Center to Reduce Cancer
Health Disparities (CRCHD)

Economic Costs of Cancer Health Disparities

SUMMARY OF MEETING PROCEEDINGS

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health

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Foreword

Why examine the cost of cancer health disparities? Disparities in cancer care and outcomes result in both economic and human costs. Public policy approaches to eliminate cancer-related disparities require an understanding of these costs to find appropriate balances between the actual dollars spent and the potential value to American society. For these reasons, understanding the costs associated with these disparities is vital to the work of the National Cancer Institute (NCI) Center to Reduce Cancer Health Disparities. This first NCI Think Tank on the economic costs of cancer health disparities was an important step in exploring these issues.

Considerations of the cost of cancer health disparities often focus principally on the expenditures associated with eliminating existing disparities. However, current disparities have an ongoing cost that is less well recognized. Specifically, all people with cancer in America eventually receive care, since severely symptomatic patients seldom are denied hospital care. But if treatment is ineffective because the disease already is advanced, the associated costs likely will be higher both in dollars and in human suffering.

The Think Tank participants emphasized the distinction that must be made between cost and value. They further underscored that both cancer disparity costs and the value accruing from reducing these disparities may be tangible and intangible. For example, tangible costs may include dollars spent on treatment and lost wages, whereas tangible value may include reduced individual and health system costs, lives saved, and restored productivity. Intangible costs of cancer may include emotional anguish and diminished quality of life for patients and their families, whereas intangible value may include reduced suffering and the opportunity to redirect health care resources to disease prevention.

Disparities specific to cancer may be among the more easily measured types of health disparities because of existing cancer-specific data collection infrastructure. Even so, based on the limited studies to date using these data, we cannot yet quantify the full costs of existing cancer disparities, the cost of eliminating these disparities, or the real and perceived value of eliminating them. Nor can we assess, except at a philosophical level, whether the value is worth the cost.

Moreover, perceptions of cost and value may vary according to different cultural and societal norms. Cancer health disparities differ by disease, by population, by geographic region, by age, by gender, and by other parameters. Therefore, the economic costs of cancer health disparities must be assessed from many perspectives, including those of society in general, government, population groups, employers, insurers, and each affected individual.

The fundamental question centers on the cost-benefit that could be realized over time compared with the current economic and human costs of cancer health disparities. Exploring this and other related crucial questions illuminated the current gaps in knowledge that must be filled to appropriately frame and address the issues. It was clear from the Think Tank deliberations that no consensus currently exists on how to measure or balance the costs and benefits to the nation of eliminating cancer health disparities.

Most Americans would agree that in the aggregate, we have made great advances in this nation with respect to disease in general, as reflected by the remarkable increases in average life span and quality of life since 1900. But some groups of people have not enjoyed these benefits as much as others, as evidenced by their outcomes of cancer and other diseases. Many people, regardless of economic status, education, and insurance coverage, have great difficulty negotiating the health care system and getting from the point of an abnormal finding and a cancer diagnosis through the treatment of their disease.

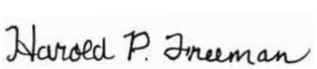
This problem, often resulting in reduced survival, inflicts the greatest burden on the poor, who typically lack fiscal, educational, and information resources.

A cascade of problems—such as financial and geographic barriers to treatment; ineffective provider-patient communication; inadequate screening, and insufficient post-treatment and long-term follow-up—can occur in varying combinations over time, resulting in increased cancer-related costs. We do not fully understand all of the potential interrelationships of these problems, but our knowledge of them has improved. One thing has become clear: social injustice leading to unfair inequities is at the core of most of these problems.

Realistically, we know that disparities will always exist at some level, because our social and health care systems cannot be corrected such that every person will have equal access to care, comparable living conditions, and equal amounts of resources. Nonetheless, we suggest that we can dramatically minimize disparities and their costs by agreeing as a society, and committing to the belief, that it is unacceptable for any person with cancer to go untreated. Further, we must ensure that any inequities in care are not caused or exacerbated by biases related to race, ethnicity, culture, or socioeconomic status.

The participants in this Think Tank were drawn from diverse disciplines, including health care delivery, health economics, health policy, statistics, health services research, public health, and social science research. They were charged to consider the underpinnings of this complex problem and offer suggestions for better understanding and addressing these issues. Their deliberations provided the basis of the recommendations in this report.

Cancer health disparities are not only an economic and medical concern but also an extraordinary moral and ethical dilemma for this nation. We hope that the considerations and recommendations contained in this report will be a tool to stimulate vigorous discussion and bold action to address these issues.



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Executive Summary

There is a significant disconnect between the development of efficacious prevention and treatment options established through cancer research and the delivery of this care to all population groups, most notably cancer patients from certain racial and ethnic minority groups, individuals with low socioeconomic status, residents in certain geographic locations, and individuals from other medically underserved groups.[1] Improving the delivery of cancer care to these population subgroups may help to reduce cancer health disparities in the United States.

There are several different definitions of disparities and the conclusions regarding the impact of disparities can differ based on the definition used.[2] The NCI's definition of cancer health disparities is as follows:

"Disparities, or inequalities, occur when members of some population groups do not enjoy the same health status as other groups.

Disparities are determined and measured by three health statistics: incidence (the number of new cancers), mortality (the number of cancer deaths), and survival rates (length of survival following diagnosis of cancer). Health disparities occur when one group of people has a higher incidence or mortality rate than another, or when survival rates are less for one group than another.

Disparities are most often identified along racial and ethnic lines, i.e., African Americans, Hispanics, Native Americans/Alaska Natives, Asian Americans/Pacific Islanders, and whites have different disease rates and survival rates. However, factors contributing to disparities extend beyond race and ethnicity. For example, cancer health disparities can also involve biological, environmental, and behavioral factors, as well as differences on the basis of income and education."[3]

Disparities in care exist along the entire cancer care continuum—from primary prevention, to screening and diagnosis, to treatment and follow-up services. Examining and understanding the economic and human costs of cancer health disparities to patients, families, employers, providers, and society as a whole may be helpful in developing strategies to eliminate or reduce such disparities. There could be significant benefits to eliminating these disparities, including a reduction in mortality, decreases in cancer- and treatment-related morbidity, and improved quality of life. Measurement of these human benefits can be captured in part through estimates of quality-adjusted life years (QALYs), which are composite measures that include improvements in the length of life and in the quality of life associated with a particular healthcare intervention. The overall economic value to society of reducing disparities can be assessed through cost-effectiveness analyses and cost-of-illness and/or value-of-health studies. Components of these studies may include the direct medical and non-medical costs (related to provision of health services), indirect costs (e.g., time lost from work and other economic activities), and concurrent changes in population mortality and morbidity.

The costs related to cancer health disparities have not been systematically and comprehensively assessed to date. To address this critical need, the Center to Reduce Cancer Health Disparities (CRCHD) of the National Cancer Institute (NCI) convened a Think Tank meeting on December 6–7, 2004. The Think Tank meeting was convened upon recommendation of an ad-hoc group of experts that met prior to this meeting. The meeting consisted of individual presentations from an interdisciplinary team of experts, as well as group discussions and breakout sessions to explore identified issues in greater depth. The key areas of discussion were the total costs of providing cancer care including a critical assessment of the data limitations, challenges in measuring the value of reducing cancer health disparities, and the importance of measuring the cost-effectiveness of interventions to reduce cancer health disparities. At the conclusion of the two-day meeting the participants provided a list of recommendations and future research activities. This report synthesizes the presentations and discussions of the Think Tank.

Several key conclusions were reached by the Think Tank participants. First, existing data sources have not been used adequately to explore issues related to cancer health disparities and there are no population-level data sources available currently to systematically estimate patient-level costs of these disparities. Improvements in the available data sources may allow for the estimation of overall patient-level cost burdens related to disparities. The data sources can be improved in several ways: by increasing the sample of minority populations (e.g., African Americans, Native Americans/Alaskan Natives; Asian Americans/Pacific Islanders) available for analysis; by developing a national database on cancer epidemiology, outcomes and resource use; by performing linkages among currently available databases and by clearly understanding and adopting national standards (e.g., Office of Management and Budget [OMB] Directive 15)[4] on race/ethnicity coding. In addition, decision analytic models can be used to combine effectiveness and cost information from these various data sources to estimate the cost of cancer health disparities. Second, there are significant overlapping determinants of disparity and therefore there is considerable challenge in identifying the cost impact of specific determinants. As cancer health disparities are not just an issue

among racial minority groups, the association between factors such as low socioeconomic status (SES) and cancer health disparities should also be examined (although African Americans have the highest rate of poverty, about 25%, the majority of Americans below the federal poverty level are white).[5] Third, since resources available for health care and other services are finite, economic evaluations are essential to identify interventions that are cost effective. Interventions that are likely to be cost effective are those that address target populations with high degree of disparities, those interventions that are highly effective, and those that are low cost.

Through breakout group discussions, the participants addressed the economic consequences and costs of cancer health disparities and made numerous recommendations of cost-effective interventions for eliminating these disparities. The recommendations are summarized below in two subsections—research and policy.

Research Recommendations

1. Focus on cancers with modifiable attributes and fund prospective clinical trials to evaluate primary prevention strategies;
2. Study processes to develop improved data sources that will facilitate collection and analysis of cost and outcomes data;
3. Develop better methods and tools to measure disparities;
4. Assess geographic variation and other factors that result in disparities;
5. Include cost-effectiveness assessments in clinical trials and other intervention studies that address disparities;
6. Identify changes in the health care delivery system that can reduce the economic burden of cancer health disparities; and,
7. Initiate studies to quantify uncompensated cancer care.

Policy Recommendations

1. Improve and expand current insurance coverage;
2. Sponsor health policy research to assess impact of cancer payments on quality of care;
3. Reduce geographic differences through community-level interventions;
4. Eliminate health care network disconnects; and
5. Promote primary prevention for cancer sites where evidence supporting primary prevention exists (e.g., HPV vaccine).

The research topics and recommendations identified by the Think Tank participants will help direct NCI's efforts in quantifying the economic burden of cancer health disparities and inform policies to eliminate cancer health disparities. A number of specific next steps were identified. First, convene a panel of experts to identify a detailed process for improving both the epidemiological and cost data available to study and assess measures to reduce cancer health disparities. Second, sponsor studies to develop better methods to measure cancer health disparities and to evaluate the costs associated with cancer health disparities. Third, include cost-effectiveness assessments in any clinical trials or interventions sponsored by NCI to reduce cancer health disparities. Fourth, coordinate activities with other federal agencies, including Centers for Medicare and Medicaid Services (CMS), to implement initiatives to reduce cancer health disparities.

Introduction

SECTION 1

1.1 Background

There is a significant disconnect between cancer research *discovery/development* (i.e., what we know) and the *delivery* of care to cancer patients (i.e., what we do).[6] This disconnect is an important factor contributing to an imbalanced and unjust burden of cancer in our society—the burden falling on some racial and ethnic minority groups, individuals with low socioeconomic status (SES), residents in certain geographic locations, and other medically underserved groups. Improving the delivery of cancer care to these population groups would help to reduce cancer health disparities in the United States.

Examining and understanding the economic and human costs of cancer health disparities is an important step in eliminating such disparities. Understanding the economic costs and human costs of cancer health disparities may provide guidance to policy makers with regard to cancer health care. To address this need, the Center to Reduce Cancer Health Disparities (CRCHD) of the National Cancer Institute (NCI) convened a Think Tank meeting on December 6–7, 2004. This meeting brought together health economists, cancer care providers, insurers, and policy experts to explore the economic costs to the nation resulting from cancer health disparities among certain population groups (including racial and ethnic minority groups and individuals with low SES) and to identify potential interventions to address these disparities. The purpose of this report is to provide a summary of the ideas and discussions that occurred during this meeting and to review the current knowledge on the economics of cancer health disparities.

1.2 Objectives

The original objectives of the meeting were:

- To examine the current evidence regarding the costs of cancer health disparities;
- To assess the currently available cost data and data needs related to costs of cancer health disparities;
- To explore new and creative ways of examining and estimating the economic costs of cancer health disparities (since there are currently not enough databases containing data of this nature);
- To strengthen the economic evidence base regarding the cost of cancer health disparities; and,
- To explore new and creative strategies for reducing and eventually eliminating cancer health disparities.

During the initial discussions among Think Tank participants, it became clear to the participants that the evidence to support the completion of the objectives listed above was not available; therefore, the participants focused on intervention strategies and future research areas which will enable completion of these objectives.

1.3 Think Tank Process

The Think Tank meeting consisted of individual presentations from the interdisciplinary team of experts, as well as group discussions and breakout sessions to explore certain issues in greater depth (see ***Appendix A*** for a list of meeting participants). Participants for the meeting were selected based on their expertise in specific areas of relevance to the Think Tank discussions, including clinical epidemiology, health care policy, and cost-effectiveness analyses. Prior to the meeting, all participants received a package of pre-planning documents, including a copy of the notes from the planning meeting convened by CRCHD (***Appendix B***) and a background paper on economic costs of cancer health disparities prepared by the CRCHD staff (***Appendix C***).

The two-day meeting began with introductions and discussions regarding the purpose and rationale behind convening this Think Tank meeting and the core questions to be discussed and answered. The agenda for Day 1 of the meeting consisted of six individual presentations followed by group discussion (The agenda and brief descriptions of the presentations are provided in ***Appendix D***). Additionally, the six individual presenters participated in a panel discussion, during which both participants and observers asked questions and discussed the major issues from the day-long session. Day 2 began with a breakout session where participants were divided into two groups and given the same set of key questions:

- What is the total cost of cancer care?
- What proportion of the total cost of cancer care is related to health disparities?
- What would be the cost of eliminating cancer health disparities in America?
- What is the value of reducing cancer health disparities in America?
- What are the policy implications of reducing cancer health disparities?
- What is the cost of changing policies?

Deliberations and discussions from the breakout session were summarized and followed by final discussions and wrap-up.

1.4 Organization of Report

This report begins with an overview of the determinants of cancer care disparity and a description of the "cancer care continuum" (Section 2). Section 3 discusses the total cost of cancer care and limitations of currently available data sources. Section 4 presents the methodological issues related to reducing cancer health disparities, followed by Section 5, a discussion of the costs and cost-effectiveness of implementing interventions to reduce cancer health disparities. Finally, Section 6 summarizes the Think Tank's recommendations for future research and policy initiatives.

Overview

SECTION 2

2.1 Definition of Disparity

There are several different definitions of disparities and the conclusions regarding the impact of disparities can differ based on the definition used.[2] The NCI's definition of cancer health disparities is as follows:

> "Disparities, or inequalities, occur when members of some population groups do not enjoy the same health status as other groups.
>
> "Disparities are determined and measured by three health statistics: incidence (the number of new cancers), mortality (the number of cancer deaths), and survival rates (length of survival following diagnosis of cancer). Health disparities occur when one group of people has a higher incidence or mortality rate than another, or when survival rates are less for one group than another.[3]"

The Minority Health and Health Disparities Act of 2000 provides the following definition of "disparity population":

> "A population is a health disparity population if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population. In addition, ... [the definition may include] populations for which

there is a considerable disparity in the quality, outcomes, cost, or use of health care services or access to, or satisfaction with such services as compared to the general population."[7]

2.2 Determinants of Disparities

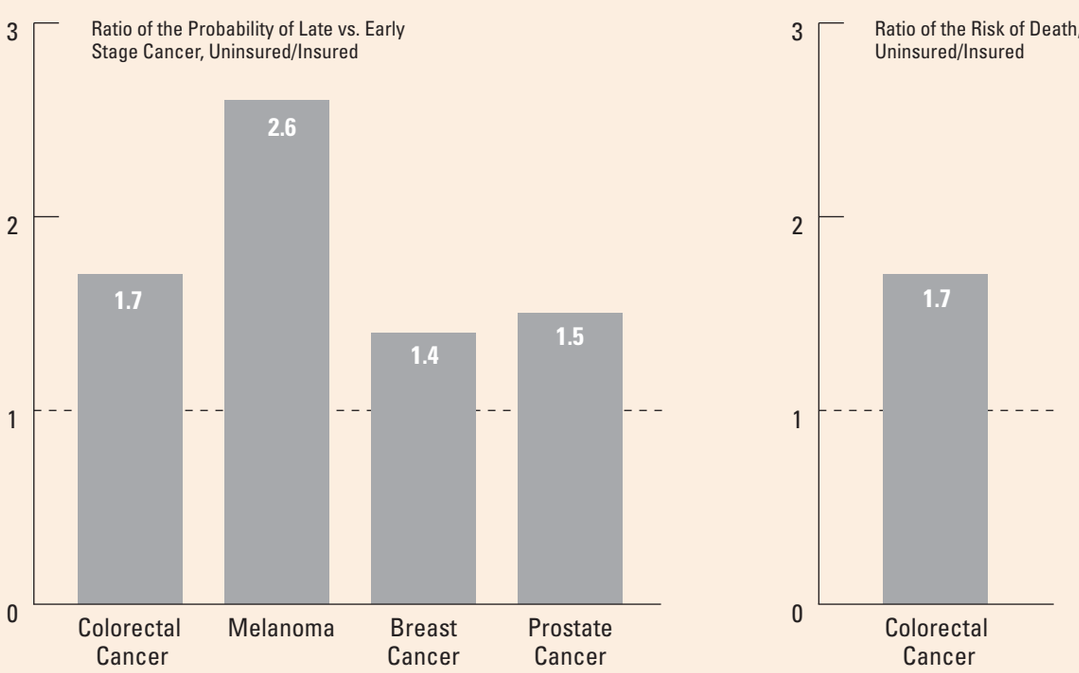
Determinants of cancer health disparities are underlying factors that may have an effect on individual outcome measures. Disparities are most often identified along racial and ethnic lines, i.e., African Americans, Hispanics, Native Americans/Alaska Natives, Asian Americans/Pacific Islanders, and whites have different disease rates and survival rates. However, factors contributing to disparities extend beyond race and ethnicity though.[3] They include factors within the health care delivery system (e.g., access to health care, insurance coverage, health care network disconnects) as well as factors outside of the system (e.g., education, SES, geographic differences).

