resources. Just the fact that the patients stay well, can manage their chronic illnesses, have tools, and are undergoing a validated program are effective points with physicians.

Organization and Operations

Notices about the program were sent to Lahey Clinic physicians, who referred patients into the program. A nurse performs a geriatric risk assessment with outcome measures and identifies main issues/functional needs. The patient and she then develop an individualized plan of action including self-management and exercise, nutrition counseling, stress management, etc. This program is done in a community setting at low cost. The mail questionnaire can even be done on-line by clients. A VNA trained nurse could do the geriatric assessment; since the process measures and outcome measures are built into the evaluation, this saves time. It is possible that a social worker or another health professional or a good program director can do the geriatric assessment instead of a nurse. However, it is important that this person have links to the healthcare system and is respected by the MDs at the healthcare system and knows how to deal with the system in order to relay information, do referrals, etc. Costs are already built-in for a healthcare system that has RNs, social workers, physical therapy etc. Thus, this type of program directed by a health center can have links with senior centers, churches, etc.

Resource Requirements, Effectiveness, Costs, and Cost Effectiveness

The program is sponsored by the Robert E. Wise Foundation and Harvard Pilgrim Health care Foundation. It is currently free for participants. The funding covers salary costs for personnel, including the Program Director, another part-time nurse instructor, and a half-time nurse case-manager. Facility costs are covered by the Senior Center. The half-time case manager carries a load of 100 patients. Data was collected at baseline, and at 6 months, Initially, it has demonstrated a 28% decrease in inpatient admission for the intervention group. Emergency room, observation, ambulatory surgery, and out-patient usage have remained about the same.

Massachusetts General Hospital/ Chelsea Health Care Center

Avon Breast Cancer Project

Overview

The Massachusetts General Hospital (MGH) Cancer Center employs 50 full-time clinical faculty dedicated to the care of cancer patients. The Center includes ambulatory medical, surgical, and radiation treatment, chemotherapy infusion units and inpatient facilities. The Cancer Center is divided into disease centers. The Center for Women's Cancer is a multidisciplinary facility treating breast, cervical, endometrial and ovarian cancer. The Avon Breast Cancer Project at MGH is a plan with two distinct objectives; one relating to cancer research, not the focus of this case study. The second objective is to enhance access of minority and underserved populations in the greater Boston area to high quality clinical care for breast cancer, Project A, the focus of this case study. More specifically, the goal is to increase the numbers of women following up in a timely fashion with the diagnostic work-up and treatment as needed at MGH or other hospitals by coordinating care through the affiliated community centers.

The project strives to meet this objective by establishing community based, culturally appropriate, teams to work closely with established Breast and Cervical Screening Collaborative (BCSC) programs to increase screening and transition of minority patients to the MGH Center for Women's Cancer and other hospitals for further diagnostic testing and cancer treatment as necessary. In regards to mammography screening, the Breast and Cervical Screening Collaborative (BCSC) was already begun by Partners Health Community Benefits Program and hospitals (MGH and Brigham and Womens Hospital) in conjunction with the Dana Farber Cancer Institute.

The BCSC program is part of the CDC's Breast and Cervical Cancer Early Detection Program (BCCP). Seventeen health centers in the greater Boston area make up the collaborative; administered locally through the Massachusetts Department of Public Health. The BCSC funds mobile mammography units and cervical cancer screenings at the neighborhood health centers without charge to low income uninsured and underinsured women. Begun in 1998, during its second year the BCSC screened approximately 1,200 women, forty-one percent African American and sixteen percent Latino. Twenty-one percent of women screened never had a mammogram and their average education level was tenth grade and over sixty-six percent were non-English speaking. The number of women screened was estimated to represent only about five percent of the 30,000-50,000 disadvantaged female population in the greater Boston area.

Initially, two of the community health centers were selected for the Avon Breast Cancer Project at the Massachusetts General Hospital (MGH); one in Chelsea at an MGH

affiliated community health center serving a primarily Latino population and another in Mattapan serving a primarily African-American population. A third site in Dorchester is in the planning phase. This case study emphasizes the program as implemented by MGH and the MGH Chelsea Healthcare Center.

This is the second year of a six-year program. The program was initially proposed for two years and was then extended an additional four years. The program received $2 million in funding. The model of care developed for the project aims to provide the following:
- community based identification of women for further screening
- transition from the health center to the MGH Cancer Center by community based staff as appropriate
- community based psycho-social support for patients and their families
- coordination and support for transportation, day care, and incidental expenses for patients as needed

The services provided by this program include follow-up on missed appointments, case management services for patients requiring further screening, providing or referral to escort or translation services, conducting community based outreach regarding services and prevention, short-term counseling, and support groups.

Outcomes measured are the numbers of referrals to the Avon Breast Health Program, women receiving further diagnostic work-up at MGH or other hospitals in a timely fashion and continuing in treatment as needed.

Theory of Change and Primary Learnings

Medically underserved women experience barriers to health care related to language, culture and access. Latino and African American women are often uninsured and underinsured. Data from the 1999 Boston Behavioral Risk Surveillance Survey (BRSS) demonstrates that 23% of African American women aged 40 or older have never had a mammogram (eight times the rate of Caucasian women). About three years ago, a review of follow-up for abnormal mammograms at a Boston City Hospital and twelve neighborhood health centers found that 25% of these women did not keep follow-up appointments. Focus groups that took place with Latino and African American women suggested that factors such as mistrust of the medical system, lack of knowledge, inability to pay for mammograms and other services, and fear of being used for experimentation contribute to low rates of screening. Avon Breast Health Program staff believe that given difficulties faced by many in this population in meeting immediate needs for work, food, shelter and clothing, participating in preventive health services in the absence of symptoms may seem like a luxury. During the Chelsea site visit, Dr. Engel, the physician advisor, noted that breast cancer prevention was not routine in the countries of origin of many of the patients and women are scared that the discomforts of treatment will be worse that the disease. Logistical barriers may also be overwhelming. Patients may not be able to take the time off from work and/or forgo a half a day's wages to receive health care. Finding transportation and childcare can often be a challenge, particularly since both screening mammography and diagnostic mammography are only

offered in locations somewhat removed from the health center and often difficult to reach on public transportation.

The disparities in health care extend beyond low screening rates and follow-up appointments.

In the Boston area, statistics compiled by the Department of Public Health demonstrate that the rates of breast cancer for African American women are rising and they have a higher mortality rate. Although Latino women have a lower than average rate of breast cancer mortality, the rate has increased over the last decade with a thirty-eight percent increase from 1991/94 to 1995/97.

Finally, disparities exist for minority women utilizing the leading institutions for cancer treatment after diagnosis. Support for this theory is based on the following facts. The largest health care systems in the greater Boston area are the Dana Farber/Partners, Partners Cancer Care and the Care Group, which form the clinical arm of the Dana Farber/Harvard Cancer Center (DF/HCC). Minorities are under-represented in the patients treated at DF/HCC. In 1997, minority patients (African-American, Hispanics, Native Americans, and Pacific Islanders) composed 11% of the Boston area but only accounted for 8.8% of the new patients seen at DF/HCC.

To address this problem, the Avon Breast Cancer Outreach Program seeks to create stronger ties between DF/HCC and community health center physicians and patients. The following sections focus on the program delivery at the Chelsea community center site.

MGH Chelsea HealthCare Center Breast Health Program
The site was founded in 1971 as a small primary care practice. The city of Chelsea is considered a gateway city for many immigrants in the Boston area and the population it serves is approximately 54% Hispanic. The site currently serves 30,000 patients annually and offers both primary and many specialty services.

Bilingual professional and paraprofessional staff deliver the Avon Breast Cancer Outreach Program. A Breast Health Care Coordinator (1 FTE) ensures that women in the targeted community receive appropriate breast cancer screening, follow-up care and support services.
The Breast Health Care Coordinator was chosen from existing staff at the Chelsea site and she was a community health worker. A part-time Support Group Facilitator (5 hrs per week) is responsible for patients and their families receiving culturally appropriate psycho-social support services. A Physician Clinical Advisor, Dr. Engel (2.5 hrs per week) provides clinical consultation, oversees the program, and acts as liaison at DF/HCC and adult medical practices in the community.

More specifically, the Breast Health Care Coordinator performs the following tasks:

- provide referrals for further screening
- follow-up patients who miss appointments

- perform case management for all women requiring diagnostic and treatment services
- refer or provide escort and/or translation services for diagnostic and treatment services
- maintain a list of community and health resources
- prepare quarterly reports.
- helps arrange transportation services - shuttle bus

The Breast Health Coordinator (BHC) leads the program at the Chelsea site, working with the Nurse Practitioner (NP) at the MGH Breast Health Clinic. The BHC is Hispanic and lives in the community. In her role, she follows up on missed appointments, provides support and coordinates ancillary care and whatever has to be done to bring the patient into the health care system. There is a transfer of navigation from the community health center site where the initial breast screening is completed to the MGH Breast Health Clinic, where the Nurse Practitioner follows the patients. There is a dedicated weekly breast clinic staffed by surgical residents and a full-time Spanish interpreter for this program that focuses on extended diagnostic and post-treatment follow-up mammography.

The NP phones or e-mails results to the PCPs and also informs the health center PCP and BHC who did not show for appointments (approx. a 25-30% no show rate). This is the critical point in the process and the NP provides immediate feedback. In usual practice, a medical assistance might call once or twice to follow-up on a missed appointment of not at all. If a patient is diagnosed with breast cancer, although the patient is not formally tracked, due to the NP's role within the multidisciplinary breast cancer clinic, she continues to follow the patient. Follow-up is also provided informally at the Chelsea health clinic. Although the BHC does not have a formal role during treatment, patients may call her for support and she may become involved when requested. A considerable amount of time is spent documenting numerous phone calls and e-mails to the patient and various providers in order to ensure follow-up diagnosis and care.

The Support Group Coordinator facilitates a bi-weekly Spanish support group for women diagnosed with breast cancer (only one in the state) and provide short-term counseling for patients requiring diagnostic and treatment services.

In addition to the above noted positions, a full time Outreach Coordinator (1 FTE) located at MGH was proposed to initiate and support outreach efforts at the selected sites and promote understanding and awareness in the minorities communities at large. The position is supported equally by Avon and the BSCS. Outreach activities have not begun in earnest to date, given the time needed to get the two sites up and running and planning the third site.

Overall, the program views evidence of success in terms the number of patients to date who have been followed and connected to the health care system for further follow-up and treatment. Another success is coordinating and/or supplying important social supports to facilitate the process to patients, whether it be child care, helping with

insurance, transportation, wigs, or accompanying the patient to the hospital, etc. In Chelsea, the first Hispanic cancer support group in the state was established and another support group for English-speaking women was added.

At Chelsea, the site's established relationship to MGH has facilitated the programs success.

At all three sites, the program is different based on the organization and systems in place. Barriers include the need for more transportation and ancillary services that come from the national Avon Cares fund but are a limited resource.

For the national Medicare Demonstration, the need for the funding of this type of ancillary role as well as ancillary services is important. Many patients do not have the luxury of pursuing further work-up and treatment given their life constraints. For example, many do not have phones to facilitate follow-up. For the elderly especially, there is a need for coordination of services and a lot of hand-holding.

Organization and Operations

The Breast Health Program is supervised by an advisory committee chaired by Dr. Bruce Chabner, Clinical Director of the Cancer Center at MGH and the Associate Director for Clinical Sciences at DF/HCC. The Vice-Chairs include Wanda McClain, Program Director of the Partner's Community Benefit Partnerships and Anne Levine, Director of Planning at Dana Farber. The committee is composed of clinical staff of the health centers, breast cancer services at the DF/HCC, a member of the Harvard School of Social Science and Medicine Department, and representatives of the community housing, churches, and media. The Program Advisory Committee offers input to the development and implementation of the program, and review progress at six- month intervals. A subgroup of the parent committee is responsible for the program oversight and evaluation.

Cultural tailoring is primarily focused on the ethnicity and community relationship of the BHC, the dedicated Spanish interpreter at the MGH Breast Clinic (although the providers are not Spanish speaking), and the identification of and coordination of services for this target population to allow them to pursue further diagnostic work-up and treatment. This is of primary importance at the Chelsea site where the staff is very conscious that it was not only language, but developing and maintaining relationships, taking the time to talk things through, that made the difference for their patients.

A patient interacts with the program by referral from their PCP (after an abnormal mammogram or clinical breast exam) or the MGH breast clinic due to a missed appointment. The BHC will contact the patient to schedule an appointment at the MGH Breast Clinic and provide encouragement and assistance based on the patient's needs.

Resources Requirements, Effectiveness, Costs and Cost-Effectiveness

Summary measures of program outcome and activities are produced by the site on a scheduled basis. Among the measures tracked are the following: number of referrals, patient demographics (age, race/ethnicity, primary language, insurance type) referral source and reasons, program activity (phone calls, faxes, letters, meetings, etc.), reasons for program activity, and program impact.

To date, at the Chelsea site there have been 144 referrals, the average age of the patient is 47, Hispanic is the primary ethnicity and Spanish is the primary language. Almost 60% of patients referred to the program receive free care or have Medicaid. The primary reason for referral is for a missed appointment for a diagnostic test or diagnostic mammogram, 28% and 27% respectively. Other reasons for referrals are; assistance to make or keep an appointment, assistance with follow-up concerning a breast problem, a missed routine mammogram, assisting patients with diagnosed breast cancer, missed biopsy appointment, and insurance assistance.

For program activities, there were 1,105 activities associated with 144 referrals. Primary activities associated with referrals were phone calls and e-mails, 54% and 32% respectively. Additionally, searches were performed on the information system, there were phone or in-person meetings with the providers, and letters and faxes were sent to the patient or provider. Nineteen meetings occurred with patients, either at their home or at the health center, and on seven occasions, the Breast Health Coordinator accompanied a patient to MGH. The reasons reported for program activities, 70% of the time, related to either booking, providing information for or delivering a reminder about appointments or follow-up with the PCP or MGH Breast Center.

For the 142 unduplicated referral to the program, there were 15 cases of patients diagnosed with breast cancer, 60 patients were following-up on abnormal radiologic or physical findings, 59 patients with normal findings, 6 instances in which the patient could not be located, and 2 cases in which the patient was unresponsive to contact.

The budget for 2002, the second year of the program, totaled approximately $132,000 for the MGH Chelsea HealthCare Center Breast Health Program, $90,0000 at the Mattapan Community Based Health Center Model, $32,000 for Community Outreach, and $125,000 for the MGH Cancer Center. The money budgeted for the Chelsea site includes salaries (based on time and including fringe), interpreter services at MGH, mammography expanded service hours, educational material, staff training, Saturday shuttle to MGH, and other patient services (support groups, etc). The cost clinical services and supplies are not included. The Chelsea budget includes the full time BHC, Support Group Facilitator (5 hours per week), Clinical Advisor (2.5 hours per week), and 0.5 FTE Spanish Interpreter (0.5 FTE). Mammography expanded service hours $21,038, educational material $5,000, staff training $2,000, and other patient services (translation, support groups, etc) $3,750 complete the budget. Of the 144 referrals to the program that

occurred from May 2001 to June 2002, a rough estimate can be made of the cost per referral utilizing the Year 2 budget for the Chelsea site. The cost is $623 per referral.

National Center for Farmworker Health

Cultivando la salud / Cultivating your health

Overview

The National Center for Farmworker Health (NCFH) is a national organization located in a rural town approximately 15 miles south of Austin, TX. This private, non-profit corporation provides technical assistance in the form of leadership development and training, network support, and network expansion activities to a national network of 500 migrant and community health centers. (NCFH, Overview, received 5/02). With funding from the Centers for Disease Control (CDC), the NCFH developed Cultivando la salud, a "Train-the-Trainers" – model program targeting breast and cervical cancer education for farmworker women ages 50 and older. Begun in 1997, the program is in its 5th and final phase, dissemination, training, technical assistance, and overall analysis. The program's goal is to raise awareness about the importance of prevention, early detection and control of breast and cervical cancer among farmworkers and, specifically, to increase screening rates for farmworker women 50 and older. To accomplish these goals, a curriculum, based on a peer education model, was developed to train "promotoras" or lay health workers (LHWs), so that they can serve to educate and refer women in their communities.

