

***Strengthening Our Culture of
Collaborations for Reducing
Cancer Health Disparities***

Report of the Cancer Health Disparities Summit 2006

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LETTER FROM DRS. SPRINGFIELD AND RUFFIN

The Cancer Health Disparities Summit 2006 provided a unique opportunity for individuals committed to eliminating cancer health disparities to come together to:

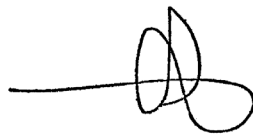
- Examine issues of common need;
- Share strategies, models, and tools; and
- Begin to network and collaborate to identify real solutions to real problems in communities experiencing a disproportionate share of the cancer burden.

Discussions centered on defining research gaps, enhancing existing programs and resources, and identifying the best ways to translate research into practice to help solidify our efforts to achieve the common goal of eliminating cancer health disparities. This was our first attempt to expand conference participation to include extramurally funded cancer health disparities researchers, public health professionals, and community health educators from large-scale disparities-focused programs supported both by the National Cancer Institute (NCI) and the National Center on Minority Health and Health Disparities (NCMHD).

The spirit of collaboration evident at the Summit encourages us all. Recommendations from this report will be used by NCI and NCMHD to inform our future work and will be disseminated to other agencies and organizations working with public health professionals and the community to advance efforts to reduce and eliminate health disparities. This report and conference resources are available on our Web sites: <http://crchd.cancer.gov/> and <http://ncmhd.nih.gov>.

We are eager to begin planning for next year's Summit and look forward to continuing to work across programs to put our plans for the coming year into action. We thank you for your support in 2006 and look forward to seeing you in 2007.

Sincerely,



Sanya A. Springfield, Ph.D.
Director
Center to Reduce Cancer Health Disparities
National Cancer Institute



John Ruffin, Ph.D.
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LETTER FROM THE SUMMIT PLANNING COMMITTEE

Summit 2006, held July 17-19, 2006 in Bethesda, MD, was the first meeting of its kind to be sponsored by the National Cancer Institute (NCI) and the National Center on Minority Health and Health Disparities (NCMHD). It aimed to engage broad participation of individuals from extramurally funded comprehensive cancer health disparities research, training, education, and outreach programs supported by the Institute and Center.

The overall theme for Summit 2006, *Strengthening Our Culture of Collaborations for Reducing Cancer Health Disparities*, reflected the current climate of fiscal constraint and the need to maximize existing resources through strengthened collaborations. Summit objectives were to: 1) examine issues of common need; 2) share strategies, models, and tools for providing solutions within respective programs and communities; 3) empower partnerships to access the resources needed to sustain programs that benefit the community; and 4) facilitate networking and discussion on unique issues that influence programmatic progress.

We convened a 2006 Trans-NCI/NCMHD Cancer Health Disparities Planning Committee comprised of representatives from seven large-scale NCI- and NCMHD-funded programs focused on eliminating health disparities. This committee met several times during the planning stages to develop a comprehensive agenda to meet the Summit goals and objectives.

At Summit 2006, we welcomed over 700 attendees to participate in an introductory session, plenary presentations, and breakout working groups. Participants examined not only concerns faced by individual programs but also addressed the larger issue of eliminating the unequal cancer burden among minority and underserved communities as discussed in the NCI Strategic Plan (Strategic Objective 8—Overcoming Cancer Health Disparities) and the NCMHD Health Disparities Strategic Plan. Consistent with the activities described in the plans, recommendations from Summit 2006 focused on increasing the number of minority cancer researchers, enhancing techniques to develop community-based interventions such as integration of services, increasing utilization of emerging technologies, and examining the role of health policy in cancer health disparities.

Our vision for moving forward includes a final review of all of the recommendations from the general sessions and breakout groups, and a determination of ways to prioritize and implement the recommendations across NCI and NCMHD. We will explore ways to enhance program oversight and strengthen resources. Final recommendations from Summit 2006 will be used to inform the work of the NCI Health Disparities Integration/Implementation (I²) Team and disseminated to other agencies and organizations working with public health professionals and the community.

We appreciate the support and participation of the various Centers, Divisions, and Offices throughout NCI and NCMHD. We would especially like to thank all of the members of the Planning Committee for their tireless efforts in committing time and resources to a new kind of Summit for now and future years.

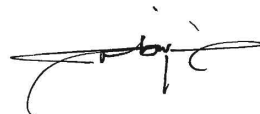
Sincerely,



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Peter Ogunbiyi, D.V.M., Ph.D.
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Participating Programs

Cancer Disparities Research Partnership Program
Cancer Information Service
Centers of Excellence in Partnerships for Community Outreach, Research on Health Disparities and Training (Project EXPORT)
Centers for Population Health and Health Disparities
Community Networks Program
Minority-Based Community Clinical Oncology Program
Minority Institution/Cancer Center Partnership
Patient Navigation Research Program

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EXECUTIVE SUMMARY

On July 17-19, the National Cancer Institute (NCI) and the National Center for Minority Health and Health Disparities (NCMHD) hosted over 700 participants at Cancer Health Disparities Summit 2006: Strengthening Our Culture of Collaborations for Reducing Cancer Health Disparities. The first meeting of its kind, Summit 2006 brought together researchers, public health professionals, and community health educators from comprehensive disparities research, training, education, and outreach programs supported by NCI and NCMHD for the purposes of:

- Gaining program knowledge and experience, and discussing accomplishments and challenges;
- Facilitating networking and collaborations;
- Sharing strategies, models, and best practices;
- Promoting the importance of leveraging resources and talents to sustain programs; and
- Addressing concerns about the impact that budget cuts and reallocations may have on achieving programmatic goals during periods of fiscal constraint.

Summit 2006 initiated a process through which cancer health disparities researchers, practitioners, and community members can develop a comprehensive plan for guiding the future of their programs and influencing the direction of the commitment of NCI, NCMHD, the National Institutes of Health (NIH), and the Department of Health and Human Services (HHS) to overcome cancer health disparities. The conference also provided an opportunity to build on existing partnerships and establish new ones to help sustain work in the area of cancer health disparities, and emphasized a need to build unique partnerships to bridge existing gaps. Summit 2006 provided attendees with the chance to network with individuals from other programs and showcase their materials through the Grantee Resource and Poster Networking Sessions. Detailed information about these resources, along with contact information, can be found at <http://www.cancermeetings.org/CHDSummit06/resource.cfm>.

“Current funding levels cannot effectively reach underserved populations; therefore, creative strategies are needed to bridge the gap between need and reality.”

—Elektra Paskett
Ohio State University

A major outcome of Summit 2006 was the generation of a series of recommendations directed toward NCI and NCMHD; researchers and health care professionals; and the community. Organized into seven cross-cutting themes – Accrual Strategies, Collaborations and Partnerships, Communication Systems, Community Engagement, Health Policy, Managing and Sustaining Programs, and Training – these recommendations are the result of discussions that took place in both plenary and breakout sessions of Summit 2006 and are summarized in this report. A more detailed description of Summit 2006 plenary sessions and slides of plenary presentations are available at <http://www.cancermeetings.org/CHDSummit06/index.cfm>.

Next Steps

The vision for moving forward includes a final review of all of the recommendations from the breakout groups and determination of ways to prioritize and implement the recommendations across NCI and NCMHD. This will include contributing to the overall planning and guidance of cancer health disparities efforts, from developing new initiatives to fostering the growth of current activities, disseminating the recommendations to other agencies and organizations, working with public health professionals and the community, and planning for Summit 2007.

SUMMARY OF RECOMMENDATIONS



The following recommendations are drawn from statements made during plenary and breakout group discussions from the community-based participatory research community over the course of the meeting. In response to a priority statement and discussion questions for each breakout theme, individuals working on an operational level with the community had the opportunity to provide valuable input from diverse viewpoints to describe the successes and challenges they face in their community-based participatory research settings. NCI and NCMHD administer numerous programs and increased efforts are needed to address duplications, overlaps, and gaps in service. Through coordinated short-, mid-, and long-range planning, programs can ensure that the most promising discoveries arising from one project are rapidly advanced into development and delivered by others to the communities that would benefit. Grantees and the communities they serve must incorporate strategies for sustainability of these projects beyond NIH funding by strengthening collaborations and partnerships.

Table 1. Recommendations Summary

	NCI/NCMHD	Researchers/Health Care Professionals	Community
<i>Accrual Strategies</i>	<ul style="list-style-type: none"> ■ Work with partners to ensure patient access to clinical trials and medical care. ■ Expand clinical trials design and eligibility to include patients with comorbidities. ■ Collect information about factors that influence clinical trials accrual. ■ Support core facilities for clinical trials recruitment. ■ Provide incentives for physicians and clinical researchers to work in geographically isolated areas and centers where minority and underserved populations receive care. 	<ul style="list-style-type: none"> ■ Work with the community to increase education and trust. ■ Further develop cultural competence methods and ensure that educational materials are appropriate for target populations. ■ Involve local leaders, patients, and cancer survivors to engage the community. ■ Train and utilize culturally matched patient navigators. ■ Engage in partnerships with government agencies, academic centers, and physicians to increase access to patients from minority and underserved populations. 	<ul style="list-style-type: none"> ■ Actively work with health professionals and promote community involvement in clinical trials and research studies.
<i>Collaborations and Partnerships</i>	<ul style="list-style-type: none"> ■ Facilitate information exchange and networking through additional meetings. Allow time for group discussion and involve representatives from other sectors (e.g., insurance companies, foundations, private companies). ■ Establish health disparities as a discipline and create incentives for researchers to conduct health disparities research. ■ Require cancer centers to incorporate health disparities research into all aspects of their research programs. ■ Provide adequate funds for partnership development, personnel support, and the development of outreach materials. ■ Address the need for Federal agencies to work more closely and improve coordination across initiatives. ■ Foster a culture of partnership. ■ Provide sufficient funds to support involvement of physicians. 	<ul style="list-style-type: none"> ■ Assist minority institutions in developing research programs and securing funding. ■ Utilize cancer centers to help form partnerships with biotechnology companies. ■ Evaluate and hold accountable hospitals and health plans for their effectiveness in reducing health disparities. ■ Engage the business community, which can invest in equipment and resources (e.g., media and marketing groups). ■ Engage individuals and/or organizations with partnership-building expertise to help identify partners and facilitate the formation of successful partnerships. ■ Leverage NCI funds to attract funding from other sources. ■ Foster a culture of partnership. 	<ul style="list-style-type: none"> ■ Realize the community has a central role in forming partnerships.
<i>Communication Systems</i>	<ul style="list-style-type: none"> ■ Provide information on the goals, activities, findings, and resources of funded programs. ■ Facilitate interaction between grantees working in geographical proximity. ■ Facilitate publication of methodological manuscripts to encourage communication of best practices. ■ Require grant applications to include communication plans. ■ Provide communications training to junior faculty and community program staff. ■ Enhance existing communications resources. ■ Develop an Internet-based index of resources related to cancer health disparities. 	<ul style="list-style-type: none"> ■ Focus research on interventions that will be of real value to the community. ■ Improve health literacy, cultural competence, and cancer communication skills. ■ Engage family “gatekeepers” (e.g., mother, wife) to disseminate health care messages to the entire family. ■ Utilize technology to enhance communication. ■ Ensure that educational and research materials are appropriate for target populations. Engage community groups to review materials before use. ■ Communicate the value and accomplishments of health disparities research programs to funding agencies and other sources of funding. 	<ul style="list-style-type: none"> ■ Utilize available communications tools and strategies. ■ Partner with other organizations to co-brand messages of overlapping interest. ■ Work with the NCI Office of Communications to identify opportunities to talk to the media about cancer health disparities and minority outreach.