Factors Within the Health Care Delivery System

Within the health care delivery system, lack of insurance coverage is a major contributor to cancer health disparities. Furthermore, the stability and quality of insurance coverage is even more important than simply being insured. The U.S. Census Bureau reports that, in 2005, approximately 16% of the population (46.6 million people) had no health insurance coverage.[5] The percentage of persons without health insurance was higher in certain racial groups and in groups with lower SES. Of Americans under 65 years of age who are diagnosed with cancer, 20% of Hispanics, 14% of African Americans, and 10% of whites do not have health insurance.[8]

An Institute of Medicine (IOM) report "Care Without Coverage: Too Little, Too Late, " found that uninsured patients with breast, colorectal, or prostate cancer are in poorer health and more likely to die prematurely than their insured counterparts, primarily due to delayed diagnosis.[9] For example, an uninsured

FIGURE 1 Ratio of the Probability of Diagnosis of Cancer at Late Stage,Uninsured Compared with Insured,* 1994



* Privately insured all had commercial indemnity plans. ** Among cancer cases identified in 1994; mortality followup through 1997.
All differences are statistically significant after adjusting for age, sex, race/ethnicity, co-morbidity, marital status (when appropriate), smoking status, socioeconomic status, education, stage at diagnosis, and treatment.
SOURCES: The Kaiser Commission on Medicaid and the Uninsured, 2003.10

woman with breast cancer faces a 30%-50% higher risk of dying compared with her insured counterpart, and an uninsured person with colorectal cancer has a 50% greater chance of dying compared with someone who has private insurance.[9] This finding is also true for other cancers, as shown in ***Figure 1***.

Over time, high rates of persons without insurance coverage lead to unstable connections to care, disruptions in care, and greater costs. Lack of adequate insurance coverage limits access to care, partially due to cost-related issues[12] and partially due to the lack of a primary care provider.[13] Finally, even in persons with low incomes who are insured, cost-sharing and out-of-pocket expenses compromise receipt of effective medical care.[11]

Factors such as availability of appropriate providers and services at an affordable cost and access to appropriate referral services are important to receiving high quality health care and, if compromised, can contribute to health care disparities. For instance, in rural areas there may be a lack of specialists which can lead to delays in diagnosis of cancer and treatment, or language barriers can result in non-English speakers not seeking or receiving appropriate care.[9] Disruption of traditional community-based care can also lead to disparities as providers familiar with individuals in a particular locality may no longer be available.[14]

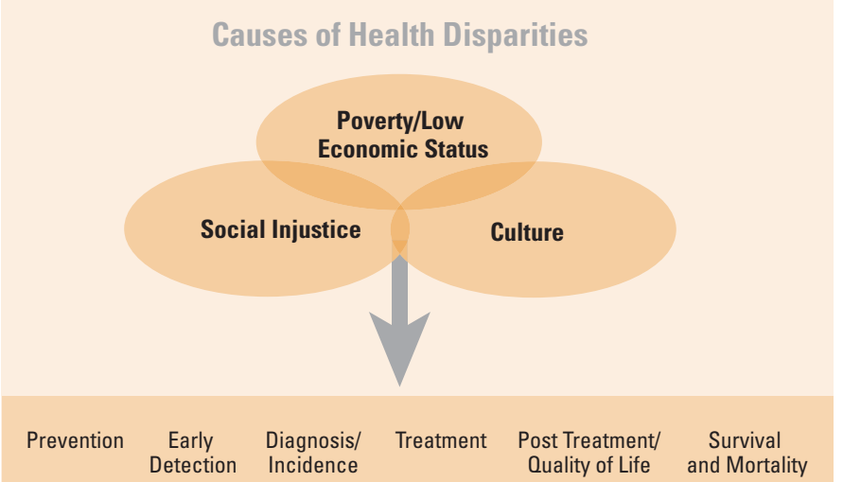
Factors External to the Health Care Delivery System

Factors external to the health care delivery system which contribute to disparities include gender, race, ethnicity, SES (income, education), and geographic location. According to Freeman (2004)[1], the three principal determinants of cancer disparities (***Figure 2***) are:

- Poverty (low SES);
- Culture; and
- Social Injustice.

Poverty is generally correlated with lack of information, risk-promoting behaviors, and reduced access to appropriate health care. The percentage of individuals living in poverty is disproportionately high among African Americans, Hispanics/Latinos, Native Americans, Pacific Islanders, and Native Hawaiians compared with white Americans. The poor are at greater risk of being diagnosed and treated for cancer at late stages of disease and are less likely to survive a diagnosis of cancer. Among the three main determinants, poverty contributes to health disparities more than the other two factors.[1] A study of colorectal cancer screening among Medicare beneficiaries concluded that much of the disparities in screening rates can be explained by differences in socioeconomic status. Disparities in socioeconomic status decreased but remained significant even after adjustment for personal and health system factors. [15]

FIGURE 2 **Causes of Cancer Health Disparities**



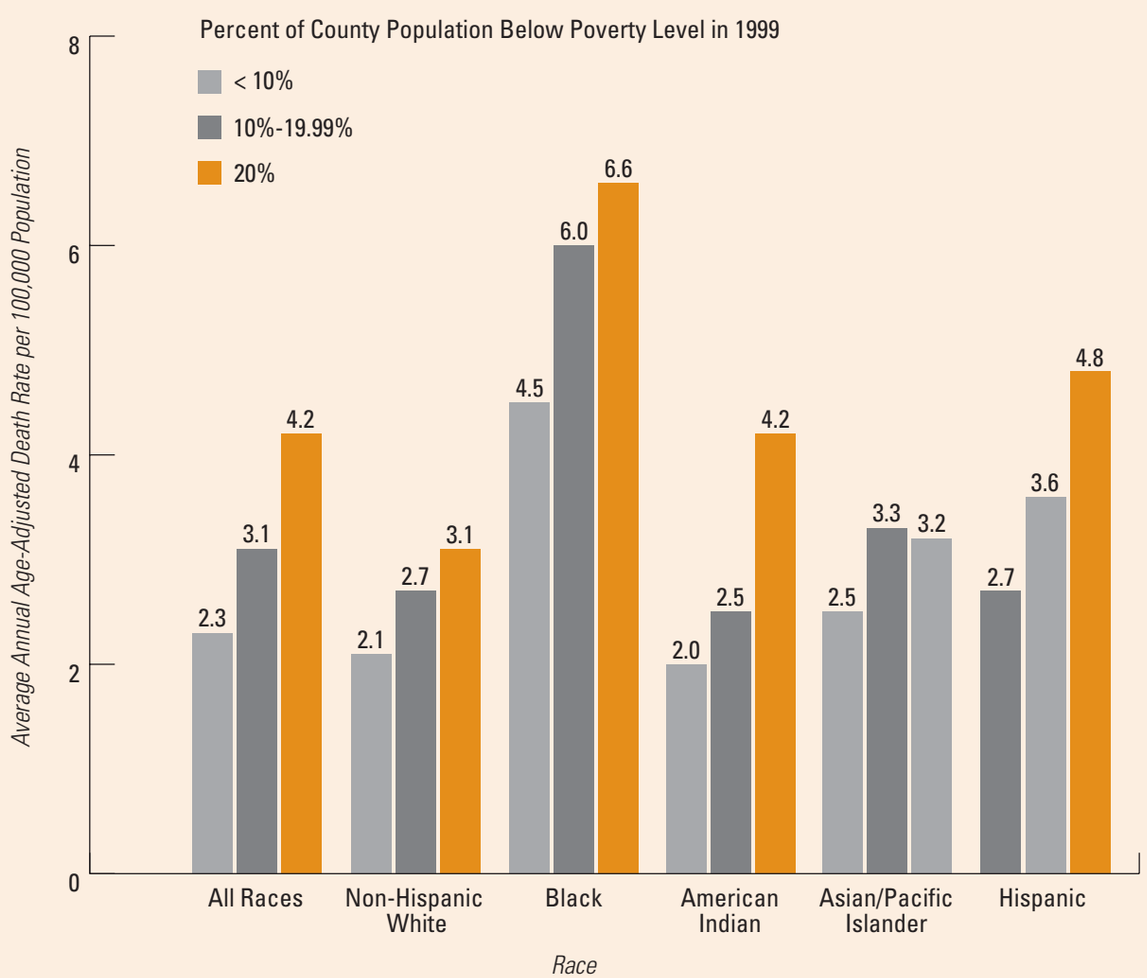
SOURCE: Freeman, Adapted from Cancer Epidemiology Biomarkers & Prevention, *April 2003.*

A recent report published by CRCHD on cervical cancer (2005) and research by Singh and colleagues[16] highlights the correlation of SES and disparities in the incidence and mortality of cervical cancer at the county-level in the United States. The study found substantial inequalities in both the incidence and mortality of cervical cancer, with rates of disparities becoming higher with increasing poverty and decreasing education levels. Patients living in lower SES census tracts were also significantly more likely to be diagnosed at late stages of the disease and were less likely to survive. ***Figure 3*** highlights these disparities.

Although poverty is considered a primary determinant of cancer health disparities, much of the statistics on disparity are also related to racial differences. Race itself does play a role in determining cancer disparities.[17, 18] A recent IOM report (2002) found that racial and ethnic disparities in health care exist in the context of broader-scale social and economic inequalities. The report concluded that these disparities persist even after controlling for SES (i.e. income and education). Selected statistics from the NCI and the National Center for Health Statistics (NCHS) indicate several racial disparities. [19]

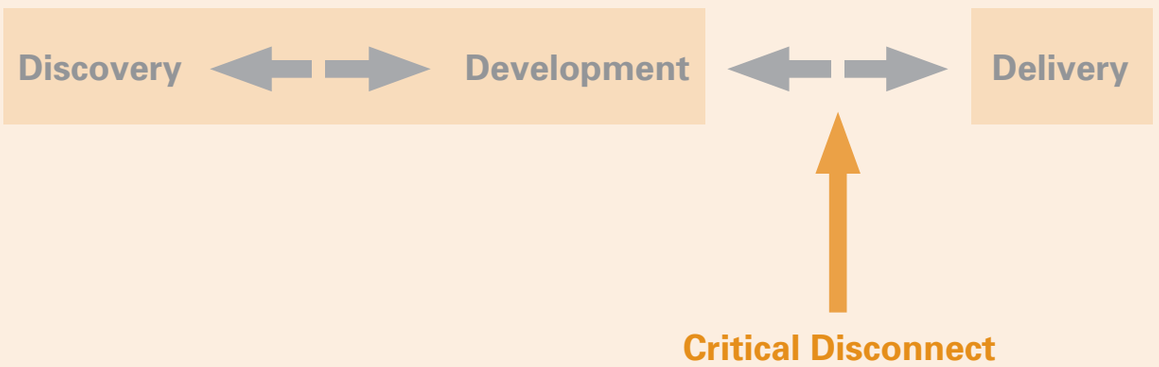
- African Americans have the highest cancer incidence and cancer-related death rates overall;
- African American males have the highest incidence and mortality rates for colon, prostate, and lung cancers;
- While Caucasian American females have the highest incidence of breast cancer, African American females have the highest death rates for breast cancer;

FIGURE 3 **U.S. Cervical Cancer Mortality by Race and Poverty Level, 1996-2000**



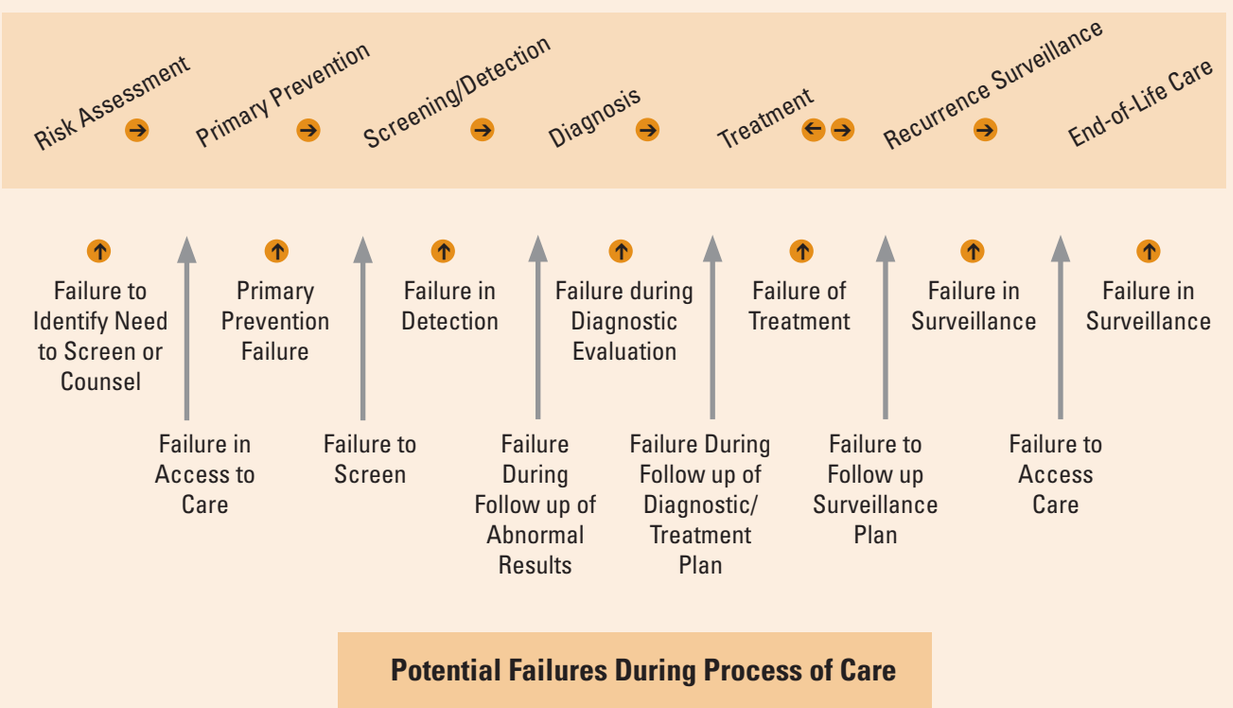
SOURCE: Singh et al., 2004.[16]

FIGURE 4 Critical Disconnect Between Research/Discovery and Delivery of Care



SOURCE: Freeman, 2000.[6]

FIGURE 5 Cancer Care Continuum



SOURCE: Zapka et al., 2003.[20]

- Hispanic/Latina females have the highest incidence rates among all racial groups for cervical cancer, and Vietnamese females [a subset of Asian-Pacific Islanders] have the highest mortality rates among all racial groups for cervical cancer; and,
- Asian/Pacific Islanders have the highest incidence rates of liver and stomach cancers for both sexes.

2.3 Screening, Diagnosis, and Treatment Disparities: The Cancer Care Continuum

Freeman has hypothesized that there is a critical disconnect between cancer research *discovery/development* and the *delivery* of care to cancer patients[6] as illustrated in ***Figure 4***.

Even for those who have access to care, the Cancer Care Continuum (***Figure 5***) illustrates that disparities in cancer care can occur at any stage of screening, diagnosis, or treatment. In the continuum from risk assessment through end-of-life care, a patient can fail to receive adequate care during any or all steps of the process. For example, a patient may not be screened appropriately, may not receive adequate treatment, may not be able to access end-of-life care, or may experience all three as well as other failures during the process.

Total Cost of Cancer Care

SECTION 3

Potential critical disconnects in the cancer care continuum may result in additional costs to both the health care system in terms of potentially higher costs of treating late-stage cancers and to society as a whole due to premature mortality. Several presentations and numerous discussions were held during the Think Tank meeting to better understand the costs related to cancer care and the challenges of measuring these cost impacts. In this section, the key themes from these presentations and discussions are summarized. The section begins with a background on the cost domains, followed by a summary of the overall cost associated with cancer care, and finally an in-depth discussion of the challenges of measuring the costs related to cancer health disparities.

3.1 Overview of Cost Domains

Economic costs of cancer include all resources required and used to provide a service—and the value of foregone opportunities to use these resources for a different service. The economic costs of cancer care and control include a wide range of factors: expenditures for cancer health care services; costs associated with time and effort spent by patients and their families and by cancer treatment providers; and costs associated with lost productivity due to cancer-related disability and premature death. Disparities in cancer care may increase the costs for individuals, families, employers, governments, and society.

Health care costs can be divided into direct, indirect, and intangible costs.

- *Direct costs* are related to expenditures for goods, services, and other resources used in the direct provision of a service. Both direct medical (e.g., cost of medications) and direct non-medical (e.g., paid child care) costs are categorized as direct costs.

TABLE 1 Specific Cost Elements Required for Measuring Total Cost of Cancer Care

Core Direct Costs:

- Screening
- Hospitalization
- Outpatient clinical care
- Physician visits
- Rehabilitation/ home health care
- Prescription and non-prescription drugs
- Medical devices (walkers, wheel chairs, etc.)
- Nursing home/long-term care
- Hospice care

Other Direct Costs:

- Transportation to health care providers
- Child care related to obtaining health care services
- Special diets
- Lodging for remote treatment facilities

Core Indirect Costs (impact on patient):

- Reduced productivity
- Job loss/Shift to lower-wage employment
- Loss of promotion opportunities
- Lost wages due to premature death

Other Related Indirect Costs (impact on family/friends):

- Time lost from work and housekeeping by family members or friends
- Loss of volunteers/caregivers to the community

Intangible Costs:

- Pain and suffering
- Bereavement
- Psycho-social impairment
- Familial health

SOURCE: Gold et al., 1996[23] and Fryback et al., 2004.[24]

- *Indirect costs* are generally resources related to days lost from work (i.e., loss of productivity). Medical or health-related indirect costs are generally broken down into morbidity (e.g., lost productivity due to work disability) and mortality (e.g., lost productivity due to premature death).
- *Intangible costs* are those related to adverse health effects for which there are no market prices (e.g., reduction in quality of life due to physical pain, emotional problems, and lifestyle changes). A reduction of intangible costs does not free up resources that could be used to produce other goods and services. This makes it difficult to estimate the impact of these costs, which can also extend beyond the patient to relatives who experience grief, bitterness, or depression.[21,22]

Understandably, economic studies often focus only on direct and indirect costs due to the difficulty in assessing intangible costs. In presenting direct and indirect costs, an additional distinction is often made in economic studies between costs primarily within the health care system (core costs) and costs outside of the health system (non-core costs). The costs used in assessing the cost of cancer are shown in ***Table 1***.