This site was selected for inclusion in this study because of its use of LHWs and to better understand their roles in reducing the particularly intractable barriers to health care for this primarily Hispanic population. Among the special challenges being addressed are the target population's needs related to migratory living patterns, temporary housing arrangements, occupational and environmental hazard exposures, and other unique health, social, and cultural traditions. The program has been pilot tested at four sites and is now in the data collection and analysis phase. As the program continues with its evaluation and analysis, NCFH is prepared to disseminate its Comprehensive (Train-the-Trainer) Cancer program, composed of a Comprehensive Cancer Training Curriculum, a Breast and Cervical Cancer Curriculum, and a breast and cervical cancer toolbox, to migrant and community health centers (M/CHCs), interested in implementing the program.

Theory of Change and Primary Learnings

There are an estimated 3.5 to 5 million farmworkers in the U.S. Though farmworkers are located throughout the U.S., Texas is one of four largest "home base states" for this population. Forty-nine percent of these workers are migratory, 51% are seasonal workers. Approximately 80% are Hispanic and 10% African American. Barriers to health care access for this population include: lack of funds, lack of local provider resources, and

lack of familiarity with local resources; language and cultural differences; transportation barriers; frequent migration; and a lack of health care financing for this population (NCFH, presentation, 5/9/02). The NCFH program is attempting to address these barriers by providing a culturally sensitive community outreach program aimed at training trusted community health workers to deliver breast and cervical cancer screening education in the farmworker women's homes, and by providing access to healthcare through financial assistance and referral services.

To support its assertion that farmworker women are a medically underserved population, NCFH compiled the following data. Hispanic women (nationally and in Texas) are known to have a higher incidence of cervical cancer, a lower rate of early stage cancer diagnosis, and a higher mortality rate. Most problematic is the region along the Texas-Mexican border where there is the greatest population of farmworkers, the Lower Rio Grande Valley (LRGV). The goal for Healthy People 2010 is to increase the rate of Pap testing and to reduce the rate of cervical cancer deaths. Similarly, the rate of breast cancer and mortality due to breast cancer is higher in the LRGV. The region has among the lowest rates of early stage breast cancer diagnosis and the lowest rates of mammograms and other forms of breast cancer screening. Though the rate of breast cancer deaths is lower than the Healthy People 2010 goal, the goal for this project is to further reduce it and to increase the number of women having a mammogram. (This information excerpted from the NCFH presentation, 5/02, which cited ACS, TX Cancer Facts & Figures, 2000, SEER Cancer Statistics Review, 1973 – 1998, NCI, and The Lower Rio Grande Valley Community Health Assessment UT-SPH, 2001, as well as other sources.)

Using a systematic planning model as a tool (Intervention Mapping), Prochaska's Theory of Stages of Change, and a health promotions model, a program was developed that was specific to the needs of the targeted population. Interventions were aimed at improving organizational capacity (to provide training, to improve access to screening through supplemental funding, and to reduce environmental barriers), increasing the LHW capacity to provide education (through recruitment, training, and monitoring of LHWs using the curriculum), and to increase utilization of services by farmworker women (through door-to-door outreach and group sessions, and influencing both personal and external factors that influence women's decisions to seek care). Critical factors in program development, according to the Project Team, have been the use of focus groups to design the curriculum, survey instruments, and educational materials; it's foundation as a community-based model; and the use of local volunteers. The program was designed to "train-the-trainer" (Outreach workers or supervisors from the local health centers), and to send the trainers into the local communities, thus building on the existing health care infrastructure. The curriculum provides a means to standardize training and ensure quality. At the same time, it is composed of training modules so that it can be tailored to the needs and resources of the local center.

Success of this program is being evaluated based on:

- the development of a breast and cervical cancer module for 1) use by LHWs to educate and refer women in the community for screening services and 2) to be used as a curriculum to train LHWs;
- implementation of the breast and cervical training package at two sites;
- specific screening outcomes – increased breast cancer screening rates, increased cervical cancer screening rates;
- behavioral outcomes – increased knowledge, favorable attitudes and beliefs, self-efficacy, and intention related to breast and cervical cancer screening; reduced negative attitudes and beliefs and barriers to breast and cervical cancer screening;
- and dissemination of the training package to 20 farmworker community health centers.

The program has completed the pilot study and is in the process of collecting and analyzing the data on this phase of the program. The pilot study resulted in changes to the instruments used and educational materials. To date, two intervention sites have received the training. Two control sites were selected. Expected outcomes include an increase in mammographies, clinical breast exams, BSE, and Pap test screening among the target population (farmworker women 50 and over), as well as an increase in knowledge and positive health beliefs.

In a detailed presentation, the project team has outlined their program's challenges and successes at each phase of intervention development, implementation, and evaluation. To deal with the challenges created by cultural, language, socioeconomic, and health care access barriers of the targeted population, the culturally-sensitive cancer training program was developed as a partnership with communities, collaborating with state agencies for funding and health care resources. A module dealing with "how to" recruit and train promotoras (LHWs) as well as efforts to reduce clinic waiting times was implemented in response to the need for women to return to their homes and work. Culturally sensitive instruments, created and revised through the use of feedback from focus groups in the community, one-on-one interactions, along with relationship building and seeking opportunities for feedback were used to overcome challenges to data collection and study design and evaluation. Women reported that they could relate to the women and the stories in the instructional video and flipchart used in the one-to-one teaching sessions. Coalition-building, partnering, and team collaboration was evident not only in the bottom-up development and refinement of the curriculum, but also from the top-down, as observed in the project team presentation.

The NCFH team made several recommendations for Medicare demonstration projects as well. To summarize their suggestions, services must be culturally sensitive and accommodating to specific population needs and must be based on community collaborative efforts. Buy-in, commitment, and involvement of key stakeholders must occur early and regularly in the process. Development of the training program requires a systematic approach that considers identification of environmental factors, behavior determinants, a recruitment plan, and quality assurance measures. Another critical success factor for this program has been the consideration and ensuring of an appropriate

infrastructure providing the necessary services and links to a funding source at intervention sites.

Organization and Operations

Program outreach / marketing design
The NCFH utilizes its existing organizational network, community resources, and partnerships for the provision of services, funding, and recruitment of lay health workers. With approximately 500 migrant health worker service sites, it has expansion capability as the program enters the dissemination phase. Its basic premise was to start the intervention in communities where an infrastructure exists to provide screening services. Funding for women is made available through the Breast and Cervical Cancer Control Program (through CDC) and through NCFH's Call for Health Project and The Friends of Farmworker Families Fund. Further utilizing existing community resources, the program can be used to train existing community health workers in breast and cervical cancer screening education or it can be adapted to recruit and train new promotoras on a variety of topics as well as breast and cervical cancer care. The program is designed to use known community resources as the best way to reach out to women in the community. With access to continued funding, the long-term plan is to export the training program to the network of migrant health worker service sites.

This was accomplished through hands on dissemination, including hands-on training to the two intervention sites, as well as training sessions at regional Farmworker Stream forums and a NCFH Conference. More training will be conducted at Forums this year. The second phase, hands-off dissemination (which incorporates technical assistance through e-mail and phone calls and distribution of replication packages), will incorporate several strategies. First, the program will be promoted through a bimonthly newsletter, produced by NCFH, "Migrant Health Newsline", conference presentations, and special newsletters highlighting successful promotora programs that are implementing the program. Secondly, copies of the replication package (including training curriculum, program manual, video, flipchart, and promotora teaching guide) will be available at the conferences for distribution, and will be provided to each of the M/CHCs who receive funding from the Bureau of Primary Health Care. Without further funding, hands-on training and technical assistance will not be provided.

Program operations
The actual intervention involves three levels of implementation:
The first is at the systems level – The Migrant and Community Health Center decides to adopt the program and receives the program materials and technical assistance from NCFH to implement the program. This training consists of 3 days of training in the use of the Comprehensive cancer curriculum, the breast and cervical cancer curriculum, and the use of the toolbox materials that are provided for individualized, interactive training with women farmworkers. Sites should receive the training curriculum 2 –3 weeks prior to the training in order to review the materials. NCFH also provides supplemental funding (vouchers) where women do not otherwise qualify for funding.

The second level is the Training of the LHWs, by the Outreach Director or LHW Supervisor using the NCFH- developed curriculum, who will carry out education and referral in the community. During the pilot study, the Supervisors were health center staff that had previous experience in training and supervision of promotoras, usually a member of the health education department. Based on pilot evaluation, a 3-day training session for promotoras is recommended. It is also suggested that LHW Supervisors have experience in program development and are knowledgeable about the needs of the community.

The third level is the education and referral of farmworker women in the community, through door-to-door outreach and small group sessions (fewer than 4 women), utilizing the Breast and Cervical Cancer materials. It is recommended that promotoras be provided 15 hours per week to recruit and educate women and be provided with 4 hours of supervision per week. All women should receive at least 2 one-on-one sessions and 1 group session. The promotoras follow up with women to make sure appointments are kept. Recruitment of promotoras is generally conducted by word-of-mouth and through referrals from other agencies doing community outreach (the "best source of referrals"). Some advertising in local community centers, Laundromats, and grocery stores may be helpful, but NCFH has relied primarily on referrals.

The M/CHC received the necessary tools for adoption, implementation, and maintenance of the LHW program, in their program manual. LHWs are responsible for documenting their educational contacts on encounter and referral forms. LHWs learn how to make referrals and the importance of follow-up during their training sessions. The role of the supervisors is to track and monitor their daily educational contacts and referrals.

Cultural tailoring

As noted earlier in challenges and recommendations, NCFH has found the promotora model to be especially beneficial in providing culturally appropriate care that leads to improved health outcomes. The Project Team relates that program success is related to the fact that the promotoras are intrinsically motivated individuals, well known and respected, and knowledgeable of their community's needs and resources. One of the aspects of this program that makes it particularly capable of replication is its modular design that enables trainers to adapt the program to specific center needs and resources.

Potential billable services

The potentially billable services in this program are the costs of training-the-trainers, the costs of training the LHWs, salaries and transportation for the LHWs, and costs of the replicated training materials, including a video, teaching guide, flipchart, pamphlets, and a breast model for each participating site. This program is currently established to work with either a paid or voluntary promotora model. Finally, the program is presently limited to sites where screening services are available within a 20-mile radius. As funding is available for the replication packages or an extended supply of screening services, the program can be expanded.

Resource requirements, effectiveness, costs, and cost effectiveness

Program costs are estimated to be approximately $12,000 per site, for a 6-month program for personnel, training and material. Specific budget items include:

- Health Center Staff Time (4 hours / week for 24 weeks at $15 per hour) to provide training, monitoring, documentation, and communication (Total of $1,440);
- Lay Health Worker Time (3 LHWs for 15 hours / week for 24 weeks at $8 per hour) to attend training, provide presentations, driving time, and paperwork (Total of $8,640);
- Local transportation (3 LHWs driving 400 miles per month for 6 months at .30 per mile) (Total of $2,160)
-

Total costs are budgeted at $12,240.

The program has identified both proximal and distal outcomes, but has not yet analyzed the available data from the existing sites. It is expected to be completed by September 30, 2002.

Expected proximal outcomes include:

- At the M/CHC level - an expanded LHW program, increased referral and tracking of farmworker women, increased outreach capacity
- At the LHW level – improved knowledge, educating, and motivating capabilities
- At the Farmworker level – increased screening rates, improved attitudes and behaviors, improved awareness.

Expected distal outcomes include:

- At the M/CHC level – Adoption, implementation, and maintenance of LHW programs with breast and cervical cancer screening and referral; improved capacity for screening and referrals
- At the LHW level – a team of trained and committed LHWs
- At the Farmworker level – practice of consistent screenings, reduced rates of undetected cancers, reduced cancer-related morbidity and mortality.

Another benefit to this program, if implemented, may be the enhanced ability to network between M/CHCs, resulting in the capability to track referrals, provide follow-up care for this migratory population, and eventually feed into a network of referral to other social and economic resources.

Conclusions

This program provides us with a model for a systematic approach to development of a culturally appropriate training program for breast and cervical cancer education and screening, reaching out to a subset of the Hispanic population with unique cultural, socioeconomic, and occupational needs. The Breast and Cervical Cancer Education Program is a program building on an existing infrastructure; partnering with other organizations, including the National Cancer Institute, the American Cancer Society, the TX Dept of Health, CDC, and the University of Texas, and providing resource access and funding for migrant workers through its Call for Health Project and Friends of Farmworker Families Fund.

The 3.5 – 5 million farmworkers face unique challenges everyday related to the nature of their work, including heavy manual labor, occupational and environmental risks, child labor issues, lack of sanitation, crowding, and housing issues. Because of their migratory patterns, farmworkers have reduced access to care, lack of knowledge of health care and social resources, and a diminished ability to seek and obtain funding for care. On our visit to this site, the National Center for Farmworker Health and the network of migrant Health Center Service sites was compared to the "underground railroad", the system of supporters who helped fugitive slaves. As a network dedicated to improving the health status of farmworkers, it seems an appropriate comparison as a critical resource for an underserved and vulnerable population.

North General Hospital/ Breast Examination Center of Harlem (BECH)

Patient Navigation Programs

Overview

The Breast Examination Center of Harlem (BECH) – an outreach program of Memorial Sloan-Kettering Cancer Center (MSKCC)—was founded in 1979 as the country's first free screening facility for breast cancer. Under the leadership of Dr. Harold Freeman, it began offering free cervical screening, in addition to breast cancer screening, in 1994. Located in a New York state office building on 125th Street in New York, BECH has grown to 15 professional staff and conducted over 5900 mammograms and 4090 pap smears in 2001. In total, the program has served 49,246 women, 92% of whom have been African American or Latino.

MSKCC and North General Hospital in Harlem, where Dr. Freeman is President and Medical Director of the Cancer Center, are now establishing a Ralph Lauren Center for Cancer Care and Prevention. A building for the Center is under construction. North General Hospital is a 200-bed voluntary community hospital located at the border of the East and Central Harlem neighborhoods. It offers a range of inpatient and specialty ambulatory care services and also operates the Paul Robeson Center that extends its primary service area to West Harlem. With over 900 staff, it is one of the largest employers in Harlem. North General Hospital's service area includes nearly seven hundred thousand people, with 55% are self-described as Black or African American and 36% as Hispanic. It is one of the lowest income areas in New York City with over 40% being Medicaid eligible or enrolled.

Both BECH and the Cancer Center at North General Hospital operate active patient navigation programs. The BECH program targets all breast and cervical cancer screening participants with suspicious findings and follows them at least until a definite diagnostic conclusion has been reached or treatment initiated. New York State's Breast and Cervical Cancer Treatment Partnership program covers services at BECH for otherwise uninsured patients. The patient navigators are required to take responsibility for these screening participants through the treatment process. The primary measure of program success is the proportion of cases with suspicious screening results for which a resolution (either definite diagnosis and treatment or the conclusion that further action is unnecessary) is achieved.

The program at North General Hospital's Cancer Center serves all patients referred for cancer diagnostic, treatment, and follow-up services, but it has also developed a targeted colorectal cancer screening and prevention program using colonscopy and polypectomy. Patient navigation begins with an individual's first contact with the Cancer Center and continues through final case resolution. Emphasis is placed on resolving financial and other practical barriers to diagnostic and treatment follow-through, while also ensuring continuity of care by addressing patient questions, concerns, and fears in a cultural appropriate manner. Program success indicators include: the time interval between initial referral and completion of all needed treatments and reductions in differences in both treatment patterns and timeliness of treatment between privately insured and publicly insured/uninsured patients.

Theory of Change and Primary Learnings

The BECH and North General Hospital patient navigator programs responded to observations on patients treated at the Harlem Hospital Center between 1964 and 1986. During this period, only 6% of 606 patients treated for breast cancer had early, readily curable breast cancers and 47% had Stage III and IV cancers. Survival rates were far worse than in other studies of Black women in communities with less poverty and in white women (Freeman and Wasfie, 1988). Furthermore, analysis of tumor registry records of colorectal cancers treated at Harlem Hospital during 1973-1992 found that only 30% of patients were in the curable localized stage at the time of treatment and fewer than 20% of patients survived five years or more, figures far lower than national averages in both cases. (Freeman and Alshafie, 2001) Systematic barriers to adequate care appeared to be at the root of these findings. These included financial barriers (no insurance, inadequate insurance, or difficulties accessing coverage), communication barriers (explanations of medical findings and recommendations that were unclear to patient), medical system barriers (difficulty scheduling appointments, lost results), and emotional barriers (fear, concerns about meeting other life responsibilities) (Freeman, Muth, and Kerner, 1995).