	NCI/NCMHD	Researchers/Health Care Professionals	Community
<i>Community Engagement</i>	<ul style="list-style-type: none"> ■ Make a clear commitment to community-based participatory research and provide funds necessary to carry it out. ■ Identify standards of evaluation for community-based research. ■ Ensure patient needs are supported throughout the cancer care continuum (e.g., prevention, screening, treatment). ■ Develop and disseminate appropriate cancer information and services to the community. ■ Alter the funding process to allow sufficient time for partnership building. ■ Facilitate dialogue between researchers and the community about the need for the community to have increased control over research and data. ■ Address the issue of immigration and working with undocumented people. ■ Provide support for nonresearch activities that will build the capacity of communities to participate in research in the future. ■ Allow community members to be key investigators on research projects. ■ Ensure that community partners receive adequate funds to carry out their responsibilities. 	<ul style="list-style-type: none"> ■ Demonstrate substantial involvement with the community beyond research projects. ■ Modify medical school curricula to emphasize cultural competency. ■ Educate and engage junior investigators in community-based research. ■ Recognize that resources and data developed and/or collected in the community belong to the community. ■ Ensure research results are available to the community for advocacy purposes. ■ Integrate services that will benefit the community into pilot projects. ■ Develop venues through which to teach communities about research discoveries. ■ Communicate with the community before beginning a project, and continue communicating throughout the course of the project. Inform community partners about funding cuts and other needs. ■ Conduct evaluations following research studies to assess community satisfaction. ■ Solicit and work to implement community-initiated ideas. ■ Work with the community to develop community-based institutional review boards. ■ Assess the characteristics, needs, and priorities of a community to determine the best ways to engage the community. 	<ul style="list-style-type: none"> ■ Actively participate in defining the agenda for research programs. ■ Work together and be sensitive to different cultures to maximize the effectiveness of limited funds. ■ Realize the solution to health disparities lies within the community. ■ Undergo training to become spokespersons for cancer research.
<i>Health Policy</i>	<ul style="list-style-type: none"> ■ Support the development of infrastructure to support health policy efforts in health disparities programs beyond the constraints of short-term research grants. ■ Partner with worksites and industry on a national level. ■ Extend the funding period for cancer health disparities studies to allow sufficient time for impact of interventions to be measured. ■ Document the economic return on investment in health disparities research. ■ Work with the Centers for Medicare and Medicaid Services to determine the feasibility of creating provider-level incentives to address health disparities. 	<ul style="list-style-type: none"> ■ Emphasize the economic cost of health disparities when promoting health policy. ■ Monitor adoption and implementation of legislation and recommendations that address cancer health disparities. ■ Encourage state and local governments to create a database of health care providers willing to treat medically underserved populations on a volunteer basis. ■ Encourage businesses and other groups to adopt policies that promote health by publicly recognizing effective policies and exposing harmful or negligent activities. 	<ul style="list-style-type: none"> ■ Work with researchers and advocates to attract national attention to the issue of health disparities. ■ Track legislation and implementation of recommendations from reports such as the Trans-Department of Health and Human Services Progress Review Group on Health Disparities. Develop report cards to evaluate progress in policy development and implementation. ■ Provide policymakers with data that support the need for policy changes to address health disparities.

	NCI/NCMHD	Researchers/Health Care Professionals	Community
<i>Managing and Sustaining Programs</i>	<ul style="list-style-type: none"> ■ Provide opportunities for interaction among grantees. ■ Create a central database of cancer health disparities projects, tools, and resources. ■ Consider requiring future grant applications to include a sustainability plan. ■ Add ad hoc reviewers with health disparities expertise to standing study sections. ■ Fund cancer centers to conduct outreach activities and address disparities. ■ Have realistic and clear expectations for program outcomes. ■ Engage public and private partners to develop joint funding opportunities. ■ Provide grantees with examples of exemplary grant applications and make the review process more informative. ■ Assist minority scientists in becoming competitive, independent researchers. 	<ul style="list-style-type: none"> ■ Take steps to ensure optimal review of grant applications. Examine the membership of standing study sections and request review by the study section most qualified to address the proposal. List expertise needed to review the application. Make sure the language used in the grant will be clear to different types of reviewers. ■ Make research outcomes accessible to the community and share information about best practices. ■ Establish the value of programs through rigorous evaluation. ■ Inform elected officials about the importance of maintaining funds for programs that address health disparities. ■ Engage in partnerships across disciplines as well as within and between institutions. ■ Partner with other NCI-funded programs. ■ Pursue funding from multiple sources. 	<ul style="list-style-type: none"> ■ Become familiar with the Freedom of Information Act and utilize it to make public programs accountable. ■ Inform elected officials about the importance of maintaining funds for programs that address health disparities.
<i>Training</i>	<ul style="list-style-type: none"> ■ Expand support for training and career development grants. Ensure that guidelines for all training grants promote inclusion of minority and underserved researchers and require that a portion be awarded to minority and underserved investigators. Develop systems to monitor the diversity of awardees. ■ Expand the requirements for Comprehensive Cancer Centers to recruit, retain, and promote investigators from minority and underserved populations. ■ Modify guidelines for existing partnership programs to better meet the needs of investigators at Minority Serving Institutions. ■ Develop mechanisms to help tribal colleges and community colleges improve their ability to train minorities and be used as pipelines to research institutions. ■ Provide training and incentives for mentorship of minority and underserved researchers and encourage institutions to develop internal mentoring programs. ■ Broaden access to the NIH Library to improve access to research journals. ■ Incorporate training modules (e.g., grant writing, networking) into future cancer health disparities meetings. ■ Develop integrated grant mechanisms to provide continual support for cancer health disparities researchers and researchers from minority and underserved populations throughout the career continuum. 	<ul style="list-style-type: none"> ■ Solicit pharmaceutical companies to invest more money in training cancer health disparities researchers. ■ Incorporate education about health disparities into medical and biomedical graduate school curricula. ■ Create systems and infrastructure within universities that facilitate the formation of mentoring relationships between senior faculty and junior faculty or students, particularly those from minority and underrepresented populations. ■ Pursue funds from multiple sources. ■ Partner with training programs in other disease areas that exhibit the same risk factors. 	<ul style="list-style-type: none"> ■ Work with legislators to secure funds for health disparities research, scholarships, and training. For example, the community could encourage legislative action that would provide tax breaks for companies that support cancer health disparities research and training and suggest allocations for tobacco tax funds to be directed to cancer health disparities research and training. ■ Encourage national community organizations that are involved in health-related activities to collaborate with researchers.

REPORT OF SUMMIT 2006 PROCEEDINGS



Introduction

On July 17-19, NCI and NCMHD welcomed over 700 participants to Cancer Health Disparities Summit 2006. The theme of Summit 2006, *Strengthening Our Culture of Collaborations for Reducing Cancer Health Disparities*, mirrors the current climate of fiscal constraint and the pressing need to maximize existing resources by enhancing collaborations. To promote these collaborations, Summit 2006 provided the opportunity for extramural programs to interact with NCI and NCMHD program officials in order to share concerns and accomplishments, identify gaps, and discuss next steps to reduce cancer health disparities. NCI and NCMHD representatives provided an overview of current efforts to address cancer health disparities; leaders from communities experiencing health disparities shared their perspectives; and invited panelists imparted information on funding opportunities, emerging technologies, and the influence of health disparities research on health policy. Grantees from a number of NCI and NCMHD programs also presented during plenary and poster sessions, providing project overviews as well as insight into best practices.

Each Summit attendee was given the opportunity to participate in two breakout sessions, each of which addressed one of the following topics:

- Accrual Strategies
- Communication Systems
- Managing and Sustaining Programs
- Collaborations and Partnerships
- Community Engagement
- Training
- Health Policy

Each breakout group was led by a team of two facilitators (one representative from a Government agency and one nongovernmental employee) and considered a previously developed topic-specific priority statement designed to direct and catalyze discussion. Participants shared best practices on how to address each of these areas during times of increasing budget cuts and identified opportunities for collaboration to maximize existing resources. Finally, each breakout group was charged with

generating recommendations for the different stakeholders in cancer health disparities research—NCI and NCMHD, healthcare professionals and researchers, and the community.

The following report summarizes discussions that took place during plenary and breakout sessions of Summit 2006 and outlines recommendations that emerged from these discussions. This report will assist NCI and NCMHD in prioritizing and implementing their respective programs. It is hoped that community members and cancer health disparities researchers will also utilize this document to improve their efforts to reduce cancer health disparities. A detailed summary of the Summit 2006 plenary sessions can be accessed at <http://www.cancermeetings.org/CHDSummit06/index.cfm>.

A portfolio analysis revealed that 5.6% of the NCI budget was devoted to health disparities research in fiscal year 2004

General Session Highlights

NCI/NCMHD Funding Community: Our Investment in Disparities Research

The Summit featured several presentations from NCI and NCMHD regarding current efforts to eliminate cancer health disparities. Several Division, Center, and Office directors and staff provided brief overviews of health disparities initiatives to extramural investigators and community representatives.

Health Disparities Community Voices: Surviving the 3 U's (Underserved, Underrepresented, and Underfunded)

A panel of well-known researchers and advocates in the health disparities field presented reflections from the community on how disparate cancer prevention and care are impacting minority and underserved populations. Despite the challenges faced by these populations in terms of being underserved, underrepresented, and underfunded, progress can be made by empowering communities to talk about their experiences, demystifying cancer myths, and providing access to necessary resources and information. The panel emphasized the need to incorporate cultural competency into health care to ensure that patients do not feel mistreated during interactions with the health care system. It is important to understand cultural backgrounds and values and work with communities regarding gaps they have identified such as lack of resources and financial assistance, treatment-related complications, and recurrences. Informative materials that discuss resources and support

options must be tailored for spouses and children of cancer patients. Efforts must also address barriers that deter patients from telling others of a cancer diagnosis such as family obligations, medical expenses, lack of social support, and fear. The audience was asked to consider the following critical questions regarding community involvement in research projects:

- How have cancer health disparities been worked into recent NCI/NCMHD Requests for Proposals?
- What is the track record of NCI/NCMHD for awarding grants on this issue?
- What is the commitment to translation of these clinical findings into practice?
- Are there any advisory committees on which community members could seek representation?
- Do Medicare-eligible physician directories list the linguistic competence of health care providers?
- Are there some cancers (e.g., liver cancer) for which we should be demanding redoubled efforts (e.g., increased hepatitis B vaccination)?