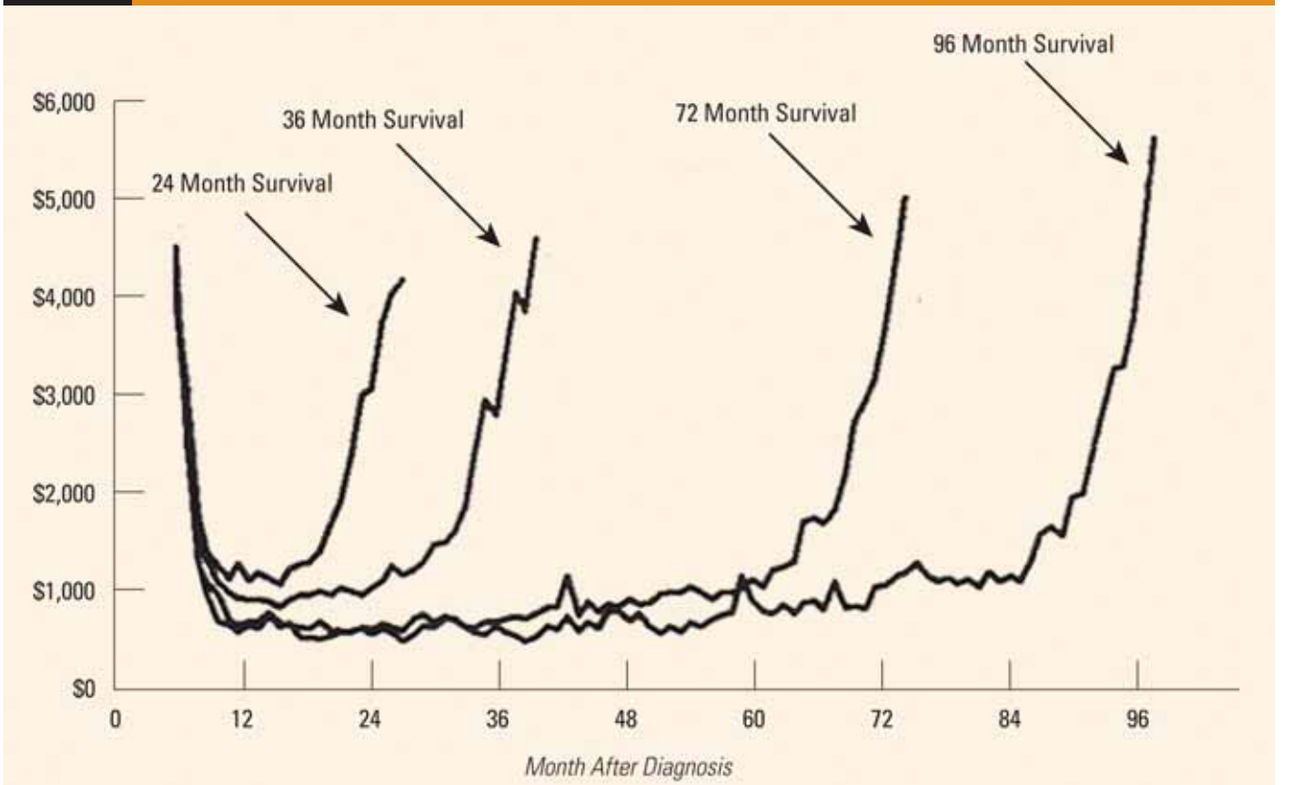
3.2 Overall Cost of Cancer Care

Costs related to cancer care contribute significantly to the overall health care costs in the United States. Hence, reliable and timely estimation of cancer-specific costs can help to assess the following:[25]

- Overall economic burden of cancer morbidity and mortality;
- Magnitude of economic resources needed to effectively care for patients with cancer;
- Cost-effectiveness of cancer prevention, screening, and treatment policies and programs; and,
- Societal benefit/cost return on investment from cancer research and control.

One approach to measuring the economic costs associated with cancer care is to measure the Cost of Illness (COI) associated with cancer. COI is an evaluative approach that considers the treatment-related economic costs as well as the economic value associated with loss of health and life.[26] COI estimates

FIGURE 6 Treatment Cost and Survival: Breast Cancer



SOURCE: Brown et al., 2002.[25]
Cancer Care Costs by Stage at Diagnosis

generally consist of direct costs, morbidity costs, and mortality costs. The estimate of total cost of cancer in the year 2005 is $209.9 billion: $74.0 billion in direct costs, $17.5 billion in morbidity costs, and $118.4 billion in mortality costs.[27]

Several studies on cancer care have reported on the direct health care costs and patient time and employment costs. The findings from these studies are reported in the sections below.

TABLE 2 **Cancer-Related Treatment Cost of Colorectal Cancer**

Stage	Without Unrelated Costs
In Situ	$28,000
Stage 1	32,700
Stage 2	34,400
Stage 3	41,600
Stage 4	29,400

SOURCE: Etzioni, Ramsey, et al., 2001.

TABLE 3 **Estimates of Direct Costs for Cancer Based on SEER Medicare Data, 1996**

Cancer Site	Direct Costs ($ billions)
All sites	42.39
Female breast	5.98
Colorectal	5.71
Prostate	4.61
Lung and bronchus	4.68

SOURCE: Brown et al., 2001.[26]

TABLE 4 **Time Costs Related to Colorectal Cancer Treatment: Difference in Cost for Cases Versus Controls (Net Costs)**

	Phase of Care	Patient Time Costs	Direct Medical Costs	Patient Time as % of Direct Medical Costs
Net Costs	Initial (average)	$4,592	$23,743	19.3%
	Continuing (per month)	25	158	15.8
	Terminal (average)	2,788	7,577	36.8

SOURCE: Yabroff et. al. (2005).[32]

Direct Health Care Costs

Distribution of Cancer Care Costs

Using data from SEER-Medicare, Brown and colleagues[25] generated estimates of total Medicare payments for Medicare enrollees following a cancer diagnosis, as well as estimates of cancer-specific payments by cancer site, stage at diagnosis, and type of treatment. Examination of the distribution of breast cancer care costs (See ***Figure 6***) revealed that cost curves were U-shaped, with the two vertical segments of the U (i.e., high costs) representing initial and terminal phase costs (costs occurring around the time of diagnosis and at the time of death), and the bottom of the U (lower costs) representing continuing care costs (costs occurring during the periods in between diagnosis and death).

Cancer Care Costs by Stage and Diagnosis

A confounding variable in estimating cancer care costs is the stage at diagnosis. Overall, costs are generally highest for Stages II and III and lower for in situ, Stage I, and Stage IV. [25] For example (See ***Table 2***), an analysis of cancer-related total Medicare payments (includes only those 65 years and older) for up to 25 years after the date of diagnosis for colon cancer reveals that the long-term costs for Stage II are higher ($34,400) compared with long-term costs for Stage IV ($29,400).[28] While initial cancer care costs are higher for patients with Stage IV diagnoses, long-term costs are higher for patients with Stage II diagnoses due to the additional continuing care costs that accumulate over the longer average survival period.[25]

Cancer Care Costs by Type of Cancer

Costs of cancer care not only differ based on stage of disease, but also by type of cancer. For example, the 1996 cost estimates by Brown et al. presented in ***Table 3*** show that 50% of the direct medical costs for cancer care for Medicare patients are associated with four types of cancers.

Medicare Expenditures versus National Expenditures for Cancer Care

A comparison of Medicare expenditures for cancer care versus national expenditures for cancer care (1996 data) showed remarkable agreement in terms of both overall magnitude and expenditure components by gender.[25] When expenditures based on the 13 most common cancer types were compared, breast, colon, prostate, and lung were consistently the top four highest-cost cancers.

Cost of Cancer Patients Compared with Controls

Several studies have compared the cost of care for patients diagnosed with cancer to that for controls without cancer, and consistently found that care for patients with cancer has higher direct costs. In a recent case-control study, the overall average direct health care cost for patients with cancer was estimated at $32,629, compared with $3,218 for controls without cancer, showing a significant difference in cost.[29] A study of female employees aged 50-64 diagnosed with breast cancer reported the average annual direct cost associated with breast cancer to be $13,925 compared to $2,951 for a random sample of female employees.[30] An analysis of the SEER-Medicare database estimated the lifetime cost for long-term colorectal cancer survivors (at least 5 years) were $19,516 higher than costs for controls without cancer.[31]

Time Costs

Time costs represent the value of the time patients and family members spend on activities related to the patients' cancer screening and treatment—time that could be spent engaged in other activities. Since time costs are not generally measured by traditional health care accounting systems, it is difficult to place a value on time costs. ***Table 4*** presents patient time costs for colorectal cancer expressed in terms of wages lost. As seen from the table, time costs can add significantly to the total costs of cancer care. The initial phase was the first 6 months after diagnosis, the terminal phase was the final 12 months before death.

Employment Costs

A diagnosis of cancer may influence both an employee and an employer's decisions regarding employment status and the number of hours worked. Furthermore, a decision to discontinue employment following a diagnosis of cancer has economic effects for the patient, his or her family, and society. [33–35]

Analysis of the 1992 National Health Interview Survey[36] revealed that nearly one fifth (18.2%) of the cancer survivors who worked before or after their cancer diagnosis experienced employment problems because of their cancer. These included on-the-job problems from an employer or supervisor, the inability to change employers, and loss of their job because of cancer. Another study reported that 13% of all adult survivors of a variety of cancers had quit working for disease-related reasons within 4 years of diagnosis.[37] The disability and work loss experienced by cancer survivors may ameliorate over time. A study of breast, colon, lung, and prostate cancer survivors 35 to 75 years found that, 5 to 7 years after diagnosis, of those who were working at the time of their initial diagnosis, 67% remained employed and that there was no negative impact of survivor's decision to retire or the quality of the retirement experience.[38] The ability to return to work may depend on the type of cancer: for example, patients with central nervous system, head and neck, or Stage IV blood and lymph malignancies are more likely to experience adverse employment outcomes.[37] A study on the impacts of Hodgkin's and non-Hodgkin's lymphoma on work initiation after cancer treatment found that only 54% of patients in remission who were able to work returned to work.[39] Overall, cancer does have a significant impact on ability to work. Kessler and colleagues[40] analyzed a nationally representative telephone-mail survey and found that cancer was associated with the highest reported prevalence of any impairment (66.2%) and the highest number of impairment days in

the past 30 days (16.4 days) compared to other chronic medical conditions such as major depression and heart disease.

The work impacts specifically attributable to breast cancer have been examined in a large number of studies. A recent study by Bradley and colleagues[41] examined the effect of breast cancer on women's labor supply and found that:

- Compared to women who had never had the disease, survivors of breast cancer had a 10% lower probability of being employed; and,
- Breast cancer may force a woman to give up her employment, which may lead to economic hardship for the patient and her family. In some cases, women undergoing breast cancer treatment continue to work despite the negative consequences on their health because of the need to retain health insurance coverage through their employer.

A notable finding in the study was that, among employed women, those with breast cancer may work more hours per week compared with women without the disease. The authors hypothesize that survivors and their families may be attempting to restore funds spent during the illness or else survivors approach their work with renewed vigor. Other studies on breast cancer survivors also support the findings in this study that survivors who were working at the time of their diagnosis experienced negative impacts.[42–45] A study by Stewart and colleagues[45] found that over 40% of breast cancer survivors reported that cancer had affected their work. In addition, breast cancer survivors were more likely to be functionally impaired even 5 years after breast cancer diagnosis and this, in turn, resulted in reduced work effort over the long-term. Overall, breast cancer survivors had significantly larger reductions in annual market earnings than working controls about 5 years after diagnosis. Furthermore, Chirikos and colleagues[44] found that this reduction in earnings mainly resulted from reduced work effort and not change in pay rate.

This work loss or reduction in work hours related to cancer is a significant indirect cost. Sasser and colleagues[30] analyzed disability claims from 7 large employers from 1998 through 2000 for females 50–64 years with breast cancer diagnosis and found that the average annual indirect costs associated with breast cancer was $8,236. Another study found that among insured women with breast cancer, the out-of-pocket expenditure and lost wages averaged $1,455 per month and represented a significant financial burden.[46]

The employment-related cost of cancer is a very complex field, in which several interacting factors may influence a survivor's decisions to work and thus his/her overall productivity. While there is some published evidence available in this area, the employment costs of cancer needs to explored further. Further research is needed to identify key factors that guide work decisions and the range of adaptations necessary to reach the desired level of economic productivity.[47] No research to date has focused on the work impacts associated with populations who experience health disparities in cancer care.

3.3 Data Limitations

In order to correctly measure the economic burden of a disease, adequate incidence and mortality data must be available. In addition, reliable and timely data must be available at the level of cancer site, stage at diagnosis, and type of treatments.[25] Currently, there is no reliable data source to systematically estimate patient-level or population-level costs of cancer health disparities. There are several limitations to performing cancer economic assessments based on data currently available.

1. **Lack of recent data on cancer outcomes linked with resource use.** The SEER-Medicare data is the only national linked cancer registry and administrative claims data source and provides a valuable source to perform economic assessments of cancer burden and treatments. Unfortunately, the latest year of data for cancer incidence is 2002 with Medicare claims available for this cohort till 2003. Therefore, at best, the data available for analysis is 4 years old. Given the rapid changes in cancer screening, diagnosis, and treatment, the availability of more current data would provide better estimates.

2. **No comprehensive national data on cancer epidemiology and outcomes.** The most reliable data on diagnosis, treatment, and survival comes from the SEER cancer registries. However, the availability of high-quality SEER data is limited to approximately 26% of the U.S. population, residing in areas with SEER registries. The NCI and Centers for Disease Control and Prevention (CDC) are working cooperatively through the CDC's National Program of Cancer Registries (NPCR) to improve the collection of high-quality data and coordination between the two registry programs. Potentially, these collaborations could result in more universal data systems to assess cancer outcomes and costs.

3. **Small sample sizes for studying minority populations.** In general, only a small sample of the non-white population is available for analysis, leading to unstable estimates for minority groups (for example cervical cancer mortality rates among Vietnamese). The SEER cancer registry program has been expanded recently to cover more of the racial, ethnic, and socioeconomic diversity of the country, allowing for the better description and tracking of trends in health disparities. [25] This could allow for better representation of minority groups in future data.

4. **Limited data on individuals younger than 65 years.** The data systems available to assess the quality of care on a national or regional basis are fragmented,[48] particularly for those under 65 years of age. Reflecting the U.S. health care system, data for those under 65 years are limited by payer source, and longitudinal analysis is often not possible because of limited enrollment periods with a specific provider. Therefore, unlike SEER-Medicare data, which is largely limited to those 65 years and older, there is no national linked cancer registry and administrative data to perform long-term assessments of health care resource use for those under 65 years. In performing economic assessments, outcomes data are limited in use unless supplemented with utilization and expenditure data.[49] In addition, given the importance of cancer stage, data sources not linked to clinical endpoints [for example, the Healthcare Cost and Utilization Project (HCUP)50] are of limited use.

5. **Lack of standardization in collecting non-medical resource use and cost data.** There is a great need to better quantify the resources expended by patients, families, and caregivers outside of the health care system.[24] In fact, recent estimates have shown that indirect costs associated with cancer are higher than direct costs,[51] therefore data sources that accurately quantify these costs are required.

6. **No national standards for race/ethnicity categories despite OMB Directive 15 which provides guidelines for racial and ethnic categories in the United States**. Federal, state, and private institutions do not coordinate in their attempts to code race, which makes it difficult for compare between these data sources. Race is often self-reported and therefore the reliability of the data available is questionable. In some cases (e.g. 2000 Census), mixed race individuals only select a category to indicate "more than one race" and do not provide any details on race which significantly limits the information available for analysis. In addition, most private payer administrative data sources do not include race as a category.[52]

7. **Limited information on costs related to cancer care.** A thorough assessment of a wide variety of costs is required to generate a reliable total cost of providing cancer care and to estimate the cost associated with cancer health disparities. Currently, we do have reliable data to estimate hospital costs for uninsured patients (uncompensated care costs), but not for estimating out-of-pocket payments made by patients, indirect costs incurred by patients, family members, and the community as a whole.

SECTION 4

Economic Benefits of Reducing Cancer Health Disparities

Clearly, the reduction or elimination of disparities and improvement in cancer care outcomes would have significant benefits for patients, the community, and society as a whole. In this section, a synthesis of the Think Tank discussions on approaches to measure the economic benefits of reducing cancer health disparities and potential challenges are presented.

4.1 Benefits of Reducing Cancer Health Disparities

Final health outcomes are the ultimate measures of disease impact, including mortality, morbidity (e.g., side effects, disability) measures, and Health-related Quality of Life (HRQL) measures. By definition, intermediate outcomes—measures such as response rate and disease reoccurrence rate—lead to final outcomes. The elimination of "failures" (i.e., inabilities to provide patients with appropriate screening and interventions) across the cancer care continuum would result in improvements in intermediate outcomes, which would result in improvements in final outcomes and may result in the reduction of disparities.

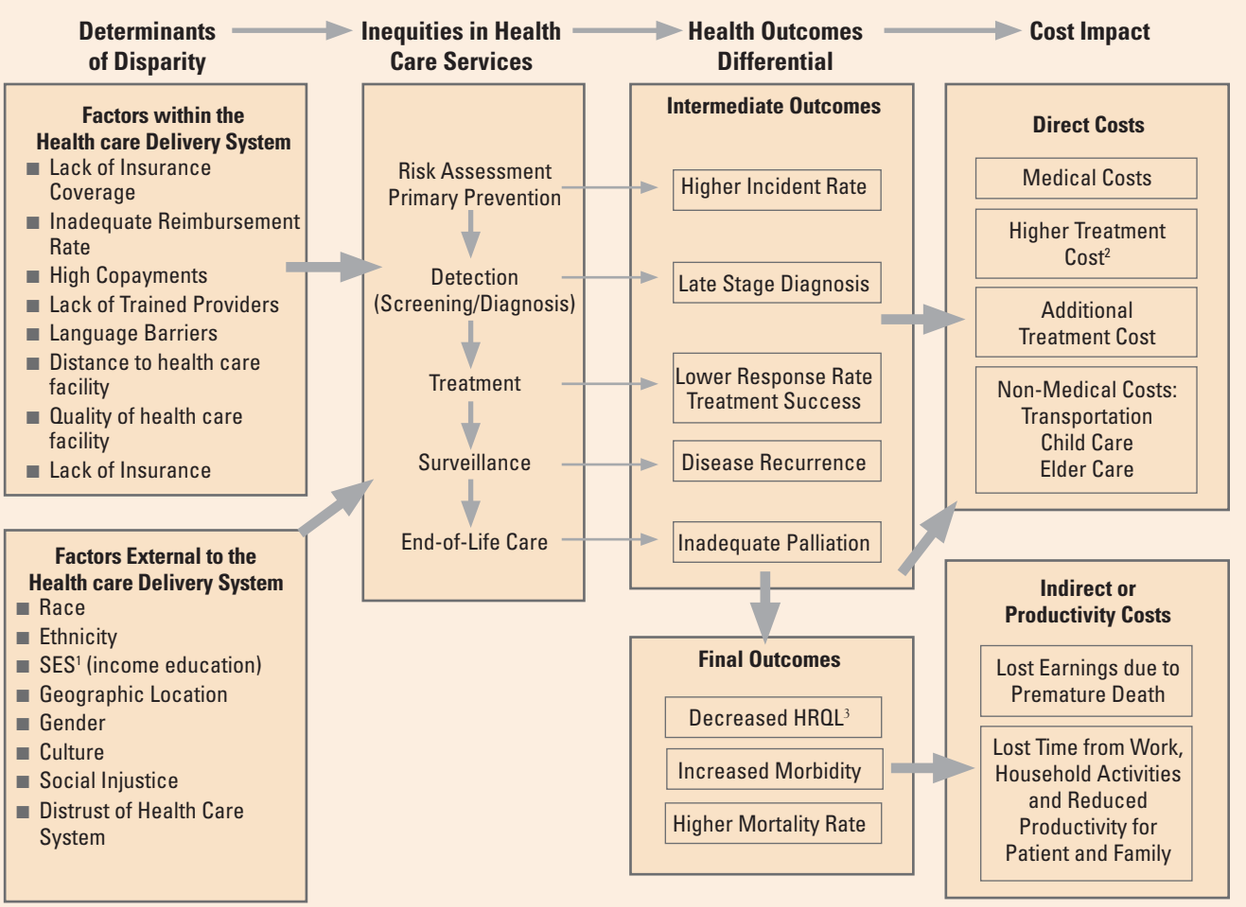
A framework for assessing the economic costs of cancer health disparities is provided in ***Figure 7***.

Overall, a decrease in cancer disparities should result in the following benefits to stakeholders at all levels:

- Increase in HRQL;
- Decrease in morbidity;
- Less burden on family members and community;
- Improved ability to work; and,
- Decrease in mortality.

HRQL refers to the impact that health conditions and their symptoms have on an individual's quality of life. In the context of health care, the term "quality of life" is referred to as "HRQL" because of its focus on health. The usual focus of HRQL assessment encompasses the physical, emotional, and social well-being

FIGURE 7 Framework for Assessing Economic Costs of Cancer Health Disparities



[1] SES- Socioeconomic Status [2] Stage IV cancers may have lower cost than Stage II and III cancer [3] HRQL – Health Related Quality of Life

of the patient. HRQL can be defined as health status and viewed as a continuum of increasingly complex patient outcomes: biological/physiological factors, symptoms, functioning, general health perceptions, and overall well-being or quality of life.[53] It describes the effectiveness of treatment or health status as the extent to which health care needs have been met, and HRQL measurement is often performed using patient responses to questionnaires and is therefore a measure of the impact of the disease or treatment from the patient's perspective.[54]

A survey of long-term survivors of breast cancer found that younger women with breast cancer had greater psycho-social stress compared with older women, and that long-term, disease-free survival resulted in excellent HRQL, with survivors experiencing many years of high levels of functioning and good HRQL.[55] Results from a second study of women who were diagnosed with breast cancer at a young age and who were long-term survivors of the disease showed that inadequate management of disease-related pain or other symptoms substantially affects the everyday lives of survivors.[56] Additionally, Casso and colleagues[56] note that HRQL in cancer survivors may be affected by socioeconomic status. A study conducted in long-term, female survivors of colorectal cancer also found that long-term survival results in HRQL that is comparable to that seen in women of similar ages in the general population, and that comorbidities had the strongest influence on HRQL.[57] In an evaluation of health utility in patients with melanoma, breast cancer, colon cancer, or lung cancer, Ko and colleagues[58] note that pain and comorbidities, items which can be improved through high quality medical care, substantially affect HRQL.

Changes in the health care system have resulted in a shift of cancer care from the inpatient arena to ambulatory and home settings. This shift has translated into increased family involvement in the day-to-day care of a person with cancer. Patients with cancer often require intensive care,[59,60] which can result in a significant burden to family members. Often, caregivers who are employed experience problems in their ability to work, and a large proportion miss work because of their caregiving responsibilities.[61] When family members are not available, health care workers will have to be employed to provide the necessary care which adds to the overall expense.

Decrease in cancer-related mortality and morbidity can have a profound impact on the patient, their family, friends, employer, the community, and the nation. For example, detecting cancer at an earlier stage will require less intensive treatment, resulting in quicker recovery for the patient—often back to the health status prior to cancer diagnosis. Patients can therefore return to employment or engage in normal activities sooner. Thus, family caregivers would have to spend less time accompanying patients to their treatment and less time in care-giving with a quicker recovery period.

4.2 Measuring the Value of Reducing Disparities

Estimating Mortality, Morbidity, and HRQL Impacts

Global health measures that include mortality, morbidity, and HRQL are increasingly used by policy makers to assess the overall impact of a disease. This approach, often referred to as "health-adjusted life years" (HALYs), integrates the biomedical and psycho-social models, and therefore has been labeled as the bio-psycho-social model.[62,53] It incorporates the features of several summary measures: Quality-Adjusted Life Years (QALYs), Disability-Adjusted Life Years (DALYs), Healthy Life Years (HLY), and Years Lived with Disability (YLDs). All these measures have two components: (1) life expectancy or mortality estimates and (2) morbidity and HRQL impacts of the disease. These two components are then combined in a mathematical formula to derive the composite measure.[49] QALYs and DALYs are two methods for measuring disease-specific burden.[63,64] QALYs have been criticized because the measurement can be biased and the QALYs estimated can differ based on the methodology used and type of population from which the utilities or values are derived. The disability classification of DALYs, on the other hand, is derived from secondary data analysis (for example, mortality and injury data) and/or is based on an expert panel classification of disease and disability.

Estimating Economic Impacts

As indicated in ***Figure 7***, the value of reducing cancer disparities should be assessed by estimating the economic costs specifically associated with cancer health disparities. Most studies estimating disease burden are based on the traditional COI approach, which permits the valuation of the economic burden of diseases and premature deaths. The methods usually used to perform COI estimation are based on a series of studies by Rice and colleagues. [48, 65-70] COI estimates provide order-of-magnitude indicators of the economic burdens imposed on society by various diseases and conditions. Economic burden generally comprises the cost to the patient, caregiver, payers, and society as a whole. The primary cost categories in COI studies are the direct costs and indirect costs discussed earlier.

Willingness-to-pay (WTP) is another approach to assess costs associated with cancer. The WTP method attempts to assign dollar values to the resources that individuals are willing and able to forego for a reduction in the probability of developing cancer and potentially dying from cancer. WTP is more aligned with conventional concepts in welfare economics, but it is generally more difficult and expensive to implement than COI, and there is no consensus on reliable and standardized survey instruments for doing so.[71] The WTP estimates are also often difficult to infer as there could be variability based on the respondent's economic status and their physical and mental condition at the time of the survey.[72] COI therefore currently remains the preferred practical methodology to estimate the economic burden associated with cancer.

In general, when using the COI approach, consensus exists over the measurement of direct costs. Costs associated with health care services (core direct costs) are often estimated from the amount reimbursed by insurance (payment). In some instances, detailed bottom-up, micro-cost data may be available, but this requires significant effort and detailed cost-accounting systems in place in order to calculate the cost. Charges are not recommended, as they are not a reflection of costs; but charges can be converted to costs using cost-charge ratios.

The optimal method for estimating indirect costs, whether the human capital approach, frictional cost estimation, or WTP, remains a subject of debate. The human capital method is the simplest to implement and is often used in COI assessments to estimate indirect costs. The human capital approach generally uses national data on population, life expectancy, labor participation rates, and earnings to develop annual and lifetime earnings profiles by sex and age. This approach excludes the costs associated with pain and suffering, leisure time, and volunteer work. Researchers have argued that this method could bias results and have suggested alternatives.[73] The frictional cost method only accounts for the potential production loss for the time it takes a firm to adapt to the loss or reduced productivity of the sick person, and therefore produces estimates that are generally much lower than the human capital approach.[74,75] WTP, although potentially resource intensive, can be used to assess indirect costs and serve as a complement to the overall COI approach.

Generally, a COI study must answer the following three questions:

- What adverse **outcomes** are associated with cancer health disparities?
- What is the degree of **causality** between cancer health disparities and these outcomes?
- What **economic values** ought to be assigned to the consequences?

COIs can be performed either using a top-down or a bottom-up approach.[49] The top-down approach involves using national data to infer through statistical methods the share of each specific diagnosis or disease grouping.[76] The bottom-up, micro-analytic strategy derives estimates of costs based on expenditures on specific services. An example is analysis of SEER-Medicare data to assess the cost of a specific type of cancer, as discussed earlier in the report.[25,77,78] In the majority of cases, the ranking order of cost estimates for cancer types using these two methods was similar.

As discussed in Section 3, data limitations may affect the ability to accurately quantify economic costs associated with cancer health disparities. Although COIs have been used since the 1960s to assess the

relative burden of diseases, there remain several challenges with using the COI methodology in general and specifically for estimating the cost of cancer health disparities. These issues are discussed below and potential solutions are offered:

- **Traditional COI approach does not capture all aspects of the burden of illness:** Estimates of *economic* costs based on the human capital approach exclude the burden of illness related to intangible costs that result from reduced functioning, pain and suffering, and deterioration in other dimensions of HRQL, including emotional and psychological impacts on families, friends, and co-workers. The WTP approach has the advantage that it does capture intangible costs, which makes it possible to assess the quality of life as well as the economic consequences of disease or treatment.[79] A potential solution is to perform an extended COI study[80] that combines the WTP approach and general COI approach. For instance, the human capital approach is applied to assess the tangible costs, while the intangible costs can be valued by the contingent valuation (CV) using the restricted WTP.[81]

- **Prevalence estimates versus incidence estimates.** COI studies can be performed using either prevalence- or incidence-based methods. The prevalence method estimates the consequences and costs incurred during a year or specified time period. For instance, this approach tallies all health care costs in a year associated with cancer diagnosis. The *incidence* method sums the direct and indirect costs of disease from its onset in a base year and for every subsequent year over the natural course of the disease. The total cost of disease equals the discounted sum of illness-related events over the lifetime of each individual with the disease. Incidence-based costing is based on life-cycle costs and therefore provides a more complete picture of the patient-level costs and baseline total costs against which new interventions can be assessed.[82] But the incidence-based method requires a considerable amount of data, such as disease incidence, survival rates, long-term morbidity, and lifetime impact on employment.[69,83] The prevalence method which has less extensive data requirements, is more frequently used than the incidence-based method[84] and does provide useful estimation of the potential magnitude of the cost burden.

- **Use of COI for policy assessment.** While COI studies have some influence in establishing the magnitude of the burden, a number of economists and analysts have questioned the usefulness of the COI methodology as a guide to resource allocation compared with methods that assess both costs and benefits. Their criticism is that COI studies point to the areas of greatest economic burden—but cannot suggest the most cost-effective manner to reduce it.[85,86]

- **Assigning costs to a specific disease.** Many patients have more than one disease/condition simultaneously, such as cancer and diabetes, or have other underlying risk factors, such as smoking or alcohol abuse. In such instances, it may be difficult to establish causality and to attribute costs to specific diseases. Faced with this scenario, researchers could choose to allocate costs on the basis of primary diagnosis only, or to develop methods of allocating costs to comorbidities or contributory conditions. In addition, the collection and use of mortality data in estimating the burden of illness poses a challenge, since disease-specific mortality rates are based on the systemic coding of causes of death, and competing-risks effects can make interpretation of mortality data difficult.[26] For example, the cause of death in a patient with multiple diagnoses may not be clear or correctly stated.

- **Variation in burden and cost by type of cancer.** There is wide variation in the total cost burden and the distribution between direct and indirect costs among different types of cancers. For instance, the direct health care costs for colorectal cancer is estimated at more than $3.5 billion, compared with about $0.5 billion for ovarian cancer.[25] The person-years lost from cancers vary from about 2.2 million for lung cancer to 130,000 for oral cancers. [25] Given these large differences, reporting total costs associated with all cancers will mask important information on specific cancers—information that policy makers require. Therefore, providing both cancer-specific costs and the total burden related to all cancers is useful.

Given these challenges, it is critically important to develop a theoretically sound framework based on the principles discussed above to guide the cost estimation process and to ensure the generation of valid and reliable estimates of costs related to cancer health disparities. In addition, systematic data on patient outcomes associated with health disparities is also required in order to perform valid cost-effectiveness assessments.

SECTION 5

Benefits and Costs of Policies to Reduce Cancer Health Disparities

The assessment of the economic burden of cancer provides a monetary value of the benefits of reducing cancer disparity but this does not provide information required to assess the cost and benefits of various approaches to reduce or eliminate cancer disparities. In this section, an in-depth discussion is provided on the importance of and approaches to assessing the cost-effectiveness of interventions to reduce cancer health disparities.

5.1 Why Economics Matters

Resources available for delivering health care and other services are finite. Economic assessments are essential to identifying the burden of cancer (as discussed in sections 3 and 4). In addition, economic evaluations play a key role in determining selection of interventions and policy changes to improve cancer care and reduce cancer health disparities. Specifically, economic studies guide two important decisions:

- **Efficient allocation of resources:** Economic analysis allows the comparison of interventions to identify the ones that are the most cost-effective—that is, the interventions that provide the highest level of benefits for the resources expended; and,
- **Resource planning:** Economic analysis provides information to assess the costs required in various budget periods—critical for the implementation of selected cost-effective interventions.

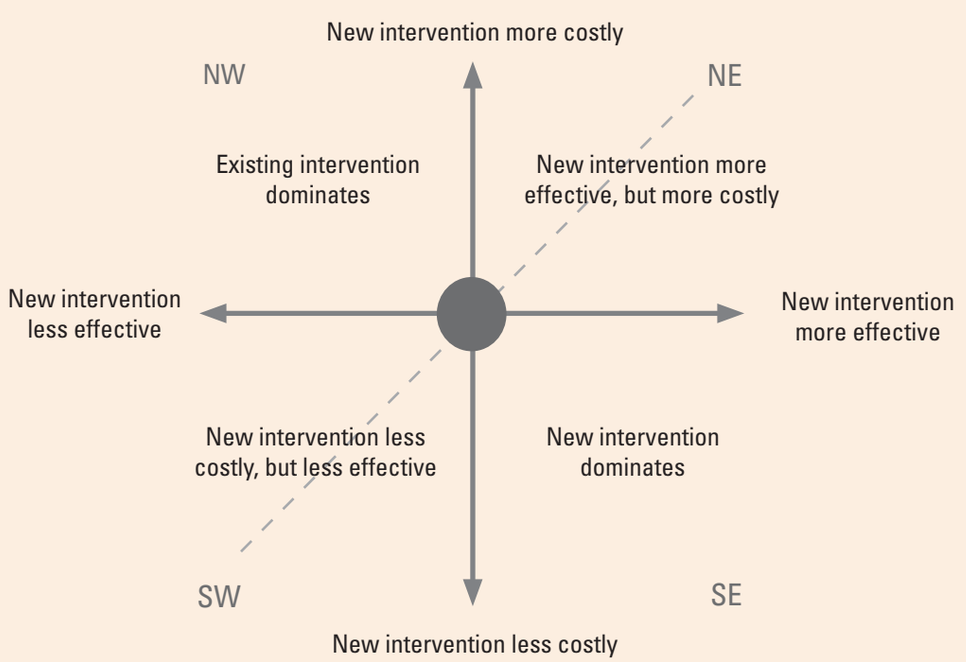
Cost versus effectiveness comparisons are performed to identify efficient interventions, and budget impact analyses are performed to facilitate and inform resource planning. These are discussed in detail below.

Comparing Cost and Effectiveness

The alternative scenarios used when comparing two interventions are provided in ***Figure 8***. If the new intervention both saves costs and improves outcomes, it is favored; this principle is called dominance (SE quadrant). If the new alternative is more costly but yields better outcomes (NE quadrant), then additional assessment is required. And the new intervention is only cost-effective if the additional effectiveness justifies its additional cost.

There are three approaches to simultaneously considering the cost and effectiveness of an intervention: cost-effectiveness analysis, cost-benefit analysis, and cost-utility analysis. In each of these three approaches, a ratio of the cost divided by the effectiveness units is generated and therefore results are presented as a cost per unit of effectiveness (see ***Table 5***).