The authors saw the patient navigator approach as one means to help low-income, racially diverse individuals overcome these barriers. Their objective was to bring a human interface between the health system and individuals suffering from cancer. They concluded that patient navigators needed to be culturally attuned to the community being served and thus able to serve as translators and cultural brokers between the health system and the patient while maintaining a compassionate and understanding approach. At the same time, patient navigators needed to understand the delivery system and environment through which patients would be moving and to have the respect and support of critical decision makers and gatekeepers (both clinical and financial) throughout the care system. As the Latino and other limited English proficiency populations have grown in their service areas, both the BECH and hospital-based navigation program have come to place special attention on linguistic translation as well. Both programs rely on multi-lingual staff and have strong links to other translator programs.

A major element of the program at North General is the development of first contact paraprofessionals who are thoroughly attuned to solving financial and scheduling problems in a timely fashion. Financial issues are not as likely to be initial contact issues for BECH since the screening services are free. In both settings, navigators have developed skills in helping patients access other practical resources such as transportation to screening, diagnostic, treatment and follow-up services, arrangements for child care, assistance accessing social services, and assistance negotiating time away from work or other responsibilities to get needed care.

The introduction of the patient navigator program cannot be fully disentangled from the free screening services available through BECH, and it is unclear to what extent the free screening service could achieve its goals without the navigator program. Regardless, a recent study provides compelling evidence that the BECH program has been associated with impressive improvements in the proportion of women whose breast cancers were diagnosed in the earlier and more treatable stages. During the period from 1995 thorugh2000, 46 percent of 181 breast cancers in 178 women identified had cancers in Stages 0-1 and 31 percent were in Stage 1-2. Of cancers treated surgically (92%), 80% received breast-conserving surgery. For about 8% of the cases, chemotherapy was offered for locally advanced or metastatic disease (Liberman, Freeman, Chandra, Stein, McCord, Godfrey, and Dershaw, 2002). These findings present a dramatic contrast to those from Harlem Hospital two decades earlier, when Stage 0-1 cancers were found in only 6% of patients and locally advanced or metastatic cancers in 49%.

Based on their experiences, Freeman and his colleagues have become convinced that racial/ethnic and social class gradients in cancer care and outcomes are complexly linked to multiple societal challenges and health care financing and delivery failures. They argue that Medicare and other public payers should spearhead improvements in care. Among needed improvements are systematic reductions in the financial barriers due to lack of insurance, inadequate enrollment in supplemental plans, gaps in coverage, and administrative barriers to receipt of coverage. In particular, they emphasize the importance of reducing barriers caused by Medicare's failure to cover cancer medications given as outpatient chemotherapy. At the same time, they recommend patient navigator systems as being cost-effective approaches to assisting with the complex processes associated with cancer screening, diagnosis, treatment completion, and follow-up.

Organization and Operations

Patient navigation services are integral components of clinical services at both BECH and North General Hospital.

At North General Hospital, patient navigation begins with the scheduling of an appointment for a colonoscopy or other service. A "first encounter" staff person sends a personalized confirmation letter and also calls prior to the appointment to confirm the date. Upon arrival at the cancer center, the first encounter staff person conducts a

preliminary financial interview, completes an intake form, and arranges for the hospital's financial office to complete financial assessment and insurance applications. Missed appointments have not been a big problem, but, when necessary, "no show" letters are sent and followed by telephone calls and contacts with the referral source. About 70% of the referrals, at present, come from BECH. Others come from the Paul Robeson Center and other outpatient clinics at North General Hospital, and referrals from community practitioners. Most colonoscopy referrals have had positive FOBTs or suspicious findings on clinical exams.

All North General cancer center patients are connected to a navigator by first encounter staff, but the level of involvement depends on the clients' needs. Navigators are particularly important for patients who face complicated financial barriers to the diagnosis and care process, including coverage for drugs or lost income as a result of time spent in getting care. Although not finance experts, navigators have developed personal connections with people in the hospital and elsewhere who can address the patient's needs. Navigators also provide emotional support, help patients understand the treatment options being offered, and provide a human contact with the health system throughout the care process. A relational database, monthly written reports on numbers seen and problems encountered, bi-annual and annual program reviews, and weekly staff meetings support the program. Program staff emphasize the importance of personal involvement by senior clinicians and administrators in oversight of the navigation system. The patient navigation program has emerged as a competitive advantage for North General, and particularly for African American and Latino patients, who report selecting the hospital because of the way that patients are helped to solving clinical and financial aspects of cancer care.

Patient navigation at BECH is fully integrated in its activities. The program is conceptualized as a 3-stage process that includes: 1) scheduling referred patients for follow-up diagnostic services; 2) tracking them to ensure scheduled services are received and results are retrieved; and 3) completing follow-up until case resolution. Each stage includes entry of data into the patient navigation database. Clinical staff are required to refer all cases to the patient navigators if the MSKCC radiologist finds suspicion of cancer upon review of a mammogram, a nurse practitioner indicates the need for additional tests based on clinical examination or pap smear findings, or a surgeon or other physician has scheduled further clinical tests. Outreach activities include the use of volunteers and cancer survivors/support group participants to contact individuals who miss appointments. Inreach - getting former screening participants to return on a biannual basis - receives a major emphasis at BECH. The medical records department generates a letter in anticipation of the need for rescreening, and, if an appointment is not scheduled, the client may receive a 2nd or 3rd letter, followed by a phone call from a volunteer, and perhaps a call from a health educator. As one staff commented "We never let them go." A similar strategy is used to ensure follow-up on recommended additional diagnostic activities. When a patient indicates she does not want follow-up services, she may be contacted by a cancer survivor/support group participant to try to turn this around. Very few cases are reported to end up refusing follow-up services. Because BECH services are free to persons without insurance, financial issues have not been barriers. Patient

navigators have become adept, however, at helping people enroll in public programs that provide coverage for follow-up services. As one component of BECH's information system, patient barriers are coded (as emotional, financial, fears, language, transportation, or other) and efforts are made to resolve these barriers.

Cultural tailoring of the patient navigation programs at BECH and North General Hospital is primarily a function of who provides these services. Both sites use English and Spanish speakers who have long-term commitments to the neighborhood. They focus on providing navigators with the tools they need to be respected and effective in their work. Other elements of cultural tailoring reflect understanding of how persons from the various racial/ethnic communities feel about cancer. For example, older African American patients often report on the conflicting messages they receive from clinicians and public sources. Older patients may have real difficulties using public transportation, particularly when follow-up diagnostic services require going to a facility outside of their neighborhoods. Latinas may be particularly concerned about the dangers of radiation, and cultural matching with a navigator can create a setting in which this fear can be raised and addressed. Some patients have experienced pain or discomfort in prior mammograms, and BECH mammographers and patient navigation staff encourage open and honest conversation between the technician and patient about their experiences.

Evidence on the Effectiveness, Costs, and Cost-Effectiveness

The patient navigation programs at BECH and North General Hospital have not been the subjects of formal evaluations of their effectiveness, costs, or cost-effectiveness. Moreover, because navigation is so deeply embedded in these multi-component programs, it would be difficult to assess its impacts independent of other innovative program attributes such as the availability of free or low-cost screenings, easy access to care, and the involvement culturally competent staffs with committed, activist, visionary, multi-disciplinary leadership. Secular trends within Harlem towards earlier identification, diagnosis and treatment of breast cancer are indirect indicators of BECH's overall impacts.

Measures of Program Effectiveness: Measures that are being tracked by both programs include case volumes, rates of positive screens, success in timely completion of the diagnostic process, completion of the treatment process, and cancers detected and treated and success of rescreening (where repeated screens at regular intervals are indicated). It was not clear whether patient satisfaction was being examined in a systematic manner. Differences by racial/ethnic group, insurance status, and other non-clinical factors are tracked. Clinical outcomes such as stage of cancer at the time of diagnosis and short-term and longer-term outcomes of surgery and chemotherapy including morbidity as well as mortality were acknowledged to be the ultimate determinants of program success. Some combination of these indicators could be used to compare navigator services across programs and cancer centers. The Liberman et al (2002) study provides indications of

positive program outcomes and improved rates of early detection and efficient screening for BECH. Similar data are not yet available on the North General colorectal cancer screening and prevention program or other navigated groups.

Program Costs: Costs of patient navigators need to be viewed within the context of the overall programs within which they operate. Salaries for these workers are an important element, but effects of the addition of patient navigators on other program costs also need to be considered. On the one hand, navigators may create efficiencies by taking over some responsibilities from other workers. On the other hand, they may increase other program costs by increasing throughput and increasing the need for additional staff. We were only able to obtain information on patient navigator salaries during our visits to BECH and North General.

In the North General Hospital Cancer Center, about 100 new cases are seen annually. Navigation activities are performed by two staff members: a first encounter staff/receptionist who is the clerical staff member responsible for conducting pre-appointment calls and generating letters (reminders, no-shows etc.) and a navigator who works directly with patients and staff within the cancer center, the hospital, and referral networks to resolve barriers to completion of multi-step diagnostic and treatment regimens. Only the navigator is an add-on to the administrative and clerical staff. The navigator is paid in the range of $40,000-$50,000/year plus 25% in fringe benefits. Because one navigator has held this position since the inception of the program, it is difficult to assess start-up and training costs. Additional costs can be attributed to increments in effort by Cancer Center clinical and administrative leadership as reflections of their investments in enhancing the program and insuring that the patient perspective is fully incorporated. Research costs in this program include the times of a health services research associate and technologist/computer consultant to facilitate measurement and feedback of program activities and outcomes. Dr. Freeman pointed to additional start-up costs associated with defining boundaries on the navigator role within the hospital.

Costs associated with the navigator program at BECH include the annual salaries of two navigators at $40,000-$50,000/year range plus 25% fringe benefits. This center conducts about 14,000 breast and cervical cancer screenings each year that in turn yield about 1500 cases per year that meet the requirements for patient navigation. Each navigator, therefore, services about 750 patients each year. Other costs at BECH include the amortized expenses for a 2-year project with MSKCC information technology services aimed at developing the patient navigator database. Staff functions that might be attributed to the navigator system include the conduct of cancer-survivor support groups and the engagement of cancer survivors in helping to contact women and ensure adherence with rescreening intervals.

Conclusions

The MSKCC-affiliated Breast Examination Center of Harlem (BECH) and North General Hospital's cancer treatment and prevention center, developed under the leadership of Dr. Harold Freeman, demonstrate multiple-component comprehensive cancer control centers

that have been well adapted to Harlem's dense, low-income, African American and Latino communities. The opening of the Ralph Lauren Center in coming months will offer the opportunity to document and quantify the costs and benefits of the patient navigator model more fully. At present, evidence of the benefits of these programs derives primarily from the impressive numbers of women being screened for breast and cervical cancer at BECH and by the fact that breast cancer is being detected at earlier, more readily treated stages than two decades ago. Patient survival has also improved substantially and now compares favorably with national patterns.

The BECH and North General Hospital patient navigator models suggest program components that deserve replication and careful evaluation. Among these are the use of the community health worker as a human interface between the health system and the patient: in screening and diagnostic settings to work with individuals with suspicious screening findings to ensure that diagnosis is completed in a timely fashion, and in acute care settings to ensure that patients complete the diagnostic process and indicated primary and secondary treatments and adjuvant services. In both settings, the navigator combines an intimate and committed connection to the communities being served, sensitivity to cultural and individual beliefs and feelings about cancer care, with an understanding of how to negotiate multiple financial, practical, and clinical barriers to cancer care.

Planned Parenthood

Witness Project of Connecticut

Overview

The Witness Project is a national program with headquarters in Little Rock Arkansas and partners in 17 states. The Witness Project of Connecticut is currently located in Bridgeport, a small city. The goal of the project is to reduce mortality and morbidity from breast and cervical cancer in African American women 40 years and older utilizing a culturally competent community-based cancer education program in which cancer survivors and lay health advisors educate women about the importance of early detection, including knowledge of breast self-exam, and resources for diagnosis and treatment. The program offers breast and cervical cancer education and a support group program. Additionally, the program partners with several organizations to provide screening and diagnosis/treatment referral services to the women it reaches.

The Project was introduced in Bridgeport Connecticut by Qualidigm, formerly Connecticut Peer Review Organization in 1996. They nurtured the project from 1996-June 1998. In mid-1998 the program was subcontracted to Planned Parenthood. The major organizational partners of this project are The American Cancer Society, National Cancer Institute and Cancer Information Services, local hospitals and the Connecticut Breast and Cervical Cancer Early Detection Project. The cancer organizations provide literature, videos, and other information to the project. Local hospitals have partnered with the project to provide mammography services, equipment, and outreach through their own internal mechanisms. As part of the initiative, the Witness Project also refers women to the Connecticut Breast and Cervical Cancer Detection Program for free or low cost mammograms, pap smears, pelvic exams and clinical breast examinations.

In cooperation with Cancer Care, the Witness Project implemented the first cancer support group for African-Americans in the state. The project also sponsors mammography screening days in African-American communities. One of the most significant achievements of the Witness Project is the collaborative relationships that have developed between organizations throughout the state. The project has also been successful in leveraging resources and working with leading charities typically accustomed to working alone, or with only mainstream constituencies.

The Witness Project is housed at and operated by Planned Parenthood of Connecticut through funding received from the Centers for Disease Control. The Witness Project is in the process of separating from Planned Parenthood, and it is currently applying for 501c(3) status to independently seek funding from outside sources to continue its operations.

The current overall budget from the project is estimated at $100,000 - $120,000 per year. Funding is also received from the Connecticut affiliate of the Susan B. Komen Foundation, and private individuals and organizations. The total proposed budget for the 2003 is estimated at $195,000, including three part-time outreach coordinators, who also would serve as Lay Health Advisors. A full-time executive director and staff assistant/trainer are also included in the personnel line item.

The project has conducted over 100 educational sessions reaching over 2500 women Sixty-eight percent of these women were over the age of fifty. The project has provided mammography screening to 153 women and has participated in 23 health fairs. Over 50% of the programs are conducted in churches. Additionally, the Witness Project has built strong partnerships with the faith community, cancer organizations, and hospitals throughout Connecticut.

The Witness Project of Connecticut is the only project to have licensing from CDC to conduct the project in an entire state. The Witness Project in Connecticut serves women throughout Connecticut, specifically in the cities of Bridgeport, Hartford, Waterbury, New Haven, Norwalk, Torrington, Meriden, Ansonia and most recently Stamford. However due to lack of resources they have not been able to start projects in other parts of the state with large African-American populations. Approximately 9% of Connecticut's population is African-American and in urban areas the population is significantly higher. Approximately 11% of the population is uninsured.

The target population for this project is African-American women over 40 years old who reside in the State of Connecticut, approximately two-thirds of the women are 50 years of age and older. However, the project is currently developing a model intervention for Latina women.

Major interventions of the project are breast health education via the lay health advisors and educators. Two primary types of interventions are provided through the Witness Project—education and support group program. The Project also provides a bridge for women to receive screening and diagnosis and treatment through referrals to collaborating agencies/organizations.

Education: Programs are conducted in churches, community centers, senior retirement facilities, civic organizations and other community-based organizations. Lay health advisors (volunteers) teach breast self-exam, benefits of early detection, advise of screening guidelines and provide information on free or low cost screening. This component also provides powerful and important insight on breast cancer from breast cancer survivors.

Support Groups – The Witness Project established the first breast cancer support group for African American in 1998 in Stamford Connecticut. The project also works closely with Cancer Care who provides a social worker for professional counseling services.

Screening – Through the Connecticut Breast and Cervical Early Detection Program (CBCCEDP) women are provided with free clinical breast exams, mammograms, pap tests and diagnostic services. Medicaid and Medicare eligible recipients are referred to area providers. The project works with local hospitals and cancer centers to assist women without insurance. Community mammography days are conducted with the help of local hospitals.

Diagnosis and Treatment – Through the CBCCEDP women who are diagnosed with breast cancer are enrolled in the CBCCEDP Medicaid program. Women who are not eligible for the programs are referred to Cancer Care, Inc, and other support agencies for financial support. The Witness Project does its best in keeping track of all women referred to other programs, agencies or organziations, with the aim of following up later and making sure that the women are receiving the necessary help and care. However, the referral to and enrollment in these programs do not ensure that women will receive all the needed and appropriate services.

Theory of Change and Primary Learning's

Barriers to Care
The biggest source of racial/ethnic cancer disparities for breast and cervical cancer in the community is lack of knowledge about the causes and methods of prevention or early detection of these cancers. According to the Witness Project Director another barrier is fear and distrust of the medical system. She also noted that traditionally African-American women saw breast cancer as punishment from God and a death sentence. Other barriers mentioned were that older women are the hardest to convince that they need a mammogram or pap smear because it is their belief that if they are not sexually active these tests are not necessary. In addition, she noted that in some instances their doctors do not really encourage the women to utilize these screening tests. There are many other myths associated with diagnosed breast and cervical cancer and the treatment. For example, Project staff related how many African American women, especially older ones believe that having surgery once diagnosed with breast cancer would spread the cancer to other parts of the body.

The project addresses these barriers by providing services through trusted individuals and institutions and organizations in the community, including African-American churches and community-based organizations. Education conducted by the Witness Project is delivered by African-American women matched by age and locality, whenever possible. Women speak in their own voices, vernacular and spirit about their experience with cancer. This methodology seeks synergy with the basic values and concerns of African-American women. There is also a conveying of a central perspective and a commonality of experiences.

Principal Learnings

There were a number of Principal Learnings that derived from the project. These included:

- Using peers to train other women is a highly effective model to influence behavior change and provide an avenue of trust for the women around the health care system.
- Using African-American women to educate African-Americans women also provides a way to facilitate learning in this community
- Age congruence is also a factor, women of the same age who were Witness role models and health advisors present their stories and provide education to women of similar age when possible. This seems to be the most effective strategy.
- Professionals although important are usually not the ones who motivate women to change their behaviors as compared to the non- professionals
- Culturally competent and sensitive literature and materials are also of key importance to the successes of the project. Women were very pleased and glad to see brown breast models and literature that is targeted to African- Americans in a positive light.
- The importance that videos and other audio-visuals reflect the culture and concerns of communities of color.

Desired Services Under A National Demonstration

The Witness Project expressed the following when asked what the program would like to see a national Medicare demonstration:

- Staff support for data entry, data analysis and consultation
- Support for staff through a national lay advisor group
- Development of a community database to identify individuals who are dually eligible for outreach for this project.
- A mobile van to serve 3 towns which could travel from site to site
- Conduct more than one session per group to increase the impact of the project
- Multi-year CMS grant
- Benefits for workers

The Project staff realizes that many of these recommendations may fall beyond Medicare's scope of work. However, they felt these were critical components of any successful program addressing cancer among older women of color.

Program Measures

The Witness Program currently measures successes using primarily process measures. Process measures include how many Witness Programs were offered per locality, the level of growth of the projects within localities, the number of women attending the Witness educational sessions. These measures can only inform the project about women's exposure to information on breast and cervical cancer. It does not provide pre and post knowledge of breast cancer knowledge.

The Project also measures its success through the recent growth in funding sources and partnerships. Other process measures include the growth of and variety of community contacts and collaboration, as well as the number of new localities being opened throughout the state.

Other program measures currently utilized to measure success include the number of referrals made for screening tests to CBCCEDC programs, and other private sources.

Overall, it has been difficult for the project to measure success due to lack of a database to track progress, and lack of technical support from the national Witness Project office in Arkansas.

Other data collected by the original Witness included knowledge, attitudes and beliefs at baseline, 6-month and post intervention (6 months or other if appropriate). The following were measured:

- Percentage who sought a mammogram who pre-intervention normally did not get a mammogram, within the six-month post-intervention period.
- Percentage who currently conduct a breast self-exam (BSE) who normally did not pre-intervention who had participated the intervention
- Percentage who received a clinical breast exam who had not received one pre-intervention in the past, who had participated in the intervention
- Pre and post knowledge relating to breast self-exam, breast cancer screening, diagnosis, and treatment and support services. The original project found that a high percentage of women acquired new knowledge as a result of the Witness interventions.
- Long-term behavior change to determine whether women who had received one mammogram were planning or had received a second mammogram within one or two years of the previous exam.

Griffin Hospital, a Witness Project partner, implemented a navel tracking process to assist in evaluating the effectiveness of the project. They developed a navigator system to identify the women that the outreach coordinator educated and referred to the hospital. This allowed Planned Parenthood to measure project success in motivating women to securing screening, diagnostic services and support for women who participate in the project. This system also allows the hospital to conduct follow-ups and identify the number of women who actually received mammography service through a referral from CBCCEDP. Additional measures could include satisfaction and benefits derived with Witness support groups including financial help, ability to cope with the disease and career development of Witness volunteers, as well as staff continuing to work with the project. This can be measured by who returns for training on an annual basis. This would be a measure of community capacity building.

It is important to note that currently there is no database for tracking success in Connecticut. All data is collected and analyzed by hand. There is little feedback from the national office.

About five publications demonstrating the effectiveness of the original project and the Witness model are available for review from the national office and in peer reviewed journals.

Organization and Operations

The Witness Project was the first project in Arkansas to target socio-economically disadvantaged women through African-American churches to reduce the risk of breast cancer. Deborah O. Erwin, a medical anthropologist at the Arkansas Cancer Research Center, University of Arkansas, and Theas Spatz, Ed.D, a certified health education specialist at the University of Arkansas at Little Rock initiated the Witness Project (WP) in 1990. It was developed in cooperation with the American Cancer Society, Arkansas Department of Health, Delta Health Education Center, local churches and community groups.

Drs. Spatz and Erwin used anthropological fieldwork, individual interviews, and focus groups to assess the needs of the population to guide the development of the intervention. The intervention follows the 4MAT System, which presents educational material sequentially to address four distinct learning styles and brain hemispheric preferences. Storytelling and experiential learning techniques are used in the intervention, rather than a traditional didactic presentation. The Witness Project creates a personal connection between the messenger and the audience in a non-threatening atmosphere.

In 1991, Title XX for the Arkansas Department of Health funded a pilot study. In 1995, a 3-year proposal to the National Cancer Institute (NCI) for an R25 Training Grant to expand the project in additional Delta counties was funded.

Concurrently, a supplemental grant from the Center for Disease Control and Prevention, funded through the Arkansas Breast and Cervical Control Program was awarded to support research to validate the intervention's effectiveness in increasing utilization services through local health units. These results indicated that the Witness Project was an effective model.

In 1996, the Witness Project expanded beyond Arkansas to include national partners in Bridgeport, Connecticut, Hattiesburg, Mississippi, Long Branch, New Jersey, Bloomington, Illinois, and Wichita, Kansas. These projects signed a trademark agreement license agreement to use the Witness Project logo and training materials. These projects became part of a national coalition and were included in the national expansion of the Witness Project from the CDC and therefore received grant funding from the federal agency. Other projects that joined could not receive funding but were eligible for technical assistance.

Between 1996 and 2001 over 31 projects were implemented in 17 states. The replication process ended in September 2001.

Description of Witness Educational Sessions
The Witness project intervention sessions is a new and different type of intervention. The sessions are presented by Witness Role Models (WRMs) and Lay Health Advisors (LHAs). WRMs are African- American women who are breast cancer survivors. The LHA, who may or may not be a cancer survivor, is there to provide information, especially about screening—including breast self-examination, and to answer questions about cancer and about services.

- The program begins with a hymn and a prayer
- The Lay Health Advisor and Witness role models thank the group for inviting them to present
- The lay workers express why they come to share, and the group would explain why they are there
- The Video " If I Can Help Somebody" is shown.
- Two or three Witness Role models share their experience with cancer, stressing the importance of early detection, and answering questions about their personal experiences, fears, concerns, challenges and successes. This takes three to five minutes each. Witnessing by witness role models is conducted to small audiences. The educational sessions addresses the fears and beliefs many women hold of cancer, demonstrates that the diagnosis of cancer is neither a death sentence nor a punishment, and provides participants with accurate, personal information about cancer, early detection and treatment models.
- The lay health advisor provides information about breast and cervical cancer screening, and breast self-care materials and information.
- The group is taught breast self-exam.
- Questions from the audience are addressed.
- Closing remarks.
- Witness Role Models and Lay Health Advisors are recruited.
- The group would be told how to contact the Lay Health Advisors.
- Program Closing.

Programs will differ somewhat dependent on length of the program and the size of the audience. There is an option as to who is picked to be role models for a particular presentation, based on age and other demographic categories. Programs take place in church halls, senior centers and other community-based facilities. A role model or role models are paired with a lay health advisor. Typically more than one role model presents to a group of women.

Cultural Tailoring of the Program
The program is culturally tailored by providing information in a familiar and trusted environment by other African-American women. The stories of cancer survival are presented in their own words and language. The language used by the survivors utilizes the vernacular and idioms of the church. Spirituality and dependence on not just ourselves but heaven above is stressed. Information on cancer treatment, screening and diagnosis is also provided. According to the national Witness Project the intervention changes behavior because the messages are crafted to meet rather than to change the

women's belief. Instead of trying to dispel a belief or a myth, or overcome beliefs which center on the power of God's will versus the power of biomedicine, the Witness Role Models present their stories within a framework that honors culture and local health beliefs. The very presence as cancer survivors is evidence supporting God's will. Presentation of education and delivery of services within this context of African-American women's culture facilitates the acceptance of messages provided and motivates women to seek diagnostic services and treatment.

The director of the Connecticut project, an African- American women, has strong ties with individuals and organizations within the African- American community which is essential to the growth and success of the project.

Potential Billable Services
Potential billable services could relate to billing for a service or an activity provided by Witness staff or associates.

- Lay Health Advisors – provide information on breast health facts, breast self-exam, including providing a demonstration, answers question in lay terms about breast care, provide screening guidelines for state or other screening programs and provides in formation about resources for services, and referrals.
- Witness Role Model – provide education about breast and cervical cancer to women based on their personal experience.

In addition, the Witness Project staff believes that Medicare can make a difference in addressing cancer disparities among older women of color, particularly African Americans, if several areas could be funded to ensure proper screening, diagnosis and care. Some of these areas, according to project staff, include:

- Surgeon- for Witness staff education, treatment consultation, diagnosis and treatment.
- Support group social worker for support group facilitation and individual counseling.
- Outreach coordinators- if their role is expanded from identifying community-based organizations and churches to outreach and follow-up to individuals who attended the Witness educational project to further encourage them to utilize diagnostic and treatment services.
- Mammography screening provided to a women.
- Training costs which are conducted at least annually for eight hours should also be taken into consideration for billing. The following is part of this effort that takes one eight-hour day.

Partnerships
Partnerships are key to program success. The program has formal partnerships with local hospitals in collaboration with the Witness Project that support mammography screening through the loan of diagnostic equipment and technicians. The American Cancer Society, NCI and CIS provide the literature, posters, and videos. Cancer Care facilitates support groups and information for families. One of the most important partnerships of the project is with the Connecticut Breast and Cervical Cancer Early Detection Program.

Program Outreach and Marketing. Acquiring the support of the community and participation in the Witness project was not an easy endeavor. Lessons and strategies were learned in the process. Initially, in 1996 when Qualidigm began recruiting volunteers and seeking support from area ministers to implement the project in Bridgeport churches, two nurses became the volunteer program directors and began recruiting women from their own churches where several women were survivors, including one of the pastor's wives. They collaborated with:

Qualidigm also systematically approached ministers in hopes of securing their commitment to implement the programs in their churches. The program was initially implemented in one church. The majority of the participants were from the church leadership. Asking women to bring a friend increased enrollment.

Enrollment was moved beyond one church when Qualidigm recognized the need for a community liaison. Hiring a person who was very familiar with the African-American community was helpful in being successful in conducting outreach in communities of color. One way that she reached out was by beginning to volunteer for many community projects. These collaborations helped to build her and the organization's credibility and visibility in the community. It also offered her access to the women she needed to reach and their pastors.

The Witness project further conducted outreach and education by participating in many different community projects, events, and activities, such as presentations and luncheons, to name a few.

Lessons learned from the numerous outreach activities include: approaching the head of the women's group at each church (if applicable) and getting pastor's approval, sometimes through his own wife.

Resource Requirements, Effectiveness, Costs and Cost-Effectiveness

The measures for program output are the number of staff, which includes the Director, part-time outreach coordinators, Lay Health Advisors and Witness Role Models, surgeons for Witness staff education, patient consultation and treatment, mammography technicians, support group leaders and the number of hours utilized within a typical week. Output also relates to the in-kind resources that are utilized by the program from ACS, NCI, and Cancer Care. Additional output includes transportation costs to and from Witness educational events and other meetings from program staff. According to the Director there are certain areas with large programs where more than a part-time coordinator is needed. She also suggests that the project could utilize an administrative person to provide support to the director and outreach coordinators. This would allow them to spend more time in the community and provide a person dedicated to support of the volunteers. In addition due to lack of funding certain cities have not been able to

implement projects. However it was noted that the project has had a few mammogram days in these areas. Even when funding has not been available in one town in the Valley, a local hospital area sought funds from Avon to hire a full-time outreach person.

The measures of success would not change as a result of the organization's operational phase. It would not be difficult to develop a detailed measure of total project costs and costs per unit. The costs for project coordinator can paid or reimbursed at the rate of a project coordinator at the federal level with commensurate work experience and skills. Lay Health Advisors and Witness Role Models would probably be paid at the level of and outreach workers. The Outreach Coordinator may be paid at a somewhat higher scale, due to coordination responsibilities. Pay scales for these types of services/positions may be available on the municipal level. There should be different levels of pay and titles within the outreach level to reward and compensate for experience, skills, and responsibility. A career track within and outreach of this job category would be important. Costs of educational materials are readily available for cost estimation, however the concern is the amount of materials/resources that are adequate given questionable numbers in relation to program participation.

Surgical consultation costs are available from medical procedural codes. Transportation costs are standard at the federal level. This budget is basically not difficult to project. It appears that these estimates will be fair because of the similar positions at the local, state or national level. These estimates would not change in a different operational phase per unit, but the overall costs would probably be lower in the early phases because there would be less staff and less educational sessions, if recruitment were conducted in the same way of the current program. If the program operates by cite or locality, it is possible that these Witness role models and lay health advisors will be hired on the onset of the project.

It is possible that the cost/output or cost/impact could be higher or lower upon replication. It is most likely the impact would be stronger because replication models can take advantage of lessons learned from other Witness projects throughout the country, as well as a Witness manual. However it is very important that in the replication process that the community nature of the project stay intact, otherwise the socio-cultural advantages of the program will be lost and therefore its potential effectiveness. The national Witness replication project ended September 30, 2001. Data collected for all projects has been sent to CDC.

Effectiveness also relates to the strength of the community network. This program might also be expanded to Latino, Native American, or Asian- American women.

Conclusion

The Witness Project is a promising model for addressing the prevention of breast cancer. This project has already proven it replicability. It would be important\ to assess the projects across the country to determine what are the factors which seem to make some

projects more successful than others and utilize those factors in replication. Potential billable service components will be relatively easy to determine and appear fair, however they are amenable to change based on service delivery. One caution is to ensure that community-based employees are provided with career advancement within their professions. It is also important to utilize the lessons learned from other Witness Projects across the country to strengthen future projects. One major concern for the project is that data is collected to ensure that project success can be measured. This project is a model that is culturally appropriate to the African- American and can provide an excellent model to educate women about and provides services to prevent breast and cervical cancer.

Seattle Indian Health Board

Breast and Cervical Cancer Health Program and Nutrition Program

Overview

The Seattle Indian Health Board (SIHB) is a multiservice community health center located in downtown Seattle, Washington. The health center provides health care to American Indians and Alaska Natives living in the Seattle/King County region of western Washington State.

SIHB is governed by a 15 member board of directors. All health care services are managed by the Executive Director, Associate Director, Medical Director, and division managers and supervisors.

The SIHB divisions include:

Healthcare Services (medical, dental, lab, pharmacy, mental health, nutrition, and the family practice residency program)
Chemical Dependency Services (operates at Thunderbird Treatment Center)
Behavior Health Services
Community Services (drug and alcohol abuse prevention through the Healthy Nations program, Microsoft Mentoring Program, Sprit Walk)
Fiscal and Administrative Services

Care is provided on a sliding fee basis. Public and private insurance are accepted for payment. SIHB also receives funding from federal, state, and local agencies and is a Federally Qualified Health Center for Medicaid and Medicare services. SIHB is also nationally accredited by JCAHO. SIHB is not an Indian Health Service facility, but does contract with the Indian Health Service under Title V of the Indian Health Care Improvement Act.

The principle intervention related to cancer prevention at SIHB is demonstrated in the breast and cervical cancer health program funded by the CDC. As part of this program, a medical assistant tracks the mammogram/gyn appointments of all patients and makes sure that they schedule their next exam. The coordinator of the breast and cervical health program also organizes outreach campaigns (primarily at pow-wows) to get more Native American women screened for breast and cervical cancer.