Profiles of Selected Best Practices within Disparate Communities: Putting Our Best Foot Forward

Grantees from several programs were asked to present promising practices gleaned from their projects that provide perspectives in addressing barriers in cancer health disparities research. Grantees were able to highlight successful strategies, share tools and resources, and solicit input regarding barriers facing their programs.

“Who suffers when resources are underfunded, when communities are chronically underserved, and when individuals are members of populations that have been historically underrepresented? Among those who are affected are our family members, our friends, our neighbors, our communities, and ourselves.”

—Jennie Joe, Native American Research & Training Center

Programs were urged to incorporate strategies from the following areas to meet program goals:

Managing/Leveraging Project Resources

Develop a core process to identify reliable and available resources to meet program obligations. The process must include effective management of funds and personnel, development of institutional commitment as part of the program infrastructure, support for release time and career development, and establishment of timelines and processes to overcome potential risks (e.g., competing initiatives). Efforts should also be made to work with partners and secure funding from non-NCI/NCMHD sources. Program sustainability practices will help ensure program continuity in times of flat and decreasing budgets.

Training

Incorporate innovative strategies to increase the number of minority and underserved investigators in cancer research. Potential solutions include developing curricula, mentoring, providing training opportunities, improving retention practices, and leveraging funds. Barriers to minority and underserved investigator recruitment, such as reliance on standardized test scores, unsupportive institutional cultures, and inadequate sources of funding, must be identified and addressed on all levels.

Communication Systems

Share communication tools, resources, and processes within and across programs, institutions, and all levels of the community that have been instrumental in facilitating program activities. It is also important to utilize available technology and engage partners to assist in the development of effective communications tools. Efforts need to be made to reach cancer patients and the public through multimedia approaches with information that is patient and family centered.

Accrual Strategies

Adopt cultural competency techniques and reexamine trial design to increase recruitment of minority and underserved populations to clinical trials and research studies. This will require incorporation of appropriate attitudes and practices to treat diverse populations and focus on the inclusion of community participants in primary and secondary prevention research. Early identification of eligible patients and financial support for clinical trials infrastructure will also contribute to increased accrual. Efforts to dispel fears about clinical trials and ensure that patients continue to receive care after a trial is completed may increase the number of individuals from health disparities populations accrued to research studies.

Community Engagement

Share specific examples of project activities that enable the community to take on greater leadership in addressing cancer health disparities. Roles and responsibilities in meeting community and researcher expectations should be outlined.

Collaborations/Partnerships

Address bringing cancer centers, academic institutions, researchers, students, and community members together with the common goal of reducing cancer health disparities. This includes meeting and documenting the goals and needs of partners, leveraging the expertise of partners to the fullest, establishing formal agreements and program outcomes, and addressing regulations/statutes of each partner organization that might affect program goals.

Capturing Emerging Technology

New and emerging technologies have the potential to enhance biomedical research activities and improve cancer outcomes. These technologies could contribute to the reduction of health disparities, but efforts are needed to ensure that all have access to and the opportunity to benefit from new technologies. Panelists were asked to consider the following questions:

- How might access to these technologies improve cancer outcomes among minority and underserved populations?
- What is the potential for imaging and bioengineering to improve the prevention, diagnosis, and treatment of cancers for which disparities are more pronounced?
- What is the role of the cancer Biomedical Informatics Grid (caBIG) in helping NCI reach its challenge goal of “eliminating the suffering and death due to cancer”?
- What opportunities are available for minority and underserved populations to participate in nanotechnology and genomics training programs?

Community outreach activities and community engagement are essential to bring technological advancements to fruition. Determining how technologies are best utilized and disseminated for the benefit of all will require input from all communities. The caBIG community is attempting to build an infrastructure that will link the patient care, regulatory, and clinical research worlds. The goal of caBIG is to provide tools to support the entire cancer enterprise—from basic science discovery to delivery of care and patient support—through an open-source, open-access, and open development framework.

“Disparities, including cancer disparities, pose an interesting dilemma for technology. Left unchecked, the fruits of technology are often constrained by the social and economic arrangements of society, and reduction of disparities does not necessarily flow from technological advancements.”

—Kaytura Felix-Aaron, Health Resources and Services Administration

The Influence of Health Disparities Research on Health Policy

Policymakers can contribute to the reduction of health disparities in a number of ways, including developing new or modifying existing legislation to create offices and task forces, initiating studies, and directing resources to certain programs. They can also convene meetings to encourage collaboration and raise public awareness about issues of interest through public speaking opportunities.

Panel members discussed the influence of health disparities research on policy efforts to close the disparities gap and provided examples of research that has been translated into policy. There was overwhelming consensus that policies are needed to integrate interventions known to be effective into standard practice.

Those interested in health disparities can assist elected officials in a number of ways. For example, they can ensure that policymakers are educated about health care disparities by inviting them to attend conferences and sharing written materials. They can also build collaborative relationships with legislators and serve as informal advisors or information sources. Other ways to contribute include reviewing legislative language and providing testimony at hearings.

Discussing Funding Opportunities with Federal Agency and Foundation Partners

Leveraging funds from various sources is crucial to sustaining health disparities research programs. Nonprofit organizations such as the Legacy Foundation are able to provide resources to support grassroots efforts, large research grant applications, and innovative community-level interventions.

The Congressionally Directed Medical Research Program (CDMRP) is a series of partnerships between Congress, the Department of Defense, consumer advocates, and scientists and clinicians. Consumer advocates sit on all CDMRP panels and help decide which proposals should be funded; community members associated with cancer health disparities programs should consider becoming involved in this capacity. In 1998, the CDMRP established the Minority and Underserved Populations Program, through which proposals are solicited from researchers and investigators at Minority-Serving Institutions (MSIs) who focus on health disparities. The various CDMRP disease programs have also created or adopted funding mechanisms focused on health disparities.

The American Cancer Society (ACS) decided several years ago to focus the majority of its funding on new investigators. In order to foster the best and brightest scientists at the beginning of their careers, approximately 80% of ACS extramural funds supports this effort. ACS is committed to a balanced portfolio that contains basic, clinical, preclinical, and applied research in addition to some training. ACS has also created a research program that specifically encourages research on poor and medically underserved populations.

“This is the first time I’ve heard all of these ideas and themes in one place”

—Howard Koh, Harvard University

Breakout Sessions Emerging Themes

1. Accrual Strategies

Priority Statement: Implement culturally competent approaches to educate and recruit disparate populations to clinical and prevention trials/studies.

Cancer incidence and mortality and the response of tumors to treatment are affected by a number of factors, including environment, behavior, and genetics. Culture, race, and ethnicity often have a bearing on these factors, making it critical that diverse populations are included in clinical research. Unfortunately, for a number of reasons, many minority and underserved populations continue to be underrepresented on clinical trials.

Barriers to clinical trials accrual vary depending on the type of trial (e.g., prevention, screening, treatment) as well as the trial site (e.g., NCI-designated Cancer Center, community

hospital, veteran's hospital), and effective strategies to address these barriers must take these characteristics into account. Successful accrual strategies have been developed by the NCI intramural research program and others; it is hoped that these results will inform subsequent phases of clinical trials development that are carried out in the extramural cancer community, including academic medical centers and private enterprises. Additionally, a number of groups¹ have recently studied and made recommendations regarding cancer health disparities and clinical trials.

Promoting and Sustaining Accrual Rates

In order to improve recruitment and retention of minority and underserved populations to clinical trials, clinical researchers must continue to be involved at sites where these populations seek medical care. Furthermore, recruitment methods must accept and reflect the needs of the community.

Education will also contribute to increased accrual. Health care providers should be provided information about the value of clinical research and encouraged to refer patients with early- to mid-stage cancer, not only those with late-stage disease, to clinical trials. Patients and members of the community also need to be informed of the benefits of cancer research and clinical trials participation.

Educational efforts will be enhanced through community engagement. Local leaders (e.g., church leaders) and media outlets (e.g., newsletters, radio) have direct knowledge of the communities in which they are located and are often well trusted. These venues can be helpful for disseminating information about clinical research. Patients and cancer survivors should also be involved as spokespersons. Importantly, the overall medical needs of these populations must be met through their involvement in clinical trials. Failure to do this will lead to mistrust and resentment.

Resources for Accrual

There are a number of resources available to facilitate education about clinical trials. The NCI Clinical Trials Education Series offers several tools for health care professionals, organizations, and lay people. The Cancer Information Service partnered with a number of groups to develop Cancer 101, a culturally relevant cancer education and training program designed for use in American Indian and Alaska Native communities. It is important that materials

such as these are translated into multiple languages and modified as appropriate for various populations.

Accrual of minority and underserved populations to clinical trials could be improved by the development and use of additional resources, including culturally matched patient navigators. Incentives should be provided for physicians and clinical researchers to travel to geographically isolated areas and centers where minority and underserved populations receive care. Clinicians and researchers who demonstrate notable expertise, respect, and creativity in effectively addressing the challenges of including these populations should be rewarded. Finally, NCI-sponsored trials should explore mandating the inclusion of disparate populations and ensure that trials are sensitive to the needs of community participants.

Although cancer incidence is lower among African American women than White women, African American women experience significantly higher mortality rates. However, low referral rates, stringent eligibility criteria, and a focus on postmenopausal risk of most breast cancer prevention trials have contributed to underrepresentation of African American women. Efforts are currently under way to improve risk modeling for this population.

Enhancing Accrual through Collaboration

Collaborations can help leverage resources to more effectively recruit minority and underserved groups to clinical trials. Strengthening partnerships between clinical researchers and NCI programs such as the Cancer Information Service, Community Clinical Oncology Programs, and NCI-designated Cancer Centers may improve access to clinical trials for patients from medically underserved populations. Other health disparities research programs, as well as local, state, and Federal programs including the Indian Health Service, may provide additional opportunities for fruitful collaboration. Creating mutually beneficial relationships with physicians can also be of benefit; physicians may refer more patients to clinical trials if they are provided support in the areas of patient evaluation, registration, and follow-up.

Recommended Steps

NCI/NCMHD

- Work with partners to ensure patient access to clinical trials and medical care.
- Expand clinical trials design and eligibility to include patients with comorbidities.

¹ National Cancer Advisory Board Clinical Trials Working Group, 2005; Community Clinical Oncology Program Report (1983-2003), 2004; Agency for Healthcare Research and Quality Evidence Report, 2005; President's Cancer Panel, 2001; Cancer Health Disparities Summit 2005; Trans-Department of Health and Human Services Cancer Health Disparities Progress Review Group, 2004.