FIGURE 8 **Cost Effectiveness Plane**



SOURCE: Ramsey, 2004.[87]

- **Cost-effectiveness analysis (CEA)**: Consequences or effects of the intervention are expressed in natural units, such as years of life saved, lives saved, cases detected, cases successfully treated, or some other improvement that is due to the cancer care-related intervention.
- **Cost-benefit analysis (CBA):** Both costs and benefits are expressed in monetary terms of net savings or a benefit-cost ratio. A positive net savings or a benefit-cost ratio greater than 1 indicates that the intervention saves money.
- **Cost-utility analysis (CUA):** Consequences are expressed as the utility or quality of the health outcome. CUA results are generally expressed as cost per QALY gained, recognizing that all life years are not equivalent and taking into account morbidity and HRQL impacts.

The majority of the studies assessing cancer care interventions are based on CUA where the cost per QALY is presented. Due to the chronic nature of the disease process and the substantial impact on HRQL of the patients, cancer assessments are appropriately focused on years of life adjusted for quality. CUA is overall the most appropriate method for assessing cost-effectiveness of cancer interventions. CEA is sometimes performed instead of CUA because of a lack of information on HRQL impacts. Survival time or mortality rate can be used as the effectiveness measure to calculate the cost-effectiveness ratio. The Think Tank panel recommendation was to use mortality, since this is a more reliable statistic than survival time. CBAs are rarely performed due to the challenge of quantifying both costs and benefits in monetary terms.

Budget Impact Analysis

Critics of the cost-effectiveness approach argue that CEA studies neglect the budget impact of the services or interventions under study, and therefore do not provide adequate information for implementing the interventions.[88,89] The budget impact analysis involves the estimation of the cost of providing the selected intervention or health care service to the eligible population. For cancer screening services, the budget impact analysis will include the cost of screening tests, follow-up diagnostic tests, and treatments that will be required. The cost estimate can be projected for each budget period to facilitate decision making and allocation of resources.

5.2 Importance of Perspective in Economic Assessment

CEA can be undertaken from a number of different perspectives. The broadest and most comprehensive is the societal perspective, since it encompasses all costs and outcomes impacts. In the societal perspective all costs incurred, including indirect, direct and tangible costs, are included. Analyses performed from the payer perspective or the provider perspective considers a narrower range of costs and effectiveness measures. The findings can differ based on the perspective selected, and therefore is an important methodological decision. The consensus is that all assessments should incorporate the societal perspective. The Panel on Cost-Effectiveness in Health and Medicine, a non-federal panel of experts convened by the U.S. Public Health Service (PHS), also endorsed this approach.[90] If other perspectives need to be considered, these should be used in addition to the societal perspective.

TABLE 5 Comparison of CEA, CBA, and CUA

Approach	Cost Measure	Effectiveness Measure	Ratio
CEA	Dollar	Natural units (Life years gained)	Cost per unit life year gained
CBA	Dollar	Dollar	Cost per $1 of benefit
CUA	Dollar	QALY	Cost per QALY

SOURCE: Gold, et al., 1996.[23]

5.3 Calculating Incremental Cost-Effectiveness Ratio

The incremental cost-effectiveness ratio is required to evaluate the cost and benefits of the proposed intervention against the "gold standard". Cost-effectiveness comparisons are most useful when the comparator being considered is the standard care, since this allows the decision maker to consider whether an innovation is better than the status quo. If there is no intervention in place, the comparator can be "no intervention." When comparing two interventions—for instance, programs A and B where program A is more effective but also more costly—this ratio is simply the change in cost divided by the change in effectiveness of program A and B:

$$\frac{\text{Cost Intervention A} - \text{Cost Intervention B}}{\text{Effectiveness Intervention A} - \text{Effectiveness Intervention B}}$$

The resulting value is the cost to obtain each unit of increased effectiveness associated with program A. This incremental cost-effectiveness ratio for program A needs to be compared with the threshold for cost-effectiveness ratios to consider recommending its use. When effectiveness is measured in terms of QALYs, a commonly used threshold for the cost-effectiveness of medical therapies is $50,000 per QALY. A cost-effectiveness ratio above $50,000/QALY is usually considered not to be cost-effective while one below $50,000/QALY is generally accepted to be cost-effective. Rankings can also be made comparing cost-effectiveness ratios of the intervention under study to other health care services, using League tables.[91]

5.4 Characteristics of Potentially Cost-Effective Interventions

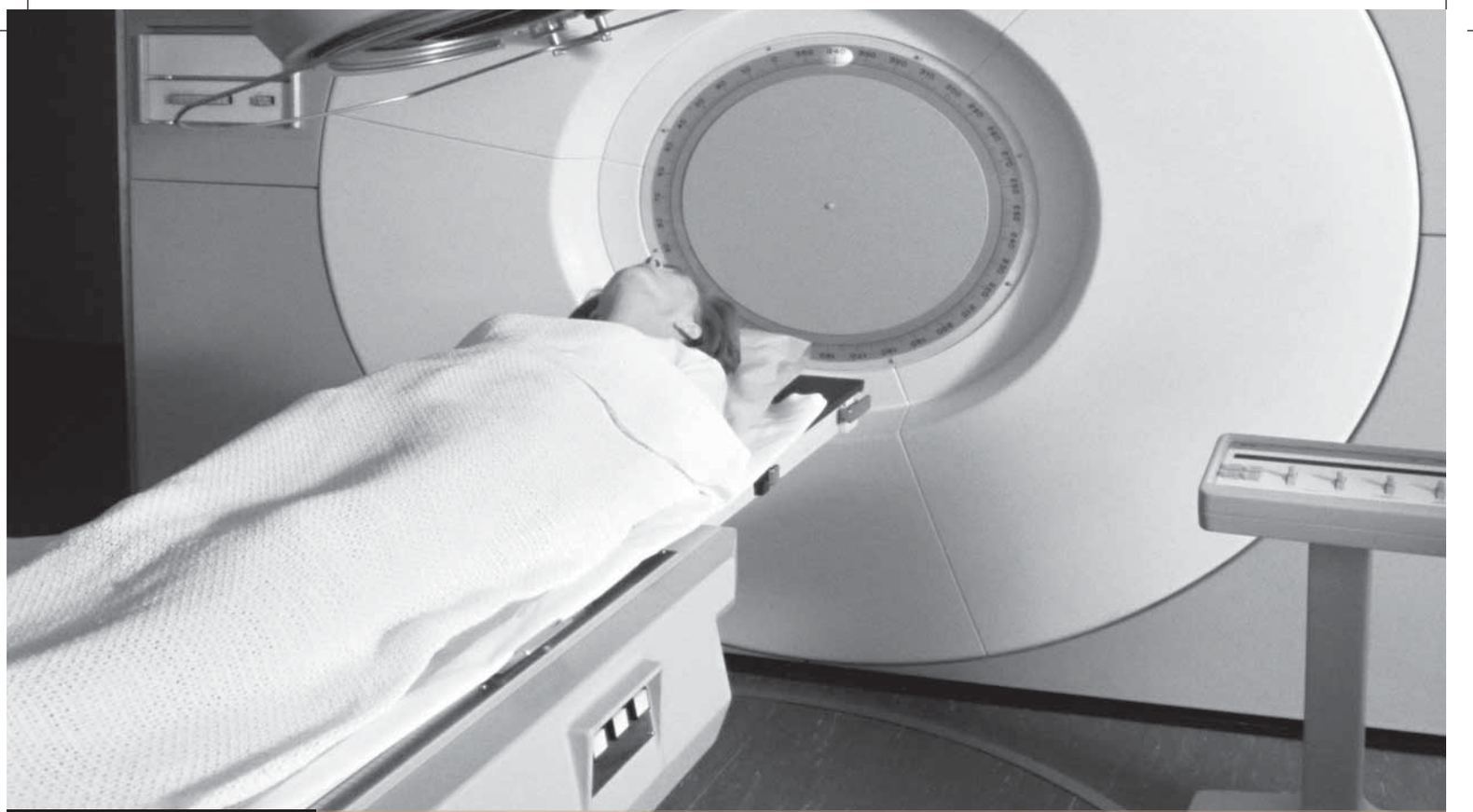
Not all interventions to reduce cancer health disparities will be cost-effective. Interventions that meet one or more of the following criteria are those most likely to be cost-effective:

- **High degree of disparity in targeted group.** When there is a substantial disparity that needs to be overcome in the intervention population there is a lower chance of diminishing returns (an increase in cost required to obtain the same level of effectiveness);
- **Highly effective intervention.** Such an intervention could be cost-effective even at a high cost; and,
- **Low cost of intervention.** A low-cost intervention would potentially be cost-effective even if it was not highly effective, since the cost per unit will be low.

The key driver overall is the disparity that exists in the underlying population—that is, the extent of the benefits to be realized. If there are significant benefits to be gained from an intervention then even an intervention that is costly can prove to be cost-effective. For example, if minority group X has a mortality rate of 30% while the norm is 5%, then even a costly program can be cost-effective because of the potentially large incremental effectiveness if the mortality for the minority population can be improved to the norm (30%-5%=25% reduction). On the other hand, a mortality rate of 8% for the minority group would only result in a small incremental benefit (8%–5%= 3% reduction) which may not justify the use of an expensive program. In this later case, the intervention will have to be highly effective and inexpensive to be cost-effective.

5.5 Provider Incentives and Barriers to Change

The cost-effectiveness of a given intervention needs to be considered in the context of the budget impact to the payer. Short-term cost impacts versus long-term benefits can hinder coverage for preventive and screening services, since many insurers only insure patients for a short period of time. Under this scenario, costs are immediate and measurable while the savings are long-term and hard to measure.[92] Therefore, payers may be unwilling to cover high-cost preventive services whose benefits may not be realized by the insurer. Insurers are often reluctant to pay for screening for diseases that are not likely to present until someone else covers the patient. As an illustration, HMOs may be reluctant to pay for colonoscopy screening for people aged 50 to 55 because these individuals are more likely to get colon cancer after age 65, when they will be covered by Medicare.



SECTION 6

Recommendations and Research Agenda

Although health care disparities in cancer have been clearly documented, there is still a need to further understand the complex, multifaceted nature of these disparities. The participants addressed the economic consequences of cancer health disparities and made numerous recommendations of cost-effective interventions for eliminating them. The recommendations are summarized below in two subsections—research and policy.

6.1 Research Recommendations

The Think Tank participants recommended seven specific areas where additional research is needed in order to direct future initiatives aimed at eliminating disparities.

1. **Focus on cancers with modifiable attributes** and fund prospective clinical trials to evaluate primary prevention strategies. There was consensus that resources and effort should be focused on those cancers that are highly preventable and curable: lung cancer through primary prevention activities aimed at smoking prevention and cessation; cervical and colon cancer through both primary prevention and secondary prevention (screening); and breast cancer through secondary prevention only. Colon, breast, and lung cancer are also among the cancers with the highest economic burden. Targeted interventions to promote primary and secondary prevention of these priority cancers may help ensure that limited resources are expended on the most beneficial activities. In addition, the interventions should be targeted at groups that have the highest need (e.g., high incidence of lung cancer, low screening rates for colon, breast, and cervical cancer), since these interventions are most likely to have a high impact in reducing cancer health disparities and prove to be cost-effective.

2. **Study processes to develop improved data sources.** Better data are required to analyze both outcomes and cost assessments. Databases that allow for comprehensive assessments of disparities in outcome and their cost impacts for younger (under 65 years) and older (over 65 years) patients are required. Specifically, there are limited data on individuals younger than 65 years and an urgent need to develop better data sources for this population. In addition, the scope and timeliness of data collection within cancer registries and other sources should be enhanced, with particular attention to indicators of socioeconomic status (e.g., education level and income). This would allow future analyses of disparities to sort out more decisively the association of racial/ethnic variables and SES on observed differentials in the receipt of cancer care, health outcomes, and costs. A number of efforts are currently underway to improve the quality of cancer data available including the NCI-Department of Veterans Affairs Cancer Care Outcomes Research and Surveillance Consortium (CanCORS), NCI's HMO Cancer Research Network, NCI's Prostate Cancer Outcomes Study (PCOS), and CDC's Pattern of Care (PoC) studies. A joint, national-level effort—involving the NCI, CDC, Agency for Healthcare Research and Quality (AHRQ) and other major cancer organizations such as the American Cancer Society, the American College of Surgeons' Commission on Cancer, and the American Society of Clinical Oncology—is necessary to build an enduring, ever-improving cancer data infrastructure.

3. **Develop better methods and tools to measure disparities.** Although studies have been performed to understand cancer health disparities, it is a complex field with overlapping sets of determinants (such as race, sex, education, etc.) and this poses significant challenges in developing an appropriate definition of disparity. Additional research is required to develop methods to assess the role of these overlapping determinants. Some promising initial work in this area has been sponsored by NCI.[2]

4. **Assess geographic variation and other factors that result in disparities.** Additional research, both qualitative and quantitative, should be conducted at the community and neighborhood levels to identify factors that lead to differences in cancer health disparities, and studies need to be initiated to analyze interventions that can reduce the disparities in a cost-effective manner. The availability of health care infrastructure to perform timely diagnosis and offer optimal cancer treatments at high-quality health care centers should be assessed. Currently available databases should be better utilized to assess these geographic variations and, in the future, the datasets to be developed under research recommendation #2, can be used to further enhance our understanding of these geographic factors.

5. **Include cost-effectiveness assessments in clinical trials** and other intervention studies that address disparities. The collection of economic data should be systematically included in clinical trials or any other type of studies when such data will contribute to answering meaningful research hypotheses that have policy relevance. There is currently a gap in our knowledge of whether resource use and costs vary

systematically across population groups. The collection of such information is critical to performing cost-effectiveness assessments that provide valid and reliable estimates. Efforts should be made to include SES so issues surrounding disparities can be studied.

6. **Identify changes in the health care delivery system that can reduce the economic burden of cancer health disparities.** Research is needed to identify which types of inequalities within the health care delivery system that, if corrected or eliminated, can have the most impact in reducing disparities. This research would assess which interventions—primary prevention, screening, treatment, or surveillance after curative treatment—may provide the most cost-effective approaches to eliminating cancer health disparities.

7. **Initiate studies to quantify uncompensated cancer care.** Reliable data and accurate methods to assess the economic costs of uncompensated care are lacking. Research should be undertaken to evaluate alternate methods and to develop data sources that can yield valid estimates. Capturing this information in a reliable manner would provide a more complete assessment of the burden of cancer and provide policy makers with information to guide funding decisions.

6.2 Policy Recommendations

Based on what is currently known about cancer disparities and their determinants, the Think Tank participants offered specific recommendations for developing policies at the federal, state, and community levels to eliminate cancer health disparities. We summarize these under five broad categories: improving and expanding insurance coverage; ensuring adequate payment for cancer care; reducing geographic disparities through community-level initiatives; eliminating health care network disconnects; and promoting primary prevention.

1. **Improve and expand current insurance coverage.** The uninsured are at higher risk for being diagnosed with cancers at late stages and are less likely to obtain optimal treatments. Expansion of coverage and improvement in the quality of coverage are required especially for those with cancer or suspicious findings suggesting cancer (such as the Breast and Cervical Cancer Prevention and Treatment Act of 2000). The specific recommendations related to expansion of insurance coverage are as follows:
   - Providing insurance coverage to the uninsured;
   - Studying the impact of out-of-pocket costs, especially for low-income individuals, on cancer related care;
   - Reforming public health programs to offer long-term coverage for low-income adults, including changing eligibility to be based on income rather than welfare categories. Medicaid enrollment tends to be sporadic and this discontinuity needs to be eliminated to improve access and timely diagnosis of cancers; and,
   - Modifing the Medicare waiting period for patients under 65 years with cancer to qualify for Medicare disability coverage while undergoing treatment (it is currently 12 months). CMS and NCI should initiate a demonstration project to assess approaches to decreasing the waiting period.

2. **Sponsor health policy research to assess the impact of cancer payments on quality of care.** The Think Tank participants discussed the importance of performing rigorous studies to understand whether current payment policies influence treatment patterns or the quality of cancer care received. In addition, studies are required to assess whether there are payment policy-related differences in process and outcome measures among population groups. Specific recommendations include:
   - Formulating collaborative study with NCI and CMS input to assess impact of payment policies on cancer health disparities; and
   - Sponsoring additional studies through grant funding (issue an RFA) to explore the impact of payment policies and cancer health disparities.

3. **Reduce geographic differences through community-level interventions.** There are substantial inequalities in both cancer incidence and mortality by geographic location. These disparities are best addressed through interventions at the community level as interventions can be tailored to match communities' needs. Examples of interventions include:
   - Creating community-based participatory education, training, and research among underserved populations. These networks can help improve access and provide the cancer services required to eliminate the disparities;
   - Using lessons learnt from research recommendation #4, foster community-based interventions in locations the target audience frequents—for instance, at schools, churches, and other community gathering places (supermarkets, barber shops, salons);
   - Encouraging health policy research and researchers at the community level;
   - Conducting research to assess the effectiveness of using cancer survivors in the community to serve as advisors/navigators so that individuals receive information on cancer care services from someone they trust; and,
   - Developing initiatives to ensure that providers receive high-quality training and that offer incentives to promote the availability of minority health care providers in the community. Ensuring that providers understand the culture and speak the languages prevalent in the community is essential for providing optimal cancer care services. The standard of care can also be improved by ensuring that providers maintain evidence-based quality standards.

4. **Eliminate health care network disconnects.** For minority populations and disadvantaged community groups, system barriers in the form of fragmentation of care can lead to sustained disparities in cancer care services. Interventions to improve the connection between various entities in the health care delivery process (primary care physicians, specialists, surgeons, etc.) and adoption of measures to ensure that individuals receive the services required will greatly reduce cancer disparities. Several interventions can be adopted to eliminate health care network disconnects:
   - Introduce patient "navigators" to the community. These navigators will assist patients with cancer and their families through the services, programs, and resources in the community. The goal of the navigator is to ensure that patients receive timely and appropriate care. The patient navigator can assist patients and their families by arranging financial support, securing transportation to health care providers and arranging child care, identifying and scheduling appointments with culturally-sensitive caregivers who can communicate with the patient, and coordinating care among providers. However, studies are needed to evaluate a number of issues related to the effectiveness, cost, and cost-effectiveness of navigation for specifically defined populations.
   - Foster formal arrangements between primary care or community health centers and high-quality hospitals. This will ensure that all cancer patients can be referred to appropriate health centers to receive services required. These can be achieved through targeted delivery system interventions:
     (a) Establishing PBRNs to encourage providers working together to do research in a community setting. These initiatives will lead to increased understanding of the potential health care disconnects and community-specific needs to improve the cancer care provided. Demonstration projects to test the impact of these networks on reducing cancer health disparities should be conducted. Such a demonstration could, for instance, be conducted through the Primary Care (PBRNs) and Integrated Delivery System Research Networks (IDSRNs) funded by AHRQ. Assessments of these networks offer the opportunity to collect and analyze the impact of indirect costs to patients.
     (b) Creating linkages between community cancer centers and high-quality medical centers to ensure that residents receive good follow-up care. Often, cancer patients from disadvantaged communities do not have access to quality cancer care. Establishing relationships with accredited cancer care centers may ensure the availability of high-quality services and may help recruit minorities to participate in clinical trials.

5. **Promote primary prevention.** Promote primary prevention for cancer sites where evidence exists supporting primary preventions. Primary prevention activities targeted at smoking, diet, exercise, hepatitis vaccine, and HPV vaccine can be highly effective in reducing overall cancer health disparities. To be successful, these interventions must:
   - Target communities where disparities exist;
   - Focus on cost-effective interventions such as smoking prevention and cessation; and
   - Impact both demand and supply level factors whenever possible. For example, foster a reduction in youth smoking with stronger school-based education programs (demand-side) and stricter enforcement of laws banning sales to minors (supply side).

A number of specific next steps were identified for NCI to implement based on the list of research areas and recommendations. First, convene a panel of experts to identify a detailed process to improve both the epidemiological and cost data available to study and assess measures to reduce cancer health disparities. Second, sponsor studies to develop better methods to measure cancer health disparities and evaluate costs associated with cancer health disparities. Third, include cost-effectiveness assessments in any clinical trials or interventions sponsored by NCI to reduce cancer health disparities. Fourth, coordinate activities with other federal agencies to implement initiatives to reduce cancer health disparities.

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Glossary

Cost: resources spent to purchase services or other resources including direct, indirect, and intangible components.

Cost analysis: economic evaluation that focuses on the costs of the intervention and does not consider health outcomes.

Cost-benefit analysis (CBA): economic analysis in which both the inputs to produce the intervention (or costs) and its consequences or benefits are expressed in monetary terms of net savings or a benefit-cost ratio.

Cost-effectiveness analysis (CEA): economic analysis in which the consequences or effects of the intervention are expressed in natural units such as years of life saved, lives saved, cases screened, or cases successfully treated.

Cost-minimization analysis (CMA): When two alternatives have been shown to have equivalent clinical effectiveness, only their costs need to be compared to identify the most economically desirable alternative.

Cost-of-illness study (COI): analysis that computes the total costs incurred by society as a consequence of a specified health care problem, typically including both the direct and the indirect costs—such as medical costs and lost productivity—associated with an illness. There is no comparison of treatment alternatives.

Cost-to-charge ratio: method of estimating cost based on charges and assumed distribution of costs per unit charge.

Cost-utility analysis (CUA): economic analysis in which the consequences are expressed as the utility or quality of the health outcome. CUA results are generally expressed as cost per quality-adjusted life year (QALY) gained, recognizing that all life years are not equivalent and taking into account pain, discomfort, and other factors.

Contingent valuation (CV): method involves directly asking people, in a survey, how much they would be willing to pay for specific services. It is called "contingent" valuation, because people are asked to state their willingness to pay, contingent on a specific hypothetical scenario and description of the service.

Direct costs: medical and nonmedical costs associated with the provision of medical services for the prevention, diagnosis, treatment, followup, rehabilitation, and palliation of illness.

Discount: adjustment in benefit or cost in the future relative to benefit and cost in the present.

Effectiveness: measurement of treatment effect in the population in the "real world" setting. That is, based on patient care received outside of a clinical trial.

Efficacy: measurement of treatment effect based on findings from a controlled setting such as within the context of a randomized clinical trial.

Final Outcomes: health outcomes that are measures in terms of mortality, morbidity, and health-related quality of life.

Incidence-based model: quantifies the total lifetime costs of new cases of an illness with onset in the base year.

Incremental cost-effectiveness: difference in cost to achieve an additional amount of benefit with a treatment strategy usually expressed in dollars per year of life gained.

Incremental cost-utility: difference in cost to achieve an additional amount of quality-adjusted benefit with a treatment strategy usually expressed in dollars per QALY gained.

Indirect costs: cost associated with the morbidity or mortality of illness beyond the direct provision of care.

Indirect institutional costs: costs associated with the operation of the institution not directly associated with patient care and for which a charge is not generated.

Intangible costs: poorly defined costs associated with illness including pain and suffering and loss of companionship.

Intermediate outcomes: interim measures of assessment of benefit of an intervention (e.g., late stage diagnosis, lower rate of treatment success).

Life expectancy: average number of years of life remaining at a given age.

Prevalence-based model: quantifies economic costs by measuring all costs due to illness occurring within a given time period, usually a single year, regardless of the time of disease onset.

Quality of life (QOL): social, physical, emotional, psychological, and general well-being of individuals, typically measured using standardized questionnaires or interviews, such as the SF-36, SF12 or EuroQOL (EQ-5D). When assessed in the context of health and medicine, QOL is termed health-related quality of life (HRQL).

Sensitivity analysis: process of assessing the change in expected value or threshold values based on variation of the probabilities or outcome values assumed in a decision model over a range of possible values.

Threshold: value of a variable evaluated in a sensitivity analysis where the expected values of the decision choices are exactly equal.

Utility: measured patient preference for a given health outcome state.

Willingness-to-pay analysis: measures the amount an individual is willing to pay to acquire some good or service. This approach is used in performing CBA.

Appendix A Final Participant List

Economic Costs of Cancer Health Disparities Think Tank - Center to Reduce Cancer Health Disparities

National Cancer Institute • December 6-7, 2004

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Appendix B Economic Costs—Discussion Questions

Economic Costs of Cancer Health Disparities
Preliminary Grouping of Questions for the Think Tank

A. What is the total cost of cancer care?

- What should the total cost of cancer care include? (e.g., see flowchart, fig. C-3, p. 62)
- What economic models are applicable?
- Cancer care is 5-7% of all health care expenditures. We project cancer to eclipse heart disease as the leading cause of death within a few years. What is the general impact of the disconnection between funding and burden of cancer on the society? What is the impact on sub-populations?
- Costs attributable to cancer are numerous (e.g., costs related to comorbidity). How can that information be captured and used?
- Are necessary data available to make economic impact evaluations? If not, how can additional data be collected?

B. What percent of the total cost of cancer care is related to health disparities?

(Note: This might be estimated based on specific types of cancer or be reported as a % of GDP)

- What are the economic costs of finding cancers later versus finding them earlier (all cancers and/or specific cancers)?
- What additional information exists to inform these issues?
- How do uncompensated costs, patient out-of-pocket costs, and charitable care relate to disparities?
- Are necessary data available to make economic evaluations? If not, how can additional data be collected?
- How many people are included in the "health disparities population(s)"?Specifically, how many people are included in the "cancer health disparities" population(s)?
- What proportion of the "cancer health disparities population(s)" is uninsured? What percentage of them has cancer?

C. What would be the cost of eliminating cancer health disparities?

- Is equal access to quality, standard cancer care cost-prohibitive or cost-effective for health care systems (both government and private)?
- Is it economically feasible to treat every American with a cancer-related abnormality?
- What additional information exists to inform these issues?
- What economic models are applicable?
- What are the estimates of costs to reduce delays in definitive diagnosis and followup after abnormal findings for all Americans?
- How can we capture the costs that would occur if the uninsured received early detection and treatment?
- For both the individual and society, discuss cost>savings, cost = savings, and cost < savings. Sample costs for individuals include costs associated with morbidity and disability. Sample societal costs are lost productivity and missed opportunity for reduced economic burden of cancer.
- How best to deal with the moral hazard concept?
- From the perspective of total health care expenditures, early detection can be seen as increasing costs because screening programs are expensive and life expectancy is increased resulting in greater non-cancer-related health care costs over time. On the flip side, advanced screening leads to detection of many cases at stage zero, which can greatly reduce costs of cancer care. Also, there is some over-diagnosis leading to unnecessary treatment.
- How much can savings in making screening more efficient offset the costs of wider screening?
- Much of the differential in colorectal treatment outcomes is associated with surgical technique. How can structural and cultural factors be overcome to increase access?

- Are metrics to evaluate cost-effectiveness of health benefits (e.g., life years saved per dollar spent) too difficult and controversial to deal with?
- What is an appropriate cost-effectiveness threshold for estimating cancer diagnostic and treatment options? Should the threshold(s) be set by type and stage of cancer?
- Is quality-adjusted life years (QALY) an appropriate and reliable parameter in assessing cost-benefits of cancer treatment and diagnostic options?

D. What is the value to America to reduce cancer health disparities?

- What are the benefits of reducing morbidity and mortality from cancer in the United States?
- Are there economic advantages for primary care centers/hospitals, communities, and our country in creating easy access to cancer care?
- What are the economic benefits of eliminating health disparities in the United States?
- Is QALY an appropriate and reliable parameter in assessing cost-benefits of cancer treatment and diagnostic options?
- The purpose of the health care system is not to save money but improve health. Should we examine the value gained in reducing cancer health disparities?
- Are cost-benefits of prevention higher in low socioeconomic status (SES) groups than high SES groups?

E. What are the policy implications? What is the cost to change policies?

- What health care system changes could reduce the costs of cancer care?
- Can we develop cancer care models to reduce delays in and costs of care while still providing quality, standard cancer care on a timely basis?
- What research is needed to change policies?
- Predictions of cost savings associated with improved cancer control are based on longer-term societal costs, but the short-term budget savings may not occur. How can this problem be dealt with so pragmatic changes in policy are made?
- How can we make cancer interventions more accessible for all?
- What cross-incentives between parts of the health care system are needed to ensure that stakeholders "do the right thing?"
- Some stakeholders are reluctant to pay for screening for diseases that are not likely to present until the patient is covered by someone else (e.g., Medicare). What incentives exist to counter this disincentive?

Economic Costs of Cancer Health Disparities: Background Paper for Think Tank

The Center to Reduce Cancer Health Disparities
Harold P. Freeman, M.D., Director
December 6-7, 2004

National Cancer Institute
National Institutes of Health
Department of Health and Human Services

List of Appendix Figures

Economic Costs of Cancer Health Disparities

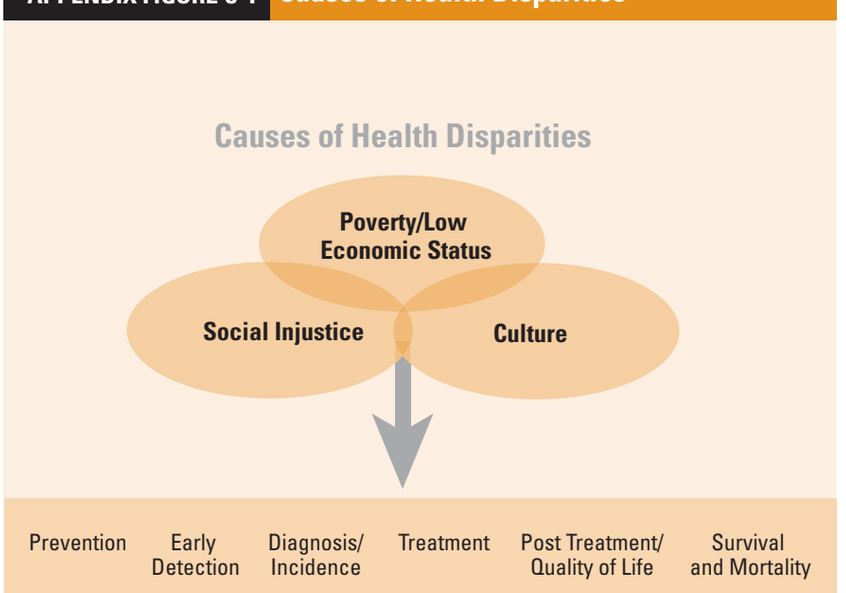
Because of the critical importance of eliminating or at least reducing cancer health disparities, there is a need to better understand the economic and human costs of such disparities to the nation. To address this critical need, the Center to Reduce Cancer Health Disparities (CRCHD) of the National Cancer Institute (NCI) is convening a Think Tank meeting December 6–7, 2004, to bring together health economists, cancer care providers, federal and private insurers, and policy experts to explore the economic costs to the nation of cancer health disparities and their implications for cancer control. The purpose of this document is to provide general background information, stimulate new and creative thinking about the economic costs of cancer health disparities, and share ideas about eliminating or reducing such disparities. This paper is not intended to define all the issues or restrict innovative thinking. In considering the subject of economic costs of cancer health disparities, Think Tank participants are encouraged to "think outside the box."

Overview

A critical disconnect exists between cancer research *discovery and development* and *delivery* of care to cancer patients. This disconnect between the phase when new knowledge is discovered and new interventions developed (i.e., what we know) and cancer care delivery, where the benefits of new discoveries should be delivered to the public (i.e., what we do), is a key factor leading to an unequal and unjust burden of cancer in our society. Receipt of cancer care is often delayed for some racial and ethnic minorities, people with low socioeconomic status (SES), those who live in rural and inner-city areas, and other medically underserved groups. Closing the gap between cancer research discovery/development and care delivery will help reduce cancer health disparities in America.

Although few individuals in America who are diagnosed with cancer go untreated, delays in receiving screening, diagnosis, and treatment for cancer are experienced to a greater degree by underserved communities, including some racial and ethnic minorities, the poor, those lacking health insurance coverage, and rural and inner-city communities.[1] These delays, in addition to cultural barriers, poverty, social injustice, and decreased access to all phases of cancer care compound disparities in care and result in higher cancer morbidity and mortality in those populations. A complex set of social, economic, cultural,

APPENDIX FIGURE C-1 Causes of Health Disparities



and health system factors are believed to drive delays in cancer care (***Appendix Figure C-1***). This is highlighted by a recent study on the racial and socioeconomic determinants of cancer health disparities[2], where 5-year survival for all cancers combined was 10% lower among persons living in poor areas compared to more affluent U.S. Census tracts.

The National Cancer Institute (NCI) has a legislative mandate to reduce the burden of cancer. In 2001, NCI issued a nationwide challenge "to eliminate the suffering and death due to cancer by 2015"[3]. Some racial and ethnic minorities and medically underserved populations bear a major portion of that suffering and death. The scientific community has a critical and unique role in addressing the moral and ethical dilemmas posed by the unequal burden of cancer in our society. We know that complex interactions among genetic susceptibilities and the risk imparted by individual and group behaviors, age, and social and environmental circumstances determine health throughout an individual's lifespan, including who becomes ill, who survives disease, and who maintains good quality of life after diagnosis and treatment. However, the economic costs associated with these documented cancer health disparities have not been fully explored. In the United States, approximately 5% (7%, including screening) of total medical expenditures are due to cancer; while over 20% of all deaths are due to cancer.[4]

As Americans age and the absolute number of people treated for cancer increases, lack of access to timely and appropriate quality care is a growing problem. Barriers to cancer care lead to a cascade of problems that result in increased cancer care costs for the nation. For example, cancers diagnosed at Stage II or III are the most expensive to treat.[5] Cancer cases that are the least expensive to treat are diagnosed at either very early (in situ or Stage I) or very late (Stage IV) stages. Addressing the gap between discovery and delivery may reduce the costs of cancer care.

The Think Tank is being asked to look at the many components of economic costs and how scarce resources of money and time could be allocated to maximize health and well-being. Potential outcomes of the Think Tank include: identification of current evidence about the costs of cancer health disparities; assessment of currently available cost data and data needs; an estimate of the costs of providing cancer care (including preventive services, followup of abnormalities, and treatment) for all Americans who are currently unable to fully access standard cancer care; cost-effective strategies for improving timely access to care across the cancer continuum; and the economic benefits of eliminating disparities and improving timely access to cancer care. Based on findings from the Think Tank, recommendations for future research programs and policies will be made to the NCI/NIH and other federal agencies. Products from the Think Tank may include an Executive Summary of the Think Tank meetings, a detailed report on Think Tank findings and recommendations, scientific publications, and plans for future actions.
For discussion purposes, the remainder of this paper is divided into sections addressing the questions listed below. Members of the Think Tank are asked to have a dialogue that will include, but not be limited to, these topics.

1. What is the total cost of cancer care?
2. What percent of the total cost of cancer care is related to disparities?
3. What would be the cost of eliminating cancer health disparities?
4. What is the value to America of reducing cancer health disparities?
5. What are the policy implications of reducing cancer health disparities?
6. What is the cost to change policies to reduce cancer health disparities?

1. What is the total cost of cancer care?

Currently, health care costs are estimated to be 15% of the gross domestic product (GDP). Total spending for cancer care has continually increased over the last 30 years; however, the proportion of cancer spending to all health care expenditures has remained stable (i.e., 4.4% to 6% of total health expenditures).[4] Direct costs of cancer treatment accounted for about $41 billion in 1995, the most recent year

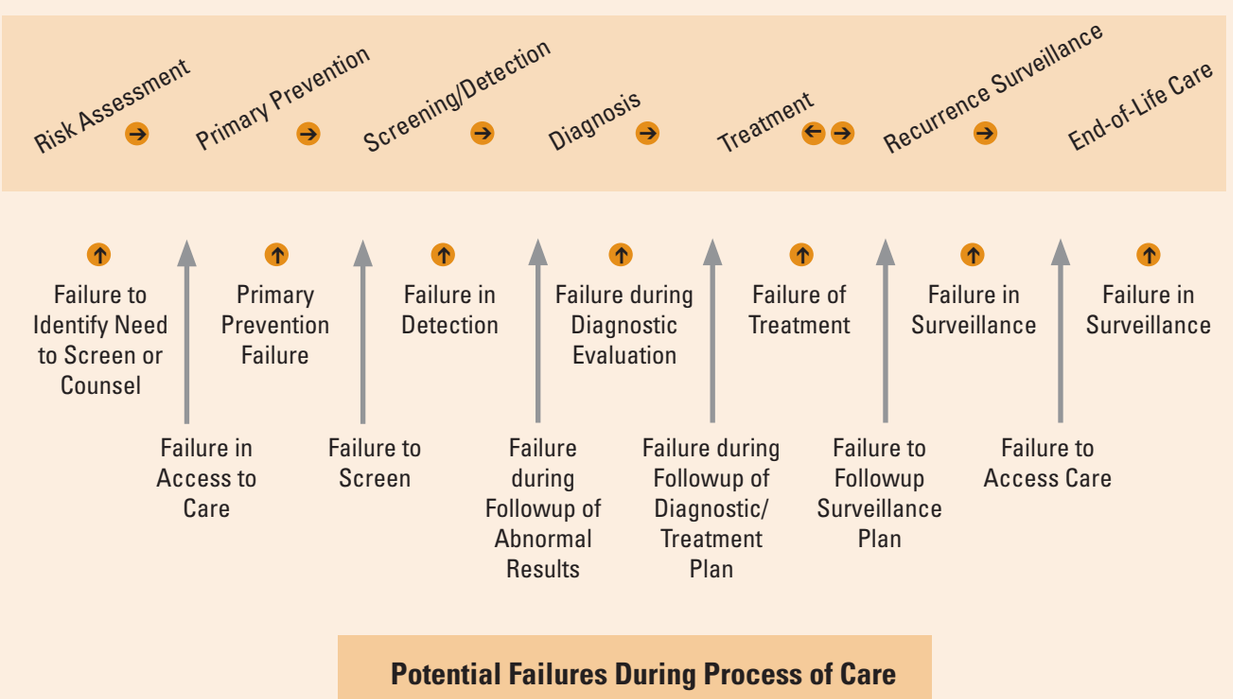
for which there is information.[6] This is just under 5% of total U.S. spending for medical treatment. The overall costs of treating cancer more than doubled between 1985 and 1995. These estimates of cost do not include out-of-pocket expenditures or prevention and screening costs. For example, Medicare does not cover certain cancer care expenses, such as common orally administered cancer medicines. Out-of-pocket costs add up to 10% to the estimates of the total cost of cancer treatment. Indirect costs, which include losses in time and economic productivity resulting from cancer-related illness and death, are not included in the above estimates. The total economic burden of cancer in 1996, including direct and indirect costs, was estimated to be $143.5 billion.[6]

The cost of cancer treatment varies by the type of cancer. Using data from the linked databases of Surveillance, Epidemiology, and End Results (SEER) and Medicare, expenditures for 1995 through 1998 were examined for the 13 most common cancers.[5] Treatment costs for the four most common cancers (i.e., breast, colorectal, lung, and prostate) were similar and ranged from 11% to 13% of total cancer expenditures. This represented $4.6 to $5.4 billion per year. However, the average cost of treatment for an individual with one of these 13 cancers varied widely, with individual average Medicare payments in the first year following diagnosis ranging from $3,117 for melanoma to $32,340 for ovarian cancer.[6]

Cost also varies by the point in the continuum of cancer care at which expenditures are measured (***Appendix Figure C-2***). For example, first-year costs of treatment are higher for lung and colorectal cancers because screening is not commonly used in their detection.[5] If screening for colorectal cancer were performed as recommended, extensive and costly treatment of advanced-stage disease could be reduced.

To fully answer any questions about the economic costs of cancer, it is important to identify types, sources, and measures of cost. Unanswered questions about measurement of cancer costs include: how do we

APPENDIX FIGURE C-2 **The Cancer Care Continuum[19]**



measure the economic costs of finding cancers later versus finding them earlier? Are different methods used to look at the cost for all cancers compared to the cost for specific cancers? What is the appropriate cost-effectiveness threshold for estimating cancer diagnostic and treatment options? Should this threshold be set by type and stage of cancer? Are QALYs appropriate and reliable parameters for assessing costs-benefits of cancer treatment and diagnostic options?

2. What percent of the total cost of cancer care is related to disparities?

One of the basic questions that must be answered in order to measure the cost of disparities is: how does one define *cancer health disparities?* The NCI Center to Reduce Cancer Health Disparities uses the following definition:

> "Disparities are determined and measured by three health statistics, incidence (the number of new cancers), mortality (the number of cancer deaths), and survival rates (length of survival following diagnosis of cancer). Health disparities occur when one group of people has a higher incidence or mortality rate than another, or when survival rates are less for one group than another. Disparities, or inequalities, occur when members of certain population groups do not enjoy the same health status as other groups. Disparities are most often identified along racial and ethnic lines, showing that African Americans, Hispanics, Native Americans, Asian Americans, Alaska Natives, and whites have different disease rates and survival rates. But disparities also extend beyond race and ethnicity. For example, cancer health disparities can involve biological, environmental, and behavioral factors, as well as differences noted on the basis of income and education."[7]

Cancer health disparities are often compounded by overlapping barriers to care. Underserved groups include some racial and ethnic minorities, people with low SES, those living in rural or inner-city areas, the underinsured and uninsured, and those with low health literacy. For example, in the United States, Hispanics have the largest percentage of uninsured persons, followed by blacks and then, non-Hispanic whites. Many low-income cancer patients not only live in rural or remote areas, but also are poor. Undocumented workers and their families rarely have insurance and often have low incomes. This can increase the complexity of measuring specific disparities and planning interventions. These overlapping categories also raise the issue of how many people are included in the health disparities population(s).

Current published research has not estimated the percentage of cancer care costs that are due to health disparities. However, several studies have found an association between late-stage cancer diagnosis and lack of insurance, low SES, and cultural barriers.[8, 9] When cancers are diagnosed at Stage II or III, the cost of treatment is more expensive than for cases diagnosed at either very early (in situ or Stage I) or very late stages (Stage IV).[5] In addition, uncompensated care, which includes charitable care, "safety net" services, and other types of uncompensated care provided by physicians, clinics, hospitals, and other providers, is often associated with cancers detected at late stages through emergency room visits by the poor. Reliable data on the economic cost of this uncompensated care are lacking.[10]

One method used to obtain more detailed cost data on health disparities is to link databases such as cancer registries (e.g., the SEER cancer registry) and administrative databases (e.g., Medicare). The SEER-Medicare linked database is the major source for estimating cancer site-specific costs. Costs can be tracked longitudinally so they can be determined for different phases of cancer treatment.[5] As an example, using the SEER-Medicare linked database, researchers reported that both total and cancer-related direct costs for treating black women were significantly higher than for treating white women ($320 higher mean monthly cost), even after controlling for stage and treatment in all phases of care.[11] The higher costs among black women may reflect differences in care after a cancer diagnosis and/or unmeasured preexisting health problems.

Changes in insurance status also give an indication of the effects of disparities on receipt of cancer services. An example is a study that examined the impact of Medicare coverage on the use of basic clinical services for previously uninsured adults.[12] The study reported that the difference between continuously insured and continuously uninsured adults was significantly reduced after they achieved Medicare eligibility. For specific cancer screening services, differences between the insured and uninsured in mammography use after Medicare eligibility decreased 15.3%. For prostate examinations in men, there was a 35.2% decrease in the difference between groups.

In order to examine economic cost issues, the following questions arise: what is the magnitude of cancer health disparities? How are cancer health disparities measured? Other persistent questions deal with the adequacy of existing cost data sources to address cancer health disparities. Do existing databases adequately cover individuals who lack access to services (e.g., uninsured, homeless, working poor) and/or use the health care system only intermittently? Are necessary data available to make economic evaluations? If not, what is missing and how can additional data be collected? What proportion of the underserved population is uninsured? Even if accurate and adequate cost data exist, do current economic metrics allow accurate measurement of the economic cost of disparities? Are the metrics to evaluate cost-effectiveness of health benefits (e.g., life-years saved per dollar spent) too complex and controversial to be useful in addressing the cost of cancer disparities? Are costs-benefits of prevention higher in groups with low SES compared to those with high SES?

3. What would be the cost of eliminating cancer health disparities?

Although we do not have an answer to this question, some researchers are using cost scenarios and cost modeling to evaluate the cost of cancer care. Key variables and assumptions made in estimating costs and benefits of an intervention are tested using sensitivity analysis.* An example of cost modeling is a recent study that examined whether the cost of increasing rates of breast cancer screening or the application of intensive breast cancer treatment would be offset by survival benefits for African American women.[14] Using stochastic modeling, the researchers reported that the incremental cost† effectiveness of increased screening ranged from $50,000 to $120,000 per life-year saved (LYS). If all patients received the most intensive treatment recommended, costs would increase but deaths decrease. Small investments of up to $6,000 per breast cancer patient could be used to enhance treatment and still yield cost-effectiveness ratios of less than $75,000 per LYS. However, the assumptions and operational definitions of variables in these models must be stated clearly. Uninsured cancer patients may receive charity care, pay for all received care, or forgo care. This is consistent with the association of lack of health care insurance with late-stage cancer diagnosis.[8] However, having health care insurance does not ensure access to cancer prevention and treatment services. Some insurance policies have only major medical coverage and do not cover many of the costs of cancer prevention and treatment. For those over age 65 without supplemental health insurance, Medicare is not a panacea for cancer costs. Until recently, Medicare did not cover prescription medications. This was particularly hard on the elderly poor. The economic impact of the new Medicare prescription law is still unknown.

The cost of health disparities is more than a matter of insurance coverage. Insurance coverage is necessary but is not sufficient to prevent economic disparities. Other barriers to cancer care that result in delivery of less than optimal care include structural access and cultural issues. Creative strategies that improve access to cancer care services, decrease delays in cancer treatment, and provide care for those lacking adequate insurance coverage need to be explored. Along with medical interventions, these strategies might include patient navigation and primary prevention, such as smoking cessation and obesity prevention programs for targeted populations.

When choosing a methodology to measure economic cost, does one want to know the value gained from interventions versus the cost-effectiveness or cost-benefit? Often the emphasis of economic analysis is on value gained (i.e., improvement in health), while common cost metrics focus on the monetary value of

human life. Although typical cost-benefit analyses look at reductions in mortality, these measures do not usually look at reduced morbidity. Eliminating or reducing cancer disparities may not be cost-saving or cost-neutral; however, it may be cost-effective relative to the social value of health.

For example, the costs of screening are large compared with the savings they achieve. Savings associated with early detection apply only to cancer-related costs. From the perspective of total health care expenditures, early detection can be seen as increasing costs, because screening programs are expensive and life expectancy is increased, resulting in greater noncancer-related health care costs over time. Insurers are often reluctant to pay for screening for diseases that are not likely to present until someone else covers the patient. As an illustration, HMOs may be reluctant to pay for screening colonoscopy for people aged 50 to 55 because these individuals are more likely to get colon cancer after age 65, when they will be covered by Medicare. This is compounded by the fact that advanced screening leads to detection of many cases at Stage 0, which can greatly reduce costs of cancer care. However, with some cancers, there is an unknown amount of over diagnosis (e.g., prostate cancer), leading to unnecessary treatment and associated increased costs. What cross-incentives between different parts of the health care system are needed to ensure that stakeholders "do the right thing," (i.e., choose cost-effective and cost-beneficial options)? Are there economic advantages for primary care centers, hospitals, communities, and the nation in creating easy access to cancer care?

Gaps in our knowledge about the cost of eliminating cancer health disparities could be addressed through studies that ask the following research questions: is equal access to quality, standard cancer care cost-prohibitive or cost-effective for health care systems? Is it economically feasible to treat every American with a cancer-related abnormality? How do we demonstrate the benefits of reducing morbidity and mortality from cancer in the United States? What are the estimates of costs to reduce delays in definitive diagnosis and followup after abnormal findings? If we make cancer screening of the underserved more efficient, will the savings offset the costs of wider screening?

4. What is the value to America of reducing cancer health disparities?

The purpose of the health care system is to improve health. However, differing perspectives about the value of reducing disparities exist in the United States. Personal and social values, preferences, personal wealth, and social wealth influence opinions about the social value of interventions and policies that reduce disparities. In the early 1990s, the Panel on Cost-Effectiveness in Health and Medicine, convened by the Office of the Surgeon General, tried to address this issue.[13] The committee could not reach definitive conclusions on measures of value.

As the value of reducing cancer disparities is examined, another issue to consider is the "moral hazard" concept under which insured individuals demand treatment for which costs exceed benefits. This might be interpreted as suggesting that it is cost-effective to allow large numbers of people to remain uninsured. It has been suggested that cost savings would be achieved if people did not stop smoking, because more people would die early. In addressing the issue of value and health costs, one can either avoid these types of issues, because they represent a political and moral "slippery slope," or try to clarify issues and the value of care through open discussion. This raises several questions, such as: what is the best way to deal with the "moral hazard" concept? What is the economic value of having a healthy population? How does one identify and measure costs that reflect the values to society of reducing/eliminating cancer health disparities?

* Sensitivity analyses identify key variables and assumptions that may alter conclusions from an economic analysis. The analysis is then reworked using a range of results for each factor that influences the outcome.[13]

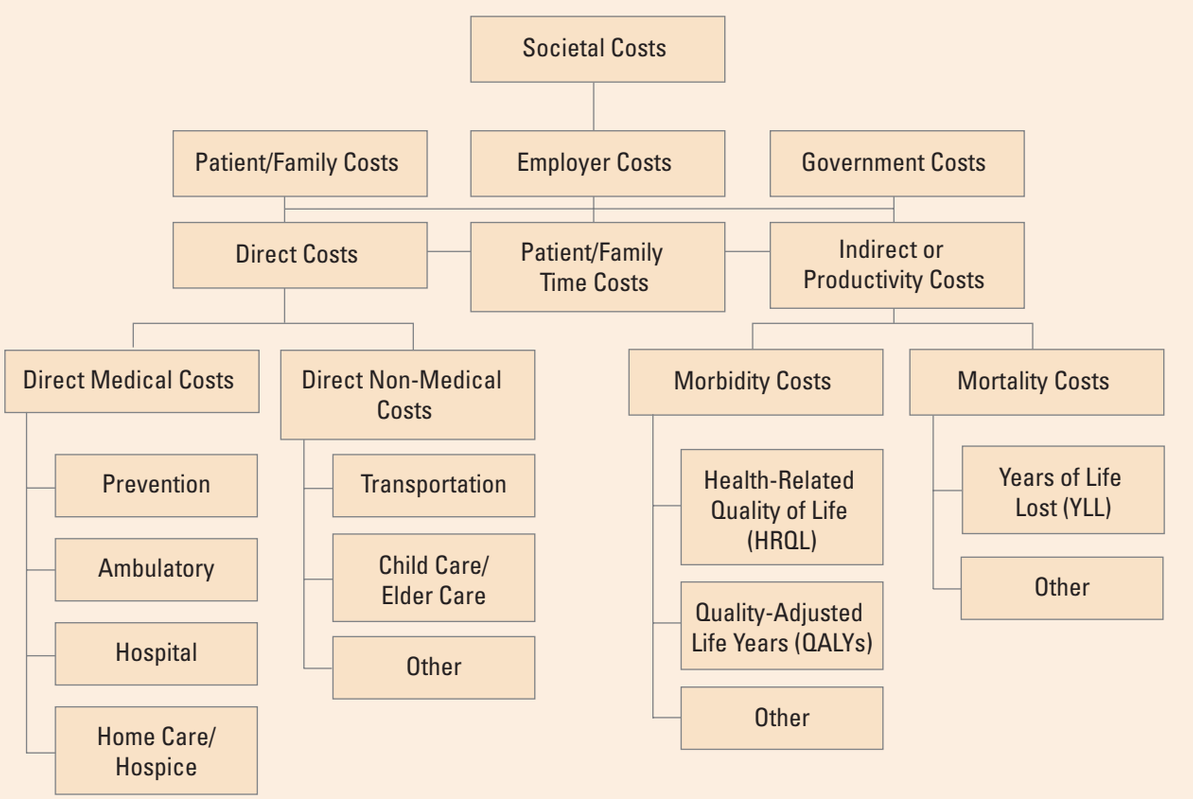
† Incremental cost is the cost of one alternative less the cost of another.[13]

5. What are the policy implications of reducing cancer health disparities?

The U.S. Department of Health and Human Services (DHHS) has as a national goal the elimination of health disparities (including cancer health disparities) by year 2010. This will require revisions to existing health policies and enactment of new ones. There have been debates about various recent health policy proposals, especially in this Presidential election year. But, policy changes could require adjustments at all levels of government.

The growing population of people diagnosed with cancer raises important questions related to cost decisions, quality of care, long-term followup, health after cancer treatment, and health-related quality of life (HRQL) for vulnerable populations. Therefore, when examining policies aimed at reducing cancer health disparities, policy makers from government (local, state, and federal) and the private health industry need to be involved. When making decisions about allocation of medical resources, what policy changes could reduce the costs of cancer care while improving health? How does one include the indirect costs of morbidity and mortality (which are reduced with early diagnosis) as well as the direct costs? Improved diagnosis presents a conundrum in that with earlier detection, survival is greater, but lifetime health costs may be higher. Is it possible to develop cancer care models to reduce delays in and costs of care while still providing timely, quality, standard cancer care? Predictions of cost savings associated with improved cancer control are based on longer-term societal costs. Short-term savings may not occur. Policy changes not related to direct medical health care costs, such as environmental factors, education, and patient navigation, could be instrumental in reducing cancer morbidity and mortality. Other policy issues to consider

APPENDIX FIGURE C-3 Types of Health Care Costs



NOVA Research, 2004

include increasing racial/ethnic minority providers, training lay health workers, and advances in technology such as telemedicine and electronic patient records.

6. What is the cost to change policies to reduce cancer health disparities?

Changing policies to reduce disparities involves costs and benefits. For example, the benefits of changing a policy such as insurance coverage include an expected reduction in mortality of 5% to 15% as well as a decrease in other costs associated with lost productivity.[16] Having health insurance may increase a person's medical care use.[15] Providing coverage for uninsured Americans is estimated to increase per person spending on health care from about $1,600 to $2,836 per year, thus increasing total annual spending on health care by $48 billion.[16] This represents an increase of 0.4% in the share of GDP going to health care. However, health insurance coverage alone does not solve all cancer health disparities. How would the costs of expanding health coverage compare to the benefits? Can cancer models be developed to reduce delays in and costs of care while still providing quality, standard cancer care on a timely basis? How can cancer interventions be made more accessible to all Americans without bankrupting the economy? How do we identify and measure cost offsets that would be realized by improving the health of America's most vulnerable populations?

Summary

A gap exists between the discovery/development of new knowledge and the delivery of cancer care services. This is evidenced by decreased access, cultural barriers, and delays in the receipt of timely cancer care, which can lead to complications, make recovery difficult, and increase cancer care costs. Some racial and ethnic minorities, people with low SES, those who live in rural and inner-city areas, and other underserved people have suffered disproportionately from barriers to cancer care. Some declines in health are preventable.[17, 18]

The concepts of economics can enrich the understanding of cancer health disparities and help close the gap between development and delivery of cancer care through policy changes and reallocation of resources. Compared to biological and psycho-social factors, economic factors change quickly. Because economic costs are changeable, they offer strong opportunities for policy interventions to change factors affecting cancer health disparities. It is crucial that the evidence base on the cost of disparities be strengthened so that strategies to allocate health resources keep pace with the burden of cancer disease in underserved populations.

The challenge to participants in this Think Tank is to think beyond what is currently known about the economic costs of cancer health disparities. This includes considering new and creative ways of examining and estimating economic costs. Thinking outside-the-box about economic costs is encouraged and can lead to new strategies for addressing disparities. The findings of this Think Tank will help inform NCI and policy makers about the cost of cancer health disparities and suggest approaches to reduce and eventually eliminate cancer health disparities.

Types of Health Care Costs

The term *cost* has many nuances and varies among different disciplines. Whenever this term is used, it is important to define what is meant. Economic costs represent the value of productive resources used in a particular economic activity, including the economic value of a complex mix of human resources.[5] These costs reflect the opportunity costs of resources used to provide an intervention compared with using the same resources for another purpose. Economic costs include direct dollar outlays for cancer care and related resources plus the value of other resources used, such as patients' and unpaid caregivers' time. Care should be taken to differentiate economic costs from charges for cancer care services.[20] *Economic costs* are inclusive of all resources needed and used to produce a service and represent the value of forgone opportunities to use these resources for a different service. The *charge* for a medical good or service is the supplier's list price. The charge or list price of health care services generally does not represent the

full economic cost of those services. Government payers and large third-party payers may negotiate discounted prices for services rendered. These types of activities influence charges or list prices. Another reason for the difference between economic costs and charges is that some services are profitable and some are not. This often leads to redistribution of charges from less lucrative services to more lucrative services in order to make a profit or break even. Finally, economic costs may be redistributed or shifted from one payment source to another. To fully capture the value of resources used to provide cancer care services, the Think Tank will address economic costs. The economic costs of cancer care and control include expenditures for cancer preventive, screening, and treatment services; costs associated with time and effort spent by patients and their families and by cancer treatment providers; and costs associated with lost productivity due to cancer-related disability and premature death. Cancer health disparities may increase these costs for individuals, families, employers, governments, and society.

Resource use and costs have traditionally been categorized according to whether they are directly or indirectly related to the provision of services (***Appendix Figure C-3***).[13, 20] Direct costs are measured by expenditures for goods, services, and other resources used to provide an intervention. Direct medical costs and direct non-medical costs are subsumed under "direct costs." Indirect costs, also referred to as *productivity costs*, are used in economics to refer to productivity gains or losses related to an illness or death. Because financial accounting systems use indirect costs to describe overhead or fixed costs of production, medical or health care-related indirect costs are often broken down into morbidity and mortality costs. As subsets of indirect costs, morbidity and mortality costs reflect lost or impaired ability to work or engage in leisure activities due to illness or death. Time costs reflect the economic value of time that patients and their families spend receiving medical care and treatment related to a disease.[13] Of the various types of economic costs, direct medical costs are the most commonly measured and those for which cost data tend to be more available.

Although the non-medical costs of cancer are often difficult to capture, researchers have tested a variety of measures to capture these costs. An example is a study that explored the non-medical costs of cancer-related productivity loss and health-related quality of life (HRQL) in a matched sample of cancer survivors and controls.[21] Cancer survivors reported a higher burden than controls. Even long-term survivors were more likely to report lost productivity and worse quality of life than persons who had not had cancer. This points out that the economic burden of cancer goes beyond the direct costs of medical care.

Costs can be further divided by costs to individuals/families, businesses, governments, and society. For cancer patients, survivors, and their families, direct costs include out-of-pocket expenses, such as insurance premiums and co-pays, and uncovered or partially covered services such as prescription drugs and home health services.[22] Other disease-related, non-medical costs faced by individuals and families include the cost of travel to health care providers and facilities, unpaid family labor to care for the cancer patient, and decreased HRQL. At the same time that cancer patients and their families are dealing with the disease and the cost of care, they are at risk of having income decrease due to time taken off for treatment (i.e., time costs) and permanent disability (i.e., morbidity costs).[23-25]

Businesses experience additional costs related to absenteeism of employees with cancer and recruitment and training of temporary replacement workers. This often leads to lost productivity. Other business costs include paid sick leave, family leave, and disability days as well as employee health insurance coverage. Federal and state governments are the major funders of health care through programs like Medicare and Medicaid. Avoidable costs due to cancer health disparities contribute to the growing cost of health care in the United States. Also, communities and society as a whole pay a cost resulting from the failure to deliver early detection and treatment services to all Americans. This failure represents missed opportunities for reducing the economic burden associated with the pain and suffering caused by cancer.

Understanding of types of health care costs has improved, yet knowledge gaps persist. Some of the unanswered questions include: what elements should the total cost of cancer include? What economic models are applicable for examining the cost of cancer health disparities? Costs attributable to cancer are numerous (e.g., costs related to comorbidities); how can that information be captured and used?

Sources of Health Care Cost Data

Access to reliable and representative health care cost data is critical. Sources of cost data include administrative databases and surveys of patients, providers, and organizations (***Appendix 3: Selected Sources of Cost Data***). The most commonly used source of cost data is administrative data. These include claims charge data from payers such as Medicare, Medicaid, private insurers, and HMOs, and data from cost-accounting systems such as Veterans Health Administration administrative data and the Resource Patient Management System used by the Indian Health Service. Administrative databases provide information on the direct costs of delivering cancer care (e.g., hospital and ambulatory care, physicians and other providers, prescription drugs) but generally do not provide information on indirect costs. Other limitations of administrative data include misclassification of diagnostic codes, lack of information about comorbidities, finite information about follow-up care, and missing racial/ethnic identification.

Data from surveys, the second most commonly used source of cost data, can provide information on direct and indirect costs of cancer. Surveys of cancer patients and their families, insurers, and care providers and clinics are becoming increasingly sophisticated in obtaining reliable cost information (e.g., Medical Expenditure Panel Survey [MEPS], Healthcare Cost and Utilization Project [HCUP]). Data sources that provide information on insurance coverage and the uninsured include MEPS, HCUP, National Health Interview Survey (NHIS), California Health Interview Survey (CHIS), Kaiser Family Foundation, Commonwealth Fund, and the U.S. Census. Although a number of surveys are now available to researchers, they have limitations. Frequently survey data are self-reported and thus cannot be verified. Specifics such as stage of disease are not included in large population-based surveys that include cost information.

Mortality data, used to calculate the costs of premature mortality (i.e., future productivity lost to society as the result of premature death), are obtained from death certificates. Although death certificates are standardized, interpretation of these data can be complex, making it difficult to identify disease-specific mortality. For example, patients with multiple diseases may have myocardial infarction (MI) listed as the cause of death when the actual cause of death was complications from chemotherapy that led to heart problems.

Over the last several years, data resources for economic research have increased. Yet the question remains as to whether necessary data are available to make accurate economic impact evaluations. If they are not, how can additional data be collected?

Measuring Costs

Different perspectives guide which cost framework is used to answer cost-related questions (e.g., equal access perspective versus actuarial bottom line for the Medicare budget). Stakeholders—i.e., patients, families, third-party payers, service providers, researchers, governments, and society in general—determine what economic questions are asked and which outcomes are measured. Because the questions asked and the variables measured determine the results, cost-effectiveness is in the "eye of the beholder." For instance, Congress determines appropriations for Medicare and Medicaid and is often more interested in the actuarial bottom line. When policy makers talk about costs, they most often mean budgetary costs. Predictions of cost savings associated with improved cancer control are based on longer-term societal costs but are often represented as short-term budget savings, which may not occur and may actually increase expenditures. Answers to "big" (i.e., societal) questions may not provide a rationale for pragmatic changes in policy. Therefore, it is important to identify which perspective is being used to analyze

economic costs of cancer health disparities. If a societal perspective is taken, all economic costs will be relevant. However, if a provider perspective is used, indirect costs for patients may be excluded.

Commonly used economic metrics include cost-benefit, cost-effectiveness, and cost-of-illness measures. These methods attempt to quantify the amount of health benefit gained through intervention and determine the best value for cost. Any of these methods may include attributable costs such as the cost related to comorbidity.

Cost-benefit analysis (CBA) is frequently used to estimate the benefit of an intervention minus the incremental cost—i.e., cost of one alternative less the cost of another.[20] All costs and health effects are expressed in monetary terms. CBA puts a dollar value on a year of life (e.g., increased productivity due to prolonged healthy life). When done correctly, it may provide a comprehensive monetary measure of benefit and cost consequences of an intervention or show how the most money can be saved. CBA may be helpful when trying to decide whether to implement a specific program or when choosing between competing options. However, CBA has been criticized because it is obtained by estimating individuals' willingness to pay for interventions. Some economists fear that this favors the wealthy over the poor.[13]

With cost-effectiveness analysis (CEA), costs and intervention effects and at least one alternative are calculated.[13] The alternative used for comparison might be usual care or a different intensity of the intervention, such as less frequent screening. The results are a ratio of cost to effect. Costs are expressed in monetary terms, and benefits are expressed in natural units such as "life-years" (e.g., years of life saved per dollar spent). CEA shows the tradeoffs involved in choosing among interventions or variants of an intervention. CEA is limited because it compares only interventions whose costs and benefits are measured in the same units of effectiveness.

Cost-utility analysis (CUA) is a specific type of CEA.[20] Benefit is expressed in quality-adjusted natural units such as "quality-adjusted life-years (QALYs)." CUA may be used when HRQL is the desired outcome. With CEA and CUA, a goal such as QALYs is established. It can then be determined how to get the best outcome for the money available or how to spend the least money to obtain the desired outcome. Often, CBA and CEA will lead to the same decision about how to allocate health resources.[13]

Cost-of-illness (COI) analysis is useful for ascertaining an aggregate, global picture of the economic burden of cancer.[4] Estimates for the national economic costs of cancer, including costs that are related to direct medical expenditures, lost economic activity due to morbidity, and lost economic activity due to premature mortality can be estimated. COI studies use the "human capital" approach to estimate mortality costs. With this approach, average age-specific and gender-specific earnings are assigned to years of life lost (YLL) that are attributable to cancer. A cost value is then assigned to YLL. Usually, all types of cancer are included in COI studies. A limitation of COI analysis is that it mixes the prevalence–based measures of direct and morbidity costs with the incidence-based measure of mortality costs.

Other approaches to estimating cancer-related costs include the use of longitudinal data to estimate cancer site-specific direct costs.[3, 26] Using data for individual incident cases of cancer, costs can be constructed for clinically relevant treatment phases that occur between diagnosis and death (e.g., continuing care following the first 12 months after cancer diagnosis). Costs can then be calculated for different stages of disease and/or for different demographic categories, allowing a variety of cost comparisons. Another evolving approach is the use of economic modeling to evaluate the cost of cancer care.

Technical issues related to measuring economic costs include adjusting for unit cost differences for different years and for different settings. Also, discounting, pricing non-market goods, and incremental and marginal cost pricing must be dealt with in a health economic analysis. Several statistical issues related to measuring cost have to be managed. Economic data tend to be skewed with a large number of observations with zero costs, and cost histories are censored, so adjustments are needed. Intervention studies with clinical endpoints (e.g., increasing access, decreasing morbidity) may be underpowered for economic and/or cost-effectiveness results.

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Appendix D Agenda and Meeting Presentations

Economic Costs of Cancer Health Disparities Think Tank Center

Bethesda, MD • December 6-7, 2004

DRAFT AGENDA

DECEMBER 6, 2004

8:00-8:30 am	**Continental Breakfast**
8:30-9:00 am	**Welcome, Introductions, Opening Remarks:** *Purpose, Rationale, Core/Principal Questions, and Desired Outcomes of the Think Tank* Dr. Harold Freeman, NCI, CRCHD
9:00-9:25am	**Presentation I** — *What is the total cost of cancer care? Direct costs vs societal cost: conceptualization and methodological issues* Dr. Martin Brown, NCI, DCCPS Dr. Brown provided background information on cost domains and presented cost-of-illness estimates for cancer for 2002, including estimates by cancer type and by stage of diagnosis. Additionally, time costs and employment costs were discussed.
9:25-9:45 am	**Group Discussion**
9:45-10:10 am	**Presentation II** — *What percentage of the total cost of cancer care is related to health disparities? Economic Costs of finding cancers at earlier vs. later stage: What is an appropriate "cost-effectiveness threshold" for estimating cancer diagnostic and treatment options - All cancers and/or specific cancers?* Dr. Scott Ramsey, Fred Hutchinson Cancer Research Center Dr. Ramsey discussed cost-effectiveness analyses and methods to assess cost-effectiveness of intervention that can be implemented to eliminate cancer health disparities.
10:10-10:30 am	**Group Discussion**
10:30-10:40 am	**Break**
10:40-11:05 am	**Presentation III** — *What would be the cost of eliminating cancer health disparities? The intercept of methods of payment and cancer health disparities: Is equal access to quality, standard care cost-prohibitive or cost-effective for U.S. health care system?* Dr. Kenneth Thorpe, Emory University Rollins School of Public Health Dr. Thorpe discussed the sources of disparities in cancer treatment and spending, including lack of insurance, lack of prescription drug coverage, and race/ethnicity.

11:05-11:25 am	**Group Discussion**
11:25-11:50 am	**Presentation IV** — *What is the value to America to reduce cancer health disparities? What are the economic benefits of eliminating health disparities in the United States: Is it economically feasible to treat every American with a cancer-related abnormality? Are necessary data available to make economic evaluations?* Dr. Jeanne Ringel, RAND Dr. Ringel discussed ways to evaluate cancer health disparities as well as strategies to reduce such disparities. Additionally, the discussion focused on benefits of reducing cancer health disparities and how these benefits should be valued.
11:50am-12:10 pm	**Group Discussion**
12:10-12:20 pm	**Wrap-up of Morning Session** Dr. Harold Freeman
12:20-1:30 pm	**Lunch** (on your own)
1:30-1:55 pm	**Presentation V** — *What are the policy implications: How can we make cancer interventions more accessible for all? What health care system changes could reduce the costs of cancer care? How best to deal with the "moral hazard" concept?* Dr. Cathy Schoen, Commonwealth Fund Dr. Schoen discussed the roles of insurance and poverty as key factors in cancer health disparities and focused on issues related to quality and stability of insurance coverage. Additionally, insurance policies that would target socioeconomic disparities were discussed.
1:55-2:15 pm	**Group Discussion**
2:15-2:40 pm	**Presentation VI** — *What is the cost to change policies? Long-term societal costs vs. short-term budget savings: What cross-incentives between parts of the healthcare system are needed to ensure that stakeholders "do the right thing"? What research is needed to change policies?* Mr. Gerald Riley, CMS Mr. Riley discussed changes in Medicare payments for cancer therapies as well as the increased emphasis on preventative care. He also presented information on demonstration projects and coverage expansions.
2:40-3:00 pm	**Group Discussion**
3:00-3:15 pm	**Break**
3:15-4:45 pm	**Panel Discussion of Main Points** *The six presenters will serve on the panel with questions and discussion from participants.*

4:45-5:00pm	**Wrap-up of Day 1** Dr. Harold Freeman

DECEMBER 7, 2004

8:00-8:30 am	**Continental Breakfast**
8:30-9:30 am	**Opening Remarks** Dr. Harold Freeman Review the Discussion & Outcomes from Day One; Charge to Breakout Groups
9:30am-12:00 pm	**Breakout Sessions** *These facilitated breakout sessions will offer participants an opportunity to dialogue and discuss the following guiding questions: what is the total cost of cancer care? What percent of the total cost of cancer care is related to health disparities? What would be the cost of eliminating cancer health disparities? What is the value to America to reduce cancer health disparities? What are the policy implications? What is the cost to change policies? Suggested research and policy recommendations (i.e. What do we do next?)*
12:00-1:30 pm	**Lunch**
1:30-3:00 pm	**Breakout Session Reports and Further Discussion** Each group will report a summary of the discussion and highlight various solutions and recommendations that resulted from the dialogue.
3:00-3:30 pm	**Wrap-up of the Think Tank** Dr. Harold Freeman