The second major intervention that is performed at SIHB is the nutrition program. Nutrition services at SIHB are primarily focused on diabetes management, but any

patient who requests the service receives an appointment for one-on-one nutrition counseling.

Theory of Change and Primary Learnings

SIHB sees access to care as the biggest problem for their community. One of the biggest challenges in providing care to this population is continuity. This population is very mobile and patients often move back and forth between the reservations and the city. The other issue is that some patients travel great distances to have care provided at SIHB. Therefore, it is difficult to tell patients to come back for a mammogram on the one day per month that the mobile mammography unit is available.

In order to address the issue of continuity of care, SIHB has culturally tailored the services they provide. SIHB has developed relationships with providers on the reservations so that phone calls can be made between facilities to get updated medical records on patients seeing providers at multiple locations. Additionally, Ivy Harris, the medical assistant who runs the breast and cervical health program, takes the lead in assuring continuity of care regarding women's cancer screenings and follow-ups for diagnosis and treatment. She calls all patients ahead of time to schedule a mammogram and, when possible tries to help schedule any other health care appointments for the same day that the mammography machine is on site. The persistence in arranging screenings and follow-up appointments is an important way in which SIHB meets the specific cultural needs of this mobile population. The measure of success for the breast and cervical health program is the number of woman receiving both their yearly PAP and their mammogram.

Organization and Operations

SIHB is a private, non-profit [501-c-3] community health center partially funded by the federal Indian Health Service. It was founded in 1970 as a free clinic, but has grown and become the largest and most comprehensive urban Indian health care delivery system in the nation.

SIHB serves the entire community, but is primarily focused on the Native populations in the Seattle area. The first line of its mission statement reads, "The Seattle Indian Health Board is a native organization targeting the American Indian and Alaska Native people as our primary service population. (value: natives first)" Specifically, the SIHB targets low-income American Indians and Alaska Natives (AI/AN).

AI/AN made up 1.7 percent of the Washington State population according to the 1990 census, representing the 7[th] largest concentration of Indian people in the United States. The SIHB is located in King County where approximately 1.3 percent of the county population is AI/AN. In 1998, SIHB estimated its target population of low-income AI/AN to be somewhere in the range of 6,320 and 8,427 individuals.

In fiscal year 2001, there were 6,422 users of outpatient services provided by SIHB. Over 140 tribes are represented in the user population. Approximately 7 percent of these users were over age 60. Eighty percent of these users had incomes below 200% of the federal poverty level, and 47 percent had no insurance.

Funding for the SIHB comes from federal, state, local, and private grants and contracts as well as billing revenues from Medicaid.

An important characteristic of SIHB is its family practice residency program. The first graduates of this residency program graduated in 1997. The program's goal is to train native physicians and others committed to Native health issues.

Resource Requirements, Effectiveness, Costs, and Cost Effectiveness

According to an administrative organizational chart provided by SIHB, there are 41.5 FTEs required to administer all program. The administration of SIHB is overseen by a 15 member board of directors.

No outcome data is collected regarding the breast and cervical health program. The medical assistant in charge of running the program performs a great deal of follow-up in order to make sure that most women receive their yearly exams, but there is no formal data collection process to track women over time.

The diabetes management program has begun a formal data collection process for all diabetes patients. This data collection is handled through the nutrition program. An ACESS database has been developed to track blood glucose levels each time a diabetic patient visits their physician. The physicians record the data and it is entered into the database. Each time new data is entered, graphs are generated and become part of the patient record so that both patients and physicians can easily track patterns over time.

Conclusion

This site is an important example of an integrated delivery system that reaches out to the Native American and Alaska Native community. The site has demonstrated its mission to provide a comprehensive set of preventive services and medical services to this population. Through the development of the residency program, SIHB has also demonstrated a commitment to training Native physicians and physicians dedicated to serving Native populations by providing education on the specific needs of the AI/AN population. By developing a trusting relationship with the Native community in Seattle, SIHB has been able to provide important preventive services including nutrition services, mammography, and PAP. The mobile nature of the AI/AN population presents an important challenge in the provision of health care services, but SIHB has demonstrated

its ability to provide prevention services by being persistent with follow-up and by understanding of the culture and needs of this population.

Senior Services of Seattle/King County

Senior Wellness Program

Overview

The Senior Wellness Project (SWP) serves Seattle area residents age 50 and older with a range of clinically tested prevention and health promotion programs. The SWP is not focused on cancer prevention or disparities directly, but sponsors believe that SWP's two components (the Lifetime Fitness exercise program and the Health Enhancement Program (HEP), a chronic disease self-management model) have proven outcomes (e.g., weight loss, increased exercise) that help prevent cancer.

The organizational location of the SWP in Senior Services of Seattle/King County helps them target low-income and minority seniors. In addition to SWP, Senior Services runs 9 senior centers, congregate meals, meals on wheels, information and assistance, home repair, homesharing, senior rights assistance, African American outreach, caregiver outreach and support, volunteer transportation, and adult day health programs. They reached 22% of persons 60 years of age and older in 2001.

Lifetime Fitness, a community-based exercise program, is a benefit for members of the largest HMO in the area and is also available to non-members for $2 per session. Lifetime Fitness is run at 33 different sites with 55 program sessions, and more than 1,000 elders participate in the program. The HEP is estimated to cost $480 per participant per year, but it is offered on a donation basis to seniors.

Theory of Change and Primary Learnings

Evidence of success of intervention. Under the leadership of researchers from the Health Promotion Research Center at the University of Washington, the SWP interventions have been shown in controlled randomized trials (CRT) to improve functional status and reduce hospitalization for elders with chronic illnesses.[1] After showing efficacy in a CRT in a senior center serving mostly Caucasian elders, SWP has focused on low-income and minority communities, which have disproportionate shares of chronic illness. A new CRT testing the HEP for diabetics enrolls Medicaid-eligibles and is set in a low-income apartment building which adjoins a senior center in a primarily African American neighborhood. Participants in the Lifetime Fitness class visited were predominantly African American but also included Asians and Caucasians. Both programs carefully measure baseline and follow-up indicators (glycated hemoglobin in the Diabetes-HEP

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[1] Leveille, SG, et al. 1998. Preventing disability and managing chronic illness in frail older adults: a randomized trial of a community-based partnership with primary care. *JAGS* 46:1-9.

trial -- performance in three exercises in Lifetime Fitness). All data are reported to researchers at the University of Washington to continue tracking achievement of targets for indicators.

Barriers to and aides to success. The implementation of the SWP in senior centers is at once a facilitator of and barrier to the wider success of these tested interventions, particularly in reaching minority populations. Combinations of research grant funding from foundations (primarily Robert Wood Johnson), service funding (primarily the Area Agency on Aging), and in kind contributions of senior center space have brought SWP programs to large numbers of low-income and minority elders. Another aid to success is that the SWP prevention/health promotion intervention model is relatively low-tech and staffed by nurses, social workers, and volunteers. It does not require participation of physicians or medical systems either for referrals or for service delivery. However, physician referrals could greatly increase participation in the program.
Paradoxically these may also be barriers to broader implementation through medical care and financing systems. For example, the diabetes HEP sends participants' physicians their health action plan, their baseline blood and creatinin levels, and contact information. They also ask physicians if there are any exercise limitations. The HEP staff think that many physicians pay little attention, but at least they have it so that they know the source of change when it happens. Apparently the experience is that most physicians do not give much credence to this kind of chronic disease self-management program.
Another indication of the barriers faced is the difficulty finding HEP nurses who fully subscribe to this kind of philosophy of interaction and care planning, including having an assessment that is function-oriented rather than disease oriented. The idea is to assess potential and to establish a relationship with the participant – the rest of the information can be gathered later. The nurses solicit health goals on the second or third visit with action plans to get to the goals. Some are embarrassed sending doctors social action plans At some sites there is always a chronic illness self-management goal, which SWP leaders know may not be participant-chosen.

Recommendations to Medicare. Staff and researchers had several recommendations for a Medicare prevention/health promotion demonstration. First is the issue of identifying priority beneficiaries. The strongest model would be for CMS to use its database to identify patients who hadn't had a preventive procedure and the physician who they last saw to mail a letter to both to say that it should happen. Or CMS could do a general mailing to beneficiaries to promote these procedures. Or the PRO could be more pre-emptive about this. Another example (not a great one) of how Medicare could cover prevention is the falls prevention program. It would come after a person has his first fall, which would trigger eligibility for PT. Second, CMS should use its data processing capabilities to create comparison groups matched to participants so that effectiveness can be demonstrated. Third, there should be requirements for measures of outcomes and standards on the measures, which should recognize that some are easier than others to achieve, e.g., nutrition is hard to change. CMS's new diabetes education benefit is an example of what can go wrong when outcomes are left out. The American Diabetes Association got the regulations to say that said that only an ADA-certified educator could deliver the benefit, and having such an educator was all you need to do, i.e., no outcome

standards. Structural requirements are appropriate, but not without outcomes, and not (as in the case of diabetes) when the structural feature becomes a barrier.

Organization and Operations

Recruitment. Both the HEP and Lifetime Fitness programs have recruitment challenges, but they differ. Lifetime Fitness gains most of its enrollment by word-of-mouth and HMO marketing efforts. Socialization is an important part of the program, and the interaction with other elders and the instructors has contributed to the success of the program. There is not much turn-over in the composition of the classes - once people join, they tend to stay on. However, there are not often waiting lists for new people to join. This may be due to the fact that there is not much advertisement of the program. The Lifetime Fitness Program is trying to increase the participation of African American and Asian/Pacific Islander elders by moving the program into new settings such as housing complexes and community centers. The program is also trying to encourage higher participation rates among the newly retired who often have more money and tend to use YMCAs and other exercise programs. The Lifetime Fitness staff fear that the decline in use of senior centers among younger, more affluent seniors is correlated to these participants' enrolling in health clubs.

As a CRT, the diabetes HEP (D-HEP) faces special problems, but they also illustrate the difficulties of targeting health promotion and prevention programs through Medicaid. To locate eligibles, Medicaid scanned records for beneficiaries with diabetes in the target ZIP codes. Then it sent on a staggered basis a letter telling beneficiaries about the trial and asking them if they would participate. To protect their rights, they could send back a letter saying "no," and no further contacts would be made. If the letter was not sent in three weeks, the trial could call and ask them to participate.
They have improved the initial letter outreach in a few ways. First, they now include a flyer from the program. Second they have shortened it a little and made it less bureaucratic sounding. Translation was not an issue in the initial letter, since Medicaid had some funds for it to be translated into the major languages in the area (Spanish, Mandarin, Vietnamese, Cambodian). But there were no more Medicaid funds to translate the shorter letter and the flyers, so SWP had to come up with the funds. They hear from some of the people who refuse that they think Medicaid should be calling them. Program staff recommend training Medicaid staff to call, but Medicaid doesn't have the staff.
One of the facilitators to participation is offering a $15 grocery coupon for being in the comparison group. An indication of the financial distress of the participants is frequent disappointment on being assigned to the treatment group, since they get the coupon only after a year in the trial. The HEP has connected with the African American Outreach Project, which has two outreach workers, but so far there has not been much impact in referrals. They are going to start to work with parish nurses and "health ministers," which many congregations have. They vary outreach by group, e.g., working with fraternal organizations for others. They set some of the HEP sites in housing authorities to reach groups that don't come to senior centers. They really believe in using community based

organizations. Organizations like the U of WA should not be going directly into communities of color if there is a CBO that they could partner with.

The medical community has not been a good source of referrals. The HEP staff have gone to discharge planners but without much success. SWP does get referrals from Group Health Cooperative of Puget Sound (GHCPS) for exercise, but they come mostly from the benefits managers not the physicians. For community physicians, the project nurses try to get out to medical offices in the community, but this is a big job. When they do get out they talk to the staff – almost never the physician. There is one physician who makes a lot of referrals – sending the people who are high visitors and problems for the office staff, which is just what HEP wants. Kate Lorig's chronic illness self-management program explicitly did not include physicians. But SWP would like to have physicians involved in referral (best), promoting the program, or at least being aware of participation and encouraging it. There is research going on in several Sacramento sites to see if there are better outcomes for participants whose physicians are active. There is also an RWJF research project that includes surveying physicians about their participation and satisfaction with the program.

Whether from community or medical community sources, it takes a long time to get credibility and knowledge. The bulk of referrals are self-referrals, often through notices and flyers in senior centers and through word of mouth.

Program operations. The majority of HEP sites are in senior centers and public housing sites. The diabetes HEP is located in a one-bedroom, ground-floor apartment in a building next to the senior center. The neighborhood is mostly single family houses about a half hour from downtown. The participant's first visit is the nursing assessment, including a review of the questionnaire, comprised of validated tests, that was mailed to the applicant, and an explanation of the social worker role. The computer system is designed to take the data from the questionnaire and to score the new participant in each of about 8 areas.

At the second visit the participant sits down with the nurse in front of the computer and goes over the assessment and how s/he scored in each area. If the participant wants to talk more about an area, there are menus to get deeper into the nature of the problem and what kinds of actions might be relevant. If the participant does not want to get into an area (or even answer the questions in an area), s/he can skip it. But there must be an action plan that has at least one action in one area.

The plan is very much participant-chosen, and it can vary a lot. The D-HEP trial tries to include a nutrition goal and an exercise goal, but the clients can reject that and choose other goals. The actions might include joining a support group, exercise group, Lifetime Fitness classes, or a hospital exercise assessment program. The nutrition program includes a food diary of a typical day in the week and weekend. The focus is on cutting fat. After agreeing on goals, the participant gets a copy of the action plan and there is an agreement on how and when s/he will get back in touch. An example of how modest initial plans can be is a woman whose exercise action plan was to uncover her exercise

bicycle and move it upstairs. Even though it was not part of the plan she was soon using it regularly, "since it was right there." Another situation that has been encountered more than once in the diabetes program is that people don't know that they can call their doctor when they need help or have a question. Their initial response is, "I don't have an appointment until next week." The nurse helps them to make the call and to feel more comfortable in making the call themselves.

The goal of the program is to make health attractive, not a punishment. At the original Northshore Senior Center site (in a white middle class area), it was the "cool crowd" who were in HEP. Health is a byproduct of participation and taking hold of your life. It is important to establish the initial trusting relationship. The initial health action plan can be limited and seemingly unrelated to health – perhaps just a social goal like making new friends. HEP will let the person go on for months with only that goal. Eventually they usually come around to taking on other goals in the second plan (at six months). And if they achieve one or two goals, they end up improving on many other measures not related to those goals. There is no set way that the participants will relate to program staff. The initial action plan may specify joining a group or getting a mentor, which would get them involved with the social worker. If they decide in the first six months to add action goals, there is no big deal about adding it to the action plan in the system. Participants are always given a copy of their "Health Action Plan" when new issues are added. Additional goals or revisions to goals are formally added at six months.

At the six month point, the questionnaire is re-administered, and the nurse and participant compare scores in all areas to baseline. They also discuss whether goals have been reached in the action plan and whether new goals will be stated. In D-HEP, participants also get their blood drawn and tested again at six months and at 12 months – the graduation from the program. They call the participant monthly at least, but contact can be more often if that is the plan. "Graduation" is set up at 12 months, but there is no formal ceremony. Different centers do different things, e.g., one has a tea in the person's honor. It's difficult to plan a big ceremony, since everyone is on his/her own timetable. There is again a review of the scores compared to the start. They also review who they were at the start compared to now. Participants can continue, and quite a few do. Some nurses tend to keep them more than others. The idea is to make them independent, so it's not encouraged, but it makes sense in the case of some persons, e.g., limited-English speaking participants.

Cultural tailoring. The D-HEP trial emphasizes being able to take the time to deal with the personal and emotional aspects of diabetes (and other comorbidities) and also with the complexity. These low-income, minority elders are unlikely to get what they need to know in the typical three-day diabetes education program. The D-HEP staff reinforce and go over the messages and questions in support groups. It's the same with Lifetime Fitness. They make it clear that you "don't need to be Jane Fonda or be at a gym to exercise." In fact, they are careful to individualize the exercise plan to the limitations that may exist. Many of the participants are very heavy and may be somewhat disabled and have never exercised. They start slowly and usually start with just stretching and breathing . They work on the idea of the stages of change and getting to the "patient in

charge" philosophy, which is also a change for the participants (and the staff – especially the nurses). The groups are central since this is where bonding and support occur.

People also bond with volunteer lay mentors, who may actually be current or past participants or people who looked at the program and refused but were interested and qualified to be mentors. The social worker oversees the mentors and also runs the groups. Mentors are sort of like community health workers. They help not only with coaching, but also with transportation, keeping appointments, etc. There have been recruitment problems, which are often a function of the views the nurse has toward them. If she doesn't think the mentor is important, she won't recruit and use them. SWP has worked with churches in the black community to recruit mentors. The pastors have been very supportive. D-HEP has had more challenge recruiting Vietnamese mentors. They have quite a few Vietnamese participants, but no Vietnamese mentors.

The different ethnic groups present different challenges. The Vietnamese are typically thin and eat plenty of vegetables. They also walk a lot because they are poor and don't have cars. But they are low on fruit and have "hidden sugar" in their diets that needs to be rooted out. They are also very compliant, but they often misunderstand instructions, so they may be complying to a faulty plan. So their understanding of the plan and medications and use of blood checking systems need to be fed back by the translator. The Russians in contrast tell them how to run the program and all the things they could be doing differently. Others think they are sick because they have been bad. Others don't think they need to do anything about their disease since they are happy that they aren't being shot at anymore. One barrier to the D-HEP trial is that they are not in the best neighborhoods for getting people out of their homes/apartments to come to any program. Danger is also a barrier to walking, as is the lack of sidewalks in some areas.

Billable and unbillable components. None of the SWP components is billable under current fee-for-service health reimbursement schemes. However, some of the D-HEP components are billable, and the whole system could be billable to interested managed care organizations. Also, there are general public health and aging services components that have been steady and reasonable revenue sources.

First, the revenue for HEP in public housing sites is from the Robert Wood Johnson Foundation This funding supports the staffing in the sites. For the diabetes HEP, there is a three-year $262,068 subcontract from U of WA with the SWP for the social worker and the nurses in the project. The head SWP nurse trains and supervises the site nurses in doing HEP. The RWJF also supports the HEP replication in other states with a three-year $749,800 grant. In addition, the grant supports researchers at the University of Washington, evaluation of physicians with patients in the program and converting the ACCESS based software program, WellWare, to a web-based program.

Second, state and local public health and aging agencies have also been important supporters of SWP services, but this support has been falling, especially as a proportion of total budgets. State Aging and Disability Services funds (mostly Older Americans Act) fell from $138,222 in 1997-8 to $128,242 in 2002, while Seattle/King County Health Department fell from $100,000 in 1997-8 to $60,000 in 2002. In the period, the total

SWP budget increased from $274,232 to $809,081, with the bulk of the recent new funds from RWJF. Local hospitals also support the program by providing nursing staff for HEP at local senior centers.

Third, Medicaid does not reimburse for any of the HEP program except for the D-HEP trial in which they pay for participant transportation, blood drawing and labs, and interpreters once people are enrolled, i.e., not during the recruitment and intake.

Fourth, for a few years it looked like SWP could be sold on a capitation basis to HMOs and at-risk medical practices. The best model was for the medical group to give patient names and addresses to SWP, which sent letters to patients with their physician's name on the letter introducing the SWP. But this all went away with the creation of Medicare+Choice and the concomitant payment cuts in the 1997 Balanced Budget Act. Most Seattle area M+C plans soon "melted down" and withdrew from Medicare, except for GHCPS, which covers Lifetime Fitness classes as a benefit. Having the program for free makes elders like to use it. Out of pocket, it's still cheap ($2) per session. But GHCPS also covers other health club exercise programs, so SWP needs to compete with them. GHCPS is a co-founder and co-owner of Lifetime Fitness. In the early 1990s, when findings were coming in on the initial trial, the savings promised were enough to allow GHCPS to develop its own in-house options for clinicians. What eventually developed was a rich set of internal programs that are easily accessible to physicians through support from their nurses and through easy checklist referrals. The irony is that a place like GHCPS prefers to do these kinds of referrals and classes internally rather than through a referral outside the program. So they trained nurses to do the HEP protocol, which reduces referrals to Senior Wellness. Moreover, Lifetime Fitness is a small fraction of the exercise benefit business of GHCPS. The much bigger share, at a cost something like ten times higher per person, goes to the Silver Sneakers program, a for-profit program run and owned by a former home health nurse from the Southwest.

Resource Requirements, Effectiveness, Costs, and Cost effectiveness

Measures of program impact. The data collected under the HEP and the Lifetime Fitness programs are monitoring achievement of immediate rather than ultimate outcomes (i.e., weight loss, strength, changes in lab values versus medical care utilization and costs), since it is assumed from the CRT results that achieving these immediate changes will effect changes in other outcomes. Their clinical trail showed efficacy in improving health measures and cutting utilization, and their current project is rolling it out to many more senior centers in WA, other states, and even Sweden. In Washington State sites, there were 597 participants during 2001 who had at least six months of participation. The most common issue chosen in health action plans was exercise, which was in 220 plans. Of these, 95 improved, 79 maintained function, and 30 declined, and 16 were not measured. Across all action areas, 46% improved, 35% were stable, 15% declined, and 5% were not measured. The biggest changes in scores are in the first six months.

Project costs. HEP is estimated to cost $480 per participant per year, but this is closer to a back of the envelope calculation than what one would do for a business plan. It is not clear how space costs, overhead, capital, or even parceling out staff by program were accounted. The SWP pays $50 annually for the license from Kate Lorig's chronic disease self-management program plus the costs of sending a person to get trained to be a trainer for the lay trainers. They also buy the participant and leader books. They would need to bring in an accountant with experience doing Medicare cost report accounting to help them think through their real costs.

There is no fee being charged for participants for HEP. There is a section in the manual for suggested fees/donations varied by family characteristics and income. They can only ask for donations in the senior center sites because of Title III limitations. The top suggested fee is $200 annually for a family with an income of $40,000 and over. But in practice they have stopped training to ask for a fee—only for donations-- in the Seattle sites, and nurses don't like to ask for it anyway. So it's all free, even in sites that are higher income and when individuals could pay. However, in sites not supported with Title III funding, donations are highly recommended and nurses are trained to ask for donations.

Replication costs. The SWP charges replication sites a fee ($10,000) to get a three-day training by three SWP staff, and then a small annual fee for followup training and support. The RWJF-supported rollout of HEP helps with some of the fees for some of the new sites, plus it supports more Seattle staff, data collection, and an annual meeting of nurses, social workers, and directors and national advisory committee. The rollout is not being run as a trial—the goal is to see if they can maintain the process and reach the outcomes of the trial in terms of improvements in strength, blood pressure, etc. Then it's asserted that there are cost and utilization effects like the trial. To prove effectiveness, the University of WA researchers asked CMS to use its data processing capabilities to help create comparison groups to participants, but this did not happen.

Conclusions

The SWP has pieced together what they can to get this program funded and replicated through research funds. Each grant has gotten a new angle funded – a senior housing site for elders who don't use senior centers (especially immigrants), the replication, the diabetes HEP. They have also convinced the AAA and local health department that these services for seniors are worth supporting, and they have been the most consistent funders. But unless SWP can come up with the next fundable demonstration, the SWP interventions - especially the more expensive HEP - are likely to slowly peter out. A more entrepreneurial organization might make a business plan, look for capital or a partner or a buyer who would "roll it out." This does not seem palatable for SWP since they might lose control and also the community base of their operations, which they consider central.

What would a SWP prevention/promotion product would look like as a Medicare service? What would they be selling? It would not be their individual providers/staff/volunteers, since most would not qualify as Medicare providers, and they would not want to change the providers to qualified nurses and social workers. So the product might better be structured as a period of participation in a program. With the data they have, they could certainly provide outcome-based data to show Medicare was getting something for its money.

Having Medicare pay for their service on a demo basis (e.g., $480/participant/year if that's the figure) would be understandable to CMS or to Congress if the demonstration was stipulated in legislation. The SWP would be well positioned to be a demonstration provider in a prevention demonstration, since they have trial-proven results, all the manuals, replication sites, a web-based data system, staff, and key partnerships between community based health and social service organizations and a university.

Texas Cancer Council

African American Breast Cancer Outreach Program (AABCO)

Overview

The Texas Cancer Council is a state agency established through legislative mandate in 1985. It is the *only* agency charged by statute with creating and working to implement the Texas Cancer Plan. The Texas Cancer Council promotes implementation of the Plan in two primary ways: by direct intervention and by funding cancer control projects. The mission of the Council is to reduce "the human and economic impact of cancer on Texans through promotion and support of collaborative, innovative, and effective programs and policies for cancer prevention and control[2]". Among the many objectives of the Council's Cancer Plan are to 1.) increase knowledge of screening and detection services 2.) increase access to and use of treatment and services, and 3.) enhance regional planning, development, and coordination of services. The Council specifically recognized the need for outreach and collaboration at the community level and approached Dr. Mary Lou Adams at the University of Texas School of Nursing in Austin, Texas to develop and serve as the Project Director for an outreach project.

Beginning in 1998, the African American Breast Cancer Outreach Program (AABCO) was developed and subsequently implemented at two urban sites, Dallas and Austin, as well as a rural site in Longview/Tyler, Texas. The project focuses its outreach activities within these three geographical locations because these areas have been identified as the source of an estimated 70% of the breast cancer cases that will be diagnosed in African-American women in Texas[3]. Services are targeted to poor and underserved women, those without any insurance.

A project advisory board oversees the project and is comprised of project and site staff, community representatives from the three sites, and representatives of important state and national cancer organizations. Project staff includes the director, coordinator, fiscal officer, evaluator, consultant, and administrative assistant. Site staff on the advisory board include three site managers and three case management/outreach coordinators. Community representatives from the sites include staff from the Parkland Health and Hospital System in Dallas, the University of Texas Health Science Center, and Harris County Hospital District. Additionally, representatives from other important cancer organizations and government serve on the advisory board including: the executive director of the Texas Cancer Council, associate vice president of early detection for the

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[2] Texas Cancer Plan: A Guide for Action, Texas Cancer Council, 1998.
[3] Texas Data Cancer Center, 1998.

Texas division of the American Cancer Society, the director of education for the Susan G. Komen Breast Cancer Foundation, and a research scientist from the University of Texas at Austin school of Nursing. From the Texas Department of Health, representatives serving on the board include, the medical consultant for the Bureau of Women's Health, chief, Bureau of Women's Services, nurse consultant BCCP, and program manager for the Texas Mammography Accreditation.

Additionally, on a local level, each site has a site advisory, professional committee, and community coalition. The groups may overlap and typically range from six to ten people who meet quarterly. Generally, the professional committee is made up of health care educators and providers (nurses, radiologists, radiology technicians, and physicians) within the healthcare system. The community coalition is composed of a broad base of community advocates. For example, at the Dallas site, volunteers make up the majority of the community coalition and consist of a core of about eight women.

The project is completing its fourth year of a five year, $1,500,000 grant. The fifth year will focus on the program evaluation and the dissemination of program accomplishments and findings.

This site was selected for a case study for a number of reasons. First, the target population is important due to health disparities and later diagnoses of breast cancer in African American women. Also, the program's focus is providing outreach within the existing infrastructure of the health care system. This is evidenced by the relationship of the Outreach Coordinators to the health care system. Finally, the relationship of the program to all the cancer organizations and efforts within the state is a strong and unique link.

Theory of Change and Primary Learnings

According to the Texas Cancer Council, African-American Texans have the highest rates of mortality for lung, breast, prostate, colon, and cervical cancers. The five-year survival rates are also lower and the differences are attributed to the later diagnosis of cancer[4]. There are several theories that attempt to explain the later diagnosis of cancer among African American women.

In 1990, the National Health Interview Survey (NHIS) included 1,727 African American respondents. The primary reason cited for not undergoing a mammogram was lack of physician referral (Breen and Kessler, 1994 in Adams 2001). In 1997, Champion and Scott utilized the Health Belief Model to explore mammogram utilization for 329 African American women ages 45-64. Significant variables affecting utilization included perceived barriers, health care professional recommendation, recent thoughts about

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[4] Texas Cancer Plan: A Guide for Action, Texas Cancer Council, 1998.

mammography and having a regular physician [5](Champion and Scott in Adams, 2001). Dr. Adams surveyed 164 African-American women in Tyler, Dallas, and Houston regarding barriers to mammogram screening using a 23 item Mammography Barriers Checklist developed by Dr. Adams. The checklist was developed based on a review of the literature and Dr. Adams clinical experience and included both internal and external barriers[6]. The survey results found that fear of finding cancer and mammography cost as the most significant reasons for not having a mammogram.

The African American Breast Cancer Outreach Program (AABCO) is designed to provide culturally sensitive outreach to increase African-American women's participation in early detection and follow-up services, especially the poor and underserved. This is accomplished through coordinated outreach and case management activities. The objectives of the program are:

1. Build the infrastructure for the project through coordinated planning and support from the advisory council
2. Select project sites with previously established BCCP programs or community organizations (in order to provide and fund the mammograms)
3. Provide technical assistance and training on culturally sensitive outreach and case management strategies
4. Evaluate the project to determine effectiveness
5. Disseminate information of the project as a model and the outcomes via published articles, conferences, and presentations

Initially Dr. Adams performed a needs assessment and community focus groups were held. The assessment resulted in the project focusing on the top three geographical areas where high numbers of the target population resided. Also, the sites selected needed to have an established BCCP program established to provide the mammogram screening (with the exception of Tyler), and available resources to provide follow-up diagnosis and treatment. For the two large urban sites, Dallas and Houston, the particular hospital system sites were selected because both cover the entire city and have a comprehensive, established clinic system. Dr. Adams identified and linked the project to health care system sites already providing BCCP services (except in Tyler where alternative arrangements were made).

The project also developed site community and professional advisory committees as well as community coalitions to promote education and awareness within the health care systems associated with the three sites. Dr. Adams subsequently hired three outreach coordinators. The role of the Outreach Coordinator is to provide outreach and education to increase the numbers of mammogram screenings for the target population under the existing BCCP or other screening program by coordinating activities with the established

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[5] Adams, M.L., Becker, H., Colbert., A. <u>African American Women's Perceptions of Mammography Screening</u>., Journal of the National Black Nurses Association, December , 2001, Volume 12, No. 2, pages 44-48.
[6] Ibid

health care system infrastructure. This is accomplished by placing Outreach Coordinators within the respective the health care system. Also, they are supervised by the site manager who is employed by the health care system.

Based on reports submitted from the sites on each and every outreach activity, as of February 2, 2002, over 4,113 women have received mammograms through this program and 63,558 people have received one or more direct services including cancer related information.

Regarding the lessons learned from designing and implementing the programs, according to Jewel Banks, Outreach Coordinator in Dallas, one-to-one contact is a critical ingredient to outreach, you cannot simply rely on educational materials to get the job done. Dr. Adams believes "the health care system needs to hire people to perform outreach, you cannot rely on the current healthcare establishment. We need to tell people where the services are available with someone who is reliable and whom they trust." Dr. Adams added that it is not the people who need to change but rather the health care system needs to change to meet client needs.

Dr. Adams also commented that it was important not to "reinvent the wheel". The ABBCO program focuses on specific, geographical locations in order to reach the target population. Sites were also selected that had an existing infrastructure to support outreach activities, i.e. screenings and access to follow-up care and treatment. This enables the ABBCO devote its resources on outreach activities. Additionally, Dr. Adams emphasized hiring the right people to do what they do best. For example, Dr. Adams hired a marketing firm to assist in ABBCO. Finally, by being well connected to the various cancer organizations (local, state, and national, private and governmental) and informed of activities, the ABBCO is a vital part of a greater effort.

Organization and Operations

Through the work begun by the Texas Cancer Council, a decision made to target outreach programs to low income and underserved African-American women. Dr. Adams selected BCCP projects or community organizations in the targeted geographical locations to serve as the sites for the outreach programs in the targeted areas and met with key community and health system leaders in order to gain their support. Site managers are the facilitator at the hospital system for ABBCO. They provide the day-to-day supervision for the Outreach Coordinator and facilitate their activities within the health care system. As part of the project advisory board, they report back to Dr. Adams how the project is working within the system. The site manager in Houston is in administration for the radiology department, the Dallas site manager is the director of community health operations in administration (clinic system), and the Tyler site manager is the director of the area health education center (a regional state-wide program in Texas).

Outreach coordinators are all African-American women well known in the community. The Outreach Coordinators are located within the health system sites and are employees of the system although their salaries are paid for by grant money for the project. One of the outreach coordinators was originally a volunteer from the Susan G. Komen Foundation subsequently recruited for the position. The Outreach Coordinators are supported locally with a site advisory and professional committee as well as a site community coalition. An Outreach Coordinators job description includes the following:

- Develop, implement and market activities involved with the project.
- Establish outreach and case management strategies to increase access and availability of screening and follow-up services for African-American Women.
- Maintain frequent interaction with and provide monthly written report of project activities to Project Director Adams at the University of Texas at Austin School of Nursing.
- Establish/Maintain community coalitions, site project advisory group, site professional group.
- Conduct needs/assets assessments for assigned areas.
- Collect and compile data.
- Record observations and evaluate results.
- Recommend new policies and procedures for improvement of program activities.
- Perform related duties as required.

Outreach activities are diverse and may involve education, presentations, education and screenings, bus trips to recruit volunteers, or assisting other cancer organization activities. Some of the screening activities associated with ABBCO outreach activities take place utilizing the mammogram van outside the hospital premises.

The Outreach Coordinators are, in turn, supported by volunteers. Volunteers are recruited to attend screenings to assist women to complete paperwork and provide emotional support, provide occasional transportation, assisting with office work such as filing or filling bags for with educational materials to distribute at an event, and get the word out about event s through a variety of media and outreach activities. Some outreach activities are in conjunction with other organizations such as the American Cancer Society's Tell A Friend. For example, with the Tell a Friend Program, volunteers would be making the phone calls. At a church event, they may be passing out fans with reminders about breast cancer and the importance of mammography.

In addition to Dr. Adams as Project Director, there is a Project Coordinator, Accounts Clerk, and an Evaluation Coordinator located at University of Texas School of Nursing in Austin. The Project Advisory Board meets quarterly with Dr. Adams and other key staff of the project and sites. Each site orally reports and disseminates updates of their activities to the Board. The role of the Advisory Board is to provide advice and feedback on the activities of the project, to support the acquisition of materials and resources to facilitate various outreach activities, and to exchange information about cancer prevention and treatment activities within the state.

The three sites have all been unique start-ups. Dr Adams approached Parkland Health and Hospital System (Dallas) and Harris County Hospital District (Houston) because both are BCCP providers. However, there was no BCCP provider in Tyler so she worked with the University of Texas Health and Science Center and the Texas Department of Health in Austin in order to make this site happen. In Dallas, the hospital system was very supportive of the project. In Houston, it was a more complicated start up because Harris County is a very large hospital system and teaching hospital. It is more of a closed system, the county commissioner oversees the hospital and the program required the approval of the commissioner. There is a patient application process for the health care system itself and therefore more paperwork for patients to complete without insurance . For the Tyler site there was also a lot of immediate support for the program and the challenge is that the site is very spread out geographically.

When a woman is screened and has a positive mammogram result, follow-up is tracked by the site and case management roles are somewhat site specific. According to BCCP protocol, suspicious results require follow-up within two days and a diagnosis must be reported within 30 days. Case management is shared between the outreach coordinator and the hospital system staff and everyone is well informed of the status of the women screened. Generally speaking, a radiology staff member will contact the primary care physician or referring agent and will call the Outreach Coordinator to help with case management. In Tyler, the Outreach Coordinator is the actual point person for follow-up but at the other sites, the Outreach Coordinators will be called in to assist if the woman cannot be contacted or does not come in for follow-up. If the patient is confirmed as having cancer, the health care systems have arrangements with other private cancer treatment centers for care per the contract between the ABBCO and the health care system.

Principal interventions of the project are the development, deployment, and evaluation of culturally sensitive, community based outreach and case management models. The activities performed at the sites to accomplish outreach are numerous and include mass media campaigns, survivors outreach volunteers (SOV) recruitment, a Mother's Day campaign during the month of May, Pink Ribbon Sunday (approx. 150 churches took part passing out pink ribbons and fans), the screenings, education, and case management. Often, mammogram vans from the sites are part of the outreach activities.

In regard to outreach, all three sites perform similar core outreach activities but the individual sites are empowered to tailor activities to meet their needs and to try new approaches. One example of an outreach activity that was not as successful as anticipated was one involving local beauty shop owners who provided educational materials to clients. This activity was modeled after a program in another state. The ABBCO tried it with mixed results. Dr. Adams noted that in Houston and Dallas, where the beauty shops are in a busy urban area, the idea did not work well but did have some success in Tyler, where the beauty shops keepers had more time in between clients. On the other hand, at the Dallas site, the outreach coordinator had an idea to have a bus trip to a shopping mall with the goal of getting survivors to sign a contract agreeing to volunteer 50 hours per year. This has been a successful and repeated activity.

The sites also partner with other cancer organizations and participate in their activities, such as the American Cancer Society's Tell A Friend or the Susan G. Komen Foundation's Race for the Cure. The sites seek funding from different sources for different outreach activities. For example, the American Cancer Society does not provide money for food incentives but does for tee shirts. Other local businesses churches and community organizations are tapped for other assistance.

By connecting with the women in the community, the outreach coordinators and volunteers, the women at the core of the outreach efforts know their clients, each other, the health care system, and their community.

This coming year, a manual for how to provide this outreach is underway and the project will focus on the dissemination of the model and evaluation of the project.

Resource Requirements, Effectiveness, Costs, and Cost-Effectiveness

It is complicated to determine a consistent unit cost to bring in one woman for screening for many reasons. The activities not only vary but many of the resources are in-kind. People, community groups, churches, local businesses and cancer organizations donate various items for different outreach activities. The outreach coordinators utilize many resources within the local communities and cancer organizations to facilitate outreach activities. Additionally, the Texas state legislators want to know that the project is pulling in money from other available sources. Dr. Adams also retained expertise from a marketing firm but the project was provided more work then what the budget reflects, given the cause. The site managers are not reimbursed by the grant. One can roughly estimate the budget at each center which includes the salary for the outreach coordinator, the money spent on various activities, and women screened per year.

Outcomes are measured by the numbers of outreach activities, women in attending the outreach activity and provided educational materials, women screened (new and repeat), stage of cancer if detected. The data are reported by the individual sites quarterly via a spreadsheet. Overall model evaluation will take place this year. Another success of the project is the beginning of an off-shoot projects such as "My Place". This is primarily a woman's resource center that also provides outreach services. The new center is just signing a lease for permanent space, has applied and is already receiving funding from other sources (i.e. a $32,000 grant from the Susan G. Komen Foundation) and is tapping into the knowledge of AABCO. Additionally, this year each site is anticipating disseminating the model by partnering with a new site. Finally, another successful outcome of the project has been the coordination of activities with many of the other cancer organizations in the state.

Conclusions

This program came about due to a well thought out, step-wise, and systematic plan. The Texas Cancer Council examined the facts regarding the epidemiology of cancer rates and mortality in Texas and devised a comprehensive plan and objectives. The council identified Dr. Adams from her previous work in outreach and engaged her in this project. Dr. Adams established a reasonable timeframe to initiate this program and the focus is outreach. The first year or two of the project concentrated on development of an infrastructure and key linkages to important community resources.

Dr. Adams identified three areas with high target populations for the interventions, performed a needs assessment, and examined established resources in these areas. The project did not attempt to "reinvent the wheel" or duplicate services, but rather provided bridges from the local health care systems and state BCCP program extending deeper into the communities and the target populations. Dr. Adams developed infrastructure that included key advisory committees within the local communities as well as state and cancer organizations.

Outreach coordinators work within the local healthcare system and are employees of the system although they are paid for by the grant. Not only are there local advisors but the advisory board for the project is representative of, and very well connected with, state and local governmental agencies and cancer organizations. The advisory board is well informed of all resources in the area and works cooperatively to promote cancer prevention and treatment, a win-win situation for all involved.

One challenge to the project is that each site does have its unique issues to contend with therefore a "one size fits all" approach cannot work although there are commonalities. For example, the rural site has less volunteers then others sites and the Houston site has received somewhat less support from the health care system than the other two sites.

Overall, any demonstration project should incorporate services in which local community resources and people should be tapped to play a critical role. Additionally, outreach services should be reimbursed in order for the healthcare system to reach people they otherwise would not as Dr. Adams pointed out. Local outreach staff should be able to assist clients to become knowledgeable about services and resources available in the community. Finally, the approach taken by this project was to overlay the existing infrastructure, not compete with existing services and programs already available.

University of Arizona at Tucson/ Mariposa Community Health Center

Juntos Contra El Cancer Prevention Program

Overview

The University of Arizona at Tucson College of Public Health is involved in a variety of border health care projects to support rural Latino communities living on the border between Mexico and the United States. Three specific projects led by the University's Rural Health Office include the Border Health Strategic Initiative (Border Health) the Juntos Contra El Cancer Prevention Program, and the Mobile Health Program. Border Health and Juntos Contra El Cancer Prevention are located at the Mariposa Community Health Center in Nogales, AZ. The Mariposa Community Health Center (MCHC) provides health care services to Latinos living on the border of Mexico and the United States. The center is located in Nogales, Arizona, a small town of about 25,000 that is situated adjacent to Nogales, Mexico, which holds a population of approximately 300,000. The Border Health project provides a variety of prevention and treatment services and employs Promotoras or Community Health Workers (CHW) to serve as educators in promoting awareness specifically about diabetes. The Border Health Strategic Initiative is funded by a Federal legislative appropriation to the University of Arizona and is a partnership between the University of Arizona College of Public Health and Arizona Border communities. The Susan B. Komen Foundation supports the Juntos Contra El Cancer Prevention Program. This program uses CHWs to provide information about breast and cervical cancer prevention and treatment to members of the community health center and others in the border community. Lastly, the Mobile Health Program conducts health care services in rural and hard to reach regions of Arizona including Rillito and Marana Yaqui Village. The Mobile Health Program provides health care services to rural areas and is staffed a by a family practice physician, a nurse practitioner, a clinic coordinator and CHWs. The University of Arizona is involved in various stages in an evaluation of each of these projects and has provided the training for CHWs.

Theory of Change and Primary Learnings

The use of CHWs to serve as a link to health care services and reduce racial and ethnic disparities in health was discussed with a number of faculty and staff from the University of Arizona and from each specific program. Meetings were held at the Center for Rural Health at the University of Arizona in Tucson and the Mariposa Community Health Center in Nogales. Faculty and staff from the University of Arizona include Jill Guernsey de Zapien, Joel Meister, Lee Rosenthal, and Maia Ingram (Need full titles) Program specific staff included JoJean Elenes, Norma Guerra (Promotora), and Dr. Pereira from

the Mariposa Community Health Center and Susan Woodruff from the Mobile Clinic. Additional participants included Maria Lourdes Fernandez, Community Health Worker from the Chronic Disease Screening Demonstration Project, and Nancy Collyer from the Arizona Community Health Outreach Worker Association. Further, the Brandeis team had the opportunity to visit an educational program delivered by CHWs involved in the Border Health project. The program representatives assisted us with understanding sources of health disparities in the community and provided detailed information about the program and interventions along the border.

According to those interviewed over the two-day visit, there are several factors that contribute to racial and ethnic disparities in cancer and other health areas along the border of Arizona and Mexico. These factors include a significant lack of knowledge regarding various cancers and health care benefits (including Medicare benefits), the need for self-exams and screening, poverty and unemployment, geographic isolation in rural areas and rural transportation issues, as well as institutionalized racial discrimination within the health care system. Lack of knowledge refers to women not knowing about or recognizing the importance of breast self-exams, mammography, and pap smears. Moreover, the staff indicated that many clients needed further information about their health care benefits, including Medicare benefits. CHWs would regularly spend time with clients educating them about these issues.

Poverty and unemployment are additional factors that appear to contribute to racial and ethnic disparities in this community and restrict many from the Latino community from getting adequate health care coverage and services. Living on the border, some clients decide and are at times encouraged to obtain health care services in Mexico. It should be noted that migratory patterns also affect the availability, consistency, and financing of health care services for this population. It is often assumed that immigrants come from Mexico seeking to reside permanently in the United States. Many of the participants noted that there appears to be much more of a consistent flow back and forth across the border. Also, for elders coming to the United States, some have little employment history in the US and therefore may be ineligible for Medicare services.

Furthermore, geographic isolation is a factor for many people in the Southwest. This isolation coupled with inadequate public or private transportation creates a gap for many in reaching necessary health care services. For some patients, to obtain services at the nearest hospital requires an hour drive to Tucson. This creates a particular burden for those needing chemotherapy and other intensive treatments. With regard to transportation, the CHWs currently provide information about rideshares with others in their community, provide information about private transportation services and also provide direct transportation themselves for many clients. Furthermore, the CHWs go into very rural areas to meet with people in a variety of community-based settings to provide cancer awareness information.

The use of CHWs in these three projects intends to empower members of the community to make their own health a personal priority by providing them with the necessary information about self-exams, personal health management, and screening. The staff

indicated some examples of institutional racism but also indicated that the Mariposa Center is staffed primarily by Latinos and this has reduced some of these pressures. In addition, some of the clinical staff indicated that time pressures forced them to reduce the information that they provide to clients. They described the importance of the CHW in filling this gap. Within the border communities, the CHWs also try to empower individuals in the community to advocate for themselves in their interactions with the health system.

The Mariposa Community Health Center currently collects some data pertaining to client interactions. Obtaining follow-up data has proven to be somewhat complicated due to tracking problems. The program would like to begin to collect follow-up information with regard to screenings.

The team discussed five primary learnings from their work:

1. Staff members should be "from the community" and ideally would have the skills to serve the community, while being able to negotiate "tensions" or barriers presented by the health system. Most staff members and administrators are from backgrounds similar to those of the clients served by the program, increasing familiarity with local conditions and barriers to facing the health care system, particularly on the border.
2. CHWs should have qualities that assist them to lead and be well recognized in the community.
3. Transportation is a key issue in resolving connections to health care services in rural areas.
4. Disparities in cancer occur at all levels of the system from lack of knowledge through the treatment process. CHWs need to be well informed about health care treatment as provided by other health care professionals in order to work more collaboratively with the health system.
5. Community collaboration is vital to the implementation of such a project. A link to with university allows for more formal and standardized training of the CHWs. Resources must be sought from various institutions.

Program representatives advocate for the further "professionalization" of CHWs. This includes paying them a reasonable living wage and providing them with adequate training.

Organization and Operations

The CHWs work to connect with community members in a variety of ways. This includes an in-reach process through the Mariposa Community Health Center as well as encouraging members of the community to share information with their neighbors. For the Border Health Project and Juntos Contra EL Cancer, informational sessions are held at various locations throughout the community on an on-going basis. Furthermore, it appeared that the Community Health Workers as served as "political" navigators of the

health system as well. If a client needed resources, they would often work to "broker" or negotiate for services when necessary.

The CHWs undergo a six-month (60 hour) training program which includes sessions on: What is Cancer?, Breast Health, Breast Cancer Treatment, Cervical Cancer, Cancer Awareness, and Community Resources and Action Planning. The sessions are led by University of Arizona staff along with guest speakers that have expert knowledge in each of the above-mentioned areas. The CHWs are also encouraged share ideas and experiences about connecting with individuals in their own communities.

The CHWs will work to make themselves available to members of the community in a number of public forums as outlined earlier in this report, but they will also serve as a point of contact for individuals seeking information about diabetes, cancer and necessary health care resources. When necessary, the CHWs will make referrals to points of entry in the health or social service system for individuals to receive further information or health care. They provide often aftercare type counseling when clients have recently had a physician visit.

Cultural tailoring of these services consists primarily of hiring people from the local Nogales and southwestern Arizona communities to work with people of the community. This model is based on the philosophy that people know their own communities best. In the Latino communities of the Southwest, this includes having knowledge about myths in the Latino community about cancer and how best to talk with individuals about these myths. Such interaction also includes sharing experiences with engaging with the health system and devising strategies to gain better access to services.

Conclusions

These three programs incorporating the use of Community Health Workers in the delivery of health services in rural Arizona on the border of Mexico represent a model for connecting people of the Latino community to the health care system towards the goal of reducing racial and ethnic disparities in the system. Furthermore, the staff show the importance of Latino leadership in the delivery and credibility of the project. Hiring people from the community at all levels of the initiative is a key factor. Other key elements in the success of the project include empowering volunteers to delivery cancer awareness, finding solutions to transportation problems, and connecting CHWs to the broader health system through intensive training that involves knowledge about the role of other professionals in the health system.

University of Colorado

Native American Women's Wellness Through Awareness (NAWWA)

Theory of Change and Primary Learnings

According to Dr. Linda Burhansstipanov, psychosocial and sociocultural barriers are powerful barriers to accessing preventive health care by Native Americans. She agrees that poverty is a major issue. But even when they implemented programs to reduce these barriers by providing easy access to free screening, culturally comfortable surroundings, transportation, child care), there was not a sufficient increase in screening. Another barrier was the use of contracted services by the Indian Health Service, with monies that are determined by Congress, not the Indian Health Service. Sometimes this results in funds being available for screening through special programs, but funds for diagnostic follow-up may be prioritized by contracted services, such that women may have to wait until monies are available for diagnostic work-ups. However, even if these issues are addressed, the larger psychosocial and sociocultural barriers remain. For example, there is a deficit in culturally relevant information that would incorporate, say, beliefs that screening invites the cancer spirit into the body or that smoking cessation activities are insulting to the tobacco spirit, which is considered good medicine. (The tobacco industry plays on this by producing a cigarette that is called simply, "Spirit" and is advertised almost exclusively to Native American audiences). Finally, the requirement that a Native American needs to live on a reservation for six months to qualify for Indian Health Service coverage also creates a barrier.

In order to address this, Dr. Burhansstipanov firmly believes that the lay health worker is the way to go, to meet the "physical, emotional, and spiritual needs" of Native Americans. Native Americans also think that if they access the health care system, they are acting "white". This comes from deep-rooted fears of assimilation. She is convinced it is cost-effective. She also believes that this care should be a comprehensive wellness approach, not disease-specific. She also believes that this should be a paid position; it doesn't make sense to rely on poor people to donate their time. However, the problem is, that once they are trained, they now have marketable skills, and they get hired away.

Dr. Burhansstipanov also prefers a model where the community-based program is firmly linked with an Academic medical center. However, the AMC has to have the right kind of leadership. Otherwise the cultural mismatch between AMCs and community organizations can lead to a lot of mistrust. Finally, she thinks that the lack of cost-effectiveness studies might jeopardize the lay health worker model. The major barrier to doing these kinds of studies is that the time horizon is too long. However, there is implicit evidence that supports this: for example, in one study, women diagnosed at Stage I and

IIa breast cancer cost $30,000 for treatment and follow-up, as contrasted with $80,000 for Stage III.

Resource Requirements, Effectiveness, Costs, and Cost-Effectiveness

Dr. Burhansstipanov speaks about the huge personal investment she and others like her make in a program like this. Many volunteer hours go into providing care. She and her cadre of workers even provide funding for drugs, labs, personal as well as professional care. It was a little hazy where all these funds come from. The hospital, (St. Joseph's) for example, provides office space. Hospital physicians provide training for lay health workers (presumably volunteer service). The hospital provides space and technology for training. There is reference to funding for actual screening available variously from CDC and the state of Colorado (the latter apparently reimbursing upto $5,000 for each woman screened and followed). At one training specifically for lay health workers to improve mammogram adherence, one MD and two PhDs trained two workers (both non-native, both already in the health care system, one a nurse) with a highly I.S. sophisticated training module. We were unable to determine how typical this scenario is. We were likewise unable to determine how many "native sisters" in total have been trained, and what exact number of services have been provided. This is not because the information is not available, but not available easily. Dr. Burhansstipanov estimates however that each Native sister's salary is approximately $30,000 per year, plus benefits. Costs of training are apparently difficult to estimate.

Conclusion

This conversation with Dr. Burhansstipanov was more of an "ask the expert" session than a complete site visit, although we observed one training session. Dr. Burhansstipanov's synopsis of a best model would consist of using full-time navigators, salaried with benefits. It would also include training and education for providers in medical establishments to be cognizant of providing culturally competent services. It would provide means for different parts of the system to provide collaborative care. The navigators should be of the community, and not persons such as social workers who have already been "stamped by academia". Finally, she was concerned about the "upper middle class beltway mentality" that does not really comprehend the issues with reducing health care disparities, and continues to use the same sets of institutions to conduct research into these issues.

University of Kentucky Center for Rural Health

Kentucky Homeplace and Southeast Kentucky Community Access Program (SKYCAP)

Overview

Kentucky Homeplace is a statewide program funded by the Kentucky General Assembly, through the Cabinet for Human Resources, designed to address deficits in health status of and health resources available to many of Kentucky's rural residents.The Southeast Kentucky Community Access Program (SKYCAP) seeks to integrate the system of care for patients, increase patient access to services from multiple entry points, and to provide a more clinically oriented approach to connecting the underserved to the health care system. Both initiatives operate under the direction of the University of Kentucky Center for Rural Health, located in the Central Appalachian city of Hazard, KY. Kentucky Homeplace program began in 1994 and is now operating in 39 counties (approximately 1/3 of Kentucky), over half of which are located in the eastern part of the state. SKYCAP, modeled after Kentucky Homeplace, began in 1998 as a partnership between the University of Kentucky Center for Rural Health and Community Ministries, using lay health advisors to improve the quality of life for severely mentally ill adults in Harlan and Perry counties. These programs were selected for a joint-site visit because of their intensive use of lay health advisors and family health navigators to connect underserved people to the health care system in rural Kentucky. Funding for Kentucky Homeplace is derived from a fixed budget appropriation under budget requests by the executive branch of the state government and the program is presently earmarked at $1.9 million per year. Funding levels for this initiative have recently risen since the 1997 funding level of $1.2 million. Funding for SKYCAP totaled $887,096 for FY 2001.

Within Kentucky Homeplace, a "Family Health Care Advisor" (FHCA) is hired in each of the participating 39 counties to provide community-based education, advocacy, referral, and health system navigation services to low-income, white, rural members of each community. Within SKYCAP, a "Family Health Navigator" works to be aware of each client's clinical needs and to assist them with navigation through the health system to appropriate services. Both the FHCA's and the Family Health Navigators receive two weeks of intensive training. After receiving this training, the staff work to assist individuals with a variety of health problems (including mental illness, asthma, diabetes, hypertension, and heart disease) to increase their access to preventive and primary health care, improve their access to prescription drugs, and to work with individuals and their families to obtain additional health and social services. Kentucky Homeplace uses pen-based computing tablets to assist FHCAs to conduct their work with clients in the community. Over the past year, the program has begun to link on-going client encounter data into a larger data warehouse for client and cost tracking. Current measures of outcome include primarily process measures such as the number of clients seen by the

program, and additional measures of reduced inpatient utilization and associated cost-offsets. With over 10,400 clients engaged with the program in 1999, the cost per client of the program was approximately $182 per client. When adding the market value of donated pharmaceuticals, free health care visits, and reduced health care debt, the unit cost per client increases to $293 per client. There is a wide variability in client costs due to some clients engaged as "brief encounters" and others having more intensive engagement in the program.

Theory of Change and Primary Learnings

During the site visit, the Brandeis team met with Lloyd Kepferly, Director of the University of Kentucky Center for Rural Health, Karen Main, Britt Robinson, Director of Kentucky Homeplace Program, Steve Newsom, Training Coordinator for Kentucky Homeplace, and Fran Feltner, Director of the SKYCAP program. The team went on two home visits in the local Hazard community, one with a Family Health Care Advisor and the other with one of the Family Health Navigators. The program representatives assisted us with understanding sources of health disparities in the community and provided detailed information about the program and interventions throughout the state.

According to the group, there are several factors that contribute to racial and ethnic disparities in health care in the community. These factors include poverty and unemployment, geographic isolation in very rural areas, transportation problems, negative attitudes about the local culture and "eastern Appalachian ethnicity", and discrimination by the health care system. Poverty was described as a condition in which many people in the community struggled to gain access to basic life necessities such as housing, adequate nutrition, and employment. These social conditions were further explained as "burdensome" and "overwhelming" for some community members. Employment was described as cyclical based on the local "coal mining driven" economy. As a result, these individuals or families were preoccupied with dealing with such social conditions that health care either became just another "complicated bureaucracy" or less of a priority in their lives due to other factors. Family Health Care Advisors in the Kentucky Homeplace program work with clients using a "systemic approach" to assess living and other social conditions as well. They make appropriate referrals as necessary to assist clients in acquiring social and employment resources. Geographic isolation is a factor for many people in eastern Kentucky. This living situation coupled with inadequate public or private transportation creates a gap in reaching necessary health care services. Family Health Care Advisors go into very rural areas to meet with clients in their homes. Furthermore, if necessary, they will assist with transportation to and from health care appointments. Negative attitudes about local culture and an "eastern Appalachian ethnicity", as described by members of the team, were also contributing factors towards disparities in the health care. Such negative attitudes include stereotypes about people having very low levels of education and an inability to take care of themselves. Kentucky Homeplace works to empower members of the community to make their own health a personal priority by working with them to obtain the necessary prevention and primary health services they need. Lastly, the members of Kentucky Homeplace and SKYCAP

indicated that the health system itself is a contributing factor to disparities in health care. Within a complicated web of services, health care providers are under pressure to move most patients through the health system efficiently, while under appropriate clinical guidance. Little resources remain to ensure that patients maintain contact with the health system in order to manage their own health. Kentucky Homeplace works with patients to gain access to the system and to acquire the necessary skills to manage their own health.

Through its intensive work outlined above, Kentucky Homeplace realized that some individuals and families have problems that are more complex such as mental illness. As a result, the Center for Rural Health created SKYCAP in which the Family Health Navigators would assist clients with accessing a holistic care management system including pharmaceutical access, mental, physical, and environmental services. The Family Health Care Advisors are currently using "pen-based" computing tablets that register data pertaining to each encounter with clients in the program. This data system has been in place for about nine months and is currently being used to capture client demographic information, encounter information, clinical diagnoses and treatments (such as medication listings). This system will eventually monitor client outcomes.

Currently collected outcome data includes process measures such as unduplicated client counts and referrals to various health services, health care utilization measures, and estimated cost-offsets due to reduced hospitalizations.

The team discussed four primary learnings from their work:

1. Staff members should be "from the community". Most staff members and administrators are from backgrounds similar to those of the clients served by the program, increasing familiarity with local conditions and barriers to facing the health care system.
2. Clients should be empowered to navigate the health system on their own. Each encounter with a client supports his or her ability to make their own decisions regarding their health and to work towards encouraging independence in this process.
3. Client issues are complex and reach beyond the health system. Both FHCA's and Family Health Navigators work with clients to obtain necessary social and economic services in an effort to deliver a "holistic" intervention.
4. The use of technology in client management is critical. Building a technological infrastructure is a key factor in delivery efficient services to clients in the community. This includes remote technologies such as pen-based computing tablets and/or palm devices.

The program envisions Medicare delivering both the FHCA and the Family Health Navigator as reimbursable services for reducing racial and ethnic disparities in health care. They acknowledge that there are alternative staffing models that could support this benefit.

Organization and Operations

While recruitment of program clients often occurs through physicians or social service agency referrals, the team indicated that clients more commonly learn about both Kentucky Homeplace and SKYCAP through newspaper advertisements that promote "neighbors helping neighbors". Word of mouth about both programs generates client flow as well. Neither program will deny services to anyone, but each of the programs will at times refer to the other depending on the needs of the client. Furthermore, Kentucky Homeplace may register a client under a "brief encounter status" depending on the request or need. An example of such an encounter would be a request for locating a smoking cessation therapy group in the community. The team further indicated that local acceptability is enhanced by the name "Homeplace". They state that such a term provides an image of a local community organization that fulfills the responsibilities that the family cannot manage. Both programs currently have very strong political support and are well known in the community. SKYCAP is looking to expand its reach to many other counties. From September 2000-March 2002, SKYCAP obtained 1,382 referrals from additional counties throughout the state.

The average length of engagement for clients in Kentucky Homeplace is somewhere between 3 and 6 months. While many interactions with clients are "brief encounters" while, others may have a length of engagement of up to one year. Due to the complexity of clinical conditions faced by most clients in the SKYCAP program, these clients generally have a longer period of engagement with a Family Health Navigator, which could be longer than 2 years. Contact is made with individuals through physicians' offices, social service agencies, and self-referral. Once a contact has been made, a client is enrolled in the program. In the Kentucky Homeplace program, home visits are initially made to clients to discuss their needs and to develop a relationship with the client. Depending on his or her needs, the client is then visited by the FHCA on a weekly to monthly basis. The FHCA will remain in close communication with the client via telephone and work on establishing necessary connections for the client with the health care system. The FHCA will provide transportation for the client as necessary to various health and social service appointments. The FHCA logs each client encounter into a handheld computer that is eventually uploaded to a main client-tracking database. In the SKYCAP program, the Family Health Navigator similarly works with the client to obtain necessary health care services, but the focus of the relationship with the client is more "therapeutic". Since over 50% of all SKYCAP referrals have mental health concerns, the Family Health Navigators are hired with the expectation of being compassionate and trained to conduct brief client assessments. Furthermore, these staff are provided bi-weekly supervision by licensed RN's. The organizational context focuses on delivering services unique to meeting the needs of each individual engaged in the program.

Cultural tailoring of these services consists primarily of hiring people from the rural Kentucky community to work with people of the rural Kentucky community. Furthermore, when individuals are applying to work for either program, one of the main factors that staff members look for in new hires is their potential to "connect" with

members of the community. Management staff and line staff in both programs strongly represent people from the surrounding rural areas of Kentucky.

Resource Requirements, Effectiveness, Costs, and Cost-Effectiveness

Both programs were able to provide budgetary information regarding the delivery of services, including personnel and non-personnel costs. Furthermore, it is critical to acknowledge that both programs have a significant amount of in-kind contributions that would add costs to the replication of either program. The programs have estimated the market value of some of these contributions. Lastly, both programs were able to provide necessary information regarding cost-offsets estimates due to reduced inpatient hospitalizations.

The total budget for Kentucky Homeplace was $1.9 million dollars for the current fiscal year, while the budget for SKYCAP was $887,096 for FY 2001. Personnel costs accounted for 81% of the Kentucky Homeplace budget, while 84% of the SKYCAP budget consisted of personnel costs. Family Health Care Advisors were paid an average of $19,390 in FY 2001 with a fringe benefit rate of 34%. Family Health Navigators were paid an average of $18,000 during FY 2001, with a fringe rate of 25%. With over 10,400 clients engaged in the Kentucky Homeplace program in 1999, the cost per client of the program was approximately $182 per client. When adding the market value of donated pharmaceuticals, free health care visits, and reduced health care debt, the unit cost per client increases to $293 per client. There is a wide variability in client costs due to some clients engaged as "brief encounters" and others having more intensive engagement in the program.

The greatest amount of in-kind contributions for both programs came from donated pharmaceuticals. Kentucky Homeplace was able to obtain over $1 million annually in donated prescription drugs from Indigent Pharmaceutical program, while SKYCAP acquired $547,000 in donated prescription medications for clients in the first year of the program.

Kentucky Homeplace reports an overall reduction in emergency room costs of $1,813 for program clients in 1999. This is based on a unit cost of $136 per visit. Reductions of $2,268 are reported for overall inpatient hospitalization for clients in1999. Reductions in Nursing Home use totaled $728,175 for program clients. This represents a 37% drop in nursing home costs. The SKYCAP program reports an 86% overall decrease in hospitalization costs for clients from $540,000 to $74,250 in 2001 and a 90% overall decrease in emergency room visits for clients from $50,055 to $4,935 in 2001. Although not yet tested to control for additional co-variates, both programs appear to have some significant impacts on cost-offsets of other health care services.

In order to improve cost and cost-effectiveness analyses, additional analyses would incorporate changes in health status and quality of life of clients over time. Preliminary

analyses show cost-offsets in health service areas, but further savings might occur in other social service sectors.

Conclusions

Assuming, continued political support and demand for services throughout Kentucky, both Kentucky Homeplace and SKYCAP appear to be well positioned to further develop their services into the next several years. Their strength in the community appears to be based on their connection to the University of Kentucky's Center for Rural Health and popularity among health service providers and clients. The Family Health Care Advisors and Family Health Navigators, each playing a distinct role in various communities in Kentucky, serve as strong examples of potentially replicable services to be reimbursed by Medicare to reduce racial and ethnic disparities in cancer. The use of both models suggests ways of empowering clients to maintain their connection to the health system. Furthermore, under initial evaluation both models seem to have impact on reducing costs of emergency rooms visits, hospitalizations, and nursing home services. Key elements in implementation include hiring compassionate members of the community, vital training and supervision of program staff, a holistic approach to client needs, and the use of technology in case management.