



Proceedings from

Enhancing Interactions to Reduce Cancer Health Disparities: An NCI-wide Workshop

November 2005

Including a Proposed Action Plan
to Achieve the NCI Strategic Priority:
Overcome Cancer Health Disparities

**Submitted to the NCI Executive Committee
February 2006**

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"We are committed"

A letter from the Workshop Co-Chairs

Dear NCI Executive Committee:

Eliminating cancer health disparities is a critical step in achieving the National Cancer Institute's goal of eliminating suffering and death due to cancer for all people. It is with great enthusiasm that we submit these proceedings from the *NCI-wide Workshop on Enhancing Interactions to Reduce Cancer Health Disparities*. The proceedings evolved from a two-day workshop approved and endorsed by the NCI Executive Committee, May 24, 2005, and convened on the NIH campus, November 17 and 18, 2005. More than 250 registrants from virtually every NCI division, office and center contributed expertise in biomedical and social sciences to:

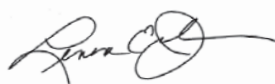
- Build synergy around NCI efforts to reduce cancer health disparities by enhancing communications, stimulating interactions across the Institute, and leveraging strengths through information sharing; and
- Propose strategies for strengthening collaborations across NCI to reduce cancer health disparities.

Working together both in plenary sessions and breakout groups, we developed a proposed path to guide NCI's strategic priority to overcome cancer health disparities. Overarching objectives emerged during the workshop's general sessions and action plans addressing seven specific topic areas were developed in the breakout groups.

These objectives and action plans provide a call to action to NCI. The content in these proceeding provide a strong foundation upon which NCI can develop a business plan to address a major priority in NCI's 2006 Strategic Plan: Overcoming Cancer Health Disparities¹.

This historic workshop energized the NCI community, catalyzed NCI's commitment, and raised awareness about the need to collaborate across the Institute in programs and projects focused on cancer health disparities research. As a group, we are committed to eliminating the disparities that affect too many Americans.

Respectfully,



Lenora Johnson, MPH, CHES
Director, Office of Education and Special Initiatives
National Cancer Institute



L. Michelle Bennett, PhD
Associate Director for Science, Center for Cancer Research
National Cancer Institute

¹National Cancer Institute: A Strategic Plan for Leading the Nation to Eliminate the Suffering and Death Due to Cancer, Objective 8: Overcome Cancer Health Disparities. NCI/OSPA, Draft 10/20/05

“We can make this happen”

A message from Dr. Mark Clanton

“ I was privileged to host and attend the NCI-wide Workshop on Enhancing Interactions to Reduce Cancer Health Disparities, November 17 and 18, 2005. It was a historic meeting for the expressed purpose of taking stock of just how well NCI is meeting the challenges presented by cancer disparities. It is clearly documented that the poor and many ethnic minorities experience the burden of cancer disproportionately. This is due to obvious, as well as less obvious, barriers to accessing cancer care, resources, and knowledge.

It was the first time since NCI formed the Center to Reduce Cancer Health Disparities (CRCHD) in 2001, that such an Institute-wide assessment was held. All of the division directors were present, with their sleeves rolled up, looking for ways to connect and collaborate across all of NCI.

I moderated the opening session on “Where We Are Today” and was honored to introduce Dr. Harold P. Freeman, a true pioneer in this field, a great surgeon, and the first director of CRCHD. Dr. Freeman reminded us that cancer is not only a disease, but also a lens through which social realities are powerfully reflected.

We also heard about the recent Trans-HHS Cancer Health Disparities Progress Review Group that was spurred into existence by NCI Director Dr. Andrew von Eschenbach. This effort has already begun to pay off by crystallizing common as well as unique perspectives among the many different HHS agencies, and leading to synergies that are welcome and necessary—particularly in an era of tighter budgets.

It is a time of exciting change at NCI, as we begin to focus on the strategic priority areas that will move us down the road toward the 2015 Challenge Goal. Reducing cancer health disparities is one of the major areas of emphasis. Integration and Implementation (I2) Teams have been established for some of the other initiatives with a clear mandate to produce quick and practical interventions. With the wealth of ideas and challenges that emerged from the workshop, an I2 Team to reduce cancer health disparities may also be established.

NCI has a long way to go—as do the rest of the nation and the world—before we can say that cancer disparities no longer contribute to disproportionate suffering and death due to cancer. The workshop’s intense dialogue and cross-cutting actions have produced a report and action plans with pledges from all of the major division directors to reenergize and recommit their staffs to this NCI goal. I have no doubt we can make this happen. ”

Mark Clanton, MD, MPH

Deputy Director, National Cancer Institute and
Deputy Director for Cancer Care Delivery Systems

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Acknowledgments

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Breakout Group Co-Chairs

In addition to members of the planning committee who served as breakout group co-chairs, we appreciate the participation and leadership of the following individuals:

- **H. Richard Alexander, Jr., MD**, Center for Cancer Research, *Narrowing the Gap between Research and Practice*
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MHHD Portfolio Analysis

The planning committee appreciates the contributions of **Kevin Callahan, PhD**, Office of Science Planning and Assessment, and **Karen Rulli**, SAIC, Inc., in the development of the NCI MHHD Portfolio Analysis. We also appreciate the significant assistance and support of the following individuals:

- **Mary Leveck, PhD**, Office of Science Planning and Assessment
- **Terri Sanders**, Center to Reduce Cancer Health Disparities
- Dashboard Contractors: **Padmaja Thallur** and **Dere Huether**, Woodbourne Solutions

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- Publications Support Branch, Office of Communications: **Donna Bonner, Del Harrod, and Paul LaMasters**
- MMG (Matthews Media Group): **Laura Anthony, Mary Partlow, Karen Davison, and Nancy Siebert Murphy**

Workshop Presenters

We gratefully acknowledge the time and commitment of the workshop presenters:

- **Mary Anne Bright, RN, MN**, Office of Communications
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- **Jeffrey White, MD**, Office of Cancer Complementary and Alternative Medicine
- **Robert Wiltrout, PhD**, Center for Cancer Research
- **Barbara Wingrove, MPH**, Center to Reduce Cancer Health Disparities

Finally, the planning committee acknowledges the support of Dr. Mark Clanton and the NCI Executive Committee and the participation of NCI staff members from across the Institute.

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“ There is a community out there that needs the work that you do. Many of them don’t understand genomics or nanotechnology. All they understand is life or death...They know there is somebody out there who knows more than they do who is going to help them. That somebody is you. ”

— Dr. Harold Freeman

Definition of Health Disparities

Cancer health disparities are differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups in the United States. These population groups may be characterized by gender, age, ethnicity, education, income, social class, disability, geographic location, or sexual orientation.¹

Despite steady improvement in the overall health of the U.S. population, racial and ethnic minorities, with few exceptions, experience higher rates of cancer morbidity and mortality than non-minorities. The reasons for these cancer health disparities are complex and poorly understood, and may largely reflect socioeconomic differences, differences in health-related risk factors, environmental influences, and racial discrimination.

¹Division of Cancer Control and Population Sciences, NCI

EXECUTIVE SUMMARY

Proceedings from Enhancing Interactions to Reduce Cancer Health Disparities evolved from an NCI-wide workshop held November 17 and 18, 2005 on the NIH campus involving more than 250 participants from virtually every NCI division, office, and center. The purpose of the workshop was to convene representatives from the entire Institute to take stock of the health disparities programs, studies, and initiatives that are being implemented across NCI; encourage trans-institute collaborations; and propose overarching objectives and feasible action plans for reducing cancer health disparities. These objectives and action plans provide a foundation for developing a business plan that:

- Aligns with NCI's priority of overcoming cancer health disparities in the 2006 Strategic Plan, and
- Contributes to achieving the NCI Challenge Goal of eliminating suffering and death due to cancer for all Americans.

Ideally, the objectives that emerged from workshop discussions and the action plans developed by workshop participants will be considered by a newly formed Health Disparities Integration and Implementation (I2) Team to develop a business plan outlining investment areas that will contribute to achieving the Challenge Goal.

Scope of Health Disparities Activities at NCI

The workshop speakers provided an overview of the major activities and initiatives that address health disparities at NCI. Through a series of presentations by NCI division, office, and center directors on activities spearheaded by their areas, as well as a report from an MHHD Portfolio Analysis, workshop participants learned that:

- NCI committed 5.6 percent of its total budget to health disparities research in 2004, using current coding criteria.
- NCI funded 778 health disparities-related research projects. Research training accounted for the majority of the projects (418 projects, or 54 percent); however,

clinical research accounted for the majority of the money spent (\$146.6 million, or 55 percent).

NCI is better positioned than ever before to address, understand, and reduce cancer health disparities. For example, research into the effectiveness of interventions to educate and motivate individuals to reduce risk factors, obtain cancer screening, seek follow-up care, and other health enhancing actions has led to the development of several highly focused, evidence-based efforts that target culturally-sensitive resources to people with the greatest need. Currently, nearly every NCI division, office, and center operates or funds initiatives or research on health disparities focused on a subpopulation or specific geographic area. Some of these initiatives include NCI's Patient Navigator Program, Community Networks Program, and the Community Clinic at Upper Cardozo in Northwest Washington, D.C. The trend, workshop presenters concluded, is toward initiatives that are practical, focused on high-need populations, and tailored as closely as possible to individual behaviors.

Emerging Challenges

The workshop revealed several challenges that NCI faces in overcoming cancer health disparities:

- The need to develop metrics to evaluate whether 5.6 percent of the NCI budget is sufficient to overcome, reduce, and eliminate the disproportionate burden of cancer in underserved and minority populations;
- The need to determine a sufficient level of funding for health disparities research;
- The need for additional research, strategies, and collaborations within NCI to make substantial progress in reducing cancer health disparities by 2015—thus the objective proposed in these proceedings and in the action plans.

EXECUTIVE SUMMARY

About the Workshop

- Open to all NCI staff
- Attendance: 250+ from every division, office, and center
- Purpose: Improve communication and collaboration across NCI to enhance existing programs and develop new initiatives to overcome cancer health disparities.
- Challenge: Identify, discuss and propose steps to address issues that contribute to cancer health disparities
- Outcome: A proposed action plan to use as a foundation for achieving the NCI Strategic Priority: Overcome Cancer Health Disparities
- Proposed Next Steps: 1. Create a Health Disparities I2 Team, 2. Elevate health disparities as a discipline, 3. Welcome future proposals to overcome health disparities through collaboration, coordination, and communication.

Challenge to Participants

With a solid foundation on the state of research activities to reduce cancer health disparities at NCI, participants divided into groups to develop action plans in seven topic areas. The groups developed plans that: address the most pressing area of concern within their area of focus; establish action steps that could be put in place now, one year from now, and/or in subsequent years; and identify NCI partners that could be involved in planning and implementation. Participants were encouraged by NCI leadership to think big, be innovative, not consider cost, and include quick and practical actions in their plans.

The seven topic areas were (1) genetic and biological differences, (2) narrowing the gap between research and practice, (3) clinical trials, (4) sociocultural and

behavioral influences, (5) cancer care delivery, (6) education and training for cancer care professionals and researchers, and (7) communications research. Full action plans for the seven areas are contained in the main body of this report.

Our Plan to Overcome Cancer Health Disparities

The major elements proposed for each of the topic areas follow:

- Conduct a pharmacogenomic study to address treatment and survival disparities and an epidemiologic study to address cancer susceptibility disparities.
- Narrow the gap between research and practice by establishing a community clinic in our area, improving our research portfolio analysis, increasing training, forging new partnerships, and expanding the dissemination and implementation of what works to the community.
- Elevate health disparities research to a discipline in clinical science.
- Include sociocultural and behavioral influences variables when conceptualizing research activities, and mandate training in cultural awareness across the Institute.
- Develop strategies that integrate cost-effective innovative public programs and models of care into the health care delivery systems which provide care to underserved, poor and near-poor populations.
- Broaden education and training efforts in health disparities beyond researchers to health care practitioners and trainees pursuing a career in cancer control.
- Develop a process for synthesizing results from communications research, disseminating what works, and enhancing NCI expertise in evidence-based communications approaches, especially for populations affected by cancer health disparities.

EXECUTIVE SUMMARY

Next Steps

The workshop planning committee presents three major recommendations to the NCI executive committee as next steps toward overcoming cancer health disparities. (The full presentation can be found on page 25.)

1. *Create an I2 Team for Health Disparities.* The overarching vision generated from the workshop (below) and the action plans (above) should be considered in the assessment and business plan development processes of an I2 Team.
2. *Elevate Health Disparities Research Across the Institute.* NCI should commit to integrating the elimination of cancer health disparities into the NCI mission and into all major NCI initiatives.
3. *Maintain Momentum.* NCI should identify an infrastructure to maintain the momentum gained by the workshop (e.g., a newly formed small or existing working group) to: publish a bulletin to keep NCI staff informed of health disparities programs and encourage trans-NCI collaboration; assess needed staff, financial, and infrastructure resources and continue coordination of NCI health disparities efforts; and maintain an Intranet portal for posting health disparities initiatives and communications. In addition, NCI should establish a mechanism for considering future proposed initiatives to rapidly impact disparities, as well as continue to strongly advocate for the implementation of Trans-HHS Cancer Health Disparities Progress Review Group recommendations.

Our Vision

The workshop planning committee and participants are committed to closing the gap in cancer health disparities. Based on themes that emerged at the workshop, the following vision is proposed for NCI: to lead the nation's effort to overcome cancer health disparities. To achieve this vision, NCI needs to commit to the following goals: actively incorporate the elimination of health disparities into "what we do;" establish health disparities as a formal research discipline; align community research problems with discovery research; communicate advances, and support team science and multidisciplinary approaches to health disparities research; support a diverse workforce; and continuously strive for social justice and equality in all of our research activities. (The full vision statement can be found on page 31.)

Milestones in Efforts to Reduce Cancer Health Disparities

1973

A crucial report by Drs. Ulrich Henschke and LaSalle Leffall from Howard University examining 25 years of data revealed the alarming increase in cancer mortality in African Americans and put health disparities on the map.

1985

The U.S. Department of Health and Human Services created the Office of Minority Health to address health disparities and other issues.

1986

The report, *Cancer in the Economically Disadvantaged*, analyzed the interrelationships between health, poverty, and race. (Freeman, American Cancer Society)

1989

NCI founded the National Black Leadership Initiative on Cancer; national hearings were held on "Cancer and the Poor."

1990

The report, *Excess Mortality in Harlem*, (McCord, Freeman, *New England Journal of Medicine*) revealed that a Black man in Harlem had less of a chance of reaching age 65 than a Black man in Bangladesh.

1992

NCI established the National Hispanic Leadership Initiative and Appalachian Leadership Initiative on Cancer.

1995

NCI established the Office of Special Populations Research to focus research funds on subgroups experiencing health disparities.

1999

Two reports, *The Unequal Burden of Cancer*, published by the Institute of Medicine, and the President's Cancer Panel's *Discovery*

Must Be Linked to Delivery, noted that the disconnect between health care discovery and delivery contributes significantly to the unequal burden of cancer when important medical advances are not made available to those most in need.

2000

NCI established 18 Special Populations Network cooperative agreements to build relationships with underserved communities across the U.S. and concentrate programs in areas of highest need.

2001

NCI established CRCHD to implement "bold initiatives to reduce, and ultimately, to end blatant injustices within the health care system;" the President's Cancer Panel issued *Voices of a Broken System: Real People, Real Problems* that made recommendations to close the gap between cancer research and delivery to the underserved.

2003

The Institute of Medicine issued *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*, which further defined disparities issues.

2004

The Trans-HHS Cancer Health Disparities Progress Review Group issued its report, *Making Cancer Health Disparities History*, including a Call to Action of 14 priority recommendations for eliminating cancer health disparities.

2005

NCI creates Community Networks Program cooperative agreements, an outgrowth of the Special Populations Network.

Source: Workshop presentation by Dr. Harold Freeman

NCI's Commitment to Overcoming Cancer Health Disparities: Past, Present, and Future

NCI is committed to understanding the basis of cancer health disparities and accelerating the development and application of interventions for overcoming disparities across the cancer care continuum and among all underserved populations. This commitment goes back 20 years when the study of health disparities first began to appear on the national agenda.

Health Disparities: A Look Back

Prior to the 1980s, there was no tailoring of prevention, screening, treatment, or research programs to the needs of special populations. Since HHS created the Office of Minority Health in 1985, the health community has asked, “Why do certain minority populations have markedly higher incidence and prevalence of cancer, heart disease, diabetes, HIV/AIDS, and other diseases than the general population?” In the late 1980s and early 1990s, NCI established the Community Based Coalitions for Cancer Prevention and Control, including the National Hispanic Leadership Initiative on Cancer, the National Black Leadership Initiative, and the Appalachian Leadership Initiative on Cancer. Over the past two decades, both the number of initiatives to reduce health disparities and the volume of health disparities research have increased significantly across the public and private sectors. Although progress has been made, cancer health disparities remains a major problem today and impedes NCI's ability to meet its Challenge Goal for all people.

Health Disparities Initiatives Today

Workshop presenters stated that NCI is better positioned than ever before to address, understand, and reduce cancer health disparities. The trend, they stated, is toward initiatives that are practical, focused on populations with the greatest need, and tailored as closely as possible to individual behaviors. For example, research into the effectiveness of interventions to educate and motivate individuals to reduce risk factors, obtain cancer screening, seek follow-up care, and other health-enhancing actions has led to the development of several highly focused, evidence-based efforts that target culturally sensitive resources to people with the greatest

need. Currently, nearly every NCI division, office, and center operates or funds programs, initiatives, or research addressing health disparities focused on a subpopulation or specific geographic area.

NCI's CRCHD, created in 2001, recently evolved its successful Special Populations Network into the Community Networks Program, which forms partnerships with clinics in underserved areas and delivers cancer care to people on an individual level. NCI's Patient Navigator Program provides one-on-one assistance to individuals who receive an abnormal finding and helps them stay within the health care system through treatment or until the finding is resolved. There is evidence that this level of assistance works—a recent study shows that in Harlem, the 5-year breast cancer survival rate increased from 39 percent to 70 percent in women who took part in the program. This example of delivery-based care is proof that, while not changing the level of poverty or people's circumstances, taking essential services to the community can contribute to reducing disparities. NCI is funding research on other Patient Navigator Programs around the country to collect evidence-based information that can be used to evaluate the value of these programs to underserved patient populations.

In the area of cervical cancer—a disease from which no one should die and yet too many impoverished women do each year—NCI can now look at county-level death rates and has targeted cervical cancer education and outreach programs to Appalachia, the Deep South, the Texas-Mexico border, and the Plains states. NCI is currently conducting phase III clinical trials in Costa Rica, where cervical cancer rates are high, to test a NCI-developed vaccine against the human papillomavirus, or HPV. The vaccine holds tremendous promise for reducing the global burden of this very preventable cancer.

Distribution of Health Disparities Funding

To gain perspective on the scope of health disparities initiatives at NCI for the use of the workshop participants, NCI performed a Minority Health and Health Disparities (MHHD) Portfolio Analysis. The analysis includes NCI intramural and extramural grants and projects, current in FY2004. Distribution of MHHD research dollars was examined by NCI division, National Center for Minority Health and Health Disparities (NCMHD) reporting category, Common Scientific Outline (CSO) categories, funding mechanism, and race/ethnicity (for NCMHD clinical research only).

The portfolio analysis revealed that NCI committed 5.6 percent of its total budget to health disparities research in 2004, using current coding criteria.

Other key findings include:

- NCI funded 778 health disparities-related research projects. Research training accounted for the majority of the projects (418 projects, or 54 percent); however, clinical research accounted for the majority of the money spent (\$146.6 million, or 55 percent).
- Of the \$264 million spent on minority and health disparities research, \$71.9 million was spent in the Division of Cancer Control and Population Sciences (DCCPS) (27.1 percent) and \$67.8 million in the Office of the Deputy Director of Extramural Science (DDES) (25.6 percent).
- By CSO category, the greatest amount, or one-third of health disparities funding, was in cancer control and survivorship (37 percent), followed by etiology (28.2 percent) and treatment (12.5 percent).
- Nearly one quarter (24.5 percent) of MHHD research funding supported cooperative agreements, demonstrating that NCI staff had significant involvement in how MHHD research dollars are spent.
- By mechanism, one third (33 percent) of MHHD research projects were conducted by independent investigators.
- Although half of all MHHD dollars were in clinical research, more than half (55 percent) were focused on Caucasians, with the remaining 45 percent devoted to other racial/ethnic groups.
- Ten percent of funding focused on Hispanic/Latino populations.

While the portfolio analysis had limitations (specific data were not available before 2004 because of a change in definition of NCMHD categories, difficulty in reporting data by race and ethnicity, rural or low socioeconomic status, etc.) information gleaned from the analysis can help determine strategies needed to increase the proportion of the total NCI budget that focuses on or applies to health disparities, as well as strategies undertaken by individual divisions.

As NCI plans for the future, the portfolio analysis presents NCI with several challenges:

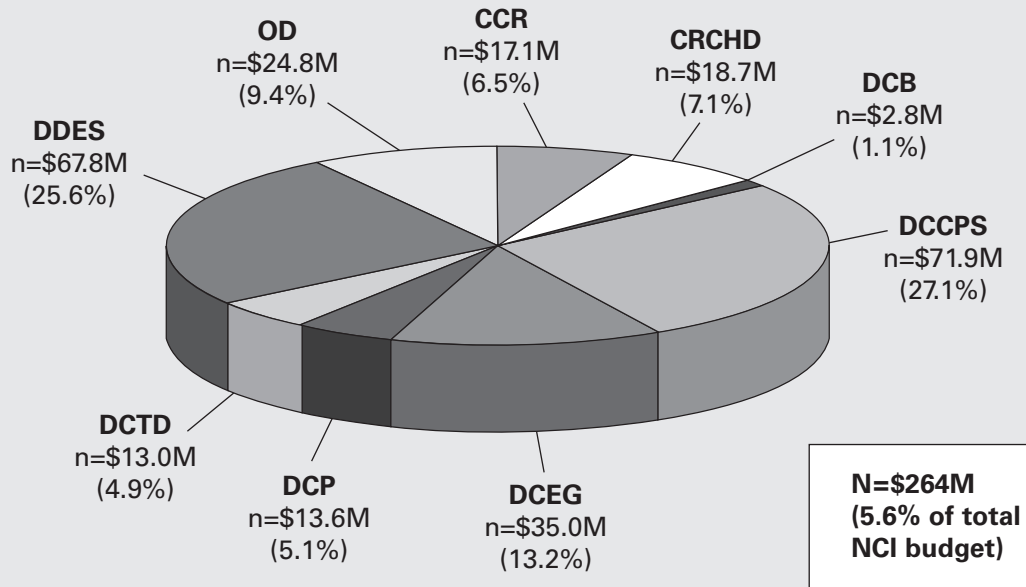
- The need to develop metrics to evaluate whether 5.6 percent of the NCI budget is sufficient to overcome, reduce, and eliminate the disproportionate burden of cancer in underserved and minority populations;
- The need to determine a sufficient level of funding for health disparities research;
- The need for additional research, strategies, and collaborations within NCI to make substantial progress in reducing cancer health disparities by 2015—thus the objective proposed in these proceedings and in the action plans.

Health Disparities Initiatives: The Future

As technology and medicine advances, NCI initiatives to eliminate cancer health disparities will require a rigorous integration of biomedicine, civil and human rights, social science, and social justice. Programs that target geographic areas experiencing excess mortality with an intense approach to providing culturally relevant education, appropriate access to screening, diagnosis, treatment, and an improved social support network are part of a trend that is catching on and could serve as models of what works.

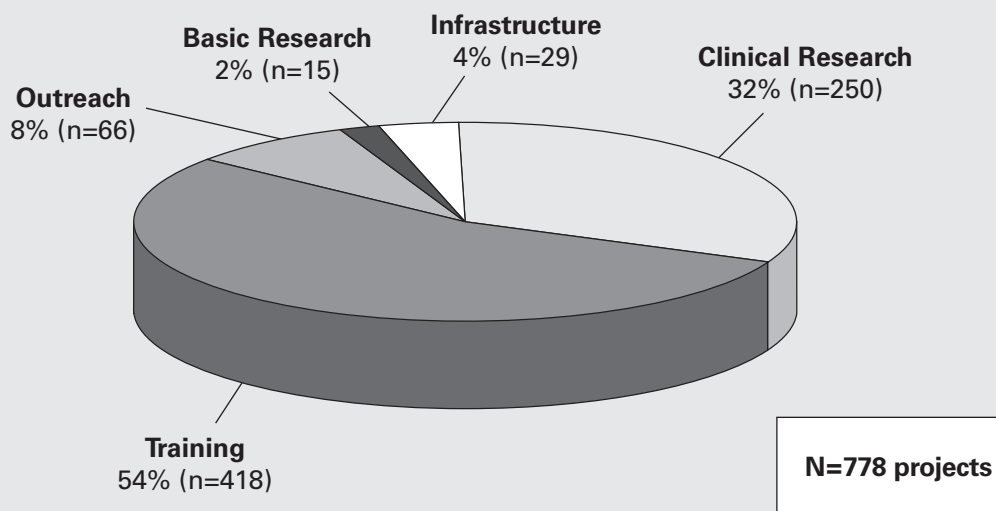
Several principles guide NCI's health disparities going forward. To be effective, NCI's internal scientific community must recognize that health disparities present a moral and ethical dilemma to the cancer research community. Perhaps most importantly, we must continue to conduct a serious dialogue to elucidate how human populations really differ and how to group people for biological and clinical study. We must expand our knowledge of population genetics and acknowledge that scientific truth must be wedded to social justice.

MHHD FUNDING BY NCI DIVISION, 2004



NCI Portfolio Review on Health Disparities Research (2006) based on 2004 data.

DISTRIBUTION OF MHHD PROJECTS BY NCMHD CATEGORY, 2004



NCI Portfolio Review on Health Disparities Research (2006) based on 2004 data.

**“ Health disparities represents an issue
about which many at NCI feel passionate
and on which we are ready to act. ”**

—Workshop Participant

NCI Action Plans to Overcome Cancer Health Disparities

A major product of the workshop was the development of highly focused action plans to reduce cancer health disparities through intra-institute collaboration. Multidisciplinary teams of workshop participants selected their break-out group in which the plans would be developed based on their area of interest:

- Genetic and Biological Differences
- Narrowing the Gap between Research and Practice
- Clinical Trials
- Sociocultural and Behavioral Influences
- Cancer Care Delivery
- Education and Training of Cancer Care Professionals and Researchers
- Communications Research

Each resulting action plan identifies one or more high priority areas requiring immediate action in order to overcome cancer health disparities. Participants were tasked with identifying actions where NCI can be most effective; major steps that can be put in place now, one year from now, and in subsequent years; and NCI partners in the plan's implementation.

Emphasis was placed on developing plans that are highly executable, practical, and hold promise for making a considerable impact in a relatively short period. Taken together, the individual action plans provide a foundation for the development of an overall NCI strategy for overcoming cancer health disparities.

Genetic and Biological Differences

Defining the Need

Understanding how genetic and biological differences affect the incidence of cancers and response to treatment is of paramount importance in eliminating cancer health disparities. In the U.S., race and ethnic background have long been used as a basis for prejudice and discrimination. As a result, scientists have been cautious in pursuing research focusing on these differences. However, the sequencing of the human genome, as well as new biological, pharmacological, and socioeconomic research, has recently enhanced our understanding of biologic mechanisms and pathways and improved our ability to distinguish hereditary from environmental factors influencing cancer susceptibility and response to treatment.

Proposed Actions

1. Conduct a trans-disciplinary pharmacogenomic study to address disparities in cancer treatment and survival by identifying genetic variance for differential metabolism, transport, and absorption of anti-cancer medications in ethnic groups worldwide.
2. Conduct a trans-disciplinary epidemiologic study to address disparities in cancer susceptibility by comparing cancer risk factors across and within genetically distinct populations under various environmental/behavioral conditions.

Impact of Proposed Actions

The pharmacogenomic study will provide variance rates for genes involved in drug metabolism, transport, and absorption for various ethnic groups. Results could reduce complications of chemotherapy by alerting clinicians to potential adverse drug therapy outcomes

in genetically diverse populations and providing guidance in choice of medication and tailoring of drug dosage.

The epidemiologic study would ascertain rates and evaluate risk factors for selected cancers among genetically distinct populations. For example, in the U.S., twice as many African Americans develop multiple myeloma as Caucasians. Comparing risk factor and genetic profiles of “black” myeloma cases from various diverse populations (e.g., Africa and parts of the

designed by an interdisciplinary team to capture the demographic, ethnic, ancestral, and environmental exposure data that are relevant to the proposed studies.

Action Steps—Short Term

- Create interdisciplinary teams to assess feasibility and potential of each initiative. Team members will need to include both biological and social scientists to identify populations and risk factors.

“ We’re asking the smart people in this room to figure out how to be creative, how to use research across disciplines to bring information and research together to provide solutions to the problems of cancer health disparities. ”

— Dr. Mark Clanton

Americas) would shed light on the relative roles of heredity and environment/lifestyle in this disease and lead to a better understanding of the complex interrelationships between heredity and environment in predicting and causing cancer.

Barriers Proposed Actions Would Address

- Duplicating efforts: Researchers need to investigate current national and international initiatives in this arena to avoid duplication and determine whether additions to ongoing protocols could be value added.
- Protecting data: Protection of human subjects guidelines are especially important in genetic research to avoid any misuse or abuse of the data that are collected.
- Developing appropriate definitions and categorizations: Difficulty in disaggregating genetic from environmental factors is exacerbated by the fact that OMB and Census classifications for race/ethnicity fulfill social and policy needs, rather than those of scientific research. Developing definitions and categorizations appropriate for scientific use will require an interdisciplinary approach, including geneticists, anthropologists, epidemiologists, and sociologists.
- Creating innovative study instruments: Researchers need a customized questionnaire and protocol

- Develop questionnaires to capture the genetic, environmental, and behavioral information, including accurate demographic and ancestral data from participants.
- Create international consortia to facilitate the coordinated collection of data from diverse racial and ethnic populations both within and outside the U.S.

Action Steps—Long Term

- Create or identify shared international databases for data collection and analysis.
- Share results publicly to facilitate dosing decisions.
- Apply the study results to other drugs that use similar pathways.

Partnership Opportunities

Both initiatives call for interdisciplinary teams such as pharmacists, epidemiologists, oncologists, geneticists, anthropologists, and molecular biologists that would draw on every NCI division, as well as transnational consortia that would enhance access to genetically distinct populations and leverage expertise worldwide. It might be possible to incorporate these initiatives into ongoing pharmacogenetic collaborations and/or large multi-ethnic epidemiologic NCI studies.

Background

The groundwork for the proposed pharmacogenomics study was provided by Dr. Douglas Figg's presentation on the influence of pharmacogenomics in anti-cancer drug development, which showed that the effects of the same medications could vary from 3- to 40-fold, depending on alleles controlling metabolism, transport, and absorption. While variant alleles exist in all populations, the proportions differ along genetic markers that correspond roughly to traditional classifications that link "races" or "subspecies" to historical patterns of continental distribution. Dr. Figg estimated that about 50 genes control the pharmacokinetics of chemotherapies.

This proposed initiative involves collecting 500 to 1,000 samples from people in a number of countries representing various ethnic groups (e.g., the U.S., Canada, Mexico, Argentina, China, India, Japan, African nations, etc.). Investigators in each country would collect detailed information on hereditary, environmental, and behavioral characteristics of subjects. An international, multidisciplinary consortium of scientists would analyze results to determine ethnic differences in drug metabolism. To date, research on drug metabolism and toxicity has included only very small samples of different racial/ethnic groups. The proposed study would yield data from much larger samples of selected racial/ethnic groups and would provide variance rates for each gene involved in drug metabolism and transport for each ethnic group. Participants believed this research could guide dosing for anti-cancer agents and reduce complications of chemotherapy.

In the U.S., cancer health disparities exist between its majority population (i.e., Caucasians) and its socioeconomically disadvantaged groups (e.g., African Americans, Hispanics, and American Indians). However, racial disparities in health cannot be explained solely on the basis of poverty, access to health care, or environmental factors. They are also dependent on interactions between these factors and genetics. The sequencing of the human genome opened up the possibility of identifying directly the genetic variations associated with differences in disease incidence and treatment response among individuals and populations. Currently, the International Haplotype Map (Hap Map) Project is working to describe the common patterns of human DNA sequence variation. This tool will make

it easier and less expensive to identify genetic factors affecting cancer occurrence and treatment outcomes. For example, polymorphisms of the gene thiopurine methyltransferase (TPMT), can have a marked impact on response to mercaptopurine treatment for childhood leukemia. Three of the 10 common TPMT alleles result in severe adverse effects if full doses are given. These alleles are distributed disproportionately among genetically identifiable populations, and genotyping for the allele is now common practice in treatment. Likewise, polymorphisms in drug targets also can affect response to medications.

Narrowing the Gap between Research and Practice: Plan 1*

Defining the Need

Despite major research advances of the 20th century in understanding the basic biological origins of cancer and the development and testing of interventions to prevent, detect early, diagnose, and treat cancer and the related sequelae, disparities remain in how different populations ultimately benefit. Recent assessments of the unequal burden of cancer in the U.S. point to gaps in understanding the causes of and solutions to health disparities and the need to improve translation of knowledge from basic research and population studies into effective interventions (Plan 1), in addition to improving the translation of evidence-based interventions (EBIs) tested in research into broad public health, primary care, and oncology specialty care practice (Plan 2).

Proposed Actions

Improve translation of knowledge from basic research and population studies into effective interventions through 1) development of a pilot community clinical program in an underserved area in Baltimore-Washington, 2) improved mapping and analysis of NCI's health disparities research portfolio, and 3) development of health disparities training programs for NCI intramural researchers.

1) Pilot Community Clinical Program in Baltimore-Washington

This proposed initiative will be modeled after the Center for Cancer Research's (CCR's) current partnership with the National Institute of Arthritis and Musculoskeletal Diseases (NIAMS) at the Community Clinic at Upper

* This topic was covered by two breakout groups. Plans 1 and 2 identify different priority areas within the topic area.

Cardozo, located in the multicultural Cardozo/Shaw neighborhood of Northwest Washington, D.C. The new proposed pilot program would establish a clinic in another underserved area of Baltimore-Washington. Under the pilot, NCI will partner with community physicians and organizations to provide cancer screening, evaluation, consultation, and enrollment into clinical treatment protocols to area residents. These patients are likely to present with multiple comorbid conditions, complicating treatment options and potential participation in clinical trials, and reimbursement issues may limit options for providing standard care.

Impact

- Serve as a model health program for the community.
- Provide access to the region's rich array of biomedical research institutions for cancer prevention and screening, evaluation, consultation, and enrollment into clinical trials for underserved residents.

Barriers Addressed

- The proposed clinical program will remove many practical barriers to care, including lack of transportation, inconvenient hours of service, and competing life demands for individuals it serves.
- To establish trust, the clinic will be staffed by members of the community in partnership with experts from NCI and local grantee institutions.
- Partners will develop new approaches to providing residents with access to culturally sensitive care, and methods to overcome such systems barriers as lack of coverage of standard care for patients on trials or those ineligible for participation.

Action Steps—Short Term

- Convene a trans-NCI working group of current community partners (Cardozo Community Clinic) and NCI experts, including those from CCR, CRCHD, and extramural divisions, to develop program concept and implementation plans.
- Hire a dedicated, full-time research clinician to coordinate the program.
- Establish partnerships with community leaders in the proposed neighborhood and larger Baltimore-Washington area to devise novel strategies to overcome barriers to providing patients with state-of-the-science care.
- Establish partnerships with biomedical institutions, NCI grantees such as those in the Community Networks Program, and

physician groups in the Baltimore-Washington area for patient treatment and referral.

- Develop outcome measures to evaluate progress and identify successful strategies and best practices that can be adapted for similar programs in other underserved communities.

Action Steps—Long Term

- Open clinic (approximately 2007)
- Conduct ongoing community education programs at clinic
- Evaluate clinical program for effectiveness
- Disseminate program results

Partnership Opportunities

- Experts from disciplines across the intra- and extramural programs to collaborate with community leaders and health care providers to refer patients for cancer screening, evaluation, consultation, and enrollment into clinical treatment protocols
- Federal and non-federal agency partners
- Biomedical research institution partners, including Community Networks Program grantees, Cancer Centers, and others
- Community physicians and other health care providers reached through Baltimore-Washington medical and health care provider associations

2) NCI Health Disparities Research Mapping and Analysis

This proposed initiative will refine coding and assessment of ongoing NCI research, including identification of key data variables. The analysis of NCI's health disparities portfolio prepared for the workshop presents only a partial picture of NCI-supported research in FY2004 and current coding does not accurately portray the scope of NCI's research to reduce cancer health disparities. Large, complex grants, such as Cancer Centers, Specialized Programs of Research Excellence (SPoREs), Program Project Grants (P01s), and cooperative agreements include multiple sub-projects which may not be coded and included in current grants data and are difficult to identify. Other tools, such as geographic information systems, provide resources to identify populations and regions of need so that research can be directed to addressing specific gaps.

Impact

Improving mapping and analysis of the NCI research portfolio will help to better characterize NCI research and activities related to understanding and reducing cancer health disparities. This will enhance strategic planning and improve our ability to evaluate progress to maximize the impact of ongoing health disparities-related programs.

Barriers Addressed

Common coding of health disparities research grants, cooperative agreements, and contracts will facilitate NCI's analysis of gaps in our health disparities portfolio and increase the number of intramural and extramural researchers who focus on disparities research.

Action Steps—Short Term

- Establish an interdisciplinary working group to be led and coordinated by the CRCHD
- Refine coding and assessment of ongoing research, including identification of key data variables
- Work with NCI data projects to integrate health disparities research information with other resources so that it can be maintained and updated regularly and considered in the full context of the NCI research portfolio
- Publish health disparities research portfolio analysis within six months

Action Steps—Long Term

- Update and release portfolio annually

Partnership Opportunities

- Interdisciplinary working group will include representatives from all NCI divisions
- Mapping project will be coordinated through CRCHD

3) Health Disparities Training Modules

This proposed initiative will help to educate NCI researchers across disciplines about the importance and opportunities in research on cancer health disparities.

Impact

Training modules will raise awareness of the relevance of all phases of the translational research continuum to understanding and eliminating disparities, and provide opportunities to recruit researchers into the cancer health disparities research community.

Barriers Addressed

Training can be developed as model programs to reduce health provider bias and/or lack of cultural awareness in communities that experience health disparities.

Action Steps—Short Term

- Establish working group
- Review existing training programs for researchers funded by NCI (e.g., R25-funded programs)
- Develop and/or adapt training curriculum to be piloted with NCI intramural investigators
- Schedule series of training programs

Action Steps—Long Term

- Conduct training programs starting in late 2006
- Evaluate and refine program based on participant feedback
- Make available to the extramural research community

Partnership Opportunities

Training will be available to all intramural research staff. The training program will be developed and implemented under CCR, DCEG, and CRCHD, with assistance from experts in the Office of Communications (OC), Office of Education and Special Initiatives (OESI), Cancer Information Service (CIS), and DCCPS.

Narrowing the Gap between Research and Practice: Plan 2**Defining the Need**

Communities affected by health disparities experience multiple challenges. Factors such as a low level of cancer research conducted in these communities, lack of trust among individuals both of the science and the source, and a corresponding low level of participation in research, are compounded by an inadequate infrastructure for delivering EBIs—interventions that have been proven through research to have a measurable effect—and limited knowledge of successful EBIs by program planners. Narrowing the gap between what is known to work in improving cancer outcomes from research and what is put into practice in high-risk communities requires a multiple-step approach by partners at all levels committed to reducing health disparities.

Proposed Action

Expand the development and evaluation of innovative approaches to integrate EBIs for populations experiencing health disparities across all service delivery levels, including community, public health practice, clinical practice, patients, and individuals at risk.

Impact of Proposed Action

- Increased understanding among scientists, researchers, community health workers, and program planners in high-risk communities where EBIs have been proven to decrease health disparities
- Increased understanding throughout NCI of the information, tools, and resources that communities would find most useful
- Increased willingness and trust of populations affected by health disparities to partner with NCI in research to reduce health disparities
- Increased number of organizations that adopt EBIs into their programs

Barriers Proposed Action Would Address

- Barriers of time, money, fear, mistrust, lack of direction, leadership, competition within NCI for funding, staff availability, and gaps in the evidence base, all inhibit the use of EBIs by communities affected by health disparities.
- Challenges in narrowing the gap between research and practice include rethinking how research is approached, reassessing how NCI chooses research partners and priorities, and strategically disseminating new tools and technologies to reduce disparities.
- NCI faces further challenges including cataloging existing research that has demonstrated impact in addressing disparities; ensuring that interventions are developed with these communities at the forefront; making research more applicable and closer to the ground; and identifying and building effective delivery mechanisms, or adapting interventions that have been proven to be successful in one population for a different community, without losing its effectiveness. The latter challenge is derived not simply from a lack of solutions, but a lack of research-tested models of knowledge translation and evidence-based service delivery in real-world settings.

Action Steps—Short Term

- Inventory existing evidence-based practices (EBPs) that have demonstrated impact on health disparities
- Conduct an evaluation of what key audiences impacted by health disparities want from NCI and the intervention research that NCI supports
- Work with non-traditional partners identified through CHCRD and NCI's Office of Cancer Complementary and Alternative Medicine (OCCAM) to increase NCI credibility about addressing health disparities and trust of research findings
- Work with OCCAM to develop partnerships with “traditional healers” who provide care in communities impacted by health disparities

Action Steps—Long Term

- Expand funding of dissemination and implementation research grants to increase knowledge on the adoption of EBPs
- Require, or provide supplements to, NCI-designated cancer centers to translate EBPs to eliminate local cancer health disparities beyond the patients seen in their own institutions
- Apply what is known from policy research (e.g., tobacco control) to influence policy makers

Partnership Opportunities

- Insights garnered from the Research Dissemination and Diffusion initiative involving DCCPS and OESI to close the gap from discovery to delivery in the general population will be adapted to identify EBIs among communities affected by health disparities. NCI will adapt this program to at-risk populations and share information with partnering organizations through meetings, workshops, and conferences.
- Education on the use of Cancer Control PLANET, another key resource from NCI's dissemination and diffusion activities, will be conducted with cancer control planners, program staff, and researchers to assist them in accessing evidence-based programs and products. Emphasis will be on using the Research-Tested Intervention Programs (RTIPs) Web site, Step 4 within PLANET, which provides an inventory of EBIs searchable by topic, age, race, ethnicity, and intervention setting.
- NCI will work with practitioners of traditional medicine identified through OCCAM.

- NCI will adapt its practice of partnering with other NIH Institutes and solicit grant applications with the intent of supporting innovative approaches to the adoption of EBIs. Adoption to date has been limited or significantly delayed.
- NCI will evaluate programs such as Cancer 101 and Body and Soul to determine their effectiveness, and based on these findings determine the level of expansion needed.

Other High-Priority Areas

- Identify and create EBIs that have demonstrated a positive effect in addressing health disparities.
- NCI must not only understand the needs of the community, it must adequately fund research that will address how to adapt and implement EBIs within community-based service settings. NCI must be committed to making the outcomes of its research available through expanded training grant opportunities to public health, primary care, and oncology specialty care practitioners within communities affected by health disparities.
- Overcoming societal/environmental barriers will require an active collaboration with community members, local health care providers, and researchers, as well as the flexibility to engage consumers through diverse and nontraditional outlets.

Clinical Trials

Defining the Need

Clinical trials represent a key approach to understanding and reducing cancer care and outcome disparities among racial/ethnic minorities and other special populations. Recruiting and accruing adequate numbers of individuals from minority racial and ethnic groups to NCI-funded clinical trials presents a significant challenge to both intramural and extramural researchers. It is important that patients understand the role clinical trials play in defining good evidence-based cancer care. Equally important is their understanding of the impact that this type of treatment can have on their prognosis.

Proposed Action

Elevate health disparities research as an academic discipline. Enhance individual, investigator, and community participation in clinical trials—with health disparity outcomes as the primary or secondary objective.

Impact of Proposed Action

Health disparities research must be elevated to a discipline in clinical science in the long term. Implementation will provide high-quality cancer care to a greater portion of underserved populations. Future NCI grant awards must be contingent on including this goal in grants.

Barriers Proposed Action Would Address

- Elevate the status of health disparities research, particularly among the cooperative groups
- Make necessary data available on minority participation and outcomes
- Encourage new studies on biological/genetic factors of health disparities
- Increase the number of faculty and clinical researchers in health disparities research
- Improve reimbursement for participation
- Increase recruitment of minority populations to clinical research

Action Steps—Short Term

- *Define and incorporate the discipline of health disparities research within the academic community.* Raise the levels of disparities research within the academic community and participating community investigators. Where appropriate, increase activities of health disparities subcommittees within the clinical trials cooperative groups that would result in protocols with primary or secondary health disparities objectives.
- *Identify scientific questions that affect minority and disadvantaged populations.* Studies defining biological and genetic differences within a population that may relate to socioeconomic status, comorbidity, and other factors would attract new investigators, researchers from cooperative groups, and more minorities to clinical trials.

Action Steps—Long Term

- *Conduct trials to evaluate health disparities interventions.* Examples include the role of navigator strategies; outreach coordinators; advocacy involvement in planning, peer review, and recruitment; and culturally competent outreach and language interpretation.
- *Annotate population registries and biological specimens with race, socioeconomic status, age, and other data.* This would ultimately result in possible biological explanations for racial/ethnic

disparities in clinical outcomes and support the study of emerging issues in minority populations, such as increasing incidence rates in certain cancer types that are not yet reflected in national databases.

- *Apply models to other health care delivery systems.* The Centers for Medicare & Medicaid Services (CMS), for example, has agreed to work with NCI to develop collaborative efforts to identify and initiate high-priority clinical trials in specific areas.
- *Increase health disparities clinical research training.* Recruit faculty and clinical investigators with an emphasis on developing a diverse staff; provide cultural competency training to physicians, researchers, and outreach staff; improve minority recruitment and support and enhance the progress from clinical trials to research and delivery.
- *Provide supplements to existing clinical trials programs to address health disparity interventions.* Issue Requests for Applications (RFAs) or Supplementals that recognize research in health disparities and will attract researchers to the field.
- *Develop an overarching plan to disseminate a specific type of research or recruitment model to other clinical trials.* Evaluate projects in terms of effectiveness and outcomes, and share information on lessons learned and barriers that need to be overcome; determine if the same successful model can be used in both prevention and treatment trials.
- *Promote a National Clinical Trials Participation Recognition Day.* The event would address the mistrust that minority groups hold about clinical research and recognize the significant role they play.
- *Partner with organizations to support prevention, treatment, and supportive care in clinical trial participation.* Develop interventions to address lack of public trust, and attempt to apply successful strategies from prevention trials to treatment trials for minority groups.
- *Create a Web site.* Support a network to facilitate communication among investigators about minority-related issues
- *Track the activities that have been implemented and share and disseminate results.*

Partnership Opportunities

- *Minority-Based Clinical Community Oncology Programs (MCCOPs).* Invite MCCOP principal investigators to meet with cooperative group chairs and the chairs of disease-specific and minority research committees to identify a core group of research questions for protocol development. Provide financial support for MCCOP investigators to design and conduct minority-focused clinical trials.
- *Clinical Community Oncology Programs (CCOP).* Facilitate the dissemination of minority-focused EBIs across the entire CCOP network; focus on clinical trials research and health disparities interventions within a large efficient cooperative group to go beyond lessons learned in health service delivery and recommend strategies that have worked in the field.
- *Cancer Therapy Evaluation Program (CTEP).* Disseminate the findings of the current “Overcoming Barriers to Clinical Trials Project” once the studies are completed and encourage investigators to apply for additional research projects that would further this research, especially to address those with advanced cancer, which is disproportionately found in minority populations.
- *Cancer Disparities Research Partnership (CDRP) of the Radiation Research Program.*
- *Patient Navigator Program.* Issue an RFA to study the issue of language barriers and the role of interpreters, test ideas within specific settings, and share findings.

Background

Certain populations are underrepresented in cancer clinical trials, including the elderly, those of low socioeconomic status, and those living in rural areas, as well as Latino/Hispanic, Asian/Pacific Islander and American Indian/Alaska Native men and women, and African-American men. Slow overall accrual means that the answers to important clinical trials questions are delayed. The low number of minority patients admitted to any one trial means that potentially important biological differences and genetic differences within a population may be obscured. However, the very small minority sample sizes in many trials make such observations difficult, if not impossible, to detect.

Recent expert recommendations to address low minority participation in clinical trials include:

- Developing well-designed, controlled studies of strategies to improve accrual to cancer prevention and treatment trials
- Creating success measures for recruitment of underrepresented populations as well as evaluation and reporting of recruitment results in a more consistent manner
- Designing relevant and pragmatic trials to address problems in underserved communities
- Ensuring community-based participatory research and community involvement through all phases of the research
- Including actual recruitment of underrepresented populations as a major outcome of cancer clinical trials and linking studies regarding barriers to accrual to the trial implementation

Sociocultural and Behavioral Influences: Plan 1*

Defining the Need

Sociocultural and behavioral (SCB) research contributes to the understanding of factors associated with disparities in cancer incidence and outcomes and the pathways that mediate these factors, and informs the development and testing of interventions to reduce cancer-related health disparities. To determine how SCB factors influence health disparities, it is essential to examine socioeconomic, psychosocial, and lifestyle variables that affect behaviors, susceptibility to cancer, and cancer outcomes. By more fully and systematically integrating the study and consideration of SCB

“Your work is meaningful to folks in churches, in community health centers, in the general U.S. population where this is really important. They are relying on us to be passionate about what we are doing and to make a difference.”

—Dr. Garth Graham

- Improving strategies to recruit African-American males and Hispanic men and women
- Investigating effective communication strategies on information delivery on clinical trials
- Building relationships with community members, including providers, before accrual
- Linking data collection about barriers and promoters of trial participation to concrete plans for intervention design to address barriers
- Developing cost-effective strategy to address barriers to care by comparing the efficacy of a recruitment intervention specialist to that of usual, opportunistic recruitment practices
- Linking efforts to improve enrollment of minority populations in cancer clinical trials with other initiatives designed to address cancer health disparities
- Developing effective mentoring programs to develop minority academic faculty and recruitment initiatives to hire minority faculty (Ford, et al., 2005; Christian & Trimble, 2003)

influences into NCI basic and clinical research, program planning, and development, NCI can dramatically increase the likelihood that scientific advances will be adopted in practice. Addressing health disparities in a comprehensive manner is a huge and overwhelming undertaking—there are countless U.S. populations varying in culture, age, and other factors. This issue needs to be addressed broadly and systematically to reach all groups and will need to be done in “bite-size pieces” with the ultimate goal of including SCB issues in NCI’s everyday work.

Proposed Action

Institutionalize a comprehensive and integrated process to include SCB variables when conceptualizing and developing research activities.

Impact of Proposed Action

The proposed action would enable NCI to improve and enhance the likelihood that scientific findings will be translated into interventions that are appropriate for

* This topic was covered by two breakout groups. Plans 1 and 2 identify different priority areas within the topic area.

groups that historically have poor cancer outcomes and are accepted and adopted for use in public health and medical practice.

Barriers Proposed Action Would Address

- New scientific advances would be disseminated for public health application by taking into account such issues as cultural sensitivity, economic feasibility, and other acceptance factors.
- Scientists would gain an in-depth understanding of the communities and thereby more effectively disseminate recommendations that are culturally sensitive and appropriate.
- Understanding SCB factors that influence screening uptake would increase the likelihood that effective tests will be used.
- Awareness would be raised about the impact that understanding SCB influences has on health disparities, reinforcing and recognizing NCI collaborations that address SCB factors.
- Surveys often measure health behaviors and utilization but do not probe into the “whys” of the responses. This approach limits the cultural meaning and understanding of the findings.
- Including SCB factors in cancer research could influence the political climate in which health messages are promoted and how.

Action Steps—Short Term

- Commission a systematic review of models and interventions from other disease areas that address SCB variables/barriers/successes.
- Create new methodologies to incorporate SCB issues into research and practice.
- Develop a model for NCI-wide integration, e.g., HPV vaccine/testing, clinical trial recruitment, tobacco control.
- Raise awareness of the impact SCB influences have in reducing health disparities.
- Demonstrate to NCI stakeholders how inclusion of SCB issues in research will increase the impact the research has on reducing health disparities.

Action Steps—Long Term

- Promote and/or establish early partnerships with underserved communities to inform research and disseminate effective interventions—“anticipatory collaboration.”
- Initiate SCB research that can and does inform policy to reduce health disparities.

- Recognize and reward NCI-wide collaborations that address SCB issues.
- Monitor and evaluate the impact of including SCB considerations/factors/expertise in the full spectrum of NCI activities/research.

Partnership Opportunities

- The Centers for Disease Control and Prevention (CDC) and other HHS agencies – Adapt strategies or best practices that address health disparities to enhance the information available to NCI and address health disparities in a more holistic manner.
- NCI’s CRCHD – Disseminate CRCHD qualitative research results from public and community gatekeepers that stress the benefit of and desire for social support, and distrust of “the system.”
- Community representatives – Continue to engage target communities to inform the development of cancer interventions and promote public ownership of, trust in, and adoption of new behaviors.
- NCI research directors – Incorporate SCB issues into current NCI research in trial recruitment, tobacco control, and HPV research, as well as intramural studies, e.g., inform strategies promoting the use of HPV vaccine or self-tests, when ready for dissemination.
- Across NCI – Provide comprehensive funding mechanisms to plan interventions on a structural level, enabling intra-NCI partnerships to further disparities research and intervention development; continue to host meetings similar to this workshop to inform NCI scientists across disciplines of projects with collaboration potential; and continually update programs in this area on progress to help build and maintain relationships across the Institute.

Sociocultural and Behavioral Influences: Plan 2

Defining the Need

Studies in the area of SCB influences on cancer health disparities focus on socioeconomic status, psychosocial factors, and lifestyle variables that are significant for healthy behaviors, susceptibility to cancer, and cancer outcomes. Topics in this area include the influence of social capital on the functioning of communities and individuals; the physical effects of inferior material conditions and their social meanings; the effects of social

injustice on risk factor behaviors, disease incidence, and stage of disease at diagnosis; and individual risk behaviors such as poor diet, lack of exercise, smoking, and alcohol abuse. While acknowledging a commitment to reducing cancer disparities, NCI scientists and researchers, for the most part, do not experience health disparities in this context and therefore require exposure and education on the SCB factors that influence cancer outcomes in at-risk populations.

Proposed Action

Develop a comprehensive, sustained, mandatory education program to address a perceived lack of SCB awareness among internal and extramural research personnel affiliated with NCI, including researchers, advocates, providers, community representatives, and lay health workers.

Impact of Proposed Action

This training and education program would improve understanding of how social and cultural factors affect health disparities across the entire cancer continuum and would address ways to remove barriers to health care. The proposed approach would make cross-NCI training mandatory (in the same way that ethics training is mandatory) to make cultural considerations and disparities part of the vocabulary of researchers as they identify areas of study and seek grants for application.

Barriers Proposed Action Would Address

- The lack of understanding across NCI on SCB issues that lead to cancer health disparities
- Fragmentation within NCI: not everyone at NCI realizes that sociocultural issues are central to addressing disparities

Action Steps—Short Term

- Convene working group to lead training initiative, including representatives from education, research, and social and cultural issues, as well as consumers, patients, providers, and targeted community members
- Develop training curriculum based on working group input

Action Steps—Long Term

- Hold first in series of training programs at NCI in second year
- Evaluate effectiveness of training (ongoing)

Partnership Opportunities

Potential partners in implementing the proposed education program include the Office of Liaison Activities (OLA) and OESI. The working group would:

- Consult with the *Consumer Advocates in Research and Related Activities (CARRA)* as a model for identifying and training individuals from diverse communities who could both perform health education in specific communities for NCI, and educate NCI about communicating appropriately and effectively with specific populations.
- Work with the Patient Navigator Program, or Culture Brokers, a framework from the mental health rehabilitation field that helps patients find their way in the medical system, to offer training in the context of culture that is meaningful to patients and families.
- Participate in, sponsor, or offer NCI speakers to the Intercultural Cancer Council's symposium on health disparities in April 2006. The symposium is expected to attract 2,000 people nationwide including legislators, NIH directors, grassroots advocates, and students.

Other High-Priority Area

- Develop programs to influence the current system of healthcare (from health promotion to treatment and follow-up) to allow for differences in perceptions and reactions by various groups to standard efforts of care. This is a health policy issue in that the system needs to change in order to incorporate awareness, understanding, and regard for sociocultural differences that affect use and compliance with programs.

Cancer Care Delivery

Defining the Need

Fragmentation in the organization, financing, and delivery of health care services in the U.S.—disproportionately high among low-income and minority communities—is a characteristic of the current health care system which underlies cancer-related disparities in prevention, diagnosis, treatment, and survivorship care. There is a need to identify and eliminate fragmentation of care delivery to underinsured and uninsured patients, including care surrounding abnormal test result follow-up, referral, use of proven and emerging therapies and technologies, and survivorship follow-up care planning.

Proposed Action

Establish initiatives across Public Health Service (PHS) agencies to promote the development of strategies that integrate cost-effective care to underserved communities and populations.

- Establish a research agenda focused on exploring the root causes of poor care coordination and follow-up along the entire cancer care continuum in underserved populations.
- Create innovative policies, programs, and models of care to improve cancer care coordination and follow-up.
- Identify key areas of fragmentation of cancer care delivery to underinsured and uninsured

Barriers Proposed Action Would Address

- A lack of resources at the community level would be addressed by directing resources toward the community itself and assessing local needs.
- A lack of access to primary care, difficulty navigating complicated care systems and inefficient and inconvenient health care systems would be studied.
- Programs will be implemented to ensure that abnormal test results during screening are followed up with treatment and strategies are put in place to ensure that once an individual starts treatment, he or she finishes it.

“ There is a disconnect between discovery and delivery. There are people who don’t get the benefits of the research that we do. That is a critical determinant in health disparities. ”

— Dr. Harold Freeman

patients—focusing on those covered by Medicaid and those “near poor” who do not qualify for Medicaid but lack adequate insurance coverage.

- Partner with other federal agencies to develop and implement programs.

Impact of Proposed Action

- The proposed action would help to increase use of preventive screening and treatment services; improve cancer care coordination; increase the potential to inform policy changes through the collection of cost-benefit data; and improve outcomes in mortality, quality of life, and satisfaction.
- Specific examples of outcome measures include delivery of cancer prevention services to “well” populations at high risk; ensuring follow-up of abnormal screening test results, appropriate and timely referral to cancer specialists at the time of initial diagnosis, the use of proven and newly emerging therapies and technologies, and the coordination of survivorship follow-up care planning.

Action Steps—Short Term

- Establish a cross-agency working group
- Evaluate existing programs and research aimed at care coordination
- Coordinate efforts to improve integration of cancer care delivery via the existing trans-NCI Cancer Care Delivery and Outcomes Group (CCDOG)
- Plan development of cost-effective strategies that integrate care delivery (e.g., telemedicine).

Action Steps—Long Term

- Develop new large cohort studies with other PHS agencies to examine best practices to ensure access to prevention and treatment care for all and, using the Geographic Information System (GIS), target the availability of provider resources to those areas experiencing the highest excess mortality rates.

Partnership Opportunities

- The Health Resources and Services Administration (HRSA), CDC, and CMS – Develop a model care system, using cervical or colorectal cancer as a model for a successful care delivery continuum, integrating federal agencies through existing programs that address health care fragmentation issues.

- HRSA's Office for the Advancement of Telehealth and Office of Rural Health Policy, or the Alaska Federal Health Care Access Network – Partner with these groups to examine the role of telemedicine in the development of integrated cancer care systems.
- NCI's Body & Soul Program – Expand beyond government partners to the community and family levels.
- The Surveillance, Epidemiology, and End Results (SEER) Program – Collect data on underinsured and uninsured populations that do not qualify for Medicaid or Medicare, and analyze state cancer registry, including SEER, data over extended periods to better understand under- and over-testing.
- U.S. Department of Veterans Affairs (VA) – Collect data on the differences in care among systems administered by the VA and CMS
- The cancer Biomedical Informatics Grid (caBIG) – Build upon its infrastructure by capturing treatment information to aid in better understanding racial/ethnic differences in cancer risk via patient-level genetic or molecular information.

Education and Training for Cancer Care Professionals and Researchers

Defining the Need

Significant gaps exist in educating and training cancer care professionals and researchers about health disparities. Contributing to the gaps are an absence of systems within NCI to clearly define, track, and assess health disparities research and training projects and a dearth of mechanisms and approaches to educate and train clinicians on the front lines of cancer care delivery.

Proposed Action

Broaden NCI's education and training efforts in health disparities to audiences beyond researchers to include health care practitioners. Dedicate more resources to enhance knowledge and skill of cancer care professionals in general, with emphasis on improving cultural competence among physicians, nurses, pharmacists, and other health care professionals, as well as trainees in pursuit of a health care career focused on cancer control.

Impact of Proposed Action

- Training would define specific and relevant issues contributing to cancer health disparities
- Effectively communicate and build trust with minority and economically disadvantaged patients
- Understand the differences in cancer epidemiology and treatment efficacy among various racial and ethnic groups
- Appreciate patients' cultural backgrounds and behaviors—acknowledging that professionals' own backgrounds might conflict—and work toward cultural competence in their cancer care practice

Barriers Proposed Action Would Address

Training would alleviate:

- A lack of information available to health care providers about specific problems contributing to disparities in cancer care and methods for eliminating these disparities
- A lack of a clear definition of health disparities research and a coordinated tracking system; this may be attributable, at least in part, to privacy concerns associated with identifying the investigators conducting health disparities-related research

Because NCI's education and training focus has traditionally been on researchers, the proposal to significantly focus training toward health care deliverers is a major challenge, particularly in resource-limited times. Nevertheless, the current culture, with its emphasis on health care delivery of therapies to complement the discovery and development processes, provides a prime opportunity to strive for a balance in focus. Such attention could serve to increase providers' efforts to address issues and modify systems and environments to better serve the needs of groups of patients most vulnerable to cancer.

Action Steps—Short Term

- Assess opportunities to forge fruitful partnerships within and beyond NCI
- Evaluate existing education/training funding mechanisms and their capacities to address health disparities
- Develop a research agenda to define the role of education and training in reducing cancer disparities

Action Steps—Long Term

- Build cancer care education/training models for disseminating information and evidence, building skills, and changing delivery practices in ways that contribute to the reduction of disparities

Partnership Opportunities

- Successful government and private-sector interventions already in place, including NCI's Cancer Collaborative to reduce breast, cervical, and colon cancer mortality by helping clinicians to close the gap between levels of cancer screening and follow-up in underserved people and the general U.S. population
- NCI-supported EPEC-O project, an expansion of the Education for Physicians on End-of-Life Care project targeted to oncology professionals
- The Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium initiative of NCI's DCCPS
- NCI's Patient Navigator Program
- An enhancement of NCI's continuing medical education offerings, "Physician Data Query" (PDQ) database; and the NIH-wide Quality Cancer Care Committee task force

Other High-Priority Area

A subordinate issue identified by the breakout group is the lack of data to determine what is actually occurring in the area of cancer health disparities research. The breakout group broke this issue down into sub-issues including NCI's lack of a useful method to track existing health disparities research projects and an inability to elucidate what constitutes cancer health disparities research. The group's proposed solution involved fashioning a Request for Application-type mechanism to increase education/training funds designated specifically for health disparities research. This approach would provide distinct funding for researching education and training approaches that have the greatest potential for impacting health disparities, while clarifying what qualifies as disparities research so that individuals impacted can be trained accordingly. Also, this would provide a simple method to follow projects to their conclusions and beyond.

Communications Research

Defining the Need

What are the most effective ways to communicate health information with at-risk populations? How does NCI ensure that effective communications initiatives, proven to be effective, are implemented in the community? Who at NCI is conducting research into these issues? The bridge between research and application needs to be supported so that the many interventions supported by NCI are informed by research on the most effective ways to communicate with at-risk populations, taking into account cultural competencies and health literacy. Within NCI, there is a need to know more about what others are doing in the area of communications on cancer health disparities in order to better collaborate and integrate resources.

Proposed Action

Synthesize results from communications research into effective strategies for reaching populations experiencing health disparities.

Impact of Proposed Action

This action would use knowledge gained from communications research to develop, implement, and disseminate effective interventions and appropriate health and scientific information to eliminate health disparities. NCI and practitioners will develop better communications activities targeting populations suffering from cancer health disparities.

Barriers Proposed Action Would Address

- Dissemination of best practices would help researchers and planners understand the language, images, and messages that will resonate with a particular group; ensure that materials are presented in a manner that can be understood by people with low literacy in English and/or another language; and use the appropriate channels to reach people, including "low tech" methods of communication.
- Knowledge of the full universe of NCI-sponsored communications research activities would allow for greater coordination and would lessen confusion among the public over cancer news and information.

Action Steps—Short Term

- Enhance internal communications about communications research and activities to more effectively collaborate and integrate resources.
- Develop a process for synthesizing communications research and research that focuses on communicating with populations suffering from cancer health disparities. Such a process would identify the scope of such a synthesis project including research questions of interest and inclusion/exclusion criteria. In addition, efficient and
- Work with the Trans-NCI Health Communication Research Activities Group and Trans-NCI Health Disparities Interest Group to enhance internal communications about communications research and activities to more effectively collaborate and integrate resources.
- Partner with OC to use its new Intranet as a method of information exchange about health disparities communications efforts; list brief annotations and contact information for each activity.

“ NCI leadership attended the workshop and voiced the need for us to communicate better across all divisions in health disparities. ”

—Workshop Participant

effective methods for conducting this synthesis project should be explored. For example, should NCI contract with a group such as the Cochrane Collaborative, which specializes in reviewing research, or should NCI attempt to nurture this expertise internally?

- Disseminate findings from the research synthesis both internally and externally, particularly among staff who are not health communicators.

Action Steps—Long Term

- Develop NCI experts who are knowledgeable about evidence-based communication approaches and can assist in the development of NCI initiatives related to health disparities.

Partnership Opportunities

While OC and OESI have leading roles to play in communicating about cancer health disparities, many NCI divisions, offices, and centers are involved with communicating with the public, or with those who interact with the public (media, health care providers, community organizations, and others).

- Work with Cancer Control PLANET to identify peer-reviewed research articles on communications interventions that have been considered effective.
- Collaborate with DCCPS to foster information exchange through a publication similar to “Recent Staff Publications and Contacts on Health Disparities.”
- Partner with regional organizations through CIS.
- Tap expertise of communication researchers in areas of health communications beyond cancer, as well as communications research beyond health, including audience analysis by the drug, alcohol, and tobacco companies.
- Review preliminary results from ongoing studies. Use a formative research compendium compiled by OESI (soon available online).

Next Steps

Based on input from workshop participants, a high level of enthusiasm exists around continuing to work together as an Institute to reduce cancer health disparities. Three major “next steps” evolved from the workshop.

1. ***Create an I2 Team for Health Disparities.*** The overarching vision generated from the workshop and the action plans should be considered in the assessment and business plan development processes of an I2 Team. The I2 Team should look for synergies and duplication of efforts among the various plans

- Publishing a periodic update on NCI health disparities initiatives for internal and external distribution. Using the list of initiatives compiled for the workshop as a platform, the newsletter or bulletin would keep NCI staff informed of programs and encourage trans-NCI collaboration.
- Assessing needed staff, financial, and infrastructure resources and continuing existing and new activities to coordinate health disparities efforts within NCI.

“ This was a great start.
We need to keep the momentum going. ”

—Workshop Participant

and emerge with one multidisciplinary approach to reducing cancer health disparities in the U.S.

2. ***Elevate Health Disparities Research Across the Institute.*** NCI should commit to integrating the elimination of cancer health disparities into the NCI mission and into all major NCI initiatives.

3. ***Maintain Momentum***

A. The workshop planning committee recommends that the executive committee or senior management team identify an infrastructure to maintain the momentum gained by the workshop. This structure could be a newly formed small or existing working group of committed staff members from across the Institute charged with:

- Maintaining an Intranet portal to post all materials gathered for and supporting the workshop (underway) and to capture forthcoming NCI-wide efforts to reduce cancer health disparities.
- B. NCI should establish a mechanism for streamlining future proposed approaches and technologies that serve to rapidly impact cancer health disparities. These initiatives should be practical, short term, and easily accomplished; identified through Institute-wide electronic brainstorming sessions; and filtered by the executive committee. In addition, NCI should continue its efforts to strongly advocate for continued actions related to the implementation of recommendations from the Trans-HHS Cancer Health Disparities Progress Review Group.

In Conclusion: Emerging Themes in Cancer Health Disparities Research

Major Themes Emerging from the Workshop

Several critical themes emerged from careful consideration and analysis of the questions, comments, and discussion during the plenary and breakout sessions. These themes are essential for NCI to consider in evolving its strategic objective for overcoming cancer health disparities

Incorporate the elimination of cancer health disparities into “what we do”

Participants and presenters expressed the need for a paradigm shift at NCI to examine the fundamental issues of access, fairness, and education as they relate to research, cancer care, and training, as evidenced in the following statements:

- The time has come for health disparities to be elevated to a formal research discipline.
- Because overcoming health disparities is one of eight objectives in NCI’s strategic plan, we must integrate components of health disparities research in all major NCI-funded programs.
- NCI must look beyond its gates to make what we do available to more people in our own backyard. We could do a better job of sharing our expertise and resources with at-risk populations in the Baltimore-Washington area through partnerships and programs, including establishment of a community clinic to serve at-risk neighbors.

Gain a better understanding of what we fund in health disparities

The review of the MHHD Portfolio Analysis was eye opening. Many comments centered on the need to continue to analyze and refine the portfolio on a regular basis. Discourse on this topic included:

- Better systems for data capture and management are needed to move us forward in understanding our own contributions to reducing health disparities.

- We know that 5.6 percent of the NCI budget was spent on health disparities in 2004. The questions are: How much should we be investing in health disparities research, and what will it take to make a significant impact toward reducing disparities? We need to consider the quality and quantity of research and whether we are generating the most appropriate innovations for addressing disparities.

Become more socially just in our research and practice

A theme introduced by Dr. Harold Freeman and threaded throughout workshop discussions was the commitment of social justice in our strides to reduce cancer health disparities. Sentiments reflected in the following statements are examples of a strong voice supporting a socially just approach to guide NCI efforts and initiatives on health disparities.

- Are the audiences we wish to affect involved in setting the research agenda?
- While investments in cancer control abroad are notable, such investments might detract from resources needed to meet the critical needs for vulnerable U.S. populations, such as those in the Mississippi Delta and remote areas with limited access to basic cancer control services.
- We must remove barriers that prevent the benefits of research from reaching all populations—if innovations are not applicable to the most vulnerable, they are socially unjust.

Align community issues with what we do

Participants stressed the need for constant interaction with the communities we wish to affect, both to learn what is needed and how best to deliver services.

- Is our science aligned with what the community wants, needs, and desires? Are our macro strategies aligned with what society needs? For example, if we invest heavily in expensive drugs that only 10 percent of the population can afford, shouldn’t we consider ways to match complex problems with effective interventions that can be delivered more cost effectively?

Increase attentiveness to evaluation of our work in health disparities

The need for greater focus on evaluation was a consistent theme. Comments were directed toward increasing NCI's evaluation efforts in the area of health disparities research and reinforcing systems supporting our ability to evaluate progress.

- We need to know what works in overcoming health disparities and divert investment in initiatives that have not been proven to work. By investing in the science of evaluation we can avoid reinventing the same approaches without an understanding of their impact.
- With the investments made in NCI's Comprehensive Cancer Centers, NCI should be able to systematically collect information that, in its aggregate, can reveal more than it could in any one center. Systematically collecting center data on accrual and participation of specific populations to studies would be beneficial in understanding our impact and reach in clinical research into health disparities.
- Policy decisions must be data driven. We need to be able to present policymakers with accurate, thorough data that reveal successes and promises in cancer control and treatment. More importantly, this information must be presented in clear and simple language that policymakers can use to develop fair and effective policies.

A diverse workforce and evaluation of training initiatives are needed

Training and development cut across several topics. Several concepts were put forward:

- Due to insufficient data systems, NCI is unable to fully understand the impact of its training and development activities. Office of Management and Budget (OMB) rules limit our ability to systematically follow up with those we train and restrict our progress toward increasing workforce diversity. Increased diversity may contribute to increased research projects that focus on disparities or minority communities.
- Because reports capture only those trained in programs that target minorities, we are unable to ascertain the number of individuals from diverse backgrounds that benefit from NCI-sponsored training initiatives.
- While there is broad support for training, we lack a clear understanding of how training for disparities research differs from training for general research. Are there specific training needs for those who intend to devote their careers to the study of health disparities? If so, we need to assure that NCI training endeavors strive to fulfill them. Likewise, there is support for complementing all training with elements of increasing cultural competency in research and practice.
- Tying back to the theme of social justice, there is a need for introspection, starting with advancement opportunities for NCI's own staff. NCI's internal actions with regard to garnering security in the future of individuals (A76 issues) and workforce development (restoring a career ladder) were cited as putting our commitment to social justice into action.

Seize the power of collaboration through support of team science

In alignment with the workshop theme, considerable emphasis was placed on working smarter, defined as consideration for how NCI might better coordinate efforts and take advantage of information already available to us. Concepts addressed opportunities for greater collaboration:

- Recognize that a substantial investment of NCI resources is in the cancer centers and SPORE programs. We should be able to expect more in return with regard to understanding the contributions they make toward reducing cancer disparities, and to capturing data on the number of diverse populations participating in both general and health disparities research.
- To better plan health disparities activities, a comprehensive inventory of current efforts, roles, skills, and structures throughout NCI, as presented through this workshop, should be developed and updated on a regular basis.
- Given that health disparities occur across disease states, we should collaborate with other NIH Institutes. Because people are whole and complex beings, we should consider who we are trying to reach, what other Institutes are striving to reach the same audiences, and how we can partner in our combined quest to improve health status.
- Periodically, the Institute needs to pause and examine what positive contributions are being made and structure awards and rewards accordingly.

“ The unequal burden of disease in society is a scientific challenge, but it is also a moral and ethical dilemma. Scientific truth must always be wed to social justice. ”

— Dr. Harold Freeman

**“ This was a long overdue event. Please do not
let this be the first and last workshop. ”**
—Workshop Participant

Final Word: A Vision for Overcoming Cancer Health Disparities

As evidenced throughout the workshop, NCI is passionate about working together to reduce cancer health disparities. This is not only a moral and ethical dilemma but part of NCI's core mission as articulated in its 2006 Strategic Plan.

The following vision statement is presented by the planning committee as a committed group of scientists, researchers, communicators, and administrators working together to close the gap in health disparities.

Vision:

NCI Will Lead the Nation's Effort to Overcome Cancer Health Disparities

Goals to Achieve the Vision:

- **Actively incorporate** the elimination of health disparities into "what we do."
- **Define and establish** health disparities as a formal research discipline and as a cross-cutting need across all research areas, making it a requirement for many NCI funding mechanisms.
- **Consistently align** community research problems with discovery research expertise.
- **Seize** the power of collaboration by effectively communicating advances in health disparities research and encouraging bold new initiatives across disciplines by supporting and rewarding team science and multidisciplinary approaches to health disparities research.
- **Strive** for social justice and equality: Define, implement, and integrate successful programs to reduce or eliminate health disparities into everyday practice to reach all populations.
- **Fully support** a diverse workforce internally and externally as evidenced by training for career advancement and cultural competence.

Appendix A: Workshop Agenda

Thursday, November 17

All activities will occur in the Main Auditorium except the Poster Session, which will be held in the Atrium.

7:00–8:00 a.m.	Registration
8:00–8:15 a.m.	<p>Call to Order Lenora Johnson</p> <p>Welcome Mark Clanton Deputy Director, Cancer Care Delivery Systems, NCI</p>
8:15–8:25 a.m.	Purpose and Charge to Participants L. Michelle Bennett
8:25–9:40 a.m.	<p>SESSION 1: Background and Where We Are Today <i>Moderator:</i> Mark Clanton</p> <p>Health Disparities Today Robert Croyle</p> <p>Recommendations to Reduce Cancer Health Disparities: Past, Present, Future Harold Freeman Garth Graham</p> <p>Portfolio Analysis Pebbles Fagan and Barbara Wingrove</p>
9:40–10:10 a.m.	Q&A with Panel <i>Moderator:</i> Mark Clanton
10:10–10:25 a.m.	Break
10:25–11:45 a.m.	<p>SESSION 2 – PART A: State of the Science in Health Disparities across NCI – Most Promising, Effective, Innovative Practices and Initiatives</p> <p>Presentations from NCI Centers, Offices and Divisions <i>Moderator:</i> Joseph Fraumeni</p> <p>DCEG – Joseph Fraumeni CCR – Robert Wilttrout DCB – John Cole DCP – Peter Greenwald DCTD – Frank Govern</p>
11:45 a.m.–12:15 p.m.	<p>Panel Discussion with Session 2 Part A Presenters <i>Moderator:</i> Joseph Fraumeni</p> <p><i>Panelists:</i> Robert Wilttrout, Joseph Fraumeni, John Cole, Peter Greenwald, Frank Govern</p>
12:15–1:45 p.m.	Lunch and Poster Session

Thursday, November 17 (cont.)	
1:45–3:00 p.m.	<p>SESSION 2 – PART B: State of the Science in Health Disparities across NCI – Most Promising, Effective, Innovative Practices and Initiatives</p> <p>Presentations from NCI Centers, Offices and Divisions <i>Moderator:</i> Robert Croyle</p> <p>DCCPS – Robert Croyle CRCHD – Nada Vydelingum OCCAM – Jeffrey White OLA – Brooke Hamilton and James Hadley OESI – Lenora Johnson</p>
3:00–3:30 p.m.	<p>Panel Discussion with Session 2 Part B Presenters <i>Moderator:</i> Robert Croyle</p> <p><i>Panelists:</i> Robert Croyle, Nada Vydelingum, Jeffrey White, Brooke Hamilton, James Hadley, Lenora Johnson, Paulette Gray (DEA)</p>
3:30–3:45 p.m.	<p>Break</p>
3:45–5:00 p.m.	<p>SESSION 2 – PART C: State of the Science in Health Disparities across NCI – Most Promising, Effective, Innovative Practices and Initiatives</p> <p>Presentations from NCI Centers, Offices and Divisions <i>Moderator:</i> Nelvis Castro</p> <p>OC – Mary Anne Bright OSPA – Cherie Nichols OWD – Teresa Estrada OCTR – Ernie Hawk NCICB – Ken Buetow</p>
5:00–5:30 p.m.	<p>Panel Discussion with Session 2 Part C Presenters <i>Moderator:</i> Nelvis Castro</p> <p><i>Panelists:</i> Nelvis Castro, Mary Anne Bright, Cherie Nichols, Leon Espinoza, Teresa Estrada, Sanya Springfield, Ken Buetow</p>
5:30 p.m.	<p>Concluding Remarks for Day 1 Dr. John E. Niederhuber Deputy Director, NCI Deputy Director, Translational and Clinical Sciences, NCI</p>

Friday, November 18

8:00–8:10 a.m.	<p>Reconvene/Announcements Lenora Johnson</p>	Main Auditorium
8:10–9:00 a.m.	<p>SESSION 3: Sharing the Promises for Discovery, Development and Delivery through Partnerships <i>Moderator:</i> Sanya Springfield</p> <p>Comprehensive Cancer Control Jon Kerner</p> <p>Trans-HHS Quality Cancer Care Committee Rochelle Rollins</p> <p>Minority-Serving Institutions/Cancer Center Partnership Sanya Springfield</p>	Main Auditorium
9:00–9:15 a.m.	<p>Workgroup Charge L. Michelle Bennett</p>	Main Auditorium
9:15–9:30 a.m.	Break	
9:30 a.m.–12:00 p.m.	<p>SESSION 4: Breakout Sessions</p> <p>Communications research – A <i>Co-Chairs:</i> Mary Anne Bright Linda Squiers</p> <p>Communications research – B <i>Co-Chairs:</i> Nelvis Castro Sabra Woolley</p> <p>Genetic and biological differences – A <i>Co-Chairs:</i> Linda Brown Douglas Figg</p> <p>Genetic and biological differences – B <i>Co-Chairs:</i> John Cole Nada Vydelingum</p> <p>Sociocultural and behavioral influences – A <i>Co-Chairs:</i> Kathie Reed Helen Meissner</p> <p>Sociocultural and behavioral influences – B <i>Co-Chairs:</i> Suzanne Heurtin-Roberts Ken Chu</p> <p>Education and training for cancer care professionals and researchers <i>Co-Chairs:</i> Lenora Johnson Vi Black Belinda Locke</p>	<p>Natcher – Room B</p> <p>Natcher – Room A</p> <p>Building 10, Room 2C118</p> <p>Building 10, Room 2C116</p> <p>Natcher – Rooms G1 & G2</p> <p>Natcher – Room F</p> <p>Building 10, Room 2S235</p>

Friday, November 18 (cont.)

	<p>Narrowing the gap between research and practice – A <i>Co-Chairs:</i> Anna Levy Richard Alexander</p> <p>Narrowing the gap between research and practice – B <i>Co-Chairs:</i> Pebbles Fagan Jon Kerner</p> <p>Clinical trials <i>Co-Chairs:</i> Wortia McCaskill-Stevens JoAnne Zujewski Martin Gutierrez</p> <p>Care systems research <i>Co-Chairs:</i> Barbara Wingrove Rochelle Rollins Arnie Potosky</p>	<p>Natcher – Rooms C1 & C2</p> <p>Natcher – Room D</p> <p>Building 50, Room 1328</p> <p>Building 10, CRC, Room 3-2550</p>
12:00–1:00 p.m.	Lunch	
1:00–4:00 p.m. (a 15-minute break around 3:00 p.m.)	<p>SESSION 5: Report Back to the Full Meeting <i>Moderators:</i> L. Michelle Bennett and Lenora Johnson</p> <p>Communications research</p> <p>Genetic and biological differences</p> <p>Sociocultural and behavioral influences</p> <p>Education and training for cancer care professionals and researchers</p> <p>Narrowing the gap between research and practice</p> <p>Clinical trials</p> <p>Care systems research</p>	Main Auditorium
4:00–4:20 p.m.	<p>SESSION 6: NCI's Commitment to Reducing Health Disparities Joseph Fraumeni Robert Croyle Sanya Springfield</p>	Main Auditorium
4:20 p.m.	<p>Concluding Remarks and Adjournment L. Michelle Bennett and Lenora Johnson</p>	Main Auditorium

Appendix B: Workshop Participant List

NCI Health Disparities Workshop Registrant List

José Acosta	Office of Communications	David Berrigan	Division of Cancer Control and Population Sciences
Tanya Agurs-Collins	Division of Cancer Control and Population Sciences	Ken Bielat	Division of Extramural Activities
Demetrius Albanes	Division of Cancer Epidemiology and Genetics	Vi Black	Center for Cancer Research
H. Richard Alexander	Center for Cancer Research	Gail Blaufarb	Division of Extramural Activities
James Alexander	Office of Communications	Mary Blehar	Office of Centers, Training and Resources
Mark Alexander	Division of Cancer Control and Population Sciences	Michele Bloch	Division of Cancer Control and Population Sciences
Lynn Amende	Division of Extramural Activities	Bonny Bloodgood	Center to Reduce Cancer Health Disparities
William Anderson	Division of Cancer Epidemiology and Genetics	Donna Bonner	Office of Communications
J. Fernando Arena	Division of Cancer Control and Population Sciences	Laura Boyle	Office of Education and Special Initiatives
Cheryl Arenella	Office of Education and Special Initiatives	Nancy Breen	Division of Cancer Control and Population Sciences
Michael Arluk	Office of Communications	Erica S. Breslau	Division of Cancer Control and Population Sciences
Janet Ayres	Office of Women's Health, OSPA	Mary Anne Bright	Office of Communications
Cathy Backinger	Division of Cancer Control and Population Sciences	Melissa Bronez	Center for Cancer Research
Charles Baffi	Health Promotion Research Branch	Diane Bronzert	Division of Extramural Activities
Tai Baker	Office of Cancer Complementary and Alternative Medicine	Linda Brown	Division of Cancer Epidemiology and Genetics
Rachel Ballard-Barbash	Division of Cancer Control and Population Sciences	Martin Brown	Division of Cancer Control and Population Sciences
Marc Ballas	Center for Cancer Research	Teri Brown	Office of Centers, Training and Resources
Jamelle Banks	Office of Science Planning and Assessment	Gail Bryant	Division of Extramural Activities
Dalsu Baris	Division of Cancer Epidemiology and Genetics	Kenneth H. Buetow	Center for Bioinformatics
Jill Bartholomew	Office of Education and Special Initiatives	Ilene Holly Burstyn	Office of Communications
Lisa Beauvois	Neuro Oncology Branch	Dionne Burt	Center to Reduce Cancer Health Disparities
Shannon Bell	Office of Workforce Development	Beth Buschling	Division of Extramural Activities
Tammie Bell	Office of Management Analysis	Victoria Butz	Center to Reduce Cancer Health Disparities (contractor)
L. Michelle Bennett	Center for Cancer Research	Tyane Calhoun	Center for Cancer Research

Philip Castle	Division of Cancer Epidemiology and Genetics	William Figg	Center for Cancer Research
Nelvis Castro	Office of Communications	Melizza Ford	Cancer Therapy Evaluation Program (contractor)
Kenneth Chu	Center to Reduce Cancer Health Disparities	Joseph F. Fraumeni, Jr.	Division of Cancer Epidemiology and Genetics
Mark Clanton	Cancer Care Delivery Systems	Neal Freedman	Division of Cancer Epidemiology and Genetics
Lin Clegg	Division of Cancer Control and Population Sciences	Dan Gallahan	Division of Cancer Biology
John Cole III	Division of Cancer Biology	Roland Garcia	Center to Reduce Cancer Health Disparities
Leslie Cooper	Center to Reduce Cancer Health Disparities	LaShell Gaskins	Comprehensive Minority Biomedical Branch
Luis Cordeiro	Division of Cancer Treatment and Diagnosis	Nina Ghanem	Office of Communications
Robert Croyle	Division of Cancer Control and Population Sciences	Jacquelyn Goldberg	Cancer Therapy Evaluation Program
Louise Cunningham	Office of Education and Special Initiatives	Jorge Gomez	Office of Centers, Training and Resources
Jane Daye	Center to Reduce Cancer Health Disparities	Nina Goodman	Office of Education and Special Initiatives
Candace Deaton	Office of Communications	Rashmi Gopal-Srivastava	Office of Centers, Training and Resources
Jean Decker	Center for Cancer Research	Lester Gorelic	Office of the Deputy Director for Extramural Science
Rhonda DeJoyce	Office of Education and Special Initiatives	Frank Govern	Division of Cancer Treatment and Diagnosis
Andrea Denicoff	Cancer Therapy Evaluation Program	Paulette Gray	Division of Extramural Activities
Susan Devesa	Division of Cancer Epidemiology and Genetics	Amanda Greene	Center to Reduce Cancer Health Disparities
Jim Dickens	Office of Budget & Financial Management	Peter Greenwald	Division of Cancer Prevention
Mary DiGaudio	Division of Cancer Control and Population Sciences	Addison Greenwood	Office of Communications
Ivan Ding	Office of Centers, Training and Resources	Lynette Grouse	Office of Communications
Clarissa Douglas	Research Analysis and Evaluation	Barbara H Guest	Division of Cancer Control and Population Sciences
Taira Duncan	Office of Education and Special Initiatives	Anjan Guhathakurta	Center for Cancer Research
David Eckstein	Cancer Training Branch	Martin Gutierrez	Center for Cancer Research
Regina el Arculli	Officer of the Director	James Hadley	Office of Liaison Activities
Nancy Emenaker	Division of Cancer Control and Population Sciences	David Haggstrom	Applied Research Program
Jennifer Eng-Wong	Medical Oncology Branch	Brooke Hamilton	Office of Liaison Activities
Leon Espinoza	Office of Workforce Development	Camille Hammond	Office of Cancer Survivorship
Teresa Estrada	Office of Workforce Development	Bethany Hanna	Office of Education and Special Initiatives
Pebbles Fagan	Division of Cancer Control and Population Sciences	Brooke Hardison	Office of Workforce Development
		Virginia Hartmuller	Division of Cancer Control and Population Sciences

Ernest Hawk	Office of Centers, Training and Resources	Edward Kyle	Division of Extramural Activities
Kimberly Henderson	Center to Reduce Cancer Health Disparities	Madeline LaPorta	Office of Communications
Marianne Henderson	Division of Cancer Epidemiology and Genetics	Kelli Langley	Division of Cancer Epidemiology and Genetics
Suzanne Heurtin-Roberts	Division of Cancer Control and Population Sciences	Colleen Lee	Office of Cancer Complementary and Alternative Medicine
Dorie Hightower	Office of Communications	Simon Craddock Lee	Division of Cancer Control and Population Sciences
Christine Holmberg	Division of Cancer Prevention	Mary Leveck	Office of Science Planning and Assessment
Gibran Holmes	Center for Cancer Research	Anna Levy	Office of Science Planning and Assessment
Ami Hurd	Division of Cancer Control and Population Sciences	Belinda Locke	Comprehensive Minority Biomedical Branch
Jane Jacobs	Office of Liaison Activities, OD	Douglas Lowy	Center for Cancer Research
Diana Jeffery	Division of Cancer Control and Population Sciences	Anne Lubenow	Office of Communications
Jose Jeronimo	Division of Cancer Epidemiology and Genetics	Francis X. Mahaney, Jr.	Center to Reduce Cancer Health Disparities
Lenora Johnson	Office of Education and Special Initiatives	Richard Manrow	Office of Communications
Maureen Johnson	Office of the Director	Patricia G. Marek	Division of Extramural Activities
Kay Johnson-Graham	Office of Equal Employment Opportunity	Padma Maruvada	Division of Cancer Prevention
Rachel Johnston	Office of Strategic Management Planning	David Maslow	Division of Extramural Activities
Jacquin Jones	Center for Cancer Research	Holly Massett	Office of Education and Special Initiatives
Abigail Joyce	Office of Communications	Christine McCann	Center to Reduce Cancer Health Disparities
Carol Kasten	Division of Cancer Control and Population Sciences	Worta McCaskill-Stevens	Division of Cancer Prevention
Mary Kelley	Office of Communications	Lois McCourt	Office of Liaison Activities
Jon Kerner	Division of Cancer Control and Population Sciences	Lisa McCoy	Office of Education and Special Initiatives
Aimee King	Office of Communications	Paige McDonald	Division of Cancer Control and Population Sciences
Julaine King	Center to Reduce Cancer Health Disparities	Devon McGoldrick	Office of Liaison Activities
Kristin Kiser	Division of Cancer Epidemiology and Genetics	Moira McGuire	Center for Cancer Research
LaTonya Kittles	Office of Communications	Ilda McKenna	Division of Extramural Activities
Marianne Kost	Office of Science Planning and Assessment/OD	Susan McMullen	Center for Cancer Research
Susan Krebs-Smith	Division of Cancer Control and Population Sciences	Nicole McNeil	Center for Cancer Research
Lisa Krueger	Division of Extramural Activities	Kathryn McNeill	Division of Cancer Control and Population Sciences
Jennifer Kwok	Center for Cancer Research	Stephen Meersman	Division of Cancer Control and Population Sciences
		Genevieve Medley	Office of Science Planning and Assessment

Helen Meissner	Division of Cancer Control and Population Sciences	Judy Patt	Office of Communications
Isis Mikhail	Epidemiology and Genetics Research Program	Deb Pearson	Office of Communications
Melissa Miller	Office of Cancer Survivorship	June Peters	Division of Cancer Epidemiology and Genetics
Michael Miller	Office of Communications	Brandy Peterson	Office of Communications
Erin Milliken	President's Cancer Panel	Raymond Petryshyn	Division of Extramural Activities
Rita Mincemoyer	Center for Cancer Research	James Pingpank	Center for Cancer Research
Lori Minasian	Division of Cancer Prevention	Laura Planas	Office of Education and Special Initiatives
Alyssa Minutillo	Division of Cancer Epidemiology and Genetics	Paris Ponder	Division of Cancer Control and Population Sciences
Terry Moody	Center for Cancer Research	Arnold Potosky	Division of Cancer Control and Population Sciences
Lee Moore	Division of Cancer Epidemiology and Genetics	Beverly Powell-St. James	OD/Cancer Care Delivery Systems
Glen Morgan	Division of Cancer Control and Population Sciences	Douglas Price	Center for Cancer Research
Thuy Morzenti	Office of Communications/ Public Affairs	Robyn Prueitt	Laboratory of Human Carcinogenesis
Traci Mouw	Nutrition Epidemiology Branch	Miranda Raggio	Center for Cancer Research
Christy Mylks	Office of Education and Special Initiatives	Kathie Reed	Office of Science Planning and Assessment
Wendy Nelson	Division of Cancer Control and Population Sciences	Sabrina Reed	Mid-Atlantic Cancer Information Service
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Meghan Newcomer	Division of Cancer Control and Population Sciences	Margaret Rhoades	Office of Communications
Sheila Nguyen	Antibodies and Proteins Purification Unit	Weston Ricks	Financial Management Branch
Cherie Nichols	Office of Science Planning and Assessment	John Risinger	Center for Cancer Research
Peter Ogunbiyi	Office of Centers, Training and Resources	Sonya Roberson	Division of Extramural Activities
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Ofelia Olivero	Center for Cancer Research	Rochelle Rollins	Cancer Care Delivery Systems
Anita Ousley	Office of Education and Special Initiatives	Julia Rowland	Division of Cancer Control and Population Sciences
Rose Mary Padberg	Office of Education and Special Initiatives	Anne Ryan	Division of Cancer Prevention
Karen Parker	President's Cancer Panel	Nicole Saiontz	Office of Communications
Linda Parreco	Office of Communications	Silvia Salazar	Office of Education and Special Initiatives
Appasaheb Patel	Division of Cancer Control and Population Sciences	Catherine Schairer	Division of Cancer Epidemiology and Genetics
Lorna Patrick	Office of Education and Special Initiatives	Sheri Schully	Division of Cancer Epidemiology and Genetics
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Susan Silk	Office of Education and Special Initiatives	Yvonne Vargas	Division of Cancer Control and Population Sciences
Felicia Solomon	Office of Education and Special Initiatives	Jaye Viner	Office of Centers, Training and Resources
Perry Soriano	Surgery Branch	Cynthia Vinson	Division of Cancer Control and Population Sciences
Cherie Spencer	Cancer Information Service	Tom Vollberg	Division of Extramural Activities
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Vaurice Starks	Division of Cancer Control and Population Sciences	Danell Watkins	Division of Cancer Control and Population Sciences
Caryn Steakley	Center for Cancer Research	Linda Weiss	Cancer Centers Branch
Michael Stefanek	Division of Cancer Control and Population Sciences	Jeffrey White	Office of Cancer Complementary and Alternative Medicine
Hillary Stevenson	Office of Workforce Development	Bernard Whitfield	Division of Extramural Activities
Laveta Stewart	Division of Cancer Epidemiology and Genetics	Jonathan Wiest	Center for Cancer Research
Angela Stowe	Center for Cancer Research	Sheila Wilcox	Office of Education and Special Initiatives
Carolyn Strete	Cancer Training Branch	Tyrone Wilson	Division of Extramural Activities
Meryl Sufian	Division of Cancer Control and Population Sciences	Robert Wiltout	Center for Cancer Research
Stephen Taplin	Division of Cancer Control and Population Sciences	Barbara Wingrove	Center to Reduce Cancer Health Disparities
Emmanuel Taylor	Center to Reduce Cancer Health Disparities	Kim Witherspoon	Cancer Therapy Evaluation Program
Sona Thakkar	Office of Education and Special Initiatives	Rosemary Wong	Division of Cancer Treatment and Diagnosis
Tracy Thompson	Center for Cancer Research	David Woods	Center for Cancer Research
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Lois Travis	Division of Cancer Epidemiology and Genetics	Grace Yeh	Center for Cancer Research
Carmina Valle	Division of Cancer Control and Population Sciences	Sandy Young	Office of Communications
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		JoAnne Zujewski	Cancer Therapy Evaluation Program

Appendix C: Strategic Objective 8— Overcome Cancer Health Disparities

From *The NCI Strategic Plan for Leading the Nation to Eliminate the Suffering and Death Due to Cancer*

To Ensure the Best Outcomes for All

STRATEGIC OBJECTIVE **8**

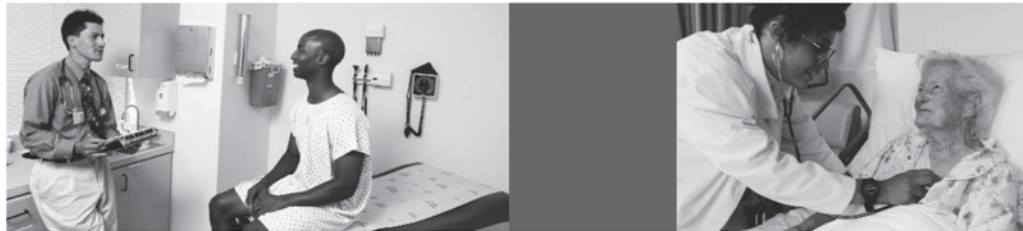
Overcome Cancer Health Disparities

We will study and identify factors contributing to disparities, develop culturally appropriate approaches, and disseminate interventions to overcome those disparities across the cancer control continuum from disease prevention to end-of-life care.

Overcoming cancer health disparities is one of the best opportunities we have for eliminating the suffering and death due to cancer. Addressing the needs of the medically underserved is a critical component of each of our NCI strategic objectives. Significant progress has been made over the past three decades in understanding, preventing, detecting, diagnosing, and treating cancer and in improving the quality of cancer survivorship and end-of-life care. Sadly, not all Americans are reaping the benefits of this progress.

Because cancer initiation and progression are determined by complex interactions among genetic, behavioral, cultural, social, and environmental factors, some level of health disparity—e.g., higher than average incidence, more rapid disease progression, poorer outcome or survival—can affect anyone. However, several assessments conducted in recent years point to the unequal burden of disease in our society as not just a scientific and medical challenge but also a moral and ethical dilemma for our Nation. Minorities and other underserved populations variously distinguished by race, ethnicity, gender, age, socioeconomic status, geographic location, occupation, and education bear a far greater cancer burden than the general population.

NCI must take the lead in accelerating the dissemination and implementation of interventions to address cancer health disparities. We must establish collaborations and partnerships with public, private, and community organizations to address inequities. We must work more efficiently and effectively with current partners, evaluate the impact of our efforts, and broaden our bases of collaboration. This kind of resource integration provides our best hope of overcoming cancer health disparities.



STRATEGY 8.1— Understand the factors that cause cancer health disparities.

A first step in eliminating disparities in cancer incidence, treatment, and survival is to understand their underlying causes and contributing factors. NCI will:

- > Assemble interdisciplinary teams of scientists and practitioners to further elucidate the complex interplay of social, behavioral, environmental, genetic, public health, and economic factors, as well as political and health system forces, that may contribute to disparities.
- > Advance research to identify and investigate race, ethnicity, and socioeconomic status and how they influence trends and rates of cancer incidence and mortality.
- > Support efforts to disaggregate large population studies in order to identify geographic areas of high cancer mortality and investigate the complex mechanisms that underlie the disparities identified across various age groups and stages of cancer.

New knowledge in these areas will support continued work with other government, academic, and private organizations to develop effective and appropriate interventions.

To Ensure the Best Outcomes for All

STRATEGY 8.2—Work with communities to develop interventions targeted to the specific needs of underserved populations.

Community-based programs like the Community Networks to Reduce Cancer Disparities, the Minority-Based Clinical Oncology Program, NCI-supported Cancer Centers, and other academic centers located in underserved areas are ideal venues for designing and testing interventions. By understanding the health experience of these communities, researchers are able to develop more culturally appropriate and accessible interventions, healthcare providers are more likely to arrange for their patients to participate in cutting-edge clinical research, and cancer patients and people at risk have access to the full range of state-of-the-art cancer services. NCI will:

- > Work with community members, leaders, and healthcare providers to implement clinical, correlative, and community research for populations known to bear heavy burdens of cancer and work to ensure broader community participation in clinical trials for patients and healthcare providers.
- > Foster the participation of community and academic partners to facilitate the development of education, research, and training programs that will increase access to and use of cancer prevention interventions such as smoking cessation, healthy eating and physical activity and the early detection, diagnosis, and treatment of cancer.

These activities will help to build sustainable alliances with local communities.

Community-Based Research Is Vital for Understanding Health Disparities

Given the complex determinants of health status, the disproportionate burden of disease, and the limited effectiveness of traditional research methods, particularly within underserved communities, more comprehensive and participatory approaches to public health research and practice are essential. Community-based participatory research (CBPR) is a collaborative approach that equitably involves academic, public health, and community partners in the research process. By combining the unique strengths of individuals and groups, CBPR aims to undertake research of importance to the community, with the goal of achieving social change.

STRATEGY 8.3—Provide the knowledge base for and develop interventions to enhance the integration of cancer services for underserved populations.

Despite new technological advances in diagnostic and therapeutic interventions, the complex interplay among behavioral, social, and environmental factors continues to undermine access to cancer services and widen the gap in healthcare disparities. This problem is coupled with escalating healthcare costs and the high numbers of uninsured and underinsured people. Under these conditions, healthcare providers must sometimes make difficult treatment decisions and underserved patient populations are less likely to have access to new advances in cancer prevention, diagnosis, and therapy. To counter this disparity, NCI will:

- > Conduct research to discover the most effective ways to address critical gaps in access to care by supporting patient navigator program development and the replication of effective models.
- > Determine the best ways to provide culturally appropriate care, taking into account socioeconomic, comorbidities, diagnostic and treatment interventions, survivorship, and end-of-life needs.
- > Conduct community-based research to develop strategies for increasing trust and encouraging participation in cancer research.
- > Promote an interdisciplinary team approach to accelerate the integration of cancer healthcare services.

These efforts will expand the participation of underserved populations in the Nation’s cancer research enterprise and the availability and delivery of associated discoveries.

Patient Navigator Programs Are Key to Cancer Care Integration

“Patient navigation” in cancer care refers to the assistance offered to patients, survivors, families, and caregivers to help them access and chart a course through the healthcare system. Navigators are experienced lay people, social workers, nurses, and others from local communities who are able to communicate credibly with patients. They work with vulnerable or disadvantaged people to help them obtain accurate information on diagnosis and treatment procedures, access to hospitals and clinics, guidance on financial assistance, and help with tracking their records and obtaining prescriptions. In some cases they also arrange for language translation, travel, social support, or religious counseling.

To Ensure the Best Outcomes for All

STRATEGY 8.4—Work with others to develop a cadre of researchers and clinicians prepared to effectively address cancer health disparities.

The success of research designed to reduce the disproportionate burden of cancer incidence and mortality in underserved populations will depend on increasing the number of culturally sensitive, well trained investigators. NCI will:

- > Support introductory science experiences for minority high school students, individual and institutional fellowships and other college level training programs, career development awards, mentored research fellowships for postdoctoral and junior investigators, and the cross training of non-minority researchers.
- > Work with schools of public health, social work, health administration, and medicine to promote health disparities communication and outreach efforts and encourage students to consider health disparities research as a career.
- > Support NCI-designated Cancer Centers and Minority-Serving Institutions conducting joint research, training, education, and outreach programs with particular focus on the disproportionate incidence, morbidity, and mortality of cancer in underrepresented minority populations.
- > Support studies to understand cultural and behavioral factors that affect the conduct of research and how cancer care is provided and ensure that new insights are used to guide research and inform practice.
- > Collaborate with Cancer Centers and grantee institutions to promote training on cancer health disparities issues for healthcare providers and scientists.

A better prepared cadre of researchers and clinicians will help to address the unrecognized and unintentional biases that impede quality cancer care.

STRATEGY 8.5—Develop and work with others to implement innovative, educationally and culturally appropriate approaches for disseminating information on research results to underserved populations.

Communication, outreach, and information dissemination with underserved populations requires innovative approaches and community involvement. NCI will:

- > Use knowledge gained from health literacy and risk perception research to develop and implement plans for disseminating new interventions and relevant scientific information.

- > Ensure that NCI publications and other communications tools are reviewed for cultural appropriateness and adapted as needed.
- > Ensure comprehensive coverage of NCI publications in communications targeted to underserved populations.
- > Team with health disparity experts, cancer advocacy groups, and cancer education specialists to disseminate consistent, current, and accurate information.
- > Partner with the minority and national media to reach their constituents with timely and accurate health messages.
- > Support public workshops and focused dissemination efforts to address the many needs related to health disparities.

Partnerships between NCI and other public, private, and non-traditional organizations will increasingly improve NCI's communication, outreach, and dissemination efforts.

NCI's Cancer Information Service Partners to Reach the Underserved

The NCI Cancer Information Service (CIS) is a national resource for information and education about cancer and a leader in translating cancer information into language the public can easily understand. Through its Partnership Program, the CIS reaches the medically underserved, including minority groups and people with limited access to health information and services throughout the United States and its territories.

CIS works with other agencies and organizations that have an established presence in the state or region and are trusted within their communities. In 2004, the CIS collaborated with over 100 partners to reach underserved African American populations with information and resources on breast and cervical cancer, clinical trials, tobacco control, and general cancer awareness. Working with others, the CIS is able to work across the country to reach those most in need with vital cancer information and services.

To Ensure the Best Outcomes for All



STRATEGY 8.6—Examine the role of health policy in reducing and eliminating cancer health disparities.

Strong evidence-based health policies can provide a critical link in helping to understand and overcome cancer health disparities. However, additional research is needed to understand factors affecting the development and implementation of health policies, their differential impact and unintended consequences, and

variations in their enforcement. NCI will identify gaps in our current knowledge and understanding, delineate areas in which further research is needed, and recommend effective policy strategies and programs for reducing cancer health disparities. NCI will:

- > Examine the interrelationships between cancer control policies and social, cultural, and environmental influences within specific populations.
- > Assess the cultural appropriateness of evidence-based policies as they apply to various population groups.
- > Examine the differential impact of policies on health systems, organizations, and institutions with multiple local, state, and national programs.
- > Build collaborations among researchers from diverse disciplines, academic settings, service delivery environments, and global communities to examine the issues of appropriateness, impact, translation, and dissemination of evidence-based health policies.
- > Support the dissemination and adoption of innovative approaches to policy issues concerning insurability and the challenges faced by the uninsured and underinsured.
- > Collaborate with U.S. and international stakeholders to identify the types of data and data training needed by decision makers to help influence policy.

These investments will improve the effectiveness of policy decisions aimed at reducing cancer risk and incidence, facilitating early cancer treatment, and increasing survival rates among those who suffer disproportionately from cancer.

Appendix D: Executive Summary

From *Analysis of the National Cancer Institute's Minority Health and Health Disparities (MHHD) Research Portfolio*

For NCI Internal Use Only

EXECUTIVE SUMMARY

It is well known and documented that the burden of cancer and its associated risk factors are not borne equally by all population groups in the United States. One's race and ethnicity, gender, geographical location, and socioeconomic status influence the risk factors for cancer and cancer incidence, morbidity, and mortality. Integrated, concerted, and innovative science, strategies, and opportunities are needed to enhance our overall knowledge and understanding of the fundamental causes of cancer health disparities. These advancements are needed to develop effective interventions for all Americans.

Closing the gap in health disparities is a top priority for the Nation. In 2004, the Department of Health and Human Services released the Trans-HHS Cancer Health Disparities Progress Review Group Report, which delineated an integrated set of 14 recommendations that would address the unequal burden of cancer. The National Cancer Institute (NCI), who was part of these efforts, plays a critical role in closing the gap in health disparities. Overcoming health disparities is also one of NCI's top priorities for reaching the Challenge Goal to eliminate suffering and death due to cancer.

In 2005, the NCI convened the NCI-Wide Health Disparities Workshop among NCI staff to enhance interactions and work across the Institute to reduce cancer health disparities. To help facilitate the goals of the workshop, the conference planning committee, in collaboration with Science Applications International Corporation (SAIC), the Office of Science Planning and Assessment (OSPA), and the Center to Reduce Cancer Health Disparities (CRCHD), conducted an NCI-wide portfolio analysis using data from fiscal year 2004. The purpose of the analysis was to summarize (1) NCI's financial investment in health disparities research and (2) NCI's portfolio of projects funded in health disparities research. NCI projects include intramural and extramural grants, contracts, and cooperative agreements that were coded as Minority Health and Health Disparities (MH/HD) by NCI staff.

Public Law 106-525, Title 1, Section 101, mandates that the National Center for Minority Health and Health Disparities (NCMHD) develop annual reports describing and evaluating the progress made and funds expended in health disparities research conducted and supported by the National Institutes of Health. The data used for this analysis were extracted from the MH/HD database that is compiled each year for the NCI by the CRCHD. These data were used by the planning committee to determine the allocation of funds for research focused on specific racial/ethnic groups, those who live in rural areas, and people of low socioeconomic status.

The FY2004 MH/HD portfolio, which is summarized in this report, contains over 700 grants, contracts, and intramural projects that are relevant to MH/HD. These projects account for more than \$264 million in NCI research funding and represent 5.6% of the total NCI funding portfolio (\$4.7 billion). There were several ways to examine funding and project distribution of MH/HD data. The data were examined by NCMHD reporting category, race and ethnicity, funding mechanism, NCI division, and Common Scientific Outline (CSO). Highlights of the MH/HD data are presented in the report.

- NCMHD Reporting Category
 - Fifty-five percent of the MH/HD funding, totaling \$146.6 million, is clinical research.
 - Fifty-four percent of the MH/HD projects are categorized as training, which includes 418 projects.
 - Racial and ethnic data examined within the NCMHD-coded clinical research category indicate that 53.8% (\$78.8 million) of clinical research dollars is allocated to research on non-white racial groups, which includes Black/African American, Asian, American Indian or Alaska Native, Native Hawaiian or Pacific Islander, and more than one race.
 - Ten percent (\$15.1 million) of the clinical research dollars is allocated to research on Hispanics.

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- Funding Mechanism
 - Twenty-four percent of the MH/HD funding, totaling \$62.3 million, are cooperative agreements.
 - Thirty-three percent of the MH/HD projects (n=229) are extramural research projects (i.e., R01, R03, R37).
- Division
 - Of the \$264 million spent on MH/HD research, \$71.9 million (27%) is funded in the Division of Cancer Control and Population Sciences (DCCPS).
 - Twenty-six percent of the MH/HD funding, totaling to \$67.8 million, is research funded through the Office of the Deputy Director for Extramural Science (DDES).
- Common Scientific Outline
 - Thirty-seven percent (\$92.8 million) of the MH/HD funding is coded to the CSO category cancer control, survivorship, and outcomes. These 171 projects represent 24% of the MH/HD portfolio.
 - An additional 24% (n=159) of the MH/HD projects are funded in causes of cancer and cancer etiology.

These five independent ways of examining the MH/HD portfolio help to identify gaps and progress in research. The MH/HD portfolio encompasses a broad range of programs, including support for predoctoral and postdoctoral training for minority trainees, investigator-initiated grants to identify and address cancer health disparities, and large multicenter programs that provide research, training, and education for underserved communities. NCI-supported investigators are studying race-related risk factors for cancer in several populations, determining the impact of genes and the environment on health disparities, developing culturally tailored interventions to prevent cancer in underserved populations, finding ways to increase cancer screening rates in selected populations, and identifying molecular markers for cancer in high-risk families. NCI funding also supports the development and assessment of novel cancer treatments, as well as culturally appropriate interventions to improve quality of life in cancer survivors.

This report is divided into two sections. In the first part of the report, the MH/HD research portfolio is analyzed by NCMHD-coded category, minority group, grant mechanism, NCI division, and CSO category. Details of these categories can be found in Appendices A–E. When possible, NCI-wide trends are presented for the same parameters to allow comparison. The second part of the report consists of tables of MH/HD projects broken out by CSO subcategory classification. The information provided in these tables may help to identify (1) gaps in the MH/HD research portfolio and (2) opportunities for future collaboration among different NCI divisions, centers, and offices.

Appendix E:

Glossary of Acronyms and Abbreviations

caBIG – Cancer Biomedical Informatics Grid
CanCORS – Cancer Care Outcomes Research and Surveillance
CARRA – Consumer Advocates in Research and Related Activities
CCDOG – Cancer Care Delivery and Outcomes Group
CCOP – Clinical Community Oncology Programs
CCR – Center for Cancer Research
CDC – Centers for Disease Control and Prevention
CDRP – Cancer Disparities Research Partnership
CIS – Cancer Information Service
CMS – Centers for Medicare and Medicaid Services
CRCHD – Center to Reduce Cancer Health Disparities
CSO – Common Scientific Outline
CTEP – Cancer Therapy Evaluation Program
DCCPS – Division of Cancer Control and Population Sciences
DDES – Office of the Deputy Director of Extramural Sciences
EBIs – Evidence-based interventions
EBPs – Evidence-based practices
GIS – Geographic Information System
HRSA – Health Resources and Services Administration
I2 – Integration and Implementation Team
MCCOPs – Minority-based Clinical Community Oncology Programs
MHHD – Minority Health and Health Disparities
NCMHD – National Center for Minority Health and Health Disparities
NIAMS – National Institute of Arthritis and Musculoskeletal Diseases
OC – Office of Communications
OCCAM – Office of Cancer Complementary and Alternative Medicine
OESI – Office of Education and Special Initiatives
OLA – Office of Liaison Activities
OMB – Office of Management and Budget
P01s – Program Project Grants
PDQ – Physician Data Query
PHS – Public Health Service
RFAs – Requests for Application
RTIPs – Research-Tested Intervention Programs
SCB – Sociocultural and Behavioral
SEER – Surveillance, Epidemiology, and End Results Program
SPOREs – Specialized Programs of Research Excellence
VA – U.S. Department of Veterans Affairs



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