- Collect information about factors that influence clinical trials accrual.
- Support core facilities for clinical trials recruitment.
- Provide incentives for physicians and clinical researchers to work in geographically isolated areas and centers where minority and underserved populations receive care.

Researchers and Health Care Professionals

- Work with the community to increase education and trust.
- Further develop cultural competence methods and ensure that educational materials are appropriate for target populations.
- Involve local leaders, patients, and cancer survivors to engage the community.
- Train and utilize culturally matched patient navigators.
- Engage in partnerships with government agencies, academic centers, and physicians to increase access to patients from minority and underserved populations.

Community

- Actively work with health professionals and promote community involvement in clinical trials and research studies.

Southeast and Mid-Atlantic Cancer Information Service centers educate African American ministers about clinical trials in collaboration with the National Black Leadership Initiative on Cancer III.

2. Collaborations and Partnerships

Priority Statement: Establish effective and mutually beneficial collaborations and partnerships between cancer centers, academic institutions, community-based organizations, Federal agencies, students, and community members with the common goal of reducing cancer health disparities.

Collaborations and partnerships are essential in the effort to reduce cancer health disparities, regardless of budget status. Partnerships between researchers and the community result in more effective research programs. Partnerships between the research community and health care professionals are also critical to ensure that advances in knowledge are effectively translated into practice.

The most effective and longstanding partnerships are based on common goals, provide benefit to all participants, and extend across a number of program activities. To be productive,

collaborations must be established in a transparent manner; expectations and responsibilities should be clearly and formally defined at the onset, and development of Memoranda of Understanding or Memoranda of Agreement are advisable. Importantly, each member of the partnership should be actively involved in identifying its role. Communication will ensure that the assets, strengths, and needs of all partners are understood. Patience and respect for the views of others will also contribute to the success of joint efforts.



Promoting and Sustaining Programs through Collaboration

Collaboration can improve the quality of cancer health disparities programs and help leverage resources, which is particularly important during times of budget cuts. Potential partners include community health centers, media outlets, schools, health care agencies, universities, and government agencies. Partners can contribute a number of valuable resources to projects, including funds, publicity/visibility, educational materials, manpower, and training.

The development of partnerships that extend beyond a single grant or funding cycle can help sustain cancer health disparities programs. Established partnerships can engage in a number of different projects, with different partners playing lead/support roles as appropriate. When possible, partnerships should focus on capacity building; for example, partners should be trained so their work can continue even if funding for a project expires. In addition to providing material resources, collaborations with reputable organizations can lend credibility to a program.

Collaborations with local public health departments and community health centers can help match patients with appropriate research programs in a timely manner. Partnerships are also a good way to educate the public and health care professionals about health disparities. Media and marketing groups can help partners develop more effective ways to deliver messages to the public. Furthermore, partnerships with medical education institutions may provide the opportunity to inform young health professionals about poor health outcomes experienced by underserved populations. Law schools may provide assistance to

organizations interested in health policy, and large universities can sometimes provide partners with access to their extensive libraries and other educational resource tools.

Resources for Partnerships and Collaboration

A number of resources are available to promote collaboration. For example, local community coalitions and regional Cancer Information Service offices often monitor community needs and activities and can match groups with complementary needs and strengths. Multiple NCI grant mechanisms also support partnerships in the area of cancer health disparities. Cancer health disparities programs can utilize individuals or organizations with partnership-building expertise to help identify partners and facilitate the formation of collaborations.

Examples of existing program activities that improve collaboration include a comprehensive database that contains information on the strengths, resources, and needs of all program partners; this asset-mapping database is used to plan future interactions and projects. Another example focuses on mapping existing partnerships/networks across a university. It is hoped that this resource will prevent duplication, streamline resources, and optimize use of limited funds.

Although there are many examples of successful partnerships in the field of cancer health disparities, there is still much room for progress. NCI and the research community need to continue to foster a culture of partnership. Skills in partnership building should be recognized and rewarded by institutions and in peer review. Increased funding is needed for infrastructure, which will help health disparities programs attract partners. Increased funds are also needed to recruit physicians, who often require substantial compensation, to participate in research programs.

Securing Non-NCI/NCMHD Funding

There are several non-NCI/NCMHD sources that may provide support for cancer health disparities programs. Partnerships with media and marketing groups may be useful for attracting



donations and grants from these sources. Economists should be engaged to help identify the costs of cancer health disparities; these data could be used to attract involvement of businesses, insurance companies, and other groups that incur these costs. Many businesses have foundations that may be able to provide funds to support health disparities programs. Interactions with legislators can also help secure funding. Other potential funding sources include nonprofit organizations, state institutions, and the U.S. Department of Defense. When possible and appropriate, NIH funds should be leveraged to attract funding from other partners.

Recommended Steps

NCI/NCMHD

- Facilitate information exchange and networking through additional meetings. Allow time for group discussion and involve representatives from other sectors (e.g., insurance companies, foundations, private companies).
- Establish health disparities as a discipline and create incentives for researchers to conduct health disparities research.
- Require cancer centers to incorporate health disparities research into all aspects of their research programs.
- Provide adequate funds for partnership development, personnel support, and the development of outreach materials.
- Address the need for Federal agencies to work more closely and improve coordination across initiatives.
- Foster a culture of partnership.
- Provide sufficient funds to support involvement of physicians.

Researchers and Health Care Professionals

- Assist minority institutions in developing research programs and securing funding.
- Utilize cancer centers to help form partnerships with biotechnology companies.
- Evaluate and hold accountable hospitals and health plans for their effectiveness in reducing health disparities.
- Engage the business community, which can invest in equipment and resources (e.g., media and marketing groups).
- Engage individuals and/or organizations with partnership-building expertise to help identify partners and facilitate the formation of successful partnerships.
- Leverage NCI funds to attract funding from other sources.
- Foster a culture of partnership.

Community

- Realize the community has a central role in forming a ultimate partnerships and relationships.

3. Communication Systems

Priority Statement: Share communication tools, resources, and processes within and across programs, institutions, and all levels of the community that have been instrumental in facilitating program activities.

Addressing cancer health disparities requires effective communication on many levels. Communication is necessary to ensure the goals of health disparities research programs are being achieved; this is particularly critical for partnerships. When underlying causes of and effective interventions for health disparities are identified, this knowledge must be disseminated to a wide range of health care professionals. Additionally, accurate, meaningful, culturally relevant health information must be communicated to the general public. Importantly, these communication systems must be two-way: the community must have a way to inform programs addressing health disparities about its needs.

Promoting and Sustaining Programs through Communication

Programs need to develop systems to effectively communicate with funding agencies and other potential sources of support. Informing funding sources about the value and accomplishments of a program will attract future support.

Effective communication among partners is important to build a foundation of trust and respect. All partners must understand their respective roles and demonstrate productivity. Direct interpersonal communication is optimal for building and sustaining partnerships and networks; however, electronic resources and the Internet can facilitate communication and collaboration at a lower cost. Teleconferences and e-mail distribution eliminate costs associated with travel and mass mailings. Listservs can be used to expedite communication among programs, partners, and funding agencies. Some programs may be able to obtain discounted high-speed Internet services through affiliations with universities or state agencies.

Resources for Communication

Public radio and television stations are excellent venues through which to disseminate cancer-related information to hard-to-reach populations, especially non-English-speaking populations who often rely on stations that broadcast in their native languages. Some cable television companies offer community-based programs free access to community service channels as well as training on how to present themselves and their messages.



Although the need to provide educational materials in diverse languages is well recognized, simply translating information from English is often not sufficient. For instance, terms such as “screening,” “clinical trials,” and “online” may be meaningless or carry different implications among diverse racial and ethnic groups. Materials may need to be revised to accommodate regional and local cultural differences among subpopulations. Community groups need to be invited to review newly adapted materials before they are disseminated. The Cancer Information Service, in addition to state and local agencies, can also provide information about the demographics of a community and strategies for effective communication and interactions.

As the volume of information available via the Internet continues to expand, programs need a mediated resource to help identify the best materials and resources to meet their needs. An Internet-based index of resources available for download would be helpful in this regard.

Enhancing Communication through Collaboration

Collaboration often provides opportunities to utilize existing communication infrastructure or optimize the use of existing tools. For example, programs may be able to add content to Web sites hosted by partners, affiliates, or funding agencies; the host may even be willing to maintain the content after the formal partnership has expired. Organizations that want to communicate similar information may co-brand a specific message. Health disparities programs may work with the NCI Office of Communications to identify opportunities to talk to the media about cancer health disparities and minority outreach.

Recommended Steps

NCI/NCMHD

- Provide information on the goals, activities, findings, and resources of funded programs.
- Facilitate interaction between grantees working in geographical proximity.
- Facilitate publication of methodological manuscripts to encourage communication of best practices.

- Require grant applications to include communication plans.
- Provide communications training to junior faculty and community program staff.
- Enhance existing communications resources.
- Develop an Internet-based index of resources related to cancer health disparities.

Researchers and Health Care Professionals

- Focus research on interventions that will be of real value to the community.
- Improve health literacy, cultural competence, and cancer communication skills.
- Engage family “gatekeepers” (e.g., mother, wife) to disseminate health care messages to the entire family.
- Utilize technology to enhance communication.
- Ensure that educational and research materials are appropriate for target populations. Engage community groups to review materials before use.
- Communicate the value and accomplishments of health disparities research programs to funding agencies and other sources of funding.

Community

- Utilize available communications tools and strategies.
- Partner with other organizations to co-brand messages of overlapping interest.
- Work with the NCI Office of Communications to identify opportunities to talk to the media about cancer health disparities and minority outreach.

4. Community Engagement

Priority Statement: Engage community members to assume greater leadership in addressing cancer health disparities.

The community is a critical component of the interdisciplinary team needed to address cancer health disparities. Effective community engagement can improve the quality and efficiency of cancer health disparities research programs. To determine the best ways to engage a community, researchers should assess its characteristics, including needs and priorities. It is important to remember, however, that the priorities of the community may not always match those of the researcher.

Promoting and Sustaining Programs through Community Engagement

Involvement of the community from the planning stages of a project will build a relationship of trust and also help

researchers better understand the community in which they will be working. It is important that researchers solicit and work to implement community-initiated ideas, which reflect the needs and priorities of the community. This will contribute to program sustainability by increasing program effectiveness.

Researchers must communicate openly with their community partners about funding cuts and other needs. The community sometimes can help secure supplemental funds or identify resources to meet nonfinancial needs. The community is an important partner when pursuing funds from non-NCI/NCMHD sources. Community organizations with nonprofit status often are eligible for funds from different types of sources. These funds may be used to support pilot projects or other projects that will lead to NCI/NCMHD grant funding. Alternatively, they may be used to directly benefit the community because, unlike NCI/NCMHD funds, they may not be restricted to supporting research activities. Community organizations may need technical assistance with grant writing, including defining a narrow area of focus and generating a fundable plan.

Community members, particularly cancer survivors, can be trained to become effective spokespersons for cancer research. They have the ability to communicate with other community members as well as elected representatives about the importance of research for addressing cancer health disparities.

Engaging Community Members

Building personal relationships through social contact is one of the best ways to increase community engagement, particularly among minority populations. Researchers need to become involved in community activities beyond those that are directly related to their research. This will help build a trust relationship with the community and encourage the community to become more involved with research.

Community members will assume greater leadership if they are provided access to resources and given opportunities. Disseminating resources into the community and training community outreach workers help empower community members. Working with the community to develop community-based institutional review boards for community review of projects is another way to engage individuals and help them to implement community-based participatory research activities.

Community members will also be more likely to assume positions of leadership in cancer health disparities programs if the culture of the research community reflects the values and needs of the community. For example, allowing



community members to be key investigators on research projects provides them incentives to become more actively engaged in research. Researchers also need to recognize that the community owns data generated through community-based research. Furthermore, research success may be judged based on the number of people who have been helped rather than the number of papers published.

It is essential that people who participate in screening programs have access to treatment they may need. Continual lack of follow-through will damage community trust, subsequently limiting future opportunities for collaboration.

Resources for Community Engagement

Activities to engage the community (e.g., meetings, health fairs) require physical space; resources are needed to secure use of locations accessible to the community.

Timeframes associated with Requests for Applications (RFAs) and grants are often incompatible with community engagement. The quick turnaround time required for many RFAs precludes development of meaningful partnerships prior to grant submission. Also, funding periods often do not take into account the considerable time required to work with the community, including Native American tribes, schools, and other groups and organizations.

It is critical that community partners receive adequate funds to carry out their role in health disparities research programs. The distribution of grant funds among researchers and community partners must be equitable; disproportionate allocation of money reduces

the credibility of the research program in the eyes of the community.

Many communities and community organizations do not have the ability to engage in research activities; however, support for nonresearch activities may help build their capacity and improve the likelihood and quality of participation in future research projects.

“Modifying existing educational messages for diverse audiences is one way to leverage funds in times of budget constraints.”

—Communication Systems Breakout Group

Recommended Steps

NCI/NCMHD

- Make a clear commitment to community-based participatory research and provide funds necessary to carry it out.
- Identify standards of evaluation for community-based research.
- Ensure patient needs are supported throughout the cancer care continuum (e.g., prevention, screening, treatment).
- Develop and disseminate appropriate cancer information and services to the community.



- Alter the funding process to allow sufficient time for partnership building.
- Facilitate dialogue between researchers and the community about the need for the community to have increased control over research and data.
- Address the issue of immigration and working with undocumented people.
- Provide support for nonresearch activities that will build the capacity of communities to participate in research in the future.
- Allow community members to be key investigators on research projects.
- Ensure that community partners receive adequate funds to carry out their responsibilities.

Researchers and Health Care Professionals

- Demonstrate substantial involvement with the community beyond research projects.
- Modify medical school curricula to emphasize cultural competency.
- Educate and engage junior investigators in community-based research.
- Recognize that resources and data developed and/or collected in the community belong to the community.
- Ensure research results are available to the community for advocacy purposes.
- Integrate services that will benefit the community into pilot projects.
- Develop venues through which to teach communities about research discoveries.
- Communicate with the community before beginning a project, and continue communicating throughout the

course of the project. Inform community partners about funding cuts and other needs.

- Conduct evaluations following research studies to assess community satisfaction.
- Solicit and work to implement community-initiated ideas.
- Work with the community to develop community-based institutional review boards.
- Assess the characteristics, needs, and priorities of a community to determine the best ways to engage the community.

Community

- Actively participate in defining the agenda for research programs.
- Work together and be sensitive to different cultures to maximize the effectiveness of limited funds.
- Realize the solution to health disparities lies within the community.
- Undergo training to become spokespersons for cancer research.

5. Health Policy

Priority Statement: Examine existing or develop new health policy models to determine how they may be adapted to address cancer health disparities related gaps in your community, translate research findings into policy, and further engage local, state, and Federal policymakers.

Health policy can be used in a number of ways to address cancer health disparities. It can create mandates or incentives to improve access to care for underserved populations or guide allocation of funds to support public health interventions and research. Beneficial policies can be adopted by local, state, and Federal government or by the private sector. Health policy

efforts can define the nature and extent of health disparities and contribute to the understanding of their etiology. Research has the ability to inform and guide the agendas of policymakers and can also be used to evaluate policies to determine whether the desired outcomes have been achieved.

“We need to listen to the needs of the community, have them define projects, encourage trust, make projects inclusive, and fund community partners.”

—Summit Participant

Cancer Health Disparities Programs Influencing Policy

It is important to present policymakers with data illustrating the need for and/or value of desired changes to policy. Many policymakers will be particularly responsive to economic data. These data can be personalized by bringing community members affected by disparities to the table with policymakers. When policymakers become convinced of the importance of reducing disparities, programs need to continue working with them and provide the expertise needed to draft legislation and plan programs. It may be useful to target policymakers with backgrounds in the health care field.

Because elected officials are responsive to their constituents, it is also advisable to educate the general public about health disparities and the potential to address this issue through public policy. Individuals from populations that experience health disparities in particular should be enlisted to influence policy that will benefit their communities. Care should also be taken to include young people, who represent valuable potential new votes for elected representatives. Celebrity and other high-profile spokespersons can also attract considerable attention and support for initiatives on health disparities and related policies.

Influencing policy is not limited to the public sector. Organizations can encourage businesses and other groups to adopt policies that promote health by publicly recognizing effective policies and exposing harmful or negligent activities.

Promoting and Sustaining Programs through Health Policy

There are a number of areas in which policy can support the activities of cancer health disparities programs. The cancer health disparities field should learn from the successes of past health policy efforts. Tobacco taxation by many states has increased revenue and decreased tobacco use; funds raised through tobacco taxes have often been used to fund

cancer screening or research programs. Some states have mandated insurance coverage for specific services, such as cancer screening. The Breast and Cervical Cancer Prevention and Treatment Act of 2000 gave states the option of providing Medicaid benefits to low-income, uninsured women for breast and cervical cancer screening. Some states and cities have also extended general health benefits to uninsured residents. Several employers and insurance plans have offered reimbursement for fitness club memberships. Some employers have adapted this model and provided paid time off for workers to be screened for cancer.

Those involved in health disparities programs must encourage policymakers on all levels to recognize the importance and efforts of health disparities programs within NIH. Also, while Federal and local programs have improved access of underserved populations to cancer screening, policies should be enacted to ensure access to follow-up care as well.

Health policy may also be used to address workforce development as a key strategy for ensuring that cancer health disparities are addressed. Efforts to recruit minorities and members of underserved populations to careers in health care delivery and research could be enhanced through increased use of incentives such as loan repayment programs. Incentives could also be devised to encourage health care professionals to treat the medically underserved or uninsured.

Policy changes could also be implemented to support health disparities research. For example, health organizations should be permitted and encouraged to collect information on race and ethnicity.

Resources for Health Policy

Effectively influencing policy requires information and funding. The NCI has several resources that can provide information. The State Cancer Legislative Database Program maintains a public database of state cancer-related legislation, which can help organizations learn about policies in their state as well as models of success in other states. Cancer Control PLANET provides links to state cancer profiles and information on evidence-based cancer interventions. Geographical information systems can also be useful when preparing data for policymakers, as information can often be presented by district.

Funds to support policy-related advocacy and outreach may be available from state and local commissions or task forces that have been created to address public health problems, whether their focus is defined as health disparities or high morbidity and mortality. State and local offices on minority health are also potential sources of support. Cancer health disparities programs may be able to partner with local Centers for Disease Control and Prevention (CDC)-sponsored

Racial and Ethnic Approaches to Community Health (REACH) groups to convene roundtables for training advocates to communicate with policymakers.

“Make sure that your policymakers are educated about health care disparities. Engage them in meetings, invite them to conferences, and send them information. Build a collaborative relationship with your legislators.”

—Delegate Shirley Nathan-Pulliam
Maryland House of Delegates

Improving Health Policy through Collaboration

Cancer health disparities programs can pool resources to develop disparities-related initiatives and promote consideration of these initiatives by local, state, and Federal policymakers. Partnerships among groups with interrelated interests should also be initiated; these may include faith-based organizations, advocacy groups, hospitals, medical societies, insurance companies, labor unions, and businesses. Partners can contribute different types of resources, including funding, experience, or influence. It is particularly useful to work with groups that have established relationships with legislators and/or high-profile groups that will attract public interest.

Policies that encourage collaboration across government agencies should also be promoted. For example, NCI has engaged in a productive partnership with the CDC and the U.S. Department of Agriculture to train state and local organizations to promote breast cancer screening interventions.

Recommended Steps NCI/NCMHD

- Support the development of infrastructure to support health policy efforts in health disparities programs beyond the constraints of short-term research grants.
- Partner with worksites and industry on a national level.
- Extend the funding period for cancer health disparities studies to allow sufficient time for impact of interventions to be measured.
- Document the economic return on investment in health disparities extended research.

- Work with the Centers for Medicare and Medicaid Services to determine the feasibility of creating provider-level incentives to address health disparities.

Researchers and Health Care Professionals

- Emphasize the economic cost of health disparities when promoting health policy.
- Monitor adoption and implementation of legislation and recommendations that address cancer health disparities.
- Encourage state and local governments to create a database of health care providers willing to treat medically underserved populations on a volunteer basis.
- Encourage businesses and other groups to adopt policies that promote health by publicly recognizing effective policies and exposing harmful or negligent activities.

Community

- Work with researchers and advocates to attract national attention to the issue of health disparities.
- Track legislation and implementation of recommendations from reports such as the Trans-Department of Health and Human Services Progress Review Group on Health Disparities. Develop report cards to evaluate progress in policy development and implementation.
- Provide policymakers with data that support the need for policy changes to address health disparities.

6. Managing and Sustaining Programs

Priority Statement: Develop a core process to ensure program continuity and identify and secure reliable resources to meet program obligations.

The complex socioeconomic and cultural factors that contribute to disparities make health disparities research a distinctive challenge, which is even more difficult in times of budget constraint. Programs must convince the research community and the general public of the value of this type of research. Creativity and innovation are necessary to adapt more traditional research methods and interventions to meet the needs of health disparities research.

Managing and Sustaining Programs Despite Budget Cuts

The best way to ensure continued funding for a program is to clearly establish its value through rigorous evaluation. It is critically important that programs establish baseline data so they can document the results of their interventions. Institutions and funding agencies will likely be willing to support productive programs even when budgets are limited.

Researchers and the community should also communicate with elected officials to emphasize the consequences

of reducing funds for health disparities programs. Policymakers must be convinced to maintain funding for biomedical research in general and health disparities research specifically.

To endure budget cuts, cancer health disparities programs often seek funding from multiple sources and engage in partnerships with both public and private organizations. Programs also pursue grants sponsored by multiple agencies and those that address multiple diseases or health problems. In the absence of funds for large, multiyear grants, many programs apply for grants to support infrastructure or funds to support pilot projects, which can lay the groundwork for future research.

From their inception, programs should work to become self-sustainable and engage in income-generating activities if possible. This will allow them to continue to address health disparities even when Federal funding expires. Creativity can also contribute to sustainability; one program negotiated an agreement with its university wherein indirect and overhead costs from grants were held in a “savings account” for use in times of lower budget allocations.

Resources to Manage and Sustain Programs

Health disparities programs must identify and utilize available resources to make efficient use of their budgets. It is sometimes possible to negotiate access to the surplus equipment or supplies of nearby institutions or organizations at reduced cost or free of charge. Technology can also reduce costs associated with communication and travel.

Sustainability is a crucial part of these community partnerships. If the programs begin to have an impact on health disparities but then disappear when the grant funding expires, nothing is accomplished.

Managing and Sustaining Programs through Collaboration

Collaborating with public and private partners improves both program quality and efficiency. Transdisciplinary partnerships within and between institutions are one way to accomplish this. NCI-funded programs can also collaborate with other NCI grantees within the same institution or in geographical proximity. Partnerships increase efficiency by allowing groups to pool their resources, share complementary expertise, and eliminate unnecessarily redundant efforts.

Sharing personnel costs is one way to save money. A full-time employee can be equally shared by two organizations,

or the services of a specialized staff member (e.g., Web designer, information technology or marketing expert) of one partner can be offered to another partner at cost or in exchange for needed services.

Securing Non-NCI/NCMHD Funding

Securing funds from multiple sources helps sustain health disparities programs, especially when NCI and NCMHD budgets are limited. Programs must be involved in the development of their state’s cancer plan to ensure that health disparities are addressed as a priority and identify opportunities to apply for state funds. States often use tobacco settlement money to support public health programs.

Businesses and other nongovernment entities are also potential sources of support. Businesses are interested in economic indicators and may be responsive to data illustrating the cost of health disparities to employers and the community. Some potential donors may be more likely to support programs if they are described as addressing “social injustices” or “inequities” rather than health disparities. Effective marketing can improve the likelihood of attracting funds. Academic programs can also work with their university’s development and public relations offices to market themselves to the public, local leadership, and potential donors in the best possible way.

Effectively Managing Funds and Personnel

Programs can stretch their budgets by scheduling meetings and other events in collaboration with partners and funding agencies to reduce or eliminate travel costs. Distance learning and other advanced technologies can be used to reduce costs of collaborative planning and training. Cancer health disparities programs should promote themselves to Federal employees as opportunities for fieldwork assignments.

Cultivating Institutional Commitment

Programs should cultivate mutually beneficial relationships with departmental and institutional leadership to help establish the value of cancer health disparities research and researchers to the institution. Investigators should become involved in service activities, including advisory groups and faculty committees, and mentor junior faculty and students. These activities will help secure institutional support to sustain health disparities programs and investigators through times of lean budget.

Recommended Steps

NCI/NCMHD

- Provide opportunities for interaction among grantees.
- Create a central database of cancer health disparities projects, tools, and resources.
- Consider requiring future grant applications to include a sustainability plan.

- Add ad hoc reviewers with health disparities expertise to standing study sections.
- Fund cancer centers to conduct outreach activities and address disparities.
- Have realistic and clear expectations for program outcomes.
- Engage public and private partners to develop joint funding opportunities.
- Provide grantees with examples of exemplary grant applications and make the review process more informative.
- Assist minority scientists in becoming competitive, independent researchers.

Researchers and Health Care Professionals

- Take steps to ensure optimal review of grant applications. Examine the membership of standing study sections and request review by the study section most qualified to address the proposal. List expertise needed to review the application. Make sure the language used in the grant will be clear to different types of reviewers.
- Make research outcomes accessible to the community and share information about best practices.
- Establish the value of programs through rigorous evaluation.
- Inform elected officials about the importance of maintaining funds for programs that address health disparities.
- Engage in partnerships across disciplines as well as within and between institutions.
- Partner with other NCI-funded programs.
- Pursue funding from multiple sources.

Community

- Become familiar with the Freedom of Information Act and utilize it to make public programs accountable.
- Inform elected officials about the importance of maintaining funds for programs that address health disparities.

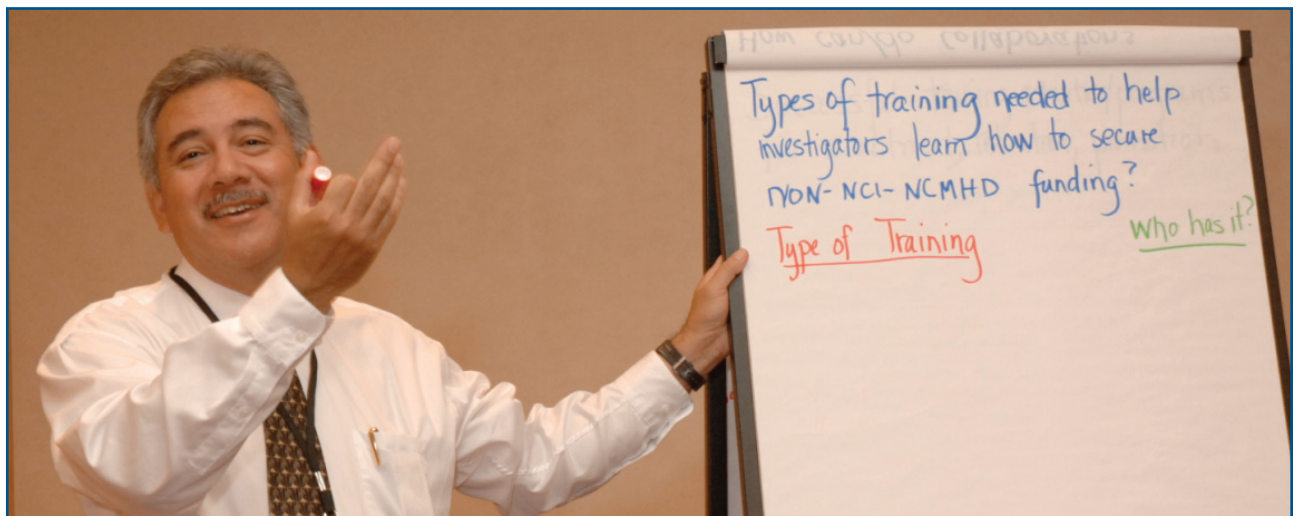
7. Training

Priority Statement: Address challenges and enhance strategies to increase the recruitment, retention, and promotion of minority and underserved investigators in cancer health disparities research.

The future of cancer health disparities research and the potential to eliminate the disproportionate burden of disease experienced by minority and underserved populations hinges on the training of young investigators. Unfortunately, the challenge of recruiting and retaining young researchers, particularly those from minority and underserved populations, is made even more difficult by current budget constraints. Programs commonly depend on multiple sources of funding to support students because single grants are often insufficient to cover all training needs. Funding for doctoral students in cancer health disparities, which is critical for building the workforce of the future, is relatively low compared with other fields. Partnerships and other innovative approaches have proven effective despite these fiscal obstacles, but there is opportunity for improvement.

Promoting and Sustaining Training Programs

Obtaining training funds from multiple sources, including both public and private organizations, is the best way to promote and sustain health disparities training programs. In academic settings, the development of health disparities courses and curricula can also be helpful. Such courses raise awareness of health disparities issues and highlight the need for research;



importantly, because these courses are supported by student tuition, they do not require external funding.

Recruiting, Retaining, and Promoting Diverse Investigators

A number of strategies have been employed to recruit, retain, and promote investigators from diverse backgrounds. Effective approaches include the creation of courses to prepare minority students for advanced-degree programs; the development of Web-based courses that can be shared between minority-serving and research-intensive institutions; and the creation of programs that assist junior investigators in preparing competitive applications for independent research funding. Partnerships have been instrumental for a number of programs. Partnerships between minority-serving and research-intensive institutions in the same city have proven particularly effective. These types of partnerships are thought to prevent “brain drain” from minority institutions and facilitate the development of shared curricula. Programs in academic settings can use a variety of creative techniques to attract students to cancer health disparities research. For example, student organizations and pertinent email listservs can be used to initiate interaction with potential trainees.

There are resources available through the Federal Government, societies, foundations, and other funding sources to help increase recruitment, retention, and promotion of minority and underserved investigators in cancer health disparities research. NCI and NCMHD provide a number of grants to support training throughout the career development continuum, including institutional training grants, minority supplements, career development awards, loan repayment programs, and research education grants. Efforts must be made to ensure that a sufficient number of slots in these training programs are available for members of minority and underserved populations. Examples of programs that have made valuable contributions to training and career development in the field of cancer health disparities are the NCI Minority Institution/ Cancer Center Partnership (MI/CCP) Program and the NCMHD Project EXPORT program.

Although there are several resources available for researchers from minority/underserved populations and for health disparities research, these support mechanisms are often fragmented. Recruitment and retention of minority/underserved investigators would be improved if integrated grant mechanisms were available to support young researchers from the time they are undergraduates through the early years of their faculty appointment.

There is particular need for increased support of minority/underserved researchers and health disparities researchers at the junior faculty level to assist them in achieving tenure.

“The number of applications for the NCMHD Loan Repayment Program for Health Disparities Research has increased since 2002; however, the number of new applications for the Extramural Clinical Research Loan Repayment Program for Individuals from Disadvantaged Backgrounds has decreased over the same period of time. The funds invested in these programs increased from \$7 million in 2002 to over \$10 million in 2005.”

—Francisco Sy, NCMHD

Faculty development at minority-serving institutions is particularly inadequate. Junior faculty and investigators at MSIs are rarely given protected time to carry out research, write publications, and develop partnerships. This makes it difficult to balance research with teaching and other obligations and prevents these young investigators from disseminating their findings to the larger research community.

Mentorship was identified as a pressing need for minority/underserved investigators. Current systems do not foster mentoring relationships, particularly for members of minority/underserved populations. Providing incentives for and training in mentorship would likely lead to improvement in this area.

Students and young investigators from minority and underrepresented populations often have difficulty developing professional networking relationships, which are essential to a successful research career. Efforts to improve the networking skills of young investigators from these populations would likely lead to increased retention.

Enhancing Training through Collaboration

Various types of collaborations can help to leverage training resources. Cancer health disparities researchers can form partnerships with researchers in other disease areas that may exhibit the same risk factors. For example, obesity is a risk factor for both heart disease and cancer, and social determinants contribute to disparities in many diseases. Interdisciplinary collaborations with schools of social work and nursing would expose students to cancer health disparities research early in their careers and potentially promote their long-term involvement in the field.

Incorporation of training components into interinstitutional partnerships is another way to leverage resources. Joint training efforts can take multiple forms. Shared curricula can be implemented independently at two or more institutions. Alternatively, an investigator from one institution might serve as guest instructor for a course at a partner institution; technology provides the opportunity for virtual interaction between students and investigators at different institutions. Students can also be given the opportunity to participate in exchange programs that allow them to conduct research projects at partner institutions. These kinds of partnerships can be of particular value for students who attend institutions that are not research intensive.

Health disparities researchers need to think creatively to identify innovative partners. For example, investigators working with Native American populations, who often experience transportation barriers, might seek a partnership with a transportation company as one way to address this problem. Efforts could be made to target young people who are training for leadership positions in the corporate business world; educating them about the importance of health disparities research might encourage them to engage in partnerships with cancer health disparities researchers later in their careers.

Securing Non-NCI/NCMHD Funding

There are a number of non-NIH potential funding sources for training activities; however, minority and underserved investigators and researchers at MSIs often have difficulty identifying and applying for these funds. These investigators would benefit from grant-writing workshops and retreats designed to teach them how to identify and apply for non-Federal funds. These types of workshops might be funded by NIH or other foundations and corporations.

Recommended Steps NCI/NCMHD

- Expand support for training and career development grants. Ensure that guidelines for all training grants promote inclusion of minority and underserved researchers and require that a portion be awarded to minority and underserved investigators. Develop systems to monitor the diversity of awardees.
- Expand the requirements for Comprehensive Cancer Centers to recruit, retain, and promote investigators from minority and underserved populations.
- Modify guidelines for existing partnership programs to better meet the needs of investigators at Minority Serving Institutions.
- Develop mechanisms to help tribal colleges and community colleges improve their ability to train minorities and be used as pipelines to research institutions.
- Provide training and incentives for mentorship of minority and underserved researchers and encourage institutions to develop internal mentoring programs.
- Broaden access to the NIH Library to improve access to research journals.
- Incorporate training modules (e.g., grant writing, networking) into future cancer health disparities meetings.
- Develop integrated grant mechanisms to provide continual support for cancer health disparities researchers and researchers from minority and underserved populations throughout the career continuum.

Researchers and Health Care Professionals

- Solicit pharmaceutical companies to invest more money in training cancer health disparities researchers.
- Incorporate education about health disparities into medical and biomedical graduate school curricula.
- Create systems and infrastructure within universities that facilitate the formation of mentoring relationships between senior faculty and junior faculty or students, particularly those from minority and underrepresented populations.
- Pursue funds from multiple sources.
- Partner with training programs in other disease areas that exhibit the same risk factors.

Community

- Work with legislators to secure funds for health disparities research, scholarships, and training. For example, the community could encourage legislative action that would provide tax breaks for companies that support cancer health disparities research and training and suggest allocations for tobacco tax funds to be directed to cancer health disparities research and training.
- Encourage national community organizations that are involved in health-related activities to collaborate with researchers.

The vision for moving forward includes a final review of all of the recommendations from Summit 2006 and determination of ways to prioritize and implement the recommendations across NCI and NCMHD. This will include presenting the recommendations to the NCI Health Disparities Integration/Implementation (I²) Team, disseminating the recommendations to other agencies and organizations working with public health professionals and the community, and continuing to assist NCI in addressing this important strategic objective. The recommendations will also directly influence the planning of Summit 2007.

NCI Health Disparities Integration/Implementation (I²) Team

Integration/Implementation Teams are groups of individuals from across NCI that help with strategic planning for key scientific investment areas. They serve as advisory subcommittees to the NCI Executive Committee. The I² Team model is an enterprise-wide rather than a program-focused activity. The plans integrate both extramural and intramural activities in a given scientific area and are signed to be transformational rather than incremental in contributing to progress. The process is built around measurable short-term and long-term goals that are carefully monitored.

The roles and responsibilities of the Health Disparities I² Team are to:

- Integrate, refine, and clarify existing plans and priorities.
- Select mission-critical objectives and milestones and specify desired outcomes.
- Develop annual and strategic plans.
- Identify resources needed.
- Propose initiatives/concepts that fill critical gaps or provide significant opportunities.
- Facilitate implementation and communicate and disseminate results and findings.

Phase I of the I² Team process is integration. This involves creating an inventory of current investment in the area of cancer health disparities as well as analyzing and reviewing the grant portfolio. The Health Disparities I² Team has accomplished these objectives and is ready to carry out the final step in the first phase of the I² process, which is the development of a plan for consideration by NCI leadership. This plan will describe activities ready for immediate implementation, identify links with other strategic areas, define outcomes and measures, and define timelines and required resources for implementation. Once NCI leadership approves the plan, the second phase of the process, implementation, will be initiated. Although I² Team implementation planning takes place within NCI, community-based researchers participate in the execution of plans formulated by these teams.

Cancer Health Disparities Summit 2007

Programs across NIH will be informed about the recommendations that emerged from Summit 2006 and invited to participate in the planning of Summit 2007. As planning partners, these programs will receive information on the goals, activities, findings, and resources of funded programs as well as ways to best facilitate interaction between grantees working in geographical proximity.

“The challenge is to create unique, nontraditional research models and funding mechanisms to accelerate research discoveries in minority populations and translate those discoveries into clinical delivery for those populations.”

—Frank Govern, NCI



The Summit 2007 planning committee will actively explore ways to incorporate feedback and recommendations from Summit 2006, including:

- Increased involvement of community partners.
- Continued emphasis on partnership building, funding opportunities available from foundation and government partners, ways to influence legislation, and promising practices from community interventions.
- Emphasis on regional and thematic opportunities for networking.
- Provision of skills-building hands-on sessions related to grant writing for new investigators and community representatives.
- Increased representation of stakeholders working in cancer health disparities.

Overcoming Cancer Health Disparities— A Strategic Objective

The formal goal as outlined in the NCI Strategic Plan is to overcome the unequal burden of cancer experienced by various population groups by discovering the fundamental causes of cancer health disparities, developing effective interventions to reduce those disparities, and facilitating intervention delivery. The strategies defined to address cancer health disparities include:

- Identifying factors that cause cancer health disparities.
- Developing community-based interventions.
- Enhancing the integration of cancer services.

- Preparing a cadre of researchers and clinicians.
- Developing innovative and appropriate approaches to disseminating research results.
- Identifying a role for health policy in reducing and eliminating cancer health disparities.

It is hoped that the Cancer Health Disparities Summits will continue to provide a venue for NCI/NIH staff, researchers, public health professionals, and the community to come together to share information, share accomplishments, identify gaps, and develop innovative solutions to eliminate health disparities to fulfill the NCI challenge goal.

“The greatest barrier, the greatest determinant of cancer mortality in the years to come, will not be our science, will not be tobacco, but will be our inability to get our science to where patients live, in the community where they live.”

—Dr. John Niederhuber
NCI Director

FURTHER INFORMATION

National Institutes of Health

Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities (2002-2006)

http://ncmhd.nih.gov/our_programs/strategic/volumes.asp

National Cancer Institute Submission (2002-2006)

http://www.ncmhd.nih.gov/strategicmock/our_programs/strategic/pubs/NCI.pdf

National Center on Minority Health and Health Disparities (2002-2006)

http://www.ncmhd.nih.gov/strategicmock/our_programs/strategic/pubs/NCMHD-REV.pdf

National Cancer Institute Strategic Plan

<http://strategicplan.nci.nih.gov/>

Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business

<http://www.nap.edu/catalog/11602.html#toc>

Summit 2006 presentations are available at the following website:

<http://cancermeetings.org/CHDSummit06/presentations.cfm>

Summit 2006 Summary Minutes

<http://www.cancermeetings.org/CHDSummit06/index.cfm>

Cancer Health Disparities Progress Review Group (CHD PRG)

<http://www.hhs.gov/chdprg/>

APPENDICES

Appendix A: Glossary of Acronyms and Abbreviations

ACS	American Cancer Society
caBIG	Cancer Biomedical Informatics Grid
CCOP	Community Clinical Oncology Program
CDC	Centers for Disease Control and Prevention
CDMRP	Congressionally Directed Medical Research Program
CDRP	Cancer Disparities Research Partnership Program
CIS	Cancer Information Service
CNP	Community Networks Program
CPHHD	Centers for Population Health and Health Disparities
HHS	Department of Health and Human Services
I² Team	Integration/Implementation Team
MB-CCOP	Minority-Based Community Clinical Oncology Program
MI/CCP	Minority Institution/Cancer Center Partnership Program
MSI	Minority-serving institution
NCI	National Cancer Institute
NCMHD	National Center on Minority Health and Health Disparities
NIH	National Institutes of Health
Project EXPORT	Centers of Excellence in Partnerships for Community Outreach, Research on Health Disparities and Training
RFA	Request for Applications

Appendix B: Summit Agenda

Sunday, July 16, 2006

4:00 p.m. – 7:00 p.m. Registration

Monday, July 17, 2006

7:00 a.m. – 6:00 p.m. Registration

7:00 a.m. – 8:15 a.m. Poster Setup

8:30 a.m. – 8:35 a.m. Call to Order

Tarsha McCrae, Center to Reduce Cancer Health Disparities, NCI

8:35 a.m. – 8:50 a.m. Welcoming Remarks

*Sanya A. Springfield, Center to Reduce Cancer Health Disparities;
Comprehensive Minority Biomedical Branch, NCI*

John Ruffin, NCMHD

8:50 a.m. – 9:00 a.m. Addressing the Cancer Burden in Minority and Underserved Communities

Mark Clanton, NCI [video]

9:00 a.m. – 9:10 a.m. Questions & Answers

9:10 a.m. – 10:10 a.m. NIH/NCI Funding Community: Our Investment in Disparities Research (Part I)

Moderator: Michael Christian, Division of Cancer Treatment and Diagnosis, NCI

Panelists:

Derrick Tabor, Office of the Director, NCMHD

Dinab Singer, Division of Cancer Biology, NCI

Robert Croyle, Division of Cancer Control and Population Sciences, NCI

Robert Hoover, Division of Cancer Epidemiology and Genetics, NCI

Worta McCaskill-Stevens, Division of Cancer Prevention, NCI

C. Norman Coleman, Division of Cancer Treatment and Diagnosis, NCI

10:10 a.m. – 10:20 a.m. Questions & Answers

10:20 a.m. – 10:35 a.m. Break

10:35 a.m. – 11:25 a.m. NIH/NCI Funding Community: Our Investment in Disparities Research (Part II)

Francisco Sy, Office of CBPR & Outreach, NCMHD

Ernest Hawk, Office of Centers, Training and Resources, NCI

Nelvis Castro, Office of Communications, NCI

Samir Sauma, Office of Science Planning and Assessment, NCI

Robert Wiltrout, Center for Cancer Research, NCI

11:25 a.m. – 11:35 a.m. Questions & Answers

11:35 a.m. – 11:50 a.m. Report from the NCI–Wide Health Disparities Workshop

L. Michelle Bennett, Center for Cancer Research, NCI

Lenora Johnson, Office of Education and Special Initiatives, NCI

11:50 a.m. – 12:00 noon Questions & Answers

12:00 noon – 1:30 p.m. Lunch

1:30 p.m. – 2:30 p.m. Health Disparities Community Voices: Surviving the 3 U's

(Underserved, Underrepresented, Underfunded)

Moderator: Louis W. Sullivan, Morehouse School of Medicine

Panelists:

Jennie Joe, Native American Research and Training Center, University of Arizona

Elena Rios, National Hispanic Medical Association

Ho Luong Tran, Asian and Pacific Islander American Health Forum

2:30 p.m. – 2:45 p.m. Questions & Answers

2:45 p.m. – 3:25 p.m.	<p>Overview of Participating Programs (Part I)</p> <p><i>Moderator: Francisco Sy, Office of CBPR & Outreach, NCMHD</i></p> <p><i>Panelists:</i></p> <p><i>Frank Govern, Cancer Disparities Research Partnership Program, NCI</i></p> <p><i>Mary Anne Bright, Cancer Information Service, NCI</i></p> <p><i>Shobha Srinivasan, Centers for Population Health and Health Disparities, NCI</i></p> <p><i>Kenneth Chu, Community Networks Program, NCI</i></p>
3:25 p.m. – 3:30 p.m.	Questions & Answers
3:30 p.m. – 3:40 p.m.	Break
3:40 p.m. – 4:20 p.m.	<p>Overview of Participating Programs (Part II)</p> <p><i>Worta McCaskill-Stevens, Minority Based Community Clinical Oncology Program, NCI</i></p> <p><i>Nelson Aguila, Minority Institution/Cancer Center Partnership, NCI</i></p> <p><i>Roland Garcia, Patient Navigation Research Program, NCI</i></p> <p><i>Derrick Tabor, Project EXPORT, NCMHD</i></p>
4:20 p.m. – 4:25 p.m.	Questions & Answers
4:25 p.m. – 5:25 p.m.	<p>Profiles of Selected Best Practices within Disparate Communities: Putting Our Best Foot Forward (Part I)</p> <p><i>Moderator: Jon Kerner, Division of Cancer Control and Population Sciences, NCI</i></p> <p><i>Panelists:</i></p> <p><i>Community Empowerment – Grace Ma, Temple University</i></p> <p><i>Training – Louise Canfield, University of Arizona</i></p> <p><i>Accrual Strategies – Luis Baez, San Juan VA Hospital</i></p> <p><i>Communication Systems – Cherie Spencer, Mid-Atlantic Cancer Information Service</i></p>
5:25 p.m. – 5:35 p.m.	Questions & Answers
5:35 p.m. – 7:00 p.m.	Grantee Poster and Resource Networking Session
7:00 p.m.	Adjourn
Tuesday, July 18, 2006	
7:00 a.m. – 6:00 p.m.	Registration
7:00 a.m. – 8:15 a.m.	Poster Setup
8:30 a.m. – 8:35 a.m.	<p>Opening Remarks (Grand Ballroom)</p> <p><i>Derrick Tabor, Office of the Director, NCMHD</i></p>
8:35 a.m. – 9:20 a.m.	<p>Profiles of Selected Best Practices within Disparate Communities: Putting Our Best Foot Forward (Part II)</p> <p><i>Moderator: Peter Ogunbiyi, Comprehensive Minority Biomedical Branch, NCI</i></p> <p><i>Panelists:</i></p> <p><i>Managing Project Resources – Electra Paskett, Ohio State University</i></p> <p><i>Program Sustainability – Mariano Rey, New York University School of Medicine</i></p> <p><i>Collaborations/Partnerships – Dwight Heron, University of Pittsburgh Medical Center</i></p>
9:20 a.m. – 9:30 a.m.	Questions & Answers
9:30 a.m. – 10:00 a.m.	<p>Capturing Emerging Technologies</p> <p><i>Moderator: Kaytura Felix-Aaron, Bureau of Primary Health Care, HRSA</i></p> <p><i>Panelists:</i></p> <p><i>Kenneth Buetow, Center for Bioinformatics, NCI</i></p> <p><i>Gregory Downing, Office of Technology and Industrial Relations, NCI</i></p>
10:00 a.m. – 10:15 a.m.	Questions & Answers
10:15 a.m. – 10:30 a.m.	Break

10:30 a.m. – 11:00 a.m. The Influence of Health Disparities Research on Health Policy
Moderator: Claudia Baquet, University of Maryland
Panelists:
Delegate Shirley Nathan-Pulliam, Maryland House of Delegates
Nina Bickell, Mount Sinai School of Medicine

11:00 a.m. – 11:15 a.m. Questions & Answers
11:15 a.m. – 11:30 a.m. Charge to Breakouts
Derrick Tabor, Office of the Director, NCMHD
Jamelle Banks, Office of Science Planning and Assessment, NCI

- *Managing & Sustaining Programs*
- *Collaborations/Partnerships*
- *Communication Systems*
- *Community Engagement*
- *Accrual Strategies*
- *Training*
- *Health Policy*

11:30 a.m. – 1:00 p.m. Lunch
1:00 p.m. – 3:00 p.m. Breakout, Round #1
3:00 p.m. – 3:15 p.m. Break
3:15 p.m. – 5:15 p.m. Breakout, Round #2
5:15 p.m. – 6:45 p.m. Grantee Poster and Resource Networking Session
6:45 p.m. Adjourn

Wednesday, July 19, 2006

8:30 a.m. – 8:35 a.m. Remarks and Administrative Notes
Nadarajen Vydellingum, Center to Reduce Cancer Health Disparities, NCI

8:35 a.m. – 9:05 a.m. Discussing Funding Opportunities with Federal Agency and Foundation Partners
Moderator: Lisa Evans, Office of the Director, NCMHD
Panelists:
Barbara Terry-Koroma, United States Army Medical Research & Materiel Command
William Phelps, American Cancer Society
Helen Lettlow, American Legacy Foundation

9:05 a.m. – 9:20 a.m. Questions & Answers
9:20 a.m. – 10:20 a.m. Reports and Recommendations from Breakout Sessions
10:20 a.m. – 10:35 a.m. Break
10:35 a.m. – 11:35 a.m. Reports and Recommendations from Breakout Sessions
11:35 a.m. – 11:50 a.m. Overcoming Cancer Health Disparities
John Niederhuber, National Cancer Institute

11:50 a.m. – 12:00 noon Closing Remarks — Acknowledgments and Next Steps
Sanya A. Springfield, Center to Reduce Cancer Health Disparities;
Comprehensive Minority Biomedical Branch, NCI

12:00 noon Adjourn

Appendix C: List of Participating Programs

Cancer Disparities Research Partnership Program

The National Cancer Institute's Cooperative Planning Grant for Cancer Disparities Research Partnership Program (CDRP) issued by the Radiation Research Program is an effort to strengthen the National Cancer Program by developing models to reduce significant negative consequences of cancer disparities seen in certain U.S. populations. The Program supports the planning, development, and conduct of radiation oncology clinical trials in institutions that care for a disproportionate number of medically underserved, low-income, ethnic and minority populations but have not been traditionally involved in NCI-sponsored research. In addition, CDRP supports the planning, development, and implementation of nurturing partnerships between applicant institutions and committed and experienced institutions actively involved in NCI-sponsored cancer research.

<http://www3.cancer.gov/rrp/CDRP/index.html>

Cancer Information Service

The National Cancer Institute (NCI), the Nation's lead agency for cancer research, established the Cancer Information Service (CIS) in 1975 to educate people about cancer prevention, risk factors, early detection, symptoms, diagnosis, treatment, and research. The CIS is an essential part of NCI's cancer prevention and control efforts.

<http://cis.nci.nih.gov/about/about.html>

Centers of Excellence in Partnerships for Community Outreach, Research on Health Disparities and Training (Project EXPORT)

The program aims to build research capacity at designated institutions enrolling a significant number of students from health disparity populations and to promote participation and training in biomedical and behavioral research among health disparity populations.

http://ncmhd.nih.gov/our_programs/project_export_awards/PrjExpFY03Awards.asp

Centers for Population Health & Health Disparities

The Centers for Population Health and Health Disparities (CPHHD) supports transdisciplinary, multilevel, integrated research to elucidate the complex interactions of the social and physical environments, mediating behavioral factors, and biologic pathways that determine health and disease in populations, leading to an understanding and reduction of health disparities.

<http://cancercontrol.cancer.gov/populationhealthcenters/>

Community Networks Program

The Community Networks Program (CNP) is designed to reach communities and populations that experience a disproportionate share of the cancer burden, including African Americans, American Indians/Alaska Natives, Hawaiian Natives and other Pacific Islanders, Asians, Hispanics/Latinos, and underserved rural populations. The overall goal of the program is to significantly improve access to and utilization of beneficial cancer interventions and treatments in communities experiencing cancer health disparities in order to reduce these disparities.

<http://crchd.cancer.gov/pnp/pnnp-index.html>

Minority-Based Community Clinical Oncology Program

The Minority-Based CCOP will: 1) provide support for expanding clinical research in minority community settings; 2) bring the advantages of state-of-the-art treatment and cancer prevention and control research to minority individuals in their own communities; 3) increase the involvement of primary health care providers and other specialists in cancer prevention and control studies; 4) establish an operational base for extending cancer prevention and control and reducing cancer incidence, morbidity, and mortality in minority populations; and 5) examine selected issues in Minority-Based CCOP performance (e.g., patient recruitment, accrual, eligibility).

<http://www.cancer.gov/prevention/ccop/>

Minority Institution/Cancer Center Partnership

Through planning activities dedicated to developing stable, long-term, comprehensive partnerships that are mutually beneficial to MSIs and NCI cancer centers, the objectives of the Minority Institution/Cancer Center Partnership (MI/CCP) program are to increase the participation of MSIs in the Nation's cancer research and research training enterprise, to increase the involvement and effectiveness of the cancer centers in research and research training and career development related to minorities, and to develop more effective research, education, and outreach programs that will have an impact on minority populations.

<http://minorityopportunities.nci.nih.gov/index.html>

Patient Navigation Research Program

The overall goal of the Patient Navigation Research Program is to develop effective interventions to reduce cancer health disparities by facilitating timely, continuous access to quality, standard cancer care for all Americans. Patient navigation for cancer care represents a new approach to providing individualized assistance to patients, survivors, and families. Navigation spans the period from cancer-related abnormal findings through diagnostic testing to completion of cancer treatment. Patient navigators are trained, culturally sensitive, health care workers who help individuals address patient access barriers to quality, standard cancer care.

<http://crchd.cancer.gov/cnp/overview.html>



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