MAKING CANCER HEALTH DISPARITIES History

Report of the
Trans-HHS Cancer Health Disparities
Progress Review Group

Submitted to the Secretary, U.S. Department of Health and Human Services
March 2004

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FROM THE TRANS-HHS CANCER HEALTH DISPARITIES PROGRESS REVIEW GROUP

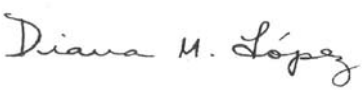
We are privileged to submit *Making Cancer Health Disparities History,* the Report of the Trans-HHS Cancer Health Disparities Progress Review Group (PRG), on behalf of our fellow Americans who experience cancer. We envision that this initiative will harness the energies and resources of the Federal government so that cancer health disparities will become a thing of the past. In preparing this report, we note two things:

- ***The historical significance of what has been done.*** Never before has the Department of Health and Human Services (HHS) embarked on such a concerted effort to make the goal of eliminating health disparities a reality. The charge to implement a Department-wide PRG to focus on cancer health disparities was unprecedented and the leadership and commitment given to this topic was unparalleled.

  Furthermore, the PRG process brought together the Nation's leading researchers, health practitioners, and advocates, as well as cancer survivors. Collectively, this group represented hundreds of years of experience dedicated to reducing cancer health disparities.

- ***The compelling need to eliminate cancer health disparities now.*** In our Call to Action, we speak with one voice … with one heart … that cancer health disparities reflect a grave injustice. The time to start is now, and we urge HHS to heed our Call.

Respectfully,



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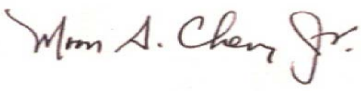

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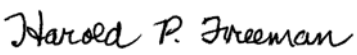

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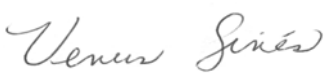

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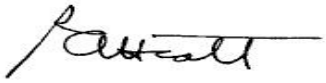

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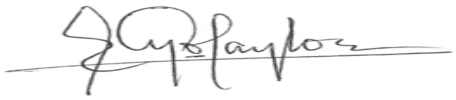

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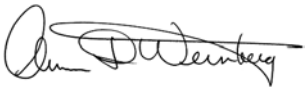

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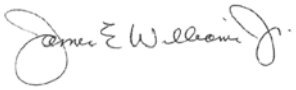

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Trans-HHS Cancer Health Disparities Progress Review Group
Planning Meeting, June 2003

Acknowledgments

The Trans-HHS Cancer Health Disparities Progress Review Group (PRG) process has been a collaborative effort involving contributions from numerous people with different backgrounds, skills, and talents. We wish to acknowledge and thank the following people for their commitment, hard work, and assistance in the development of this report.

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- The 80 individuals who joined us at our Cancer Health Disparities PRG Roundtable Meeting. Representing a wide range of experience and perspectives, they provided us with breadth and depth in all areas of importance to the field. We especially thank the 10 individuals who served, along with PRG members, as Co-Chairs of our Roundtable Breakout Groups: Claudia Baquet, Tim Byers, Camara Jones, Marjorie Kagawa-Singer, Momi Kaanoi, Cathy Meade, Amelie Ramirez, Eduardo Sotomayor, Ho Tran, and Shalini Vallabhan. See Appendix B for a full list of Roundtable participants.
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- The staff of the Scientific Consulting Group, especially Kathryn Brown-Huamani and Paula Zeller, who performed critical editing tasks for the cancer health disparities background paper.

EXECUTIVE SUMMARY

Committed to eliminating the unequal burden of suffering and death due to cancer, the Department of Health and Human Services established the Trans-HHS Cancer Health Disparities Progress Review Group.

The President of the United States and the Secretary of Health and Human Services (HHS) have made closing the gap in health disparities a top priority for our Nation. Selecting cancer health disparities as a model, HHS established, in 2003, the Trans-HHS Cancer Health Disparities Progress Review Group (PRG). We were charged with developing an integrated set of recommendations to be implemented by the Department and its agencies.

The unequal burden of disease in our society is not just a scientific and medical challenge. It also presents a moral and ethical dilemma for our Nation. Together, we have reviewed the status of health disparities related to cancer in our country and forged a common vision of how they could be reduced or eliminated. We have developed this Call to Action so that HHS can meet its objectives to:

- Define and describe issues related to cancer health disparities.[1]
- Identify areas of strength, gaps, opportunities, and priorities to address cancer health disparities in research and intervention development.
- Facilitate the adoption and implementation of cancer research, policy, community programs, and clinical interventions and evaluate their impact on specific cancer health disparities.
- Ensure unbiased access to continuous quality preventive care, early detection, and treatment of cancer for every American.

Our Call to Action consists of 14 priority recommendations for HHS to lead the Nation in eliminating cancer health disparities. Three of these recommendations are for overarching planning and coordination actions, and the remaining 11 are for research discovery, program development, and service delivery activities conducted by the various agencies within HHS. Figure ES-1 presents the recommendations in these four areas, along with a 3-year initiation strategy that allows for flexibility in the required levels of effort, resources, and collaboration.

Unanimous and enthusiastic in our support for these recommendations, we believe that their timely implementation will correct serious health- and health care-related deficiencies that will have far reaching effects on our society. Implementation of recommendations already developed by other expert panels on health disparities in recent years has been slow and incomplete. We urge HHS to follow through on its commitment to alleviate the injustice and unnecessary suffering and death faced by those who shoulder an unequal share of our nation's cancer burden.

[1] Cancer health disparities are defined by the National Cancer Institute as "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."

Here is our Call to Action.

Planning and Coordination

For Initiation within 1 Year:

- Conduct a program and budget review of all relevant HHS programs for the purpose of shifting and realigning support, where possible, to evidence-based programs[2] that are effective in addressing cancer health disparities.
- Assemble a Federal Leadership Council on Cancer Health Disparities led by the HHS Secretary in partnership with the Secretaries of other appropriate Federal departments to mobilize available resources in a comprehensive national effort to eliminate cancer health disparities.

For Initiation within 3 Years:

- Implement, in all HHS health service and reimbursement agencies, recommendations from the Institute of Medicine Report entitled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*.

Discovery

For Initiation within 1 Year:

- Evaluate specific grant and contract processes to determine what additional steps are needed to enhance the cultural competence, representative composition, and methodological expertise of peer review panels for cancer health disparities research.

For Initiation within 2 Years:

- Establish new approaches for data collection and sharing to aid in the study of the effects of cancer and their relationship to variables such as race, ethnicity, and socioeconomic status.
- Increase the proportion of HHS agency support targeted specifically to disease prevention, health promotion, evaluation, and translational research[3] on cancer health disparities.

For Initiation within 3 Years:

- Establish partnerships for and support the development of sustainable community-based networks for participatory research in areas of high cancer disparities.

Development

For Initiation within 2 Years:

- Develop and implement a new trans-HHS initiative to qualify high disparity geographic areas for special program designation as Communities Empowered to Eliminate Disparities. Communities would qualify for the program by submitting strategic plans to reduce specific cancer disparities for identifiable populations.
- Develop, implement, and evaluate education and training programs designed to create a diverse and culturally competent cancer care workforce. Apply standards to certify the cultural competence of health professionals who receive Federal support.

Delivery

For Initiation within 1 Year:

- Implement evidence-based tobacco control strategies, including those that create financial disincentives for tobacco consumption and those that provide social reinforcement for not smoking.

For Initiation within 2 Years:

- Ensure that populations at highest risk have access to age- and gender-appropriate screening and follow-up services for breast, cervical, and colorectal cancer. Expand to include these services for other cancers (e.g., prostate and lung) when there is evidence that they are effective at improving survival.
- Support culturally, linguistically, and literacy specific approaches for eliminating cancer health disparities. These should include evidence-based "best practices," proven interventions, and outreach strategies.

For Initiation within 3 Years:

- Ensure that every cancer patient has access to "state-of–the-science" care.
- Collaborate with the private and voluntary health sectors to ensure that all Americans receive the full range of lifesaving information, services, and quality care from cancer prevention to screening to diagnosis to treatment.

Figure ES-1. The Priority Recommendations of the Trans-HHS Cancer Health Disparities PRG

[2] Programs or interventions are considered evidence based when a number of studies have been conducted according to methods deemed valid and the results of the studies are consistent and also deemed valid.
[3] In this context, research that translates discovery into effective interventions to reduce cancer health disparities.

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INTRODUCTION

The President of the United States and the Secretary of Health and Human Services (HHS) have made closing the gap in health disparities a top priority for our Nation. Selecting cancer health disparities as a model, HHS established, in 2003, the Trans-HHS Cancer Health Disparities Progress Review Group (PRG). We were charged with developing an integrated set of recommendations to be implemented by the Department and its agencies.

The unequal burden of disease in our society is not just a scientific and medical challenge. It also presents a moral and ethical dilemma for our Nation. Together, we have reviewed the status of health disparities related to cancer in our country and forged a common vision of how they could be reduced or eliminated. We have developed this Call to Action so that HHS can meet its objectives to:

> 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. [4]

- Define and describe issues related to cancer health disparities.
- Identify areas of strength, gaps, opportunities, and priorities to address cancer health disparities in research and intervention development.
- Facilitate the adoption and implementation of cancer research, policy, community programs, and clinical interventions and evaluate their impact on specific cancer health disparities.
- Ensure unbiased access to continuous quality preventive care, early detection, and treatment of cancer for every American.

Unlike the other expert panels that have been convened to review cancer and other health disparities, the Trans-HHS Cancer Health Disparities PRG was initiated by the entity to which its recommendations are being directed (HHS) and not by a third party. The deliberations of the Group have been focused primarily on solution development rather than problem identification and characterization. Furthermore, the process has been unique in that the PRG has been working in partnership with – not independently from – the organization to which its recommendations are being directed.

The development of this report involved the hard work and dedication of the Trans-HHS Cancer Health Disparities Federal Steering Committee, the leaders and members of the PRG, and additional experts who participated in the Cancer Health Disparities Roundtable Meeting. Reports and recommendations from the Breakout Groups (see Appendix A) and subsequent discussion by the entire Roundtable served as the basis for the 14 priority recommendations that make up our Call to Action for eliminating cancer health disparities (see Appendix B and Table B-1).

By planning and working together, HHS agencies can lead the Nation's research, public health, and clinical delivery efforts to achieve a seamless and more assertive progression from scientific discovery to the development and delivery of evidence-based interventions to eliminate cancer health disparities. Health care policy makers, providers, payers, and other stakeholders must support innovative interventions for cancer prevention, increased early detection and diagnosis, state-of-the-art cancer treatment, survivorship support and encouragement, and dignified end-of-life cancer care.

[4] National Cancer Institute, Division of Cancer Control and Population Sciences

Historical Perspective

Some level of health disparity occurs among all people affected by cancer. This is because cancer occurs due to a variety of factors related to genes, individual behaviors, and cultural, social, and environmental circumstances. The complex interaction among these factors determines who is born healthy, who maintains health throughout his or her life, and who develops and survives cancer.

Numerous scientific studies provide the evidence that certain U.S. populations experience significant disparities in risk, incidence, disease-stage diagnosis, care received, and disease outcomes for cancer. Several reports such as the Institute of Medicine's *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* [1] (see Appendix C) have identified society-wide quality, continuity, and access problems experienced by America's medically underserved, low income, and minority populations. These and other study results provide growing evidence that many people in America receive neither adequate prevention and detection services nor the most appropriate care for their diseases. In addition, the President's Cancer Panel Report, *Voices of a Broken System: Real People, Real Problems* [2], provides substantial anecdotal evidence about the barriers to cancer treatment and care experienced by underserved populations in our society.

Much 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 have reaped the benefits of this progress. Minority and underserved populations – distinguished by race/ethnicity, gender, age, socioeconomic status, geographic location, occupation, and/or education – bear a greater cancer burden than the rest of the nation. For example, within the United States these populations are significantly more likely to:

- Be diagnosed with and die from preventable cancers.
- Be diagnosed with late-stage disease for cancers detectable through screening at an early stage.
- Receive either no treatment or treatment that does not meet currently accepted standards of care.
- Die of cancers that are generally curable.
- Suffer from cancer without the benefit of pain control and other palliative care.

Appendix A includes a bibliography that documents the specific cancer health disparities that are associated with different populations and subpopulations.

OUR CALL TO ACTION FOR ELIMINATING CANCER HEALTH DISPARITIES

The Call to Action from the Trans-HHS Cancer Health Disparities Progress Review Group (PRG), for implementation by the Department of Health and Human Services (HHS), consists of 14 recommendations derived from 29 Roundtable recommendations (see Table B-1 in Appendix B). It represents our consensus regarding the most critical and feasible means for eliminating cancer health disparities through actions that are within the purview of HHS and its agencies.

Within HHS, agency activities can be placed along a continuum from **Discovery** to **Development** of interventions based on new knowledge to **Delivery** of those interventions for all who need them. Thus, we identify challenges and opportunities and present our priority recommendations within this framework.[5] To ensure that all activities are integrated, we include overarching recommendations in **Planning and Coordination**.

HHS leadership retains ultimate responsibility and authority for the manner in which each recommendation is implemented. To increase the likelihood of success, we suggest a time frame for initiating each recommendation and encourage HHS to develop an implementation plan with a schedule for completion. We also offer some ideas on how the recommendations could be accomplished. Additional suggestions for implementation can be found in the Breakout Group Reports included in Appendix A.

[5] In the sections that follow, the PRG priority recommendations are presented according to their order of appearance in Figure ES-1. No inferences should be made, from this sequencing, regarding importance or time frame for completion.

Planning and Coordination

Challenges and Opportunities

While HHS agencies administer numerous effective programs, there remain duplications, overlaps, and gaps in service. Through coordinated short-, mid-, and long-range planning, across all agencies, HHS can ensure that the most promising discoveries arising from one agency are rapidly advanced into development and delivered by other agencies to the citizens who require them.

A centralized mechanism is needed at the Department level to coordinate and manage activities across agencies that address important issues such as:

- Culturally competent and evidence-based interventions
- High-quality and efficiency of service delivery
- Culturally competent recruitment, retention, and intervention methodologies
- Improved access to state-of-the-art cancer care, including clinical trials, and to adequate insurance coverage

Establishing a centralized mechanism for oversight of the entire process from planning to discovery to development to delivery requires a solid commitment from, and assignment of accountability within, HHS leadership and agencies.

Foremost, there is a need to conduct an internal review of allocations and realign dollars in the various programs across HHS agencies.

Priority Recommendations

Conduct a program and budget review of all relevant HHS programs for the purpose of shifting and realigning support, where possible, to culturally competent evidence-based programs that are effective in addressing cancer health disparities.

Planning and Coordination, for Initiation within 1 Year

Rationale

In the current economic environment, the reality is that no or limited additional monies may be available to implement new policies and/or programs or to improve existing ones. HHS leadership has a responsibility to identify efficiencies and inefficiencies within its agency programs to realign and reallocate funding more effectively. A serious internal review of how dollars are allocated with regard to discovery, development, and delivery of cancer-related services is required. There are many examples of duplication of services and programs within HHS. Some cancer programs of uncertain efficacy receive funding while other more efficacious programs remain underfunded. Selected examples of programs we consider efficacious are:

- Tobacco programs.
- National Cancer Institute (NCI) Special Populations Networks and other NCI programs for reducing cancer health disparities.
- Colorectal cancer screening programs, which are currently funded on a demonstration basis in a limited number of states.
- The Centers for Disease Control and Prevention (CDC) National Breast and Cervical Cancer Early Detection Program, which is very effective. Because of limited funding, however, it is only able to serve 15%-18% of the eligible population nationwide. This program's funding needs to be expanded to cover 100% of women who meet eligibility criteria for its screening services.
- The CDC National Program of Cancer Registries and the NCI Surveillance, Epidemiology, and End Results Program, which are essential to state cancer planning and identification of populations that experience cancer health disparities.
- The Health Resources and Services Administration (HRSA) Community Health Center Program, which needs adequate funding to enable the adoption of proven, effective cancer control collaborative models and guidelines.

Issues of Importance

The short-term goal of this PRG priority recommendation is a realignment of funding within HHS. The long-term goal is continued support of programs proven to be essential to the elimination of cancer health disparities. The PRG understands that a comprehensive internal review of HHS programs could potentially be a lengthy and administratively laborious process. The commitment of HHS leadership and staff is required for the success of this endeavor.

The HHS Cancer Health Disparities Program and Project Database described in Appendix B is a good starting point for conducting the review. It is recommended that HHS assign an office or agency for updating and maintaining this database over the long term.

To ensure objectivity, the review must be independent. Input from community representatives is advised, including input from the members of this PRG and its Roundtable participants.

A critical component for implementation of this recommendation is the set of criteria used for determining whether a program is evidence based. It is recommended that common terms and metrics be adopted to support such determinations.

When conducting the review, it is important to consider the maturity of the programs being evaluated. Because some programs have not been in existence long enough to have accumulated sufficient results, there needs to be a way of ensuring that such programs are not automatically disqualified from receiving additional funding. These programs should be reviewed from the perspective of their ability to contribute to an evidence base.

Assemble a Federal Leadership Council on Cancer Health Disparities led by the HHS Secretary in partnership with the Secretaries of other appropriate Federal departments to mobilize available resources in a comprehensive national effort to eliminate cancer health disparities.

Planning and Coordination, for Initiation within 1 Year

Rationale

Cancer health disparities occur within the broad context of human circumstances that encompasses behavioral, cultural, educational, environmental, genetic, and socioeconomic factors. Because cancer health disparities transcend the scope of HHS, it is pertinent to include other appropriate Federal departments. Specifically, the PRG envisions that the Secretary should assemble a Federal Leadership Council on Cancer Health Disparities that would partner with the Secretaries of other appropriate Federal departments to mobilize available resources in a comprehensive national leadership effort to eliminate cancer health disparities.

Just as the Secretary commissioned the Cancer Health Disparities Progress Review Group to consider solutions to cancer health disparities for the first time from a Trans-HHS perspective, a Federal Leadership Council on Cancer Health Disparities would elevate the concerns and leverage resources government-wide to make cancer health disparities a thing of the past. Implementation of this far reaching PRG recommendation would benefit from the endorsement of the White House.

Issues of Importance

After assessing how the various departmental policies and programs affect health and health disparities, the Federal Leadership Council would establish specific goals and targets, and ensure monitoring and accountability. The Council would also provide an opportunity to discuss a broad range of issues and challenges that impact cancer health disparities. The efforts of the Council should be made accessible to the public.

Federal departments and agencies that might participate in the Council include:

- Department of Agriculture
- Department of Defense
- Department of Education
- Department of Energy
- Department of Housing and Urban Development
- Department of Justice
- Department of Labor
- Department of Transportation
- Department of Veterans Affairs
- Environmental Protection Agency

Implement, in all HHS health service and reimbursement agencies, the recommendations from the Institute of Medicine Report entitled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*.

Planning and Coordination, for Initiation within 3 Years

Rationale

In addition to addressing many broad societal issues, the report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* [1] documents the problems associated with cancer care disparities and offers practical and specific solutions. Appendix C includes the recommendations from the report and shows how those recommendations align with the PRG recommendations in our Call to Action.

Issues of Importance

To implement the recommendations from the *Unequal Treatment* report, HHS will need to:

- Develop new surveillance tools to verify that cancer patients are receiving equal treatment. Because inequities have been demonstrated, these tools are needed in the effort to assess the role of barriers to quality health care.
- Magnify and support community involvement in the design and transformation of health care delivery systems. Strong community partnerships are vital to the continuum of cancer care from disease prevention to detection to treatment to survivorship.
- Develop a culturally competent health care workforce, which requires increasing recruitment and retention of members of minority groups.

Discovery

Challenges and Opportunities

It is highly unlikely that cancer health disparities can be eliminated in the absence of additional discovery. Research is required to expand and update our knowledge base on the extent and causes of cancer health disparities and to apply this knowledge to the identification of new intervention strategies.

Unfortunately, research in the field of cancer health disparities is hindered by:

- The diversity of factors giving rise to cancer health disparities
- The difficulty in recruiting sufficient numbers of participants for research studies
- The absence of agreed-upon terminology and methodological approaches

Table 1 shows the complex nature of this research. Progress can be accelerated by conducting research in a transdisciplinary setting that synergistically combines different areas of expertise and emphasizes cultural and community points of view. This Trans-HHS Cancer Health Disparities PRG is but one example of how a transdisciplinary approach can be effectively used.

Another matter to address is that some communities are distrustful of scientists and the institutions they represent. It is not unusual for a study deemed of high importance by a funded investigator to be deemed of low importance by the community being studied. It is also common for a community to never receive information after a study has been completed. We feel that these problems and the impact they have on recruitment and retention of study participants can be mitigated by increased funding and support for community-based participatory research (CBPR). CBPR allows a greater number of minority investigators and community members to be directly involved in research planning and execution.

Although Federal standards exist for characterizing the major racial and ethnic groups [3], there is currently no agreement on how to scientifically characterize the subpopulations that experience health disparities within these groups. There is also no national consensus on measures of inequity and its determinants. Adopting and applying minimum standards for data collection and reporting will provide the opportunity to more readily compare different studies and acquire evidence of an intervention's benefit in a more efficient manner.

Table 1. The Complex Nature of the Research Required on Cancer Health Disparities

Assessing the Extent of the Problem	Determining the Underlying Causes
• Cancer surveillance and outcomes research to address: – The full spectrum of disparities and their effects – Characteristics of populations affected by disparities – The number of people affected by disparities – The magnitude of effects produced by disparities (e.g., extent of decrease in quality of life, disability, and years of life lost)	• Cancer biology and medical anthropology research to address biologic factors that affect disproportionate cancer incidence and death rates (e.g., genetic susceptibility) • Cancer etiology studies to address the interactions among biologic, environmental, and behavioral factors that result in disproportionate cancer incidence and death rates • Cancer control, social science, health services, and marketing research to identify behavioral and cultural factors that influence how available cancer services are utilized by providers and patients

Priority Recommendations

Evaluate specific grant and contract processes to determine what additional steps are needed to enhance the cultural competence, representative composition, and methodological expertise of peer review panels for cancer health disparities research.

Discovery, for Initiation within 1 Year

Rationale

The current process for peer review of cancer health disparities research proposals within HHS agencies is thought to be limited by inadequate diversity in the constitution of review panels. Specific grant and contract review groups may need to be enhanced with the necessary expertise, knowledge, and experience to fairly review cancer health disparities research proposals and/or projects.

Issues of Importance

This evaluation will confirm whether additional trans-HHS approaches are needed to support and conduct cancer health disparities research that spans multiple disciplines and levels of study. Representation and input are required from experts, such as those who participated in this PRG and Roundtable, and lay people who would potentially benefit from the proposed research.

Establish new approaches for data collection and sharing to aid in the study of the effects of cancer and their relationship to variables such as race, ethnicity, and socioeconomic status.

Discovery, for Initiation within 2 Years

Rationale

The measurements and methods currently used to report on cancer health disparities and on terms such as "race," "ethnicity," and "socioeconomic status" are often missing or incomplete. As such, they handicap efforts to understand and reduce societal inequities. In addition, good sources of health information, such as those developed by the Indian Health Service, are not being routinely used.

Recognized problems that could be addressed by this recommendation include:

- Redundancy in data collection, storage, management, and use by HHS agencies
- Nonstandardization in data collection, formatting, and dissemination
- Loss of opportunities for a comprehensive cancer control program to set research priorities and identify communities in need
- Lack of communication and collaboration among HHS agencies

Identification and monitoring of cancer health disparities require coordinated, standardized, and continuous collection of high-quality data. Without Federal-level directives, such as the 1997 HHS Policy for Improving Race and Ethnicity Data,[6] it is difficult to establish consistent data formats and categorizations for comparisons across data sets.

Current theories, measures, and data collection modes were developed and standardized primarily within the Northern European-derived U.S. population. Although they are assumed to be generally applicable to diverse populations, there is significant and ample evidence to the contrary.

Issues of Importance

The Department should mandate that HHS agencies develop standards, timelines, personnel, infrastructure, and funding to set up a coordinated cancer health disparities informatics approach. The existing databases should be reviewed to ensure that they are consistent with the demographic categories used in government to define our current understanding of disparities. Where feasible, new measures, such as those based on life experiences and cultural factors, should be incorporated.

Measures and methods must be developed to quantify cancer health disparities. A committee of the National Academy of Sciences could be charged to outline a strategy for developing a core set of measures on race, ethnicity, and socioeconomic status (SES) for use in the collection, monitoring, and reporting of health disparities.

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[6] Policy posted at http://www.hhs.gov/oirm/infocollect/nclusion.html (last accessed on January 21, 2004).

Geocoding (i.e., assignment of geographic identifiers) of cancer data would also facilitate linkage to other geocoded data such as area-based SES and environmental data. If all HHS-collected data were geocoded, researchers could access important social- and contextual-level variables of the populations identified. This would allow for improved analysis and monitoring of cancer health disparities and facilitate the use of geocoded data in reports for state and local health departments.

Increase the proportion of HHS agency support targeted specifically to disease prevention, health promotion, evaluation, and translational research on cancer health disparities.

Discovery, for Initiation within 2 Years

Rationale

In the next few years, the biggest reduction of cancer morbidity and mortality will derive from application of what we have already learned about disease prevention, early detection, and treatment. An imbalance currently exists between the focus of the health care system on treating illness and the emphasis that should be placed on health promotion, disease prevention, evaluation, and translational research. Health promotion and disease prevention are underfunded and reimbursement mechanisms are inadequate to support full implementation of culturally relevant and effective health promotion and disease prevention strategies.

Notably, little is known about how health promotion and disease prevention strategies may work differentially in populations suffering disproportionately from cancer. There is also a gap in our behavioral knowledge regarding why different people accept or reject health-promoting behaviors or available health services.

Issues of Importance

It is time to challenge the research model that emphasizes the treatment of disease-induced morbidity at the expense of disease prevention and health promotion. The research efforts arising from this PRG recommendation should take into consideration the context of neighborhoods and where people live. The efforts need to address relevant intergenerational influences that can be translated and widely disseminated to the broader populations. They should all include scientific inquiry from lifespan, mental health, and emotional well-being perspectives.

Establish partnerships for and support the development of sustainable community-based networks for participatory research in areas of high cancer disparities.

Discovery, for Initiation within 3 Years

Rationale

Cancer health disparities research currently suffers from lack of community engagement in the research process, poor recruitment and retention of research subjects, and delayed or incomplete clinical trials. Implementation of this PRG priority recommendation would result in the following impacts:

- Beneficial engagement and increased participation of targeted communities in the research enterprise
- Generation of research ideas at the local level to reduce cancer health disparities
- Enhanced likelihood of the adoption of beneficial and relevant research results at the individual and community level

This recommendation is designed to increase community participation in creating a sustainable structure for conducting efficient research on cancer and other diseases or conditions for which disparities exist and for translating collaborative, multidisciplinary research into action. Historically, funding has been inadequate to fully support the infrastructure requirements to conduct high-quality, population-based research on cancer health disparities. The requirements include technology, training, scientific oversight, and the costs associated with research-specific patient care and participant recruitment.

Issues of Importance

Funding needs to be directed to entities within those communities that are impacted by health disparities and are interested in partnering with researchers. It is necessary that:

- Adequate rigor and high scientific standards are maintained.
- Legitimate and documentable community participation in networks is ensured.

- Culturally, linguistically, and literacy appropriate consent forms are used to obtain true informed consent from those who will be participating in the research efforts.
- Research strategies found effective are documented and disseminated for future testing and use across communities and populations.

Three types of support are envisioned:

- Grants for research planning (e.g., seed money grants)
- Developmental funding support, which must be for a minimum period of 7 to 10 years
- Matched supplemental funding to sustain networks in the outer years

Implementation of this priority recommendation requires identifying geographic areas of large disparities, examining the health resource structures of the community, and recruiting community leadership. Geographic dispersion of the networks and diversity of population participation should be a priority.

Development

Challenges and Opportunities

Research on cancer health disparities has identified interventions that appear effective at reducing disparities in small groups of people under controlled conditions. What remains unclear, however, is whether these interventions or types of interventions would be effective in larger groups of people or in groups of people with different characteristics. Additional development work is therefore needed to establish the general applicability of promising new interventions.

Challenges for development of interventions directed against health disparities include:

- Access to a sufficient number of individuals within a single population to rigorously evaluate the intervention.
- Difficulty of conducting randomized, controlled trials, regarded by some as the only way in which evidence can be collected, for certain types of interventions (e.g., community-based policies and communication interventions).
- Establishing criteria for demonstrating an intervention's effectiveness.

We believe that these challenges can be overcome by establishing partnerships that build trust and create a forum for open discussion.

Priority Recommendations

Develop and implement a new trans-HHS initiative to qualify high disparity geographic areas for special program designation as Communities Empowered to Eliminate Disparities. Communities would qualify for the program by submitting strategic plans to reduce specific cancer disparities for identifiable populations.

Development, for Initiation within 2 Years

Rationale

Cancer care and cancer health disparities are local, and solutions must originate within the community. Interventions must be implemented and sustained in the community, and the amount of time generally required to fully realize gains is longer than the typical grant cycle. HHS should establish a new trans-HHS initiative to qualify high disparity geographic areas for special program designation as "Communities Empowered to Eliminate Disparities" or CEEDs and provide support for community-based efforts within these areas. The program would designate CEEDs based on strategic plans developed by the communities, outlining how they would carry out improvements to a continuum of cancer care that would effectively reduce specific cancer disparities for identifiable populations.

This approach would empower communities to assume responsibility for their own health care. It would also spur public-private partnerships to help sustain effective initiatives and programs. This type of approach has been successful in targeting efforts, creating communication and

partnerships, and focusing on holistic and long-term problems and impacts. Local communities can best define the access, financing, and research issues faced by their populations with health disparities.

Through this initiative, communities that have populations with health disparities would develop accountable plans and partnerships with multiple HHS agencies. They would be given priority in their applications to Federal discretionary service and research programs for educating communities about effective measures for reducing cancer incidence and risk.

Issues of Importance

We have several suggestions for HHS implementation of this priority recommendation.

- Support for the initiative might be generated through a mechanism such as a trans-HHS 1% program tap.
- Substantial funds should be awarded through block grants[7] that extend over several years, based on strategic plans developed by the communities involved. These plans would be based on:
  - Analysis of cancer mortality, incidence, and risk factor data to describe and quantify types of cancer disparities and populations affected.
  - Service gap analysis.
  - Assessment of related community knowledge, beliefs, and behaviors.
  - Evaluation of past or existing targeted cancer programs of service, financing, and research.
  - Assessment of and intention to address all stages of the continuum of cancer care.
  - Potential use of evidence-based HHS programs that originate within the CDC, Centers for Medicare and Medicaid Services (CMS), HRSA, and NCI.
  - Coordination with other government programs, such as economic incentives for establishing a cancer center in a CEED made available through the Department of Housing and Urban Development or school lunch programs that follow healthy dietary guidelines supported in a CEED by the Department of Agriculture.
  - Educational needs of providers and consumers.
  - Needs for access to clinical trials.
  - A proposed plan and timeline for integrating multiple programs, community health providers, and external organizations.
  - The formation of new partnerships, with contributions from and benefits to each partner.
  - Ensuring that community advocates are incorporated, supported, and sustained in discovery, development, and delivery activities conducted in support of cancer care.
  - Establishment of an evaluation plan, under the guidance of appropriate cancer control experts, that includes multiyear outputs (services), outcomes (health indicators), and impacts (system changes).
- CEEDs would be given priority in HHS funding through competitive grants. Service programs with research evaluation and regulation waivers would receive favorable consideration (e.g., CMS service eligibility and benefits). To ensure progress and a reduction of cancer health disparities, a comprehensive evaluation process that utilizes effective assessment tools should be developed. Each designated CEED should be required to demonstrate efficacy and be evaluated on an annual basis.
- It will be important for HHS to reach out with a compelling message to communities that potentially qualify for the program to raise awareness of the opportunity to apply and to communicate the benefits of undertaking such a process.
- All strategic plans developed under this initiative should focus on evidence-based intervention methods and measurable outcomes that lead to and can document the elimination of one or more cancer health disparities within that particular community. Although the initiative would be national in scope, addressing different types of cancers and different populations with health disparities, the specific disparities targeted within each

[7] Block grants are flexible lump sum awards made to state or local governments to address a specific topic area.

community would be particular to that community.

Develop, implement, and evaluate education and training programs designed to create a diverse and culturally competent cancer care workforce. Apply standards to certify the cultural competence of health professionals who receive Federal support.

Development, for Initiation within 2 Years

Rationale

Promotoras (Latina community outreach workers), community lay workers, certified medical interpreters, and patient navigators are all health-related professionals who are retained for the express purpose of providing culturally competent assistance to individuals who have or are at risk of developing cancer. We feel that some level of cultural competence needs to extend to the entire cancer care workforce.

This PRG recommendation is directed at a system-wide approach for institutionalizing cultural competence. Increased funding is essential for developing and systematically evaluating education and training programs for reducing health disparities through cultivation of culturally and linguistically competent health professionals who are representative of the communities they serve. The education and training necessary to increase cultural competency need to begin as early as kindergarten, extend through high school and into higher education, and include opportunities for nontraditional students.

Issues of Importance

HHS should review all of its minority education and career development programs and partner with the Department of Education; other Federal, state, and private agencies; and communities to leverage resources and better coordinate efforts to increase the diversity of people entering health-related professions.

Educational training opportunities, such as continuing medical education courses, should be developed for and by the community to promote the cultural and linguistic competence of health professionals and staff. Once education and training programs become available, it will be important to systematically evaluate over time the success of the programs in building a better prepared workforce and the impact of such programs on the populations they serve. Key to the evaluation will be determining which programs are most effective at different times. Once there is evidence demonstrating the benefit of the programs in reducing cancer and other health disparities, evidence-based approaches for cultural and linguistic competence training should be:

- Incorporated as a core requirement in examination plans for licensure, relicensure, or certification for health professionals
- Linked to accreditation by the Joint Commission on Accreditation of Healthcare Organizations and professional licensing
- Certified in recipients of Federal funding (both health care providers and institutions)

HHS has already developed standards that can be applied to certification of cultural and linguistic competence. [4] Implementation of these standards would be analogous to the requirement that funded investigators demonstrate competence in their ability to protect human subjects during research studies or that policies be in place to ensure a drug-free work environment. Our suggestions for ensuring a culturally competent workforce include conducting appropriate monitoring for compliance, documenting training and infractions in human resource files, and levying penalties for noncompliance.

Delivery

Challenges and Opportunities

Cancer health disparities will not be eliminated until all individuals derive equal benefit from required services in cancer prevention, detection, diagnosis, treatment, survivorship, and end-of-life care. This requires: (1) equality in the quality

of services delivered, which is driven by policy, economic, and other factors on the "giving" end of the health services delivery pathway, and (2) equality in the ability to benefit from the services delivered, which is driven by cultural, linguistic, and other factors on the "receiving" end of the pathway. Table 2 suggests barriers to eliminating cancer health disparities on both sides of the delivery pathway.

Table 2. Barriers to Delivering Cancer Services to All People at a Consistent Level and Quality

Giving End	Receiving End
• Cancer services are not being delivered as a continuum of care. – A large number of Americans do not receive any type of preventive services. – Many individuals, including those who are at elevated risk, are not screened for detectable cancers. – In many instances, there is no provision of follow-up care after a positive screening result. – There are often long delays between biopsy and initiation of treatment. – Physicians who are not adequately trained in adult or pediatric oncology are providing treatment that is substandard. – There are terminally ill patients who never receive end-of-life care or do so too late to be of benefit. • Federal, state, and local agencies are neither implementing policies that have already been endorsed nor enforcing regulations that have already been made into law. For example: – Title VI of the Civil Rights Act – *National* Standards *for Culturally and Linguistically Appropriate Services in Health Care* adopted in late 2000 – Various antidiscrimination laws • Health care delivery systems are resistant to consider elimination of health disparities as a worthy goal for resource investment due to factors that include: – High initial cost – Absence of tangible rewards • Cost-cutting measures being applied by health care delivery systems and payer organization have a greater adverse effect on populations with low socioeconomic status. • Cancer service providers allow racism and other biases to affect their job performance.	• Individuals distrust the cancer prevention information and early detection services that they receive from those not within their own community. • Cultural, religious, and traditional tribal beliefs are not always compatible with evidence-based or best-available medical practices. • Individuals are unable to access services because of cost barriers that include: – Lack of insurance or Medicaid coverage[a] – Underinsurance (i.e., insurance that does not cover state-of-the-science preventive or treatment services) – Inability to take time off from a job to receive needed services • Individuals are unaware of available services, unable to access services, or unable to derive benefit from services because of communication barriers that include: – Not being able to speak English – Low literacy – Hearing, sight, or cognitive impairment • Individuals are unable to access services because of physical barriers that include: – Geographic isolation – Lack of transportation – Inconvenient hours of service – Frailty or physical disability – Competing life demands

[a] Findings of the President's Cancer Panel [2] indicate that 44 million people have no health insurance and nonelderly uninsured rates are as high as 25% in some states. An additional 31 million nonelderly insured Americans have inadequate coverage for cancer care costs.

We believe that the barriers are ultimately surmountable and that progress can be made toward eliminating disparities in delivery of cancer services through:

- Changes in policy, including better implementation of existing Executive Orders, so that public health care financing mechanisms (i.e., Medicaid and Medicare) cover cancer services fairly and equitably.
- Judicious use of incentives and disincentives, whereby entities that take positive actions toward reducing health disparities are rewarded and entities that take no action are penalized. We believe that incentives and disincentives can be used to:
  - Raise the level of cultural competence and reduce the behavioral manifestations of racism and other biases.
  - Increase health-promoting behaviors and decrease health-degrading behaviors in individuals who are at risk for developing cancer.
- Partnerships, in which government agencies, payer organizations, provider organizations, and communities work together to promote knowledge and trust, change policy, and solve problems in service delivery. Partnerships are most effective when their leadership is diverse and when representatives from the communities being served have equal involvement in all stages of planning, execution, and follow up.
- Adapting health information based on the specific cultural and linguistic characteristics of the communities being served. The Special Populations Networks initiative of the NCI Center to Reduce Cancer Health Disparities is an example of a program that supports development of culturally appropriate materials for cancer prevention and control in specific populations.
- Increased interest in and evaluation of the use of health advisors who can educate and assist individuals from tribal and other communities in a culturally competent manner. Patient advocates, patient navigators, community lay workers, *promotoras*, and certified medical interpreters can ensure that patients understand their risks, diagnoses, and treatment options and can improve access to the continuum of care required for favorable outcomes.

Priority Recommendations

Implement evidence-based tobacco control strategies, including those that create financial disincentives for tobacco consumption and those that provide social reinforcement for not smoking.

Delivery, for Initiation within 1 Year

Rationale

Tobacco smoking leads to higher incidence of cancer among certain populations and a strong evidence base supports the effectiveness of policy changes and prevention and cessation interventions to reduce tobacco use. [5,6] Proven interventions that should be broadly implemented include:

- A Federal excise tax as recommended by the Subcommittee on Cessation of the Interagency Committee on Smoking and Health[8]
- Comprehensive community-based, combined with school-based, smoking prevention programs targeted to adolescents
- Cessation services, including pharmacotherapy (drug-based treatment) and counseling

Issues of Importance

Available data are conclusive in demonstrating a decline in cigarette smoking or sales after cigarette prices are increased. [6] This is especially true for young, adolescent, and low-income adult smokers.

[8] *The Interagency Committee on Smoking and Health* was established in 1985 to coordinate the smoking-related activities of HHS with those of other Federal, state, local, and private agencies. The Committee's website is http://www.cdc.gov/tobacco/ICSH (last accessed on January 21, 2004).

Ensure that populations at highest risk have access to age- and gender-appropriate screening and follow-up services for breast, cervical, and colorectal cancer. Expand to include these services for other cancers (e.g., prostate and lung) when there is evidence that they are effective at improving survival.

Delivery, for Initiation within 2 Years

Rationale

There is solid and ample evidence demonstrating that appropriate screening with follow-up treatment for breast, cervical, and colorectal cancers will significantly impact survival. [6] The CDC National Breast and Cervical Cancer Early Detection Program (NBCCEDP) was established in 1991 in response to the 1990 *Breast and Cervical Cancer Mortality Prevention Act*. Since passage of this act, the U.S. Preventive Services Task Force (USPSTF)[9] has reviewed the accumulated evidence and determined that there is also benefit to screening adults, ages 50 or older, for colorectal cancer. [7]

In 2000, Congress passed the *Breast and Cervical Cancer Treatment and Prevention Act* to help make follow-up services more accessible, through state-managed Medicaid programs, to women enrolled in the CDC program who are found to have breast or cervical cancer or a related precancerous condition. Benefit can only be obtained and justice can only be served when screening is coupled with follow-up services. Thus, follow-up services are a mandatory part of the implementation of this PRG recommendation. We also recognize that, with the recent economic slowdown, states with growing budget deficits are carefully reviewing their Medicaid expenditures. This may serve as an additional barrier to full follow-up and treatment for patients in the CDC program with abnormal screening results.

Issues of Importance

The NBCCEDP is an important program that aids many, but not all, women who are uninsured and otherwise unable to access services for early detection of cancer. Expansion of the program should be explored so that it includes more community-based organizations and is no longer largely dependent on public health agencies. Once additional cancer screening techniques are recognized as effective by the USPSTF, these techniques should be added to ongoing cancer screening and wellness programs.

Support culturally, linguistically, and literacy specific approaches for eliminating cancer health disparities. These should include evidence-based "best practices," proven interventions, and outreach strategies.

Delivery, for Initiation within 2 Years

Rationale

Cancer communications that are culturally, linguistically, and literacy specific contribute extensively to quality cancer care and enhance health outcomes. [1,8] Recognizing that linguistic diversity is an integral part of American culture is essential for eliminating cancer health disparities. A report from the 2000 Decennial Census indicates that 17.9 percent of the U.S. population ages 5 and older speak a language other than English while they are at home. (The most common of the other languages spoken is Spanish. However, Chinese, Vietnamese, Korean, and Tagalog are also commonly spoken.)[10]

Currently, there are gaps in our knowledge about how interventions shown to be effective in some populations can be replicated in other populations. Also, there are gaps in our knowledge about the risk factors that are of particular importance in cancer health disparities. Providing culturally,

[9] The Agency for Healthcare Research and Quality (AHRQ) *U.S. Preventive Services Task Force* is an independent panel of experts in primary care and prevention that systematically reviews the evidence of effectiveness and develops recommendations for clinical preventive services. The USPSTF website is http://www.ahrq.gov/clinic/uspstfix.htm (last accessed on January 21, 2004).

[10] U.S. Bureau of the Census, American Fact Finder http://www.factfinder.census.gov/ (last accessed on January 21, 2004).

linguistically, and literacy specific materials will facilitate the formation of racial and ethnic partnerships that can help to effectively bridge these gaps through clear communication. In partnership with cancer survivors, caregivers, and community advocacy organizations that are able to enhance the process, these knowledge gaps can be filled.

Issues of Importance

We recognize that a large financial commitment will be needed to implement this recommendation on a national level. HHS should:

- Establish a mechanism for a two-tier peer review process for evaluating (1) the efficacy and effectiveness and (2) the dissemination and adoption potential of "best practices" and outreach strategies that include community input.
- Establish a central HHS clearinghouse for the dissemination of cancer education materials, "best practices," and outreach strategies.
- Expand resources to make federally collected administrative data (e.g., Medicare data) more available to researchers and community programs.

Ensure that every cancer patient has access to "state-of-the-science" care.

Delivery, for Initiation within 3 Years

Rationale

Ensuring access to the most effective cancer treatment is critical for reducing unnecessary suffering and death due to cancer and eliminating inequity and social injustice. Lack of adequate insurance coverage is the single most difficult barrier to achieving this objective. An analysis of data in the AHRQ Medical Expenditure Panel Survey database for 1996 through 1999 showed that over 850,000 cancer patients had no insurance. [9] A Federal precedent exists for providing lifesaving services to those in need. For example, since 1973, people of all ages with end-stage renal disease have been the recipients of Medicare benefits. [10] However, as part of the *Medicare Prescription Drug, Improvement, and Modernization Act of 2003*, reimbursement for cancer drugs is scheduled to decrease. While Medicare coverage now extends to routine patient care in clinical trials, additional steps must be taken to provide full clinical trials coverage for all Americans.

Issues of Importance

To implement this PRG recommendation, it is necessary that state-of-the-science standards of care be defined and disseminated, and that monitoring take place to ensure they are being followed. Ensuring that no person with cancer goes untreated is the goal of this recommendation. Emphasis should also be placed, however, on cancer prevention and early detection, especially in populations with the greatest cancer burdens.

Collaborate with the private and voluntary health sectors to ensure that all Americans receive the full range of lifesaving information, services, and quality care from cancer prevention to screening to diagnosis to treatment.

Delivery, for Initiation within 3 Years

Rationale

Many people do not have any insurance or sufficient insurance to receive essential cancer services in screening, diagnosis, treatment, and other aspects of care. It has been shown that people without health insurance are diagnosed with cancer at later stages and die from cancer at higher rates than those with insurance. [11,12,13]

Those who do not have adequate levels of insurance coverage are subject to the fragmentation that results when health care providers have little to no information on related co-morbidities and psychosocial health issues.

For some types of cancers (e.g., myeloma and brain cancer) or advanced stages of cancer, there are limited or no places for patients to go for supportive care. Medically underserved populations generally have limited or no access to palliative or end-of-life care.

Current health care reimbursement systems are insufficient. Eliminating health disparities requires targeting of resources to the geographic areas and groups of people that display the highest avoidable mortality rates. As the department responsible for public health care reimbursements, HHS is in a position to lead the way in this important effort.

Issues of Importance

Access to health information and quality health services should be comprehensive, timely, and equitable. These services should include outreach, disease prevention, and treatment, and, when appropriate, should be integrated with traditional healing and alternative medicine-based approaches. Funding should be sustained for these services. The ultimate goal of this PRG recommendation is to facilitate changes to public and private insurance programs so that they provide full coverage for cancer screening, diagnosis, and treatment, including cancer-related medications.

Health care as a right is being widely discussed by many stakeholders in this country. A good model of how well coordinated, multiple services can be provided to those who would otherwise be denied access is the pediatric cancer care provided by the St. Jude Children's Research Hospital. This hospital covers all costs of treatment beyond those reimbursed by third-party insurers and total costs at St. Jude when no insurance is available. The hospital also assists with transportation costs and local living expenses during a child's treatment period.

CONCLUSION

We believe that implementation by the Department of Health and Human Services (HHS) of all 14 Progress Review Group (PRG) priority recommendations in our Call to Action will improve the health and health care of those who experience cancer health disparities.

- Through implementation of our recommendations in Planning and Coordination, HHS will gain a more robust and cost-effective infrastructure for managing a broad spectrum of activities directed against health disparities and will increase both the visibility and impact of its efforts in this area.
- Through implementation of our recommendations in Discovery and Development, HHS will accelerate the pace at which "best practices" are identified and evidence is accumulated.
- Through implementation of our recommendations in Delivery, HHS will reverse the long-standing injustice of allowing Americans who have cancer to be treated unequally and will reduce cancer incidence and mortality.

Implementation of our priority recommendations will also assist HHS in meeting the overarching goals of *Healthy People 2010* [14] and the recommendations developed by the other expert panels (see Appendix C).

To allow for flexibility in the required levels of effort, resources, and collaboration, we recommend that HHS begin implementing the 14 PRG recommendations over a 3-year period (see Figure 1).

This PRG report describes our vision of a Nation without cancer health disparities and our consensus strategy for turning that vision into a reality. We hope that HHS will share in this vision and implement our 14 priority recommendations. By pursuing a comprehensive and coordinated approach, in which all HHS agencies work together and are held accountable, and in which incentives are aligned to optimize appropriateness, efficiency, and effectiveness, HHS **will make cancer health disparities *history***.

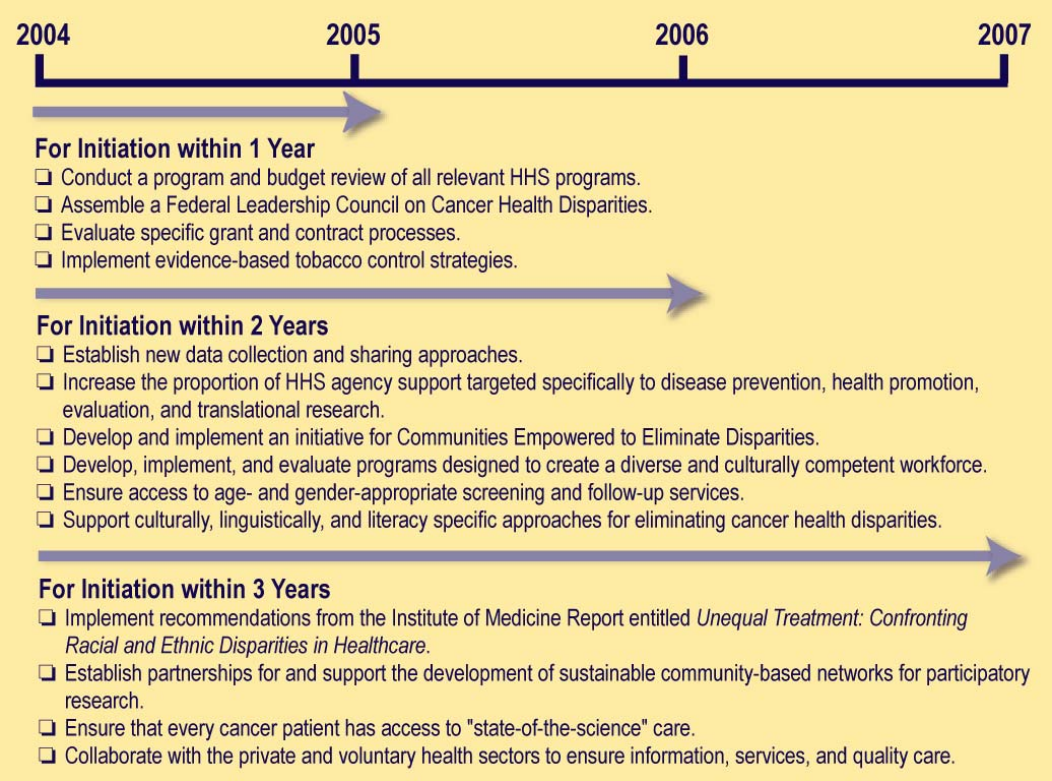

Figure 1. Timeline for Initiation of PRG Priority Recommendations

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Appendix A
Reports of the Roundtable Breakout Groups

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METHODS, MEASUREMENT, AND REPORTING

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Introduction

An effective program to reduce inequities in cancer outcomes among different subpopulations within the United States requires a foundation of rigorous methods, appropriate measurement, and informative reporting. The Trans-HHS Cancer Health Disparities Progress Review Group provides the opportunity to consider the current status of methods, measurement, and reporting relative to cancer health disparities and to offer recommendations for improvement.

Clear descriptions of disparities and the major factors believed to be responsible for them are essential. Standardized definitions and means of characterizing subpopulations are needed to identify those that sustain the adverse effects of disparities, facilitate comparisons in research findings across and among subpopulations, and assess progress over time. A national consensus on core measures of inequity and its determinants is critical. Definitions and measures must be constructed emphasizing applicability and utility in both research and programmatic settings. Efforts to establish and consistently support mechanisms and procedures for the routine collection of appropriate measures and the generation of regular periodic reports that monitor the cancer burden, the magnitude of disparities in cancer outcomes, and trends in these measures over time are crucial elements for eliminating cancer health disparities.

Characterizations of populations at the national and state level, where racial/ethnic groups are usually defined by Directive 15 from the Office of Management and Budget (OMB), need to be disaggregated into more homogeneous population groups. This is needed to provide a more accurate picture of disparities at a local level, identify where the largest inequities occur, and target effective interventions to alleviate them. While reduction in mortality remains the ultimate outcome and goal for actions to reduce cancer health disparities, the full spectrum of outcomes must be included, from prevention through early detection and treatment to life after cancer and its impact on emotional health and quality of life along the entire cancer care continuum.

A federally led program to reduce cancer health disparities will be challenging to implement. One vital methodologic approach to facilitate its realization is transdisciplinary research that synergistically combines expertise across a wide range of disciplines, including (but not limited to) biology, pharmacogenetics, and the behavioral and social sciences. Focused on common health issues, transdisciplinary research methods and teams are uniquely able to develop or refine conceptual models that incorporate multiple perspectives and more effectively capture the inherent complexity of health disparities. Methodologies developed in such cooperative settings help disentangle the relative contributions of cultural, behavioral, and biological factors and physical and social environments to observed disparities, as well as the dynamic, synergistic relationship that exists among these domains. Integration of all these levels in research designs is a vital step for understanding cancer health disparities as well as in designing interventions effective in reducing or eliminating them.

A number of transdisciplinary research efforts have recently received Federal support, among

them the National Cancer Institute's Transdisciplinary Tobacco Use Research Centers, the Centers for Population Health and Health Disparities, the National Center for Minority Health and Disparities, and other centers supported by institutes at the National Institutes of Health. The Trans-HHS Cancer Health Disparities Roundtable itself is a prime example of such a transdisciplinary effort in a programmatic setting. The support of the Federal government for these and like endeavors needs to be reaffirmed, expanded, and continued over the long term.

The policies and practices of Federal agencies have a substantial impact on efforts to reduce cancer morbidity and mortality. Many of the elements of programs effective in attacking cancer health disparities are appropriately developed, promulgated, regulated, and reported at a national level. However, the impact of Federal policies can be a double-edged sword as illustrated by OMB Directive 15 and its definitions of race and ethnicity. On the one hand, the OMB categories are widely accepted as standard, perhaps most significantly in the U.S. Census. It is by using these standard definitions that we have described and monitored cancer health disparities in the first place. On the other hand, these categories follow sociopolitical realities rather than more scientifically derived designations that take into account the complex interaction of culture, life experiences, and biology. From a scientific perspective, the standardization provided by the OMB classification is unfortunate, as it tends to confound or disguise underlying factors and to inhibit the ability to examine the effects of race or ethnicity as opposed to race or ethnicity as risk factors in and of themselves.

We recognize the unique opportunity afforded by the Trans-HHS Cancer Health Disparities Roundtable to make a substantial long-term nationwide impact on cancer care and outcomes by promoting changes in Federal policies and practices. Our consensus recommendations focus on the social, contextual nature of the challenge and emphasize what can be accomplished within the resources of the Department of Health and Human Services (HHS). Two priority recommendations are process-oriented, recommending means to establish workable and scientifically productive standards in key areas. The third priority recommendation specifically proposes to include geographical location of residence as a data category routinely collected by health agencies, promoting a major increase in the scope of potential scientific investigations at minimal cost.

Priority Recommendation 1.

HHS should require Federal agencies and strongly encourage state, local, and nongovernmental agencies to use a standardized minimum core set of measures of "race and ethnicity" and socioeconomic status in the collection and reporting of data.

Rationale

Only coordinated, standardized, and continuous collection of high-quality data will allow HHS to accurately describe cancer health disparities and monitor progress in removing them. Only Federal-level leadership can establish consistent data formats and categories for comparability across data sets (see Priority Recommendation 2). Such leadership on this central issue by HHS, perhaps working through a congressional mandate, would emphasize the fundamental need for collection of data on "race and ethnicity." Establishing a "core" set of measures serves the purpose of providing comparability across population groups while acknowledging that regional and local settings will have needs for unique measures to reflect distinct cultural and other aspects of local populations. A set of core measures is a "floor," not a "ceiling," for state and local jurisdictions. Standardized core measures of the more dynamic, cultural, and socioeconomic factors that may affect behavior are missed in the terms "race" and "ethnicity." Capturing such changes may require expansion of OMB Directive 15.

Issues of Importance

- Consensus on definitions and categories is required.
- Existing standards to characterize populations that provide denominators for critical rates (e.g., U.S. Census), although imperfect, should be linkable to new HHS data collection efforts.
- Additional research is required to address the need to continually develop and modify core measures.

Priority Recommendation 2.

HHS should commission a National Academy of Sciences committee to assess and monitor cross-cultural equivalence of theoretical models, methods, measures, and modes of administration underlying data collection with diverse populations.

Rationale

Current theories, measures, and modes of administration have been developed and standardized primarily within the majority population of peoples of European origin and assumed to be generalizable and appropriate for diverse populations. Evidence exists that the assumption of universal validity is not accurate.

Issues of Importance

- Measures to define and quantify health disparities that would facilitate the identification and monitoring of critical inequities need to be considered.
- There should be broad participation by groups concerned about cancer health disparities (e.g., departments and centers) in meetings convened to work concurrently on defining these concepts and identifying promising factors that impact health disparities.
- Ongoing development and monitoring are needed; this cannot be a one-time effort.

Priority Recommendation 3.

HHS should require geocoding of all health records to latitude and longitude or to census tract to facilitate linkage to other geo-referenced data.

Rationale

Geocoding facilitates linkage to other geo-referenced data (e.g., area-based socioeconomic data, other social characteristics, and environmental data) that would expand the scope of studies by including social and contextual level variables (e.g., community resources, hospitals, clinics, and physical environmental data). This would enable the analysis and monitoring of cancer health disparities and facilitate the use of geocoded data in state and local health department reports.

Issues of importance

- Current software permits rapid, inexpensive geocoding as address data are entered at the first point of contact with the health care system.
- Nationwide standardization is essential.

Additional Recommendations

Other suggestions for HHS action are to:

- Develop procedures and funding allocations to permit field testing of methodological questions pertaining to cancer health disparities within a wide range of studies.
- Mandate multilingual surveys in areas with linguistic minorities so that more representative samples of the various ethnic groups are included.
- Increase funding of cancer registries to promote more complete collection of data that help define and monitor disparities.
- Involve regional and local community groups in identifying specific mechanisms for interpreting and disseminating research results to communities through collaborative efforts utilizing a Participatory Action research model.
- Include time variables in analysis of health status.
- Expand the use of intra-group research to identify subpopulations within the broad OMB Directive 15 racial/ethnic groups to identify the various barriers to standard cancer screening and treatment, the causes of such barriers, and the policies needed to remove them.
- Focus reporting on targeting areas for improvement rather than on aggregate burden, including reporting of disease- and age-specific statistics.
- Promote the use of mixed quantitative and qualitative research methods to investigate health disparities.
- Encourage, through policies and funding, research to clarify the role of gene-environment interactions in cancer health disparities.

Conclusion

An effective program to reduce cancer health disparities requires a foundation of rigorous methods, appropriate measurement, and informative reporting.

Appropriate methods for investigating health disparities minimize cultural bias and insensitivity that hinder attempts to develop representative samples of subpopulations. Such methods efficiently obtain information from representative samples of relevant subpopulations. They coordinate synergistic efforts of researchers from fields as wide ranging as biology, genetics, and the behavioral and social sciences. Measurements appropriate to productive methods of investigation focus on observable quantities and qualities likely to elucidate key determining factors in health disparities. These are characterized in standard, comparable terms applicable in both research and programmatic settings. Informative reporting assembles, analyzes, and processes data regularly and routinely collected on appropriate measures. Results are presented in terms of important outcomes in sufficient detail to gauge status and progress and to direct interventions at remaining inequities.

The Methods, Measurement, and Reporting Breakout Group recognizes the Federal government's unique ability to establish and promote standards for nation-wide use and has proposed a set of priority recommendations for applying it in ways of value to scientific inquiry and program development.

ENHANCING THE LEVEL AND QUALITY OF HEALTH DISPARITIES RESEARCH

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Introduction

While racial, ethnic, and other types of disparities in health have been documented for decades, "health disparity research" has not been adequately described or defined. [1] Research on cancer health disparities is a complex undertaking that requires multifaceted, multidisciplinary, and interdisciplinary research.

Community resistance and distrust of research and researchers are significant barriers. There is a need to expand the capacity and cadre of investigators trained and committed to health disparities research. There are also inequities in the distribution of research funding targeted to health disparities.

Therefore, enhancing the level and quality of cancer health disparities research is highly dependent upon significant advances in the structure (research infrastructure), process (funding mechanisms), and content (research focus) relating to such efforts.

Priority Recommendation 1.

HHS should provide the funds necessary to fully develop and sustain community-based participatory research resource support networks that focus exclusively on multidisciplinary cancer health disparities research, independent of individual project funding.

Rationale

- Engagement of the affected communities in research enhances the likelihood of the adoption of beneficial and relevant research results at the individual and community level.
- This recommendation is specifically designed not only to increase community participation to translate the research into action, but also to create a sustainable structure for the efficient and effective conduct of research on other disease/conditions where disparities exist.
- Historically, grant funding for cancer disparities research has been inadequate to fully support the infrastructure requirements for the conduct of high-quality population-based research. Specifically, more support is needed for technology, training, scientific oversight, patient care related to research, and outreach efforts related to increasing disparity population participation.
- A collaborative process of conducting research of value to a community involves investigators working with the community in all phases of the research—defining the problem, developing hypotheses to guide action, deriving specific aims, designing approaches, implementing methods, analyzing and disseminating results, and developing courses of action.

Issues of Importance

- Developmental funding support must be for a minimum period of 7 to 10 years.
- Sustainability funding should be provided in the later years at some lesser percentage.
- Adequate rigor and high scientific standards must be maintained.
- Legitimate and documentable community participation in networks must be ensured.
- It is important to have an academic institutional link with each network.
- Funding should be directed to entities within the community that are impacted by health disparities.
- Geographic dispersion of funded networks and diversity of population should be emphasized.

Priority Recommendation 2.

Establish specific peer review grant and contract entities and processes that have the necessary expertise, knowledge, and experience to fairly and equitably evaluate health disparities research proposals and/or projects.

Rationale

- The current peer review process is limited and inadequately constituted to enable the fair evaluation of the quality of health disparities research, which is often multidisciplinary.
- There is a need to enhance the cultural competence and composition of peer review panels.

Issues of Importance

- New structures are needed that enable trans-agency health disparities research.
- The inflexibility and lack of necessary expertise in the existing peer review system are often addressed by the establishment of ad hoc and/or special review panels.
- Consumers should be represented on Institutional Review Boards.

Priority Recommendation 3.

Significantly increase the proportion of funding within each agency of HHS targeted to prevention, health promotion, and translational cancer health disparities research with an emphasis on efficacy, effectiveness, and cost effectiveness.

Rationale

- Over the next several years, the biggest impact on morbidity and mortality will come from advancements in prevention, early detection, timely treatment, and health promotion.
- A disconnect exists between the health care system's emphasis on treatment, and the need for more disease prevention and health promotion. Health promotion and disease prevention research are underfunded, and reimbursement mechanisms are inadequate to support the full implementation of culturally relevant and effective health promotion and disease prevention strategies.
- Little is known about what prevention and health promotion strategies work in different populations.
- There is a gap in behavioral knowledge of why different people accept or reject appropriate health behaviors or take advantage of health services.

Issues of Importance

- The deficit research model must be challenged.
- Research efforts must be considered in a contextual perspective, viewing issues from the context of neighborhoods and where people live.
- In designing research efforts, consideration should be given to relevant intergenerational influences that can be translated and widely disseminated to the broader populations.
- Disease prevention and health promotion research must also include scientific inquiry from a lifespan, mental health, and emotional well-being perspective.
- Greater focus should be placed on the acceptance and implementation of relevant translational research results, including resource adjudication, cost-benefit, and feasibility analyses.
- Culturally, linguistically, and literacy appropriate consent forms are necessary to allow true informed consent for disparity populations.

Conclusion

Health disparities research is an important tool for eliminating disproportionate disease burden in a variety of populations including racial and ethnic groups. Well-designed disparities research should be the foundation for clinical practice and behavioral interventions as well as for policy formulation on health disparities.

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RESEARCH POLICY

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Introduction

The traditional model of population-based research incorporates a cyclical process wherein agencies fund a scientist who then seeks the target population in which to test the research hypothesis. In places where the researcher is not a member of the community, contacts or liaisons within that community are often enlisted to help recruit participants for the research trial. When the trial is completed, the researcher analyzes the data and presents findings to the scientific community. Successful research results in more funds to continue the cycle.

This model has been successful for many diseases and in many populations; however, significant barriers of this model limit the effectiveness in certain populations. These barriers include (1) inadequate dialogue with a community to design studies that the community is most interested in pursuing; (2) inadequate feedback to the community about results of trials and discussion of potential outcomes; (3) inadequate delivery of tangible results to the community; (4) slow recruitment of participants; (5) attrition of participants leading to insignificant results; and (6) lack of support for young, minority researchers with well-designed proposals to reach communities in which they may be accepted as research investigators.

Such barriers and other cultural and societal factors have influenced certain communities to distrust clinical scientists and to perpetuate an anti-participatory sentiment. These attitudes may extend beyond a distrust of the scientist, to encompass distrust of contacts/liaisons in the community, resulting in difficulties in recruiting and retaining patients.

One successful model of clinical research has been that of international community-based research programs (e.g., the investigation in Shandong Province, China for treatment of gastric lesions). [1] Researchers enlisted physicians and community leaders in those countries to help educate both the researchers and the participants about each other's needs and expectations. As a result, researchers were more culturally aware, and local physicians and leaders participated in the research design. Tangible benefits for those communities were also arranged in advance (e.g., providing a supply of the interventions being tested to that community following the study).

An alternative model for conducting domestic epidemiology and intervention clinical trials on some populations should be considered. In this model, researchers should become more integrated with the community and should have greater cultural sensitivity to the populations being studied. Potential participants may require incentives, education, and dialogue to be comfortable with the process and their role in the process. Some tangible benefit should be delivered to research trial groups, and possibly the larger community, that experience a high burden of the targeted disease.

Priority Recommendation 1.

Establish a trans-HHS database that centralizes and standardizes cancer and cancer-related data.

Rationale

Currently multiple agencies across the Department of Health and Human Services (HHS) (including Centers for Medicare & Medicaid Services [CMS], Centers for Disease Control and

Prevention, and National Cancer Institute [NCI]) collect, store, and analyze information about health trends (including incidence and mortality due to specific cancers) in various populations; however, the data collected are not standardized, nor are the different databases compatible. In addition, redundancies exist in data collected by different agencies. These redundancies in collection and difficulties sharing the data maintained in different agencies contribute to inefficient data collection, maintenance, analysis, and dissemination. The incompatibility of databases limits researchers to using only one database for studies, which is an impediment to more comprehensive examinations needed to identify communities with health disparities and attempts to conduct research within those populations. In addition to HHS epidemiological databases, databases exist at the Federal, state, and local government levels and at non-governmental and private organizations that are not compatible.

Issues of Importance

The Secretary of HHS can mandate that agencies develop standards, timelines, personnel, infrastructure, and funding to set up a centralized, accessible database. In an initial phase, all epidemiological databases across HHS could be centralized into a single, standardized database. All new data would be imported into the single database that would be fully accessible across agencies and to the research community. By maintaining a single database with standardized data reporting, HHS could facilitate rapid analysis of gaps in data, trends in data, and opportunities to target populations more rapidly than could be done with the current system of multiple sets of incompatible data. In the long term, a universal epidemiologic database will save money by reducing redundancy of data collection and reducing the maintenance of multiple database systems.

The mandate would also require the adoption of standard measures for population data collection by HHS agencies. For entities not explicitly part of HHS, including non-Federal government agencies and non-governmental organizations, HHS would provide incentives to adopt the same data standards and shared database collection.

Another short-term opportunity that would stimulate health disparities research is an examination of the current databases to identify consistent examples of regional/local health disparities. Research on particular populations would refine the scope of health disparities, as well as evaluate the impacts of specific behavioral and medical interventions on those communities. These data could be used to identify early trends in cancer incidence and mortality as well as co-morbid conditions in those populations.

Creating a single, unified epidemiologic database will enable rapid analyses of health disparities. These analyses will enable public health researchers to deliver results to health care professionals in communities that have a high burden of selected diseases and to accelerate the identification of vulnerable populations for early screening and treatment modalities. By finding populations with high burdens of specific diseases, tailored education to those communities may be used to influence preventive behaviors and medical decisions to reduce disparities.

Priority Recommendation 2.

Establish, recruit, fund, and evaluate community research infrastructures (units), in areas of large cancer disparities, to collaborate in all stages of the research process.

Rationale

Among the different communities at high risk for specific cancers are distinct populations that are also indifferent to requests for participation in research trials or are outright anti-participatory. The reasons for these responses vary but may include one or more of the following: (1) a general distrust of the biomedical research and medical service enterprises, (2) a perceived history of condescending attitudes and even unethical behavior by researchers toward subjects, (3) inadequate knowledge about the scientific method by participants, (4) a lack of tailored education and discussions with communities to alleviate concerns about the process, and (5) inadequate cultural awareness of different communities on the part of researchers.

Negative community attitudes about biomedical studies result in poor recruitment and poor retention of research subjects. Failure to complete clinical trials is expensive and leads to further resentment in communities that had hoped to

benefit from the new results and interventions. Trials that are prolonged and extended become burdensome on participants, which in turn can lead to higher attrition rates. Additionally, the lack of community engagement in the research process is perceived as a lack of compassion and interest in the community, and this perpetuates the sense of distrust of any research program.

Issues of Importance

Infrastructures ("units") that work within a community to facilitate clinical research investigations can be established in areas of large health disparities. These research mediators would be independent from researchers, universities, and other research entities. The units would be fully integrated within a community, and they would educate the community, encourage community members to participate in research, and advocate for tangible outcomes for the community following the completion of research trials. The units would also (1) assist researchers who seek a population to study, (2) encourage collaborations with researchers from underrepresented populations, and (3) facilitate the recruitment and planning processes for conducting trials. The composition of personnel in these units would vary according to their need, but would likely include a sociologist, a grants/contracts specialist, an epidemiologist, and a clinical trials nurse. Recent examples of community research centers (e.g., Community Clinical Oncology Programs) and networks have shown promise for a future of research units maintained at the community level. Established centers or networks may be modified to develop these units, or units may be newly created.

The initiation of this program would require the identification of health disparities in communities and the examination of the health structure of such communities to evaluate potential locations for units. Individual units would recruit leaders in those communities. Research planning seed grants would be provided to initially fund these units, and as units are developed, funding mechanisms would be incorporated to sustain successful units. The units would facilitate and promote partnerships with experienced researchers and help recruit new investigators from underrepresented groups to study health disparities. Programs to recruit students and interns to learn about the scientific method and to assist with these programs would be encouraged.

Potential impacts of these units would benefit both the community and researchers. Information on simple, preventive behaviors and tangible medical service would be provided to the community. Additionally, education of these communities in medical science would improve the recruitment and retention of research participants and would lead to more trials that are of greater importance to the community. Real dialogue between clinical researchers and the community would enable the latter to participate in the planning of trials to the extent that health issues critical to them are considered. These units would be able to act as brokers of the community looking for researchers who are studying diseases of great importance to that community, in addition to their role as brokers for researchers seeking participants in trials.

Priority Recommendation 3.

Establish an HHS center to evaluate and translate cancer disparities research and coordinate implementation of the findings.

Rationale

Cancer health disparities research will achieve optimal impacts in society when there are institutional mechanisms to accelerate and coordinate (1) the development phase of clinical research, (2) the transition from development to delivery, and (3) the adoption of new standards of care in those communities with greatest need. HHS requires a comprehensive overview and centralized authority to accelerate research and enable the transition from development to delivery for the most vulnerable populations. Likewise, no mechanism exists that supports the delivery of research advances back into the communities who participated in trials.

Issues of Importance

The current model of clinical research focuses on the results of the trial and the basic safety of the participants; however, this model is not designed to address other needs of individuals recruited to participate in the trial and their immediate community. Participants in clinical trials for screening and treatment interventions are typically only

involved as research subjects in the project for the duration of the trial. Often following a trial, participants and their communities do not receive responses from the research team describing the results and potential impacts of the investigation. In many clinical trials of screening techniques, subjects who have cancers detected and who are either underinsured or uninsured do not receive adequate treatment for their disease. Likewise, in higher risk communities from which subjects in research trials were recruited, there is no mechanism to deliver affordable screening and treatment to the entire community.

Barriers to the goal of universal delivery of screening and treatment practices to all Americans exist. Offering standards of practice to all high-risk, uninsured, and underinsured Americans living in communities where clinical trials are conducted would be a prohibitive financial burden. Clinical trial investigators are not experts in community dynamics or policies to benefit communities and may not realize the expectations of the community. Investigators are not required to report the results and the potential impacts of the research to participating communities following the completion of clinical trials.

HHS, National Institutes of Health, and NCI do not have adequate mechanisms for the seamless transition of new interventions from development to delivery. The transfer process is unguided and can result in delays in delivering new interventions and practices. Likewise, no mechanisms like the CMS support for interventions-based clinical trials exist that ensure appropriate treatment for those underinsured and uninsured patients in whom cancers are detected in screening trials.

HHS can create a national center that has authority and accountability for the seamless transfer of research findings from development to delivery, ensuring greater care for people at higher risk for specific diseases. This organization should be a central authority that receives results from clinical trials, evaluates the findings for potential delivery, and guides the transfer of new interventions from development to be delivered to physicians and the communities with the greatest need. This center should engage in reciprocal communication with community centers, networks, and other units of clinical research, as well as linking researchers with research units. A challenge for this center will be the adoption of practices that encourage clinical researchers to more fully integrate with participants and their communities as well as to find mechanisms for the delivery of beneficial knowledge, practices, and interventions to those communities from which trial participants were recruited. Finally a central agency can work with other agencies to ensure that practices and interventions are disseminated to populations with greatest need.

The impact of this center on specific communities with higher incidence of disease should be felt at both the development and delivery phases. Building goodwill between the community and the research community, and improving communication between these groups could lead to additional trials being conducted within the community with more rapid recruitment and completion. Improving the perception of research programs and medical professionals might also improve the acceptance of behaviors suggested by medical professionals to reduce individual risks of diseases. Guidelines for behaviors and practices of care will be better evaluated, established, and disseminated to these communities with heightened need. These guidelines will enable the delivery of equal care across diverse and vulnerable communities to eliminate cancer health disparities. This center will accelerate the flow of research on cancer health disparities from discovery through development and into delivery.

Conclusion

The model proposed here is to introduce a community-based component to the general model of clinical research. Community research units could be established in communities at higher risk for certain diseases and could build a relationship with those communities. These units could become immersed in the culture and learn about the needs of the community. These units would be expected to identify and hold dialogues with community and advocate leaders and to educate physicians and the broader community. These units could help communicate the plans of the researchers to the community and the needs and expectations of the community to the researchers. The benefits of implementing a new model of clinical trials outreach wherein researchers are

better integrated with the community, are anticipated to be an improvement in the relationship between the researchers and participants, improvement in the recruitment of participants for clinical research, and delivery of a tangible benefit to those communities.

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ACCESS TO QUALITY CANCER SERVICES

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Introduction

Within the next year, it is expected that over 550,000 Americans will die from cancer, equivalent to three jumbo jets going down every day with no survivors. While it is widely acknowledged that all Americans should have access to quality cancer care, funding to provide comprehensive high-quality cancer services lacks political support. Insurance coverage is also lacking. Currently, 44 million Americans have no health insurance. [1] Uninsured rates are as high as 25% of the nonelderly in some sites, with much higher rates in some rural and frontier regions. In addition, at least 31 million non-elderly insured Americans are underinsured for cancer care costs. [2] Primary care providers and specialists should be permitted to refer patients to oncologic health care professionals or facilities outside the payer's network if medically necessary services are not available with the plan. Payers must provide ready access to pediatric oncologists, recognizing that childhood cancers are biologically distinct. Payers should provide patient access to and coverage of the patient care costs associated with participating in government-approved clinical trials.

Increased education of caregivers and consumers is needed. Health professionals often lack knowledge of how cultural and social factors influence health care. Many primary care providers, especially in rural and remote areas, lack information about cancer and current practices in cancer care. Not knowing how to get needed care within the health system is a barrier to obtaining quality cancer care. Information regarding health risks associated with increased cancer risk needs to be taught in the education system. Patients should be full participants in all decisions regarding care, have a clear understanding of their diagnosis, and have an awareness of all treatment options and the risks and benefits associated with each option.

Comprehensive and integrated services are needed. Fragmented cancer care systems do not ensure access to care, lack coordination, and contribute to inefficient use of resources. Partnerships between community-based organizations and care providers need to be promoted and funded. Public health care payers such as Medicaid should strive to help beneficiaries access the same health care products as privately insured patients. Cancer care requires that the patient have access to a multidisciplinary team of cancer providers across the full continuum of care and coordination of services. Timely referral for end-of-life care should be provided so that terminal cancer patients do not suffer needlessly.

Priority Recommendation 1.

Assure access to comprehensive (prevention, screening, diagnosis, treatment, quality of life, palliative, end of life), continuously funded, integrated health care for all people, including insurance coverage.

Rationale

Comprehensive Health Care

A holistic approach to health care and health promotion is needed (i.e., prevention, screening, diagnosis, treatment, quality of life, palliative, and end of life). When someone is diagnosed with cancer, the patient should be provided with the best possible care. They need a health care system where the provider has appropriate knowledge and experience regarding the particular cancer treatment needed.

Integrated Health Care

Cancer care should be integrated so that the interrelated issues of different types of disease that may impact cancer (e.g., stroke and diabetes) are addressed appropriately. The health care providers should know what other care the patient is receiving. Providers often have little to no information regarding related co-morbidities and psychosocial health issues. For some cancers, (e.g., myeloma, brain, or advanced stages of cancer), there are limited or no places for people to go for appropriate health care. There is limited or no access to palliative care for medically underserved populations. There are insufficient reimbursement systems, generating insufficient incentives for care. Increased integration of health insurance and health care systems under public oversight is needed to reduce the proportion of health expenditures consumed by administrative costs (including administrative expenses at the levels of Federal and state health care programs, health plans, hospitals, physicians' offices, and clinics). States need to be encouraged to integrate Medicaid and State Children's Health Insurance Program eligibility categories and programs to decrease administrative complexity, fragmentation, and to make them user-friendly and provide continuous coverage. Pediatric cancer care (e.g., St. Jude Children's Hospital) is a good model of well-coordinated multiple services.

Insurance Coverage

Increased insurance coverage will enable people who are presently unable to participate in screening, diagnosis, treatment, and other health services to obtain needed health care. Those that are presently medically underserved are being diagnosed with cancer at an advanced stage of development. Increased insurance coverage will enable earlier detection.

Issues of Importance

- Comprehensive services should include traditional and healing/alternative medicine.
- Sustained funding is needed.
- Public and private insurances need to be amended to provide full coverage for cancer screening, diagnosis, treatment, and medication.

Priority Recommendation 2.

Provide and sustain funding for coalitions, partnerships, and community-based quality cancer services, education, and prevention programs.

Rationale

Community-driven initiatives and partnerships are fundamental to decreasing disparities in access to health care. A more informed population will drive increased quality as people and communities demand quality care. Adequate and sufficient continued funding is needed for coalitions and committed partnerships, not "faux" partnerships.

Issues of Importance

To improve access to health care, and thus to decrease cancer health disparities, initiatives and partnerships need to be based in and include communities where these disparities occur. Community involvement should occur from the start and throughout all aspects of programs. Hard-to-reach populations need to be involved. Emphasis on men's health issues and access to clinical trials is needed. The Department of Health and Human Services (HHS) should: (1) create a system whereby all patients have a better opportunity to increase their knowledge and understanding of treatment choices, efficacy, and pros and cons; (2) ensure that communities and the public have full information that is relevant to prevention and treatment; (3) address mental health issues and disease impact on psychosocial issues in order to increase accessibility of services; and (4) emphasize strategies that focus on government, communities and individual families' empowerment.

Community partners need to be educated and given the tools to participate and partner with patients, providers, hospitals, universities, and organizations to build capacity and infrastructure to impact health and wellness in their communities. Federal leadership is necessary to build a strong community capacity and infrastructure through partnerships at the Federal, state, tribal, and local levels that will improve utilization of services, improve access to information and treatment, and therefore, improve disparate health outcomes. Partnerships that promote education and include, support, and sustain community advocacy organizations and individual patient navigator systems in discovery, development, and

delivery of health care will ensure patient access to and involvement with quality health care. A more informed population will drive increased quality as people and communities demand quality care. Examples of successful partnership programs include National Institutes of Health-funded Special Populations Networks and Health Resources and Services Administration-funded Community Health Centers. These programs and other partnerships like them need continued and sustained funding, as they work closely with communities.

Efforts are needed to increase men's awareness of behavior modification for cancer prevention, cancer screening, and cancer treatment options to promote increased participation of men in cancer care. Minorities, the medically underserved, and rural cancer patients need to be informed of the availability of clinical trials and need to be recruited into cancer care clinical trials. Education is needed to eliminate the common misconception that participation in clinical trials is more costly than "standard" cancer care.

Cancer care is multifactorial, multidisciplinary, and multileveled. Once diagnosed with cancer, many are lost in the system or do not understand their options for the best quality and comprehensive care available. In the process of one person being educated about cancer prevention, receiving the diagnosis of cancer, obtaining treatment or entering a clinical trial, and living with cancer, there are many people and steps involved in the process. Inevitably, all these factors put in place a setup for failure unless communication, coordination of care, and education are all in place. Support of community infrastructure and prevention programs also needs to be in place. Community advocates provide an invaluable resource to patients on individual and community levels. HHS should incorporate, support, and sustain community advocates in discovery, development, and delivery of cancer care. Community advocates and patient navigators should be trained and culturally competent to know what the system provides (including clinical trials), to provide case management throughout the continuum of care, and to aid individuals in obtaining maximal access to quality care services. Providers and consumers need to be educated on communicating their needs and intentions and to be continuously informed of the process of care. Communities, patients, providers, hospitals, and universities need to know their role in the care process.

Priority Recommendation 3.

Promote interventions and ensure accountability for culturally competent, quality cancer care addressing the unequal burden of disease.

Rationale

Evidence-Based Medicine

Evidence-based medicine is a conundrum until interventions have been successfully implemented within medically underserved communities. Science-based medicine must be effectively and respectfully implemented within all major ethnic groups; elderly populations; people who live in poverty; people who live in frontier, rural, or small urban communities; both genders; people who have physical or mental disabilities; and homosexuals. Although evidence-based medicine or interventions exist for the non-Hispanic white, middle class population, it cannot be assumed that these interventions are equally efficient within underserved communities. This is in part due to the lack of infrastructure, fragmentation of health and cancer care, and cultural differences. Evidence-based interventions need to be available to community organizations that can partner with scientists to adapt these interventions to be acceptable to the local communities. Evidence-based interventions will promote quality and save money. In the meantime, underserved communities cannot be denied funding for other cancer care interventions that appear to be effective, but have not yet met the criteria of science-based medicine.

Clinical Trials

Adequate funding and insurance coverage are critical to access quality cancer care (e.g., brachytherapy for early-stage prostate or breast cancer). At the present, very few medically underserved patients have access to such care. One of several strategies to obtaining quality cancer treatment may be through increased access to cancer clinical trials. There is very low participation in clinical trials (prevention, early detection, treatment, and quality of life) in medically underserved communities. The current literature cites numerous barriers for the recruitment and retention of women,

minorities, and the medically underrepresented to cancer care trials. [3-20] These barriers may be related to the type of cancer under study (the cancer may be less common in women or in a specific minority group), the site for the conduct of the study (e.g., a rural community hospital or clinic), or economics of protocol compliance (inability to travel or to pay for accommodations or medications). In addition, there is a common misconception that participation in clinical trials is more costly than is "standard" cancer care.

Navigators and Lay Health Advisors

We need to learn more about how to best utilize and train navigators. Culturally competent cancer care appears to be feasible through the paid support and training of Navigators/Lay Health Advisors from the respective medically underserved communities. [21] Likewise, these trained, salaried liaisons can also provide patient education to improve the patients' skills and knowledge. [22] Although these programs differ significantly among ethnicities, geographic regions, and health care systems, the overall outcomes appear to be improved access to quality cancer care, including outreach to initial screening and education services, throughout palliative and end-of-life care. [23]

Issues of Importance

- There is a need to improve access to state-of-the-art cancer treatments for all patients with cancer (e.g., clinical trials).
- Culturally competent recruitment and retention intervention methodologies are needed.
- Evidence-based research is also highly regarded as being "accountable."

Conclusion

Federal publications have documented insufficient and inappropriate care for medically underserved communities. There are documented case studies of patients waiting more than 6 months from the time of biopsy for cancer diagnosis and receipt of cancer care. Patients with stage 2 cancer are more likely to have progressed to stage 3; this stage is significantly more difficult to treat, requires more invasive cancer treatments, and results in poorer quality of life for both the cancer patient and the family. [24]

The United States is the richest country in the world and it is inexcusable to deny poor and medically underserved people access to quality and timely cancer services. A lack of adequate private insurance should not result in poorer quality of life or an inability to access state-of-the-art comprehensive cancer care (i.e., prevention, early detection, treatment, quality of life, and palliative care interventions).

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CULTURALLY COMPETENT HEALTH CARE SYSTEMS

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Introduction

In an era of unprecedented privilege and advances in medicine, health disparities in minority populations (such as African American, Native American, Asian American/Pacific Islander, Hispanic/Latinos) are increasing rather than decreasing over the past decade (Center to Reduce Cancer Health Disparities). As documented by a blue ribbon panel convened by the Institute of Medicine (IOM) in a report entitled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* [1], these disparities cannot be explained away by access-related factors, patients turning down care, or appropriateness of intervention. Moreover, these disparities occur over a wide range of illnesses and diseases and remain even after adjusting for socioeconomic status. [1] Because they are associated with worse outcomes, they are unacceptable.

Evidence exists of persistent racial and ethnic discrimination in most sectors of American life including health care. This pattern occurs in the context of broader historic and contemporary social and economic inequality. [1] As a result, minority patients receive a lower quality and intensity of health care across a wide range of procedures, treatment options, and disease areas, cancer included. Studies of the common cancers have shown a pattern of persistent under-treatment, [2] late diagnosis, [3] and inattention to late-stage issues such as pain control. [4] Correcting this pattern will require systemic change.

The rich cultural landscape in the United States, which includes varied traditions, attitudes, and practices, influences the doctor-patient relationship. The Department of Health and Human Services (HHS) has already established that culture and language have considerable impact on how patients access and respond to health care services. That premise serves as the basis for a report and standards entitled "Assuring Cultural Competence in Health Care." Studies suggest that a range of patient-level, provider-level, and system-level factors are involved in racial and ethnic health care disparities over and above access-related factors.

The culture of medicine and the disease-based paradigm can often be incompatible with traditional or cultural beliefs about health and wellness. Without communication, respect, and understanding of these differences, patients often experience a western medical model and system that is hostile to traditional ways of dealing with health complaints and the promotion of wellness.

Language incompatibilities significantly compound the difficulties ethnic minorities face when attempting to utilize an unfamiliar health care system. It is impossible to receive adequate health care when the patient cannot communicate with his/her health care provider, rendering health care on a par with veterinary care. This makes competent health interpreters and translators a critical need for eliminating documented disparities.

Discrimination and racism within the health care system exacerbate disparities. As a result, these racial minorities are less likely to receive appropriate diagnostic tests, therapies, and surveillance. Therefore, they experience worse outcomes. Until the health care system addresses racism at all levels within the system, significant gains in reducing disparities remain unlikely.

As a result of important and extensive work by blue ribbon panels and working groups, strategies for developing a culturally competent health care system already exist. HHS and IOM have each

developed recommendations for addressing the systemic problems that result in health care disparities. While not perfect, both sets of recommendations represent good first steps for achieving a culturally competent health care system. It is time to move from philosophy to commitment to actions.

Priority Recommendation 1.

Implement recommendations regarding cancer care from the Institute of Medicine Report entitled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*.

Rationale

This report addresses many of the broad societal issues, documents the problem associated with cancer care disparities, and offers practical and specific solutions.

Issues of Importance

- Because inequities have been demonstrated, there is a need to develop tools to verify that cancer patients are receiving equal treatment. This effort will address racism and other barriers to quality health care.
- Strong community partnerships are vital to designing and transforming the continuum of cancer care from prevention to detection to treatment to survivorship.
- Developing a culturally competent health care workforce includes increasing recruitment and retention of minority groups.

Priority Recommendation 2.

Update HHS Cultural Competency Standards and mandate compliance with these standards to qualify for Federal funding.

Rationale

These 14 standards have been published and adopted by HHS and serve as a good initial effort at creating culturally competent institutions and individuals. Updating these recommendations will reflect the linguistic needs of special populations. Specific efforts toward implementation are required.

Issues of Importance

- To achieve cultural competency, health care providers and institutions must be required to adopt these standards
- A monitoring system will assess compliance and provide consequences for noncompliance.

Priority Recommendation 3.

Require all health care professionals on all levels (Federal, academic, community, etc.) to have cultural competency training.

Rationale

Without training, a culturally competent health care system cannot become a reality.

Issues of Importance

- Appropriate monitoring is needed to ensure compliance, document infractions, and levy penalties for noncompliance.
- Specific continuing medical education courses dealing with cultural competency need to be developed.
- Participation in cultural competency training and cultural competency infractions will be documented in Human Resources files.
- Training in and compliance with cultural competency standards should be tied to Joint Commission on Accreditation of Healthcare Organizations certification and professional licensing, relicensing, and reviews.

Conclusion

Culturally competent health care systems will be able to reduce health care disparities. HHS must use its resources and authority to implement these much needed reforms. Department-level action is required to achieve this end. Because people and institutions act out of self interest, HHS should employ incentives and disincentives to achieve these goals.

Many national leaders and organizations have sacrificed time, effort, and talent. They have cajoled and cried for reform. In response, HHS and IOM have taken the first steps by eliciting recommendations to create a blueprint. Now, it is time to build a culturally competent health care system.

"Knowing is not enough; we must apply.
Willing is not enough; we must do."
--Goethe

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FACILITATING PARTNERSHIPS FOR ACTION

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Introduction

To effectively address the unequal burden of cancer experienced by underserved populations, we need to develop novel strategies that leverage partnerships among community, governmental, and academic segments of society, and that take into account the diversity of these population groups. Clearly, tailored approaches are needed. The communities that suffer disparities in health include African Americans, Hispanics/Latinos, Asian Americans and Pacific Islanders, and American Indians and Alaska Natives, as well as those who live in rural areas or impoverished elements within inner cities. For each of these population groups, unique cultures, needs, and burdens pose unique challenges for medical providers and governmental agencies. It is difficult for those outside the individual population to effect behavior change in the face of such differences. Those in the health care delivery field must develop cultural competencies that will help them meet the needs of these populations in a meaningful way.

We propose that the most effective route to gaining the required knowledge and trust of these populations and making a positive impact on their health status is by partnering with groups that are an integral part of the community and that advocate for these constituencies. Partnering will require carefully planned cooperation that emphasizes mutual trust, respect, and reciprocity.

The literature on government/community partnerships indicates that entities as varied as state governments and the World Health Organization have reached the conclusion that health goals can be met more effectively by working with existing community groups. [1, 2, 3] It is critical that community members be involved in the earliest stages of planning as well as during implementation. [4] Collaborative relationships that effect change require commitment, time, thoughtful cultivation, and development to implement strategies tailored to the culture, literacy level, and language of the underserved groups. [2, 5]

Most partnering arrangements cited in literature are in their early stages, and their effectiveness has yet to be measured. However, some have shown results. For example, among women in migrant farm-working families, academic/community partnering has made a positive impact on breast health. [4] Clearly, accurate and science-based information, materials, and resources of the Cancer Information Service have proven highly valuable for local partner groups. [6]

In our personal experiences with developing community partnerships, we have seen the positive impact of collaborative relationships in addressing health disparity issues. A partnership of three African American women's groups – the National Coalition of 100 Black Women, the Women in the NAACP and Alpha Kappa Alpha Sorority, Inc. – worked at the grass roots level with evidence-based behavior modification techniques to reduce Sudden Infant Death Syndrome among African American families as part of the "Save our Babies" initiative. Not only had their group been one of the first lay groups to be heard by an National Institutes of Health council, but they also were able to report on their considerable success. Another example can be found in collaborative efforts fostered by *Redes En Acción*, the National Hispanic/Latino Cancer Network. Over the past 3 years, this National Cancer Institute-funded Special Populations Networks initiative has successfully united academic and community groups to achieve the common goal of promoting cancer research, training, and public education opportunities benefiting the Hispanic/Latino population.

This breakout group found that opportunities exist to make significantly more effective and efficient use of partnerships between the Department of Health and Human Services (HHS) and community groups in addressing cancer health disparities among underserved populations. It is the primary aim of this group to identify programs and actions that promote awareness of the importance and the benefit of partnering among public and private organizations. Consequently, it is vital that programs be fostered that increase commitment to the cultivation of collaborative relationships. In addition, it will be extremely important to nurture healthy community infrastructures and environments conducive to the elimination of cancer health disparities.

Several factors are vital for any action toward the development of partnerships among Federal, state, local, and community groups. Among them are diverse representation of community groups; ascertaining the best practices available for partnering; and providing accurate, evidence-based material for the partnerships to use to encourage health practices.

Diverse Representation

To effectively address and eliminate disparities, diversity of representation is critical among decision makers, policy makers, and researchers involved in the partnership, and all partners must understand the needs, relevant characteristics, and influences in the communities being served. Moreover, it is essential that these communities be represented among decision, policy, and research leadership. Since communities are not static and indeed are in a state of constant dynamic flux, it is important that senior leadership be kept abreast of demographic changes, particularly those that may affect the goals and activities of the partnership. Throughout the course of the partnership, it will be necessary to recruit and retain individuals in leadership roles that reflect the diversity of the community and to support this leadership in understanding the populations that are being served.

Best Practices

There are successful community/government health partnerships. HHS must identify those that have proven effective, ascertain their best practices, and investigate how these practices work for specific underserved populations. Underserved communities may differ in significant ways; indeed, their primary commonality may be the fact that they experience disparities in health and health care. To effectively identify and define the best practices, investigators will need to learn more about these diverse populations: What makes them unique? What makes them different? What makes them similar?

In the end, such a review will help define the best practices for each of the underserved communities. The partnerships that work must be identified and analyzed so that they may be replicated for various other populations when appropriate.

To ensure the incorporation of best practices we must increase the visibility of these partnerships among public and private citizen organizations as well as government agencies. The place to begin would be with modeling intra-HHS collaborations.

Evidence-Based Programs

If they are to be effective, programs that are evidence-based and sound should be tailored for diverse populations. To develop such evidence-based programs, it is urgent to increase research conducted by minority researchers and in community-based programs. Also, we must develop effective data in the tumor registries for all populations. In addition, the benefits of input from community groups to research and government organizations must be clearly stated, and open lines of two-way communication between the community and the research/health agency must be maintained. It is vital that accountability be ensured at all levels of the partnership. It is equally important that partnerships value nontraditional data and that funding be provided to support data collection. Similarly, we should promote investment in market research to better understand behaviors and practices of diverse populations.

Guiding Principles

In general, the guiding principles for developing effective community partnerships include:

- Communications that build trust
- Equity among all of the partners
- Appropriate representation at all levels

- Mutual benefits and commitment by all principals involved in the partnership
- Accountability and realistic expectations at all levels

Breakout Group Priorities

The goal of this breakout group is to focus attention on the need to foster, encourage, and develop partnerships among government, local agencies, and community groups. Such partnerships are vital in the ongoing commitment to provide underserved populations with an effective continuum of cancer care–the full range including prevention, early detection, diagnosis, treatment, and survivorship. Equal access for all within our health care system is the key to elimination of disparities.

With this goal in mind, the group offers the following priority recommendations:

Priority Recommendation 1.

Establish a National Informed Health Choices Program to educate communities about the known risk reduction measures that are effective in reducing cancer.

Rationale

Although risk-reduction information exists, it has not been effectively disseminated to the many communities that are impacted by cancer health disparities. We know that if the public has equal access to available information and applies this knowledge in their lives, the risk of cancer for all Americans can be reduced substantially. According to the Institute of Medicine, if known risk-reduction behaviors were promoted and maintained, a 19% decline in the rate of new cancers and a 29% decline in the rate of cancer deaths could potentially be achieved by 2015. For specific individual cancers, the potential reductions are even more dramatic: the number of smoking-related cancers such as lung cancer could be cut in half and colorectal cancer by up to one third (*Cancer Prevention and Early Detection*, 2003). [7]

Issues of Importance

- It is vital to have an entity addressing cancer health disparities that can appropriately provide funding for collaborative partnerships, including public, private, and government sources.
- Impressive progress is available for underserved communities by making effective use of already known risk-reduction measures.
- To demonstrate the efficacy of programs, we need to develop comprehensive evaluation and assessment tools.
- If efforts are to improve effectively the health of communities suffering health disparities, the community must be consulted in all phases of planning and implementation.

Priority Recommendation 2.

HHS should identify and work with other public and private organizations to develop and implement a national "CALL TO ACTION" agenda to eliminate cancer health disparities.

Rationale

A participatory approach is needed to create an agenda for closing the current void in the participation and involvement of communities affected by cancer health disparities. This "Call to Action" will create effective opportunities that do not currently exist.

Issues of Importance

- Leadership must understand the importance of community involvement and be ready to solicit and act upon recommendations initiated by the community.
- Likewise, the community must understand its role and take action in reducing cancer health disparities.
- Measurable goals, timetables, and outcomes should be part of this agenda.

Priority Recommendation 3.

HHS leadership must articulate an entity within the Department that will have responsibility and resources to establish effective partnerships necessary to eliminate health disparities in cancer.

Rationale

This entity will be the vehicle to spearhead the effort within HHS.

Issues of Importance

- The entity will have the ability to link, create, and facilitate partnerships at all levels.
- The entity should have funding authority to establish partnerships and create a think tank of representatives from the communities, research organizations, universities, government, and corporate/nonprofit organizations to assist in reducing cancer health disparities.

Conclusion

We need to develop novel and effective approaches in our efforts to combat and ultimately eliminate cancer disparities among underserved population groups. Collaborative relationships, involving government agencies, academic institutions, community groups, and the public offer an optimal opportunity to achieve this goal. Through properly planned and administered partnerships, programs can effect changes to ensure that all segments of society achieve equality in the continuum of cancer care, from prevention and early detection to diagnosis, treatment, and survivorship. Moreover, through adherence to specific guiding principles, such partnership strategies can effectively address the issues of cultural diversity in guaranteeing the rights of all Americans to equal access for every aspect of cancer care.

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IMPLEMENTING EVIDENCE-BASED PROGRAMS TO REDUCE CANCER HEALTH DISPARITIES

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Introduction

In this report, we do not interpret "evidence-based" to imply that only randomized controlled trials are informative. Instead, we considered evidence from a broader range of studies. This is important because for many issues, such as community-based policy interventions or communication interventions aimed at long-term outcomes across cultures, it is not realistic to expect that randomized controlled trials can ever be done. Therefore, where evidence from randomized controlled trials was available, we considered it, but for other important interventions, we also considered a wide range of other types of evidence. The priorities addressed in the recommendations that follow reflect major health disparities and issues for which evidence of intervention effect is unequivocal. These priorities also address critical health disparity gaps for which more evidence must be generated.

Our first priority recommendation focuses on tobacco, which is the single most important cause of cancer in the United States. [1] Growing disparities by socioeconomic status in tobacco use in the United States will inevitably lead to increasing future disparities by social class in cancer. [2,3] Increasing the price of tobacco is the single most effective way to reduce tobacco consumption in the population, especially among youth. [4] Substantial variations between states in the price of tobacco will undoubtedly result in substantial disparities between states in tobacco use and in the future cancer burden from tobacco. Therefore, Federal initiatives to increase tobacco prices could prevent increases in future disparities between states. In addition to price effects on tobacco use, mass-media and community-based initiatives have been shown to be effective in reducing the uptake of tobacco by youth. [5,6] Finally, randomized trials have shown that both counseling and pharmacological aids to cessation (nicotine replacement and/or other medication use) are effective adjuncts in assisting people to quit smoking. [7,8]

Randomized controlled trials have shown substantial benefit from screening programs that lead to early detection of cancers of the breast and colon, and strong historical trends make it certain that screening for cervical cancer also reduces mortality. [9] Mortality rates from these three cancers are decreasing in the United States, in part due to screening efforts. [10] However, a socioeconomic and racial/ethnic gap remains in screening rates that will contribute to a continuing gap in mortality from these three cancers. [11] The Centers for Disease Control and Prevention (CDC)-supported National Breast and Cervical Cancer Early Detection Program, which offers breast and cervical cancer screening to the uninsured, is effective for the women it reaches, but this program currently serves only 15% of eligible women due to limited financial support. [2] Because the program is designed to directly reach underserved women of racial, ethnic, and socioeconomically disadvantaged groups, an opportunity currently exists to reduce these disparities by expanding this program. [2] Screening for colorectal cancer is also a proven strategy for reducing cancer mortality and incidence [9], but both the number and size of programs are insufficient to offer colorectal cancer screening to more than a very small proportion of the underinsured. It has also been established that efforts to promote screening by eliminating cost barriers must be accompanied by culturally appropriate promotion and education strategies. [12] It is important to offer effective treatment for anyone found to have cancer by screening, as it is the treatment that leads to reduced mortality.

Screening programs should therefore be coupled with access to appropriate treatment.

Gaps also exist between discovery and practice for evidence-based interventions that could reduce cancer health disparities. After effective interventions are discovered (typically by studies supported by the National Institutes of Health), these interventions are rarely implemented. A need exists to specifically support the implementation phase of research that is intended to understand how effective programs can be established in diverse communities and populations. Research in program implementation should be seen as a valid public health research and development activity to improve our understanding of mechanisms that result in the success or failure of evidence-based program implementation.

Priority Recommendation 1.

Broadly implement interventions that have been proven to reduce tobacco use, including:

- A Federal excise tax, as recommended by the Subcommittee on Cessation of the Interagency Committee on Smoking and Health [13]
- Comprehensive community-based prevention programs targeted to adolescents
- Cessation services, including pharmacotherapy and counseling

Rationale

Tobacco smoking is a major cause of cancer health disparities and a strong evidence base supports the effectiveness of interventions to reduce tobacco use through both prevention and cessation.

Priority Recommendation 2.

Fund screening for breast, cervical, and colorectal cancer for all age-appropriate populations in the United States that do not now have health insurance, in combination with culturally appropriate outreach and education addressing routine, repeat screening, and provide cancer treatment for anyone who would qualify for these programs.

Specifically, the funding should be provided to:

- Fully fund the National Breast and Cervical Cancer Early Detection Program to reach all eligible women.
- Add colorectal screening to the National Breast and Cervical Cancer Early Detection Program framework for both men and women.
- Fund treatment for anyone diagnosed with breast, cervical, or colorectal cancers who would have been eligible for these screening programs.

Rationale

Solid and ample evidence demonstrates that appropriate screening with follow-up treatment will significantly reduce mortality from these cancers.

Issues of Importance

- Develop evidence for use of comprehensive wellness programs instead of focusing on organ/disease-specific programs.
- Explore ways to expand the National Breast and Cervical Cancer Early Detection Program that do not depend entirely on public health agencies, but also include community-based organizations.
- As additional cancer screening techniques are recognized by the U.S. Preventive Services Task Force to reduce cancer-related mortality, these should be added.

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CULTURALLY AND LINGUISTICALLY COMPETENT EDUCATION AND TRAINING

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Introduction

The United States is more ethnically diverse today than at any time in its history; yet, this diversity is not proportionately reflected in the health professions. The inability of many health professionals to understand the language and cultural nuances of their diverse patients has contributed substantially to the well-documented disparities in cancer care outcomes.

In this environment, language barriers, stereotypical assumptions, biases, and clinical uncertainty abound. Clinicians can misunderstand the patient's description of symptoms; patients may not be able to read instructions; doctors and other health providers may fail to appreciate the significance of traditional remedies or customs; and barriers in the current health care system arguably affect certain segments of the populations.

The scarcity of culturally competent health care workers erodes the quality of care, contributes to poor health outcomes, and increases health care costs. [1] Indeed, evidence suggests that lack of culturally competent health-related workers discourages some individuals from seeking health care at all.

Also, the proportionately small number of culturally diverse health care workers sends a negative message regarding opportunities to youth. The educational system (K-16) does not sufficiently encourage and prepare underrepresented students to pursue health-related careers. Community-based partnerships that might help address this problem are not fully utilized; all too often, participation of underrepresented groups in diversity planning and training is, at a "token" level, essentially window dressing.

Despite decades of affirmative action and thousands of programs targeting diverse and disadvantaged Americans at various points in the educational process, the proportion of racial and ethnic groups in many health care professionals actually fell in the 1990s. This is especially unfortunate since "best practices" and models for culturally and linguistically competent education and training exist. Such education and training can improve cancer care and outcomes directly, by promoting entry of more racial and ethnic groups into the health professions. Training can also enhance the responsiveness of health workers of whatever race and ethnicity and socioeconomic status to patients whose characteristics and background differ from their own. Likewise, strong community partnerships, which draw upon collective knowledge and wisdom can enrich and strengthen culturally and linguistically competent education and training.

The following three recommendations provide a concrete mechanism that will transform cultural and linguistic competency training and education throughout the health care system and build on existing strengths and knowledge.

Priority Recommendation 1.

Require that all health care institutions and organizations receiving Federal funds demonstrate cultural and linguistic competency, as defined by HHS's Office of Minority Health Culturally and Linguistically Appropriate Services (CLAS).

"Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables work in cross-cultural situations. 'Culture' refers to integrated patterns

of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. 'Competence' implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and communities."

The 14 CLAS standards have been implemented around six general competencies:

- Patient Care—compassionate, appropriate, effective; culturally and linguistically sensitive and competent
- Medical Knowledge—biomedical, clinical, social sciences-based; conscious avoidance of diagnoses or recommendations based on cultural stereotypes or bias
- Practice-Based Learning and Improvement—open decision making, constant review of practice based on new research and models, self-improvement based on feedback
- Interpersonal and Communication Skills—effective listening, nonverbal, questioning, and narrative skills; linguistic competency through knowledge of patients' languages or qualified interpreters
- Professionalism—patients' interests first; sensitivity, care, and respect for patients, families, and colleagues of all backgrounds, ethnicities, and lifestyles; ethical and professional conduct in all situations
- Systems-Based Practice—awareness of systemic resources and possible barriers; collaboration with colleagues and payers to ensure cost-effective care with no slippage in quality for all patients

Rationale

This policy would immediately raise the level of cultural and linguistic competency throughout the health care industry. It would spark development and implementation of a wide variety of mechanisms and strategies to strengthen cultural and linguistic competency education and training. This includes incorporation of cultural and linguistic competency into certification and licensure and re-licensure examinations and requirements; and employee/staff training programs for the broad range of paraprofessional and administrative personnel who interact with patients. This might also include adding foreign language requirements in medical education programs.

Issues of Importance

- A national policy tying system-wide cultural and linguistic competency (similar to the current "drug-free" policy) to receipt of Federal dollars would raise the level of cultural and linguistic competency throughout the health care industry in a relatively short period of time.
- Educational programs, professional associations, and licensure bodies would work to incorporate cultural and linguistic competency as a core requirement into their standards, examinations, and programs.
- The efficacy of this recommendation depends on a broader definition of health-related professionals, to include *promotoras* (community lay workers), certified medical interpreters, and patient navigators.

Priority Recommendation 2.

Fund the development of innovative education and training programs to create a diverse and culturally competent health care workforce that is representative of the communities it serves. These programs would target education and training programs for K-16+ ethnic/racial groups and non-traditional students.

Rationale

Increased funding for science-related education and training programs for ethnic and racial minorities across the pipeline will make our health care system representative of our population and create a cadre of culturally and linguistically competent health professionals of all ethnicities and backgrounds.

Issues of Importance

- Department of Health and Human Services (HHS) should partner with the U.S. Department of Education and other Federal/state/private agencies and communities to leverage resources and increase the number of diverse and nontraditional students in health-related professions.

- HHS should fund local cultural and linguistic competency training for all health-related workers. Such programs should be planned and implemented through local community organizations that include ethnic/racial minority representation and partners.
- The wealth of workers in paraprofessional and administrative roles within the health care system provides an untapped reservoir of talent for planning and delivering cultural and linguistic diversity training.

Priority Recommendation 3.

HHS should fund development, identification, dissemination, and delivery of "best practices," model approaches, and outreach strategies for culturally, linguistically, and literacy specific cancer communications and health promotions, in partnership with cancer survivors, caregivers, and community advocacy organizations.

Rationale

Cancer interventions and communications that are culturally, linguistically, and literacy appropriate contribute extensively to quality cancer care and enhance health outcomes. You can have a great outreach strategy or best practice, but if you don't promote it in a culturally and linguistically appropriate manner, you miss the mark. Health promotions should be developed, reviewed, and disseminated by community advocacy groups and survivors who work with the specific community, with HHS funding. Too much of our current health promotions are literal translations and not cultural translations.

Recognizing that linguistic diversity is an integral part of American culture is essential for eliminating cancer health disparities and the need to tailor health promotions more regionally rather than centrally. An example of the latter is the National Cancer Institute's Spanish call lines where linguistic diversity within the Spanish speaking community requires considerable sensitivity.

Awareness about the effectiveness of model programs, which address such elements at the national and local level is often lacking. A greater knowledge of program efficacy is needed for replication and dissemination. Furthermore, the involvement of cancer survivors, caregivers, and community advocates in the process of evaluating programs and strategies is important to the identification and usability of best models.

Issues of Importance

- HHS can develop a mechanism for peer review of "best practices," model approaches, and outreach strategies that include community input. An ongoing process for peer-reviewed evaluation is essential.
- The peer review process should include substantial input from cancer caregivers, survivors, community advocates, and diverse health care workers at all levels.
- To ensure that the information is not buried or lost, the HHS could establish a clearinghouse for the dissemination of user-friendly cancer education materials, "best practices," model approaches, and outreach strategies.
- The information could be easily searchable and accessible on line. HHS regional offices can be charged with publicizing the clearinghouse and providing technical support.

Conclusion

Nearly half a century of affirmative action and laissez faire policies have failed to produce a health care system that is responsive to patients of diverse languages and cultures. In an increasingly diverse society, it is imperative that HHS take steps to guarantee cultural and linguistic competency in health care workers at all levels—from administrators and their staff, physicians, researchers, practical and licensed nurses, physicians' assistants, aides, dentists, pharmacists, optometrists, technicians, *promotoras,* clergy, and lay workers.

The three strategies described above would change the dynamics of the current situation. Requiring linguistic and cultural competency education and/or training for licensure, certification/recertification, and employment in any federally funded program would effectively reach all current medical students and researchers, and virtually all health care facilities. This mandate would immediately improve the quality of care provided to many of the nation's medically underserved populations.

The second and third recommendations increase the feasibility of the first recommendation by

providing mechanisms to support its genuine implementation. By combining forces with the educational establishment to strengthen science training (K-16), we will increase the proportion of underrepresented health care workers at all levels. This would directly improve the pool of culturally competent health care workers, and provide more role models for youth who may wish to pursue health-related careers.

More racial and ethnic minorities in health care will have a synergistic effect and add to the pool of planners and trainers for ongoing cultural and linguistic competency training. Likewise, the strengthening of community participation in community-based planning will illuminate local needs and facilitate cross-cultural strategies and programs.

As our nation grows and evolves in this key health care area, HHS should take the lead in testing, evaluating, and disseminating best practices in cultural and linguistic competency training. Given the substantial work in this area, HHS will perform a tremendous service by establishing a peer review process to identify current best practices in cultural and linguistic competency education and training. Creation of user-friendly databases and technical support mechanisms will help local health care systems respond to the health care needs of a growing diverse population.

"If you want to move people, it has to be toward a vision that's positive for them, that taps important values, that gets them something they desire, and it has to be presented in a compelling way that they feel inspired to follow." – Martin Luther King, Jr.

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INEQUITY AND SOCIAL INJUSTICE

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Introduction

Disparities in health and health care occur in the context of societal inequities and injustice, which have developed throughout the history of this nation and now define our society. Health disparities cannot be resolved without explicitly addressing these societal causes.

Differences and diversity form the crux of this nation, yet our treatment of women, minorities, and other disadvantaged groups is far from equitable. Over the course of our nation's development, equitable treatment has become codified in law; however, due to incomplete enforcement and implementation of these laws, inequities still exist. These inequities permeate the nation's health care system so that people with insurance and the same socioeconomic status receive different treatment for small cell lung cancer, according to a study conducted at Memorial Sloan-Kettering Cancer Center. [1] Similarly, researchers found in 1999 that race matters in renal transplant referrals. [2] A 2000 *New England Journal of Medicine* study of prescription opioid drug availability in New York City found that only 25% of pharmacies in nonwhite neighborhoods carried sufficient amounts of drug for treatment of severe pain. In stark contrast, 72% of pharmacies in white neighborhoods carried sufficient opioids for severe pain. [3] These and other examples demonstrate that race still matters in our society.

From cancer biology research to cancer control and outcomes, what has been developed is not reaching all cancer patients, and health disparities result. This begs the question of whether disease differences would disappear if all patients were given equal treatment. Unfortunately, we return to the realization that disease occurs within a context of human circumstances, with numerous contributors, including social position, economic status, culture, and environment. These come together as critical determinants of who

- is born healthy
- grows up healthy
- sustains health throughout his or her life span
- survives disease
- maintains a good quality of life after diagnosis and treatment

As a first step, a solution must be found that eliminates unequal health care treatment so that cancer health disparities can be eliminated. We must also attend to the factors that cause differential exposures to adverse environments by race.

Priority Recommendation 1.

Establish a Leadership Council on Health, Inequity, and Social Justice convened by the Secretary of the Department of Health and Human Services in partnership with the Secretaries of the other Federal departments. This Council will mobilize and direct national resources in a comprehensive national effort to improve the health of the American people, including the elimination of health disparities.

Rationale

Cancer health disparities occur within the broad context of human circumstances, including substandard housing, poor educational opportunities, adverse environmental exposures, and limited access to quality health care. Therefore, the solutions are beyond the scope of the health care system alone and necessitate the development of a comprehensive approach.

Issues of Importance

- Obtain endorsement from the White House.
- Establish goals and targets with monitoring and accountability.
- Assess how the various departmental policies and programs affect health and health disparities.
- Provide an explicit reference to a human rights framework.
- Explore the legal and civil rights implications of health disparities.
- Use this opportunity to discuss the impacts of racism and the other fundamental causes of disparities.

Priority Recommendation 2.

Eliminate inequity and social injustice in the delivery of what we currently know to be effective in cancer prevention and care. Specifically, no person with cancer should go untreated.

Rationale

This is in keeping with the "Discovery to Delivery" continuum and is critical for attaining the National Cancer Institute's 2015 goal.

Issues of Importance

- Define and disseminate standards of care and monitor their implementation.
- Increase emphasis on prevention, especially for populations with the greatest burden of cancer.

Priority Recommendation 3.

Target special resources to geographic areas of excess cancer mortality and work toward universal access to health care.

Rationale

Eliminating health disparities requires providing resources to areas and people with the highest mortality. Additionally, people without health insurance are diagnosed at later stages and die at higher rates.

Issues of Importance

- High cancer rates are often indicators of other health disparities.
- Access to high-quality services should be timely and equitable, and include outreach, prevention, and treatment.
- Health care as a right is being widely discussed by many stakeholders in this country.

Conclusion

Viewing health disparities through the historic and present-day lens of inequity and social injustice reveals a complex problem whose core lies in the health care system and whose solution requires a comprehensive approach to human circumstance determinants.

Effective strategies within the health care system include targeting geographic regions with excessive cancer mortality and delivering state-of-the-art therapy to all patients. Additionally, universal health care would provide a common structure under which these recommendations could flourish.

Unfortunately, implementing these recommendations alone will never overcome health disparities; the solution involves more than the health care system alone and will encompass contributors to the human and societal circumstances that breed and foster disparities. The establishment of a Leadership Council that comprises the Secretaries of Federal departments would help focus resources on a national effort to eliminate cancer health disparities and improve the health of all Americans.

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CHANGES AND IMPLEMENTATION OF PUBLIC POLICY

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Introduction

Cancer health disparities represent a major health problem in the United States, threatening ongoing efforts to achieve the *Healthy People 2010* goals and the National Cancer Institute's (NCI's) 2015 goals set for the nation. Policy and decision-makers can help eliminate cancer health disparities through legislation, regulation, and the development and implementation of public policy to increase access to care and improve the system of health care delivery. Within the Department of Health and Human Services (HHS), there are numerous opportunities to initiate and implement policy change that will improve the transfer of knowledge gained from cancer research to the actual application and delivery of that knowledge, resulting in improved access to quality health care. Because of its financial and political strength and programs, HHS has tremendous potential to make an impact on reducing cancer health disparities.

The current, unstable economic climate poses a challenge for policy makers at the state and Federal levels. Perhaps the greatest public policy challenge is securing sufficient funding to not only implement new policies and programs but to improve and effectively implement existing ones. Economic incentives for providers as well as patients are key to effecting change, as payoffs from cancer-related investments, both financial and policy-based, can take years to materialize. Lack of funding and resources, in addition to increased scrutiny of the effectiveness of Federal government programs, has heightened the need for consistent policies and increased coordination and communication among HHS agencies and programs. Further, any cost-saving efforts initiated at this time could have far reaching implications with potentially negative impacts on access to care that would in fact be exacerbated in underserved populations.

It is clear that the disparities that exist do so at the local community level. Policy change must therefore also provide an opportunity for the solutions to be found and shared at the community level. It is our belief that national policy should be framed with input from the communities in which disparities exist and utilize partnerships among the public, private, and nonprofit sectors at the community level whenever possible.

Another significant policy challenge concerns the state of our health care financing system. The current insurance system is broken; attempts to "band-aid" the system have led to quick fixes that address one small part of the equation, often without relating it back to the whole. It is also important to note that a large percentage of health policy is formulated from a highly technologic and/or treatment-based majority perspective. The populations with the greatest disparities may be operating from a wholly different cultural health perspective that affects everything from their adherence to screening to completion of treatment.

The following statements illustrate this group's beliefs regarding changing and implementing public policy to eliminate cancer health disparities:

- We can reduce disparities if we target our policy actions.
- *"Good health for everybody in the country is good for everybody in the country."* The elimination of health disparities should be a national public policy priority.

- To eliminate health disparities, we need policies that facilitate solutions in the populations suffering disparities, in the communities where there are disparities, and in the entities/institutions that can make a difference in eliminating disparities.
- Public policy cannot accomplish everything–there are limitations. Multiple strategies can work, and we need to be creative in identifying policy levers that influence and enable change.
- We recognize that there are tradeoffs between personal behaviors versus policy changes.
- Instituting significant policy changes takes courage and commitment.
- There are successful models that have been utilized in the past that could provide a framework for the future.
- Comprehensive information and surveillance systems that utilize systematic data collection, reporting, and usage at HHS are crucial to understand disparities and to better target where investments should be made.

Priority Recommendation 1.

Review of HHS programs for realignment of funds.

Rationale

HHS should conduct a Secretary-led, rapid programmatic and budgetary review of all HHS programs with the intent to shift and realign funding to evidence-based programs, where possible, that are effective in addressing cancer health disparities. The Secretary should also issue a report to Congress, making recommendations to fully fund HHS programs that are proven effective in reducing cancer health disparities.

In this current economic environment, the reality is that no additional funds may be available to implement or improve existing policies or programs. There is a responsibility on the behalf of HHS leadership to identify efficiencies and inefficiencies within the agencies' programs to better realign and reallocate funding more effectively. A serious internal review of how dollars are allocated with regard to discovery, development, and delivery of services is required. There are many examples of duplication of services and programs within HHS; in addition, questions have been raised regarding the efficacy of some federally funded cancer programs while other programs are thought to be grossly underfunded. Examples of programs considered underfunded include the following:

- State tobacco programs, which are known to be efficacious. In addition, additional funding for HHS programs emphasizing prevention should be secured.
- The NCI's Center to Reduce Cancer Health Disparities, which should receive an increase in funding levels.
- Colorectal cancer screening programs, which are funded on a demonstration basis only in a limited number of states.
- The Centers for Disease Control and Prevention's (CDC's) National Breast and Cervical Cancer Early Detection Program, which is very effective, but with limited funding levels, is only able to serve 15%-18% of the eligible population. The funding needs to be expanded to cover 100% of women eligible for screening services.
- CDC's National Program of Cancer Registries and NCI's Surveillance, Epidemiology, and End Results registries, which are essential to state cancer planning and identification of cancer disparity populations.
- Health Resources and Services Administration community health centers, which need adequate funding to enable the adoption of proven, effective cancer collaborative models/guidelines.

Issues of Importance

- A realignment of funding is the initial goal of this recommendation; the long-term goal is full funding of programs proven to be essential to the elimination of cancer health disparities.
- A comprehensive internal review of HHS programs could potentially be a lengthy and administratively laborious process.
- To ensure objectivity, an independent reviewer/party is necessary to conduct such a review.
- Input from community representatives (e.g., Progress Review Group and Roundtable Members) is advised.

- This endeavor requires the commitment of HHS leadership and staff to complete and follow through.

Priority Recommendation 2.

Comprehensive trans-HHS plan to reduce cancer health disparities.

Rationale

HHS should develop and implement a Secretary-led, trans-HHS plan to reduce cancer health disparities through a comprehensive and coordinated "business like" approach where all agencies work together to advance cancer control and treatment along the continuum of "discovery, development, and delivery" in the community, where all agencies are held accountable, and incentives are aligned to optimize appropriateness, efficiency, and effectiveness.

Currently no such plan to coordinate the cancer-related activities of HHS exists. While HHS agencies administer and operate numerous innovative and effective programs, duplication, overlaps, and gaps in service exist. A trans-HHS plan would provide the mechanism for coordination and management across the agencies, taking into account metrics, timelines, and decision points.

Issues of Importance

- To develop, plan, and implement a trans-HHS plan requires solid commitment from, and assignment of accountability within, the HHS leadership and agencies.
- In addition to the Secretary's leadership, there needs to be an appointed committee that will provide oversight for the entire process from "discovery to development to delivery."
- This endeavor involves a major culture change for the government.
- This plan provides for an internal self-elimination/realignment of dollars/review of allocations in programs across HHS.

Priority Recommendation 3.

Communities Empowered to Eliminate Disparities.

Rationale

HHS should institute a new trans-HHS initiative to invite communities to designate geographic areas as "Communities Empowered to Eliminate Disparities" or CEEDs, in which improvements in a continuum of cancer care would effectively produce outcomes to reduce specific cancer disparities for an identifiable cancer disparity population (e.g., race, ethnicity, and geographic location).

Healthy People 2010 goals cannot be met without direct intervention from communities that serve health disparity populations. Recognizing that cancer care and cancer health disparities are local, solutions and interventions must come from the community. Such actions taken at the local level can have a tremendous impact on eliminating cancer health disparities. This approach empowers communities to be responsible for their own health care, and this method of engaging HHS programs at the community level is required to address access, financing, and research issues faced by disparity populations. Such an approach will spur public/private partnerships, which will aid in sustaining effective initiatives and programs. There is evidence that this type of approach has been very successful in some areas.

Issues of Importance

- Funding would be provided through a trans-HHS program tap at a minimum of 1%.
- Substantial funds should be awarded through block grants of 10 years based on strategic plans developed by the communities. The plan should be based on service gap analysis; assessment of related community knowledge, beliefs, and behaviors; evaluation of strengths and weaknesses of executing targeted programs of service, financing, and research; potential use of Department programs (e.g., NCI, CDC, Community Health Center, and Centers for Medicare & Medicaid Services [CMS]); demonstrating a timeline and integration; formation of new partnerships; and establishment of multiyear outputs (services), outcomes (health indicators), and impacts (system change).
- Approved CEEDs would be given priority in departmental funding through competitive grants, programs of research, and regulation waivers (e.g., CMS service eligibility and benefits). CEED status should be reviewed

annually to ensure progress on the strategic plan and reduction of disparities.

- All plans would focus on accountable methods and outcomes that lead to the elimination of a cancer health disparity within that community.
- The program would have national scope including different types of cancers and different underserved populations.
- The program will lend itself to innovative integration with other government programs such as economic incentives for establishing a cancer center in a high disparities area made available through the Department of Housing and Urban Development or school lunch programs that follow healthy dietary guidelines supported in the CEEDs by the Department of Agriculture.
- It will be important to: (1) reach out to communities with disparity populations to raise awareness that such a block grant process is available, and (2) craft a win-win argument so that communities of disparity populations understand the benefits of undertaking such a process.

Additional CIPP Group Recommendations

The following are additional recommendations the Changes and Implementation of Public Policy Breakout (CIPP) Group participants believe need to be considered by the Department. These recommendations came from both CIPP Breakout Group discussions, and a concept mapping exercise conducted with Roundtable member participation from all groups. The CIPP Breakout Group participants believe that this input should not go unmentioned, as it consolidates the opinions of an even greater selection of cancer health experts than simply those of the CIPP Breakout Group.

- Amend Medicare and Medicaid authorization legislation to include the word "prevention" in statutory authority, so that the CMS can legally fund evidence-based cancer prevention without special legislation.
- Develop sustainable health insurance programs for the economically and socially disadvantaged that ensure equal access to cost-effective cancer treatments and support services.
- Pass legislation providing universal basic health coverage for all U.S. citizens and permanent residents.
- Ensure, by legislative and regulatory means, that people who are either at high risk for cancer, have been diagnosed with cancer, or treated for and survived cancer are not discriminated against in health insurance.
- Increase health insurance allowances for all cancer medications.
- Increase the Indian Health Service annual appropriation to allow all patients to receive recommended cancer screening.
- Provide Medicare coverage for all patients with a clinical or pathological diagnosis of cancer, for the duration of the cancer treatment and clinical follow-up.
- Promote and achieve environmental quality and equity by decreasing and eliminating environmental toxins in less affluent communities.
- Promote enrollment in public programs that might cover health-care costs, such as Medicaid, veterans' benefits, Social Security Disability Insurance, and Child Health Plus (CHP).
- Increase the Federal excise tax on tobacco products and use the resources to fund health promotion programs focused on populations who bear the greatest disease burden.
- Collaborate with other agencies that are affected by health disparities, and have mechanisms for positively effecting change, such as the Department of Veterans Affairs, Department of Defense, Department of Treasury, and the Department of Housing and Urban Development.
- Provide funding for adequate mental health support to address the chaotic life issues that often undermine medical adherence in underserved populations.
- Expand tax incentive programs by cities/states to grocery stores that locate in minority and poor communities.

Conclusion

The solutions for eliminating cancer health disparities need to include the communities, at the local level. In order for policy makers and policy changes to be effective, communities must be engaged and empowered to make decisions about their health care. HHS will not reach its *Healthy People 2010* and NCI's 2015 Challenge Goal to eliminate the suffering and death due to cancer if it continues to operate in the mode of "business as usual"; nor will it effectively eliminate cancer health disparities. We further emphasize that any cost-saving efforts initiated at this time by HHS and CMS could have far reaching implications with potentially negative impact on access to care that would in fact be exacerbated in disparity populations. The agencies within HHS need to conduct an honest self-assessment of their cancer-related programs' appropriateness, efficiency, and effectiveness, and the Department as a whole needs to hold those agencies accountable for the results of those programs. Ineffective programs need to be revamped or eliminated, with their funding realigned to effective existing programs and new initiatives. Only then will entities such as the CEEDs be able to flourish and effectively reduce cancer health disparities for current and future generations.

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Appendix B
About the Trans-HHS Cancer Health Disparities Progress Review Group

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OVERVIEW

By planning and working together to address cancer health disparities, Department of Health and Human Services (HHS) offices and agencies strive to lead the Nation's research, public health, and clinical delivery efforts to achieve a seamless and more assertive progression from scientific discovery to the development of evidence-based interventions and the delivery of those interventions. Toward this end, HHS established the Trans-HHS Cancer Health Disparities Progress Review Group (PRG) in early 2003 to identify new opportunities for HHS agencies to address cancer health disparities, implement new initiatives, and evaluate progress over time.

The three-phase PRG approach (see Figure B-1) has been used effectively by the National Cancer Institute (NCI) and the National Institute of Neurological Disorders and Stroke to develop national agendas for disease-specific research and promises to be equally valuable for assisting HHS in achieving its goals to:

- Define and describe issues related to cancer health disparities.
- Identify areas of strength, gaps, opportunities, and priorities to address cancer health disparities in research and intervention development.
- Facilitate the adoption and implementation of cancer research, policy, community programs, and clinical interventions and evaluate their impact on specific cancer health disparities.
- Ensure unbiased access to continuous quality preventive care, early detection, and treatment of cancer for every American.

Figure B-1. The Three Phases of the PRG Process

Completion and presentation of this report marks the end of Phase I. Although continuous effort went into planning and executing Phase I activities, two pivotal events took place over the past year.

- The Trans-HHS Cancer Health Disparities PRG and Federal Steering Committee (FSC) met June 19-20, 2003, to review the process, resources, and tools and plan the overall effort.
- The Trans-HHS Cancer Health Disparities PRG Roundtable met August 27-29, 2003, along with the PRG Membership, FSC, and additional experts, to review the range of cancer health disparities issues and develop specific recommendations for advancing HHS goals in this area.

Figure B-2 shows the roles and responsibilities of the different groups of experts who participated in Phase I activities. Listings of the individual PRG Members, FSC Members, and Roundtable participants can be found at the end of this Appendix.

Figure B-2. Organizational Structure for Phase I of the PRG Process

The three members of the PRG leadership were selected for their combined expertise and diverse backgrounds, for their ability to work effectively as a team, and for their excellent communication, management, and facilitation skills. During Phase I, this PRG leadership team communicated by conference call on a weekly basis to oversee all aspects of PRG planning, the Roundtable Meeting, and final report preparation.

The Cancer Health Disparities (CHD) PRG, in its entirety, is composed of 24 prominent members of scientific, medical, public health, and advocacy communities. The members were selected for their ability to collectively provide expertise in all areas critical to cancer health disparities and to commit time and serious thought to the PRG process. The PRG identified the topics that would be addressed during the Breakout Group sessions at the Round-

table Meeting, identified and assembled Roundtable participants, served as Co-Chairs of the Breakout Groups, worked with their Co-Chairs to prepare the Breakout Group reports, and developed the overall PRG priority recommendations. If requested by HHS, the PRG membership will participate in follow-up meetings during Phases II and III of the PRG process.

The Cancer Health Disparities FSC, composed of key HHS agency representatives and led by NCI staff, was responsible for overseeing and coordinating Phase I and will continue to play a similar role in Phases II and III of the PRG process. The 13 FSC members were selected for their expertise in cancer health disparities and program services and their ability to bring the issues and concerns of their agencies to the table. During Phase I, they assisted in the identification of potential PRG members, served in a consultative role at the Planning and Roundtable meetings, and provided insight and suggestions during report preparation.

Roundtable participants were leading members of the relevant cancer research, medical, industry, public policy, and advocacy communities selected for their expertise and diverse perspectives. Each was invited to serve on one or two Breakout Group sessions. Co-Chair teams for Breakout Groups consisted of one PRG member teamed with a non-PRG member with expertise in the topic area. Co-Chairs identified and invited the other members of their groups to serve as Roundtable participants, prepared read-ahead materials for their Breakout Groups, prepared the Breakout Group reports, and assisted in developing PRG priority recommendations.

Tools Used by the PRG

Background Paper

To assist the PRG and Roundtable participants in reviewing the current state of the field in cancer health disparities, the Health Disparities Working Group within the NCI Division of Cancer Control and Population Sciences (DCCPS) prepared a background paper that included a review of recent publications and reproducible, peer-reviewed findings concerning the nature and magnitude of cancer health disparities and their underlying correlates.

Concept Mapping

The NCI DCCPS also led a concept mapping effort that helped identify the priorities and specific subtopic areas considered important to cancer health disparities by the community of experts identified for participation in this effort. Experts from government, academia, and nonprofit organizations were asked to complete the sentence:

> *Specific actions that should be taken to eliminate cancer health disparities in the United States are (fill in the blank).*

By eliminating duplication and overlap, it was possible to cull down the 456 original responses received to a core set of 114 statements. By statistically analyzing the ways in which experts subdivided these statements into groups, based on similarity, nine clusters or related concepts were identified. These clusters plus one PRG-identified topic area formed the basis for the 10 Roundtable Breakout Groups.

HHS Program and Project Database

In partnership with the HHS Office of Minority Health, the NCI Center to Reduce Cancer Health Disparities developed a database to catalog and make available information on the major cancer- and disparities-related programs supported by HHS Offices and agencies. Included in this project database are programs and projects from:

- HHS Office on Women's Health (OWH)
- HHS Office of Minority Health (OMH)
- Administration on Aging (AoA)
- Agency for Healthcare Research and Quality (AHRQ)
- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare and Medicaid Services (CMS)
- Food and Drug Administration (FDA)
- Health Resources and Services Administration (HRSA)
- National Institutes of Health (NIH)
  - National Cancer Institute (NCI)
  - National Center on Minority Health and Health Disparities (NCMHD)
  - National Heart, Lung, and Blood Institute (NHLBI)

- National Human Genome Research Institute (NHGRI)
- National Institute of Aging (NIA)
- Substance Abuse and Mental Health Services Administration (SAMHSA)

The database can be searched by factors such as race/ethnicity, gender, cancer site, geographic location, cancer care continuum, and service provided.

Development of PRG Priority Recommendations

The priority recommendations of the Trans-HHS Cancer Health Disparities PRG Call to Action were derived via a selection process that began with the 456 responses obtained in support of the concept mapping study (Figure B-3). Of paramount importance to selection of the final 14 PRG priority recommendations were the 29 priority recommendations developed by the 10 Roundtable Breakout Groups. As shown in Table B-1, each final PRG recommendation had its origins in one or more of the Roundtable recommendations. (The recommendations developed by each Breakout Group can be found in Appendix A, along with the rationales for their selection and issues of importance for their implementation.)

An initial set of PRG priority recommendations was developed at the conclusion of the Roundtable Meeting. Through an iterative process involving the PRG and PRG leadership, these recommendations were refined into an integrated Call to Action – a plan that will allow HHS to advance in the areas of Planning and Coordination, Discovery, Development, and Delivery. During the refinement process, careful attention was paid to ensuring that each recommendation addressed actions that fall within the purview of HHS and its agencies. Although HHS retains

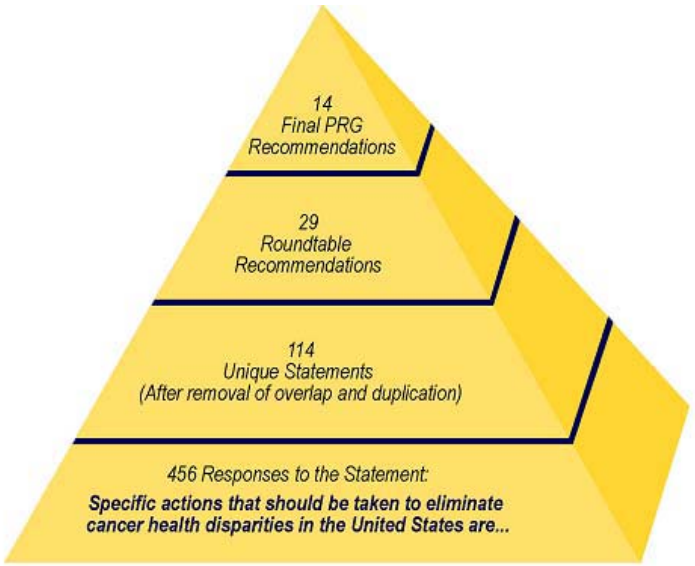

Figure B-3. Development of the 14 PRG Priority Recommendations

authority to implement the recommendations in ways deemed most fit by the Department's leadership, suggestions have been provided for HHS consideration, including a phased plan for initiating efforts on the 14 priority recommendations.

Preparation of This Final Report

This final report was prepared in the 4-month period following the Roundtable Meeting. Through frequent interaction, the PRG and FSC leadership developed a vision for presenting the PRG's findings and recommendations. The report attempts to address all of the important issues raised by PRG members and Roundtable participants and to communicate the passion that was displayed during the Roundtable Meeting.

Table B-1. The PRG Priority Recommendations Derived from the Recommendations of the Roundtable Breakout Groups

PRG Priority Recommendaton	Roundtable Breakout Group Recommendation
Planning and Coordination	
Conduct a program and budget review of all relevant HHS programs for the purpose of shifting and realigning support, where possible, to evidence-based programs that are effective in addressing cancer health disparities.	**Research Policy, Priority Recommendation 3 (page A-11)** Establish an HHS center to evaluate and translate cancer disparities research and coordinate implementation of the findings. **Changes and Implementation of Public Policy, Priority Recommendation 1 (page A-40)** Review of HHS programs for realignment of funds. **Changes and Implementation of Public Policy, Priority Recommendation 2 (page A-41)** Comprehensive trans-HHS plan to reduce cancer health disparities.
Assemble a Federal Leadership Council on Cancer Health Disparities led by the HHS Secretary in partnership with the Secretaries of other appropriate Federal departments to mobilize available resources in a comprehensive national effort to eliminate cancer health disparities.	**Facilitating Partnerships for Action Priority Recommendation 2 (page A-27)** HHS should identify and work with other public and private organizations to develop and implement a national "CALL TO ACTION" agenda to eliminate cancer health disparities. **Inequity and Social Injustice, Priority Recommendation 1 (page A-37)** Establish a Leadership Council on Health, Inequity, and Social Justice convened by the Secretary of the Department of Health and Human Services in partnership with the Secretaries of the other Federal departments. This Council will mobilize and direct national resources in a comprehensive national effort to improve the health of the American people, including the elimination of health disparities.
Implement, in all HHS health service and reimbursement agencies, recommendations from the Institute of Medicine Report entitled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*.	**Culturally Competent Health Care Systems, Priority Recommendation 1 (page A-22)** Implement recommendations regarding cancer care from the Institute of Medicine Report entitled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*.
Discovery	
Evaluate specific grant and contract processes to determine what additional steps are needed to enhance the cultural competence, representative composition, and methodological expertise of peer review panels for cancer health disparities research.	**Enhancing the Level and Quality of Health Disparities Research, Priority Recommendation 2 (page A-8)** Establish specific peer review grant and contract entities and processes that have the necessary expertise, knowledge, and experience to fairly and equitably evaluate health disparities research proposals and/or projects.
Establish new approaches for data and collection sharing to aid in the study of the effects of cancer and their relationship to variables such as race, ethnicity, and socioeconomic status.	**Methods, Measurement, and Reporting, Priority Recommendation 1 (page A-4)** HHS should require Federal agencies and strongly encourage state, local, and nongovernmental agencies to use a standardized minimum core set of measures of "race and ethnicity" and socioeconomic status in the collection and reporting of data. **Methods, Measurement, and Reporting, Priority Recommendation 2 (page A-5)** HHS should commission a National Academy of Sciences committee to assess and monitor cross-cultural equivalence of theoretical models, methods, measures, and modes of administration underlying data collection with diverse populations. **Methods, Measurement, and Reporting, Priority Recommendation 3 (page A-5)** HHS should require geocoding of all health records to latitude and longitude or to census tract to facilitate linkage to other geo-referenced data. **Research Policy, Priority Recommendation 1 (page A-9)** Establish a trans-HHS database that centralizes and standardizes cancer and cancer-related data.

Table B-1. The PRG Priority Recommendations Derived from the Recommendations of the Roundtable Breakout Groups (cont.)

PRG Priority Recommendaton	Roundtable Breakout Group Recommendation
Discovery (cont.)	
Increase the proportion of HHS agency support targeted specifically to disease prevention, health promotion, evaluation, and translational research on cancer health disparities.	**Enhancing the Level and Quality of Health Disparities Research, Priority Recommendation 3 (page A-8)** Significantly increase the proportion of funding within each agency of HHS targeted to prevention, health promotion, and translational cancer health disparities research with an emphasis on efficacy, effectiveness, and cost effectiveness.
Establish partnerships for and support the development of sustainable community-based networks for participatory research in areas of high cancer disparities.	**Enhancing the Level and Quality of Health Disparities Research, Priority Recommendation 1 (page A-7)** HHS should provide the funds necessary to fully develop and sustain community-based participatory research resource support networks that focus exclusively on multidisciplinary cancer health disparities research, independent of individual project funding. **Facilitating Partnerships for Action, Priority Recommendation 3 (page A-27)** HHS leadership must articulate an entity within the Department that will have responsibility and resources to establish effective partnerships necessary to eliminate health disparities in cancer. **Research Policy, Priority Recommendation 2 (page A-10)** Establish, recruit, fund, and evaluate community research infrastructures (units), in areas of large cancer disparities, to collaborate in all stages of the research process.
Development	
Develop and implement a new trans-HHS initiative to qualify high disparity geographic areas for special program designation as Communities Empowered to Eliminate Disparities. Communities would qualify for the program by submitting strategic plans to reduce specific cancer disparities for identifiable populations.	**Facilitating Partnerships for Action, Priority Recommendation 1 (page A-27)** Establish a National Informed Health Choices Program to educate communities about the known risk reduction measures that are effective in reducing cancer. **Access to Quality Cancer Services, Priority Recommendation 2 (page A-16)** Provide and sustain funding for coalitions, partnerships, and community-based quality cancer services, education, and prevention programs. **Inequity and Social Injustice, Priority Recommendation 3 (page A-38)** Target special resources to geographic areas of excess cancer mortality and work toward universal access to health care. **Changes and Implementation of Public Policy, Priority Recommendation 3 (page A-41)** Communities Empowered to Eliminate Disparities.
Develop, implement, and evaluate education and training programs designed to create a diverse and culturally competent cancer care workforce. Apply standards to certify the cultural competence of health professionals who receive Federal support.	**Culturally and Linguistically Competent Education and Training, Priority Recommendation 1 (page A-33)** Require that all health care institutions and organizations receiving Federal funds demonstrate cultural and linguistic competency, as defined by HHS 's Office of Minority Health Culturally and Linguistically Appropriate Services (CLAS). **Culturally and Linguistically Competent Education and Training, Priority Recommendation 2 (page A-34)** Fund the development of innovative education and training programs to create a diverse and culturally competent health care workforce that is representative of the communities it serves. These programs would target education and training programs for K-16+ ethnic/racial groups and nontraditional students. **Culturally Competent Health Care Systems, Priority Recommendation 2 (page A-22)** Update HHS Cultural Competency Standards and mandate compliance with these standards to qualify for Federal funding. **Culturally Competent Health Care Systems, Priority Recommendation 3 (page A-22)** Require all health care professionals on all levels (Federal, academic, community, etc.) to have cultural competency training.

Table B-1. The PRG Priority Recommendations Derived from the Recommendations of the Roundtable Breakout Groups (cont.)

PRG Priority Recommendaton	Roundtable Breakout Group Recommendation
Delivery	
Implement evidence-based tobacco control strategies, including those that create financial disincentives for tobacco consumption and those that provide social reinforcement for not smoking.	**Implementing Evidence-Based Programs to Reduce Cancer Health Disparities, Priority Recommendation 1 (page A-30)** Broadly implement interventions that have been proven to reduce tobacco use, including: • A Federal excise tax, as recommended by the Subcommittee on Cessation of the Interagency Committee on Smoking and Health • Comprehensive community-based prevention programs targeted to adolescents • Cessation services, including pharmacotherapy and counseling
Ensure that populations at highest risk have access to age- and gender-appropriate screening and follow-up services for breast, cervical, and colorectal cancer. Expand to include these services for other cancers (e.g., prostate and lung) when there is evidence that they are effective at improving survival.	**Implementing Evidence-Based Programs to Reduce Cancer Health Disparities, Priority Recommendation 2 (page A-30)** Fund screening for breast, cervical, and colorectal cancer for all age-appropriate populations in the United States that do not now have health insurance, in combination with culturally appropriate outreach and education addressing routine, repeat screening, and provide cancer treatment for anyone who would qualify for these programs.
Support culturally, linguistically, and literacy specific approaches for eliminating cancer health disparities. These should include evidence-based "best practices," proven interventions, and outreach strategies.	**Access to Quality Cancer Services, Priority Recommendation 3 (page A-17)** Promote interventions and ensure accountability for culturally competent, quality cancer care addressing the unequal burden of disease. **Culturally and Linguistically Competent Education and Training, Priority Recommendation 3 (page A-35)** HHS should fund development, identification, dissemination, and delivery of "best practices," model approaches, and outreach strategies for culturally, linguistically, and literacy specific cancer communications and health promotions, in partnership with cancer survivors, caregivers, and community advocacy organizations.
Ensure that every cancer patient has access to "state-of-the-science" care.	**Inequity and Social Injustice, Priority Recommendation 2 (page A-38)** Eliminate inequity and social injustice in the delivery of what we currently know to be effective in cancer prevention and care. Specifically, no person with cancer should go untreated. **Inequity and Social Injustice, Priority Recommendation 3 (page A-38)** Target special resources to geographic areas of excess cancer mortality and work toward universal access to health care.
Collaborate with the private and voluntary health sectors to assure that all Americans receive the full range of lifesaving information, services, and quality care from cancer prevention to screening to diagnosis to treatment.	**Facilitating Partnerships for Action, Priority Recommendation 2 (page A-27)** HHS should identify and work with other public and private organizations to develop and implement a national "CALL TO ACTION" agenda to eliminate cancer health disparities. **Access to Quality Cancer Services, Priority Recommendation 1 (page A-15)** Assure access to comprehensive (prevention, screening, diagnosis, treatment, quality of life, palliative, end of life), continuously funded, integrated health care for all people, including insurance coverage. **Inequity and Social Injustice, Priority Recommendation 3 (page A-38)** Target special resources to geographic areas of excess cancer mortality and work toward universal access to health care.

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Appendix C
Alignment of PRG Priority Recommendations with Goals, Objectives, and Recommendations of Importance to HHS

Implementation of the Trans-HHS Cancer Health Disparities Progress Review Group (PRG) Call to Action will assist the Department of Health and Human Services (HHS) in meeting two of the four specific HHS goals for cancer health disparities, and the overarching goals of the *Healthy People 2010* [1] agenda to increase quality and years of healthy life and to eliminate health disparities. These actions will address many of the recommendations made by the following other expert panels that were recently convened to assess cancer and other health disparities:

- Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care [2]
- National Cancer Policy Board [3]
- Committee on Cancer Research among Minorities and the Medically Underserved [4]
- President's Cancer Panel [5]

Table C-1 shows how the 14 individual PRG priority recommendations align with the goals, objectives, and recommendations of these other groups. Embedded within the table is a highlighted box listing the 21 recommendations deriving from the report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. [2] These recommendations are incorporated into the PRG priority recommendations by specific reference.

Table C-1. Implementation of PRG Priority Recommendations Will Help Meet the Goals, Objectives, and Recommendations Set Forth by HHS and Previous Expert Panels

PRG Priority Recommendation	Affected Goals, Objectives, and Recommendations
Planning and Coordination	
Conduct a program and budget review of all relevant HHS programs for the purpose of shifting and realigning support, where possible, to evidence-based programs that are effective in addressing cancer health disparities. (*For Initiation within 1 Year)*	**HHS Cancer Health Disparities Goals** • Facilitate the adoption and implementation of evidence-based policy, community programs, and clinical interventions and evaluate their impact on specific cancer health disparities. **Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care Recommendations** • Promote the consistency and equity of care through the use of evidence-based guidelines. • Conduct further research to identify sources of racial and ethnic disparities and assess promising intervention strategies. **National Cancer Policy Board Recommendations** • The U.S. Department of Health and Human Services should complete a comprehensive review to assess whether evidence-based prevention services are being offered and successfully delivered in Federal health programs.
Assemble a Federal Leadership Council on Cancer Health Disparities led by the HHS Secretary in partnership with the Secretaries of other appropriate Federal departments to mobilize available resources in a comprehensive national effort to eliminate cancer health disparities. *(For Initiation within 1 Year)*	**HHS Cancer Health Disparities Goals** • Ensure unbiased access to continuous quality preventive care, early detection, and treatment of cancer for every American.

Table C-1. Implementation of PRG Priority Recommendations Will Help Meet the Goals, Objectives, and Recommendations Set Forth by HHS and Previous Expert Panels (cont.)

PRG Priority Recommendation	Affected Goals, Objectives, and Recommendations
Planning and Coordination (cont.)	
Implement, in all HHS health service and reimbursement agencies, recommendations from the Institute of Medicine Report entitled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. *(For Initiation within 3 Years)*	**HHS Cancer Health Disparities Goals** • Ensure unbiased access to continuous quality preventive care, early detection, and treatment of cancer for every American. • Facilitate the adoption and implementation of evidence-based policy, community programs, and clinical interventions and evaluate their impact on specific cancer health disparities. **Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care Recommendations** • Increase awareness of racial and ethnic disparities in health care among the general public and key stakeholders. • Increase health care providers' awareness of disparities. • Avoid fragmentation of health plans along socioeconomic lines. • Strengthen the stability of patient-provider relationships in publicly funded health plans • Increase the proportion of underrepresented U.S. racial and ethnic minorities among health professionals. • Apply the same managed care protections to publicly funded HMO enrollees that apply to private HMO enrollees. • Provide greater resources to the U.S. DHHS Office of Civil Rights to enforce civil rights laws. • Promote the consistency and equity of care through the use of evidence-based guidelines. • Structure payment systems to ensure an adequate supply of services to minority patients and limit provider incentives that may promote disparities. • Enhance patient-provided communication and trust by providing financial incentives for practices that reduce barriers and encourage evidence-based practice. • Support the use of interpretation services where community need exists. • Support the use of community health workers. • Implement multidisciplinary treatment and preventive care teams. • Implement patient education programs to increase patients' knowledge of how to best access care and participate in treatment decisions. • Integrate cross-cultural education into the training of all current and future health professionals. • Collect and report data on health care access and utilization by patients' race, ethnicity, socioeconomic status, and where possible, primary language. • Include measures of racial and ethnic disparities in performance measurement. • Monitor progress toward the elimination of health care disparities. • Report racial and ethnic data by OMB categories, but use subpopulation groups where possible. • Conduct further research to identify sources of racial and ethnic disparities and assess promising intervention strategies. • Conduct research on ethical issues and other barriers to eliminating disparities.

Table C-1. Implementation of PRG Priority Recommendations Will Help Meet the Goals, Objectives, and Recommendations Set Forth by HHS and Previous Expert Panels (cont.)

PRG Priority Recommendation	Affected Goals, Objectives, and Recommendations
Discovery	
Evaluate specific grant and contract processes to determine what additional steps are needed to enhance the cultural competence, representative composition, and methodological expertise of peer review panels for cancer health disparities research. *(For Initiation within 1 Year)*	**HHS Cancer Health Disparities Goals** • Facilitate the adoption and implementation of evidence-based policy, community programs, and clinical interventions and evaluate their impact on specific cancer health disparities. **Committee on Cancer Research among Minorities and the Medically Underserved Recommendations** • Research and research funding relevant to cancer among ethnic minority and medically underserved populations should be more adequately assessed and should be increased. • NIH should improve the accuracy of its assessment of research that is relevant to ethnic minority and medically underserved groups by replacing the current "percent relevancy" accounting method with one that identifies studies whose purpose is to address a priori research questions uniquely affecting ethnic minority and medically underserved groups. • NCI should develop a process to increase the representation of ethnically diverse researchers and public representatives serving on all advisory and program review committees so that the makeup of these committees reflects the changing diversity of the U.S. population. NCI should develop an evaluation plan to assess the effect of increased and more diversified ethnic minority community and researcher input on changes in NCI policies and priorities toward ethnic minority cancer issues. • The research needs of ethnic minority and medically underserved groups should be identified on the basis of the burden of cancer in these populations, with an assessment of the most appropriate areas of research (e.g., behavioral and social sciences, biology, epidemiology and genetics, prevention and control, and treatment). • For NCI to address the needs of ethnically diverse and medically underserved populations effectively, the Office of Special Populations Research (or some other designated entity or entities) must possess the authority to coordinate and leverage programs and resources across the divisions and branches of NCI to stimulate research on ethnic minority and medically underserved populations. This authority can be established by providing such an office with: – special resources to fund programs specifically targeted to these populations, or – accountability for the institution-wide allocation of program resources. • Investigator-initiated research must be supplemented to ensure that the cancer research needs of ethnic minority and medically underserved populations are addressed.

Table C-1. Implementation of PRG Priority Recommendations Will Help Meet the Goals, Objectives, and Recommendations Set Forth by HHS and Previous Expert Panels (cont.)

PRG Priority Recommendation	Affected Goals, Objectives, and Recommendations
Discovery (cont.)	
Establish new approaches for data collection and sharing to aid in the study of the effects of cancer and their relationship to variables such as race, ethnicity, and socioeconomic status. *(For Initiation within 2 Years)*	**HHS Cancer Health Disparities Goals** • Facilitate the adoption and implementation of evidence-based policy, community programs, and clinical interventions and evaluate their impact on specific cancer health disparities. ***Healthy People 2010* Objectives** • Increase the proportion of all major national, state, and local health data systems that use geocoding to promote nationwide use of geographic information systems at all levels. • Increase the proportion of population-based Healthy People 2010 objectives for which national data are available for all population groups identified for the objective. **Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care Recommendations** • Collect and report data on health care access and utilization by patients' race, ethnicity, socioeconomic status, and where possible, primary language. • Include measures of racial and ethnic disparities in performance measurement. • Monitor progress toward the elimination of health care disparities. • Report racial and ethnic data by Office of Management and Budget (OMB) categories, but use subpopulation groups where possible. **Committee on Cancer Research among Minorities and the Medically Underserved Recommendations** • To further enhance the excellent data provided in the Surveillance, Epidemiology, and End Results (SEER) program database, adequate resources should be provided to expand SEER program coverage beyond the existing sites to include high-risk populations for which SEER program coverage is lacking. This expansion should address a wider range of demographic and social characteristics by using consistent nomenclature and a uniform data set and by reflecting the diverse characteristics of the current U.S. population. • NCI should continue to work with the North American Association of Central Cancer Registries and other organizations to expand the coverage and enhance the quality of the 45 non-SEER program state cancer registries, with the intent of ultimately achieving—together with the SEER program state registries—two goals: (1) a truly national data set obtained through a system of longitudinal population-based cancer registries covering the entire country, and (2) a reliable database for each state to serve as the basis for both the development and the evaluation of cancer control efforts in that state. • Annual reporting of cancer surveillance data and population-based research needs to be expanded to include survival data for all ethnic groups, as well as for medically underserved populations. • The committee recommends an emphasis on ethnic groups rather than on race in NIH's cancer surveillance and other population research. This implies a conceptual shift away from the emphasis on fundamental biological differences among "racial" groups to an appreciation of the range of cultural and behavioral attitudes, beliefs, lifestyle patterns, diet, environmental living conditions, and other factors that may affect cancer risk.

Table C-1. Implementation of PRG Priority Recommendations Will Help Meet the Goals, Objectives, and Recommendations Set Forth by HHS and Previous Expert Panels (cont.)

PRG Priority Recommendation	Affected Goals, Objectives, and Recommendations
Discovery (cont.)	
Increase the proportion of HHS agency support targeted specifically to disease prevention, health promotion, evaluation, and translational research on cancer health disparities. *(For Initiation within 2 Years)*	**HHS Cancer Health Disparities Goals** • Facilitate the adoption and implementation of evidence-based policy, community programs, and clinical interventions and evaluate their impact on specific cancer health disparities. **Committee on Cancer Research among Minorities and the Medically Underserved Recommendations** • The newly established program of behavioral and social science research at NCI addresses an area of research that has been neglected in the past. The committee urges that this program of research identify as one of its highest priorities a focus on the cancer prevention, control, and treatment needs of ethnic minority and medically underserved groups. • Collaborations between NIH and research and medical institutions that serve ethnic minority and medically underserved populations should be increased to improve the study of cancers that affect these groups and to increase the involvement of such entities and populations in scientific research.
Establish partnerships for and support the development of sustainable community-based networks for participatory research in areas of high cancer disparities. *(For Initiation within 3 Years)*	**HHS Cancer Health Disparities Goals** • Facilitate the adoption and implementation of evidence-based policy, community programs, and clinical interventions and evaluate their impact on specific cancer health disparities. ***Healthy People 2010* Objectives** • Increase the proportion of hospitals and managed care organizations that provide community disease prevention and health promotion activities that address the priority health needs identified by the community. • Increase the proportion of tribal and local health service areas or jurisdictions that have established a community health promotion program that addresses multiple Healthy People 2010 focus areas. **Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care Recommendations** • Support the use of community health workers. **National Cancer Policy Board Recommendations** • The U.S. Congress should provide sufficient appropriations to the Centers for Disease Control and Prevention to support innovative public and private partnerships to develop, implement, and evaluate comprehensive community-based programs in cancer prevention and early detection. Every state should have and implement a comprehensive cancer control plan. **President's Cancer Panel Recommendations** • Address patient and public needs for cancer information and for assistance in accessing services: – Provide funding to help communities coordinate, promote, and support community-based programs, including patient navigator programs, that help people obtain cancer information, screening, treatment, and supportive services. – Recognize that the services of non-physician personnel who are trained to conduct cancer screening, and provide cancer education and case management in varied settings are an important component of cancer care that should be reimbursed.

Table C-1. Implementation of PRG Priority Recommendations Will Help Meet the Goals, Objectives, and Recommendations Set Forth by HHS and Previous Expert Panels (cont.)

PRG Priority Recommendation	Affected Goals, Objectives, and Recommendations
Development	
Develop and implement a new trans-HHS initiative to qualify high disparity geographic areas for special program designation as Communities Empowered to Eliminate Disparities. Communities would qualify for the program by submitting strategic plans to reduce specific cancer disparities for identifiable populations. *(For Initiation within 2 Years)*	**HHS Cancer Health Disparities Goals** • Ensure unbiased access to continuous quality preventive care, early detection, and treatment of cancer for every American.
Develop, implement, and carefully evaluate education and training programs designed to create a diverse and culturally competent cancer care workforce. Apply standards to certify the cultural competence of health professionals who receive Federal support. *(For Initiation within 2 Years)*	**HHS Cancer Health Disparities Goals** • Ensure unbiased access to continuous quality preventive care, early detection, and treatment of cancer for every American. ***Healthy People 2010* Objectives** • In the health professions, allied and associated health profession fields, and the nursing field, increase the proportion of all degrees awarded to members of underrepresented racial and ethnic groups. • Increase the proportion of persons who report that their health care providers have satisfactory communication skills. • Increase the proportion of Federal, tribal state, and local public health agencies that provide continuing education to develop competency in essential public health services for their employees. • Increase the proportion of local health departments that have established culturally appropriate and linguistically competent community health promotion and disease prevention programs. **Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care Recommendations** • Increase health care providers' awareness of disparities. • Enhance patient-provided communication and trust by providing financial incentives for practices that reduce barriers and encourage evidence-based practice. • Integrate cross-cultural education into the training of all current and future health professionals. **President's Cancer Panel Recommendations** • Develop Federal policies to minimize bias in the provision of cancer care: – Raise awareness of unintended or overt bias through initial and continuing training of health care professionals at all levels, as well as administrators and others who make decisions affecting patient care. – Establish and implement systems for monitoring treatment equity. In addition, expand quality of care research to include issues of treatment equity.

Table C-1. Implementation of PRG Priority Recommendations Will Help Meet the Goals, Objectives, and Recommendations Set Forth by HHS and Previous Expert Panels (cont.)

PRG Priority Recommendation	Affected Goals, Objectives, and Recommendations
Delivery	
Implement evidence-based tobacco control strategies, including those that create financial disincentives for tobacco consumption and those that provide social reinforcement for not smoking. *(For Initiation within 1 Year)*	**HHS Cancer Health Disparities Goals** • Facilitate the adoption and implementation of evidence-based policy, community programs, and clinical interventions and evaluate their impact on specific cancer health disparities. ***Healthy People 2010* Objectives** • Reduce tobacco use by adults. • Reduce tobacco use by adolescents. • Increase smoking cessation attempts by adult smokers. • Increase tobacco use cessation attempts by adolescent smokers. **National Cancer Policy Board Recommendations** • The U.S. Congress and state legislatures should enact and provide funding for enforcement of laws to substantially reduce and ultimately eliminate the adverse public health consequences of tobacco use and exposure. • The U.S. Department of Health and Human Services should complete a comprehensive review to assess whether evidence-based prevention services are being offered and successfully delivered in Federal health programs.
Ensure that populations at highest risk have access to age- and gender-appropriate screening and follow-up services for breast, cervical, and colorectal cancer. Expand to include these services for additional cancers (e.g., prostate, lung) when there is evidence that they are effective at improving survival. *(For Initiation within 2 Years)*	**HHS Cancer Health Disparities Goals** • Ensure unbiased access to continuous quality preventive care, early detection, and treatment of cancer for every American. ***Healthy People 2010* Objectives** • Reduce the breast cancer death rate. • Reduce the death rate from cancer of the uterine. • Reduce the colorectal cancer death rate. • Increase the proportion of women who receive a Pap test. • Increase the proportion of adults who receive a colorectal cancer screening examination. • Increase the proportion of women ages 40 years and older who have received a mammogram within the preceding 2 years. **National Cancer Policy Board Recommendations** • Public and private insurers and providers should consider evidence-based cancer prevention and early detection services to be essential benefits and should provide coverage for them. These services at a minimum should include interventions recommended in the 2000 U.S. Public Health Service's clinical practice guideline on treating tobacco use and dependence, screening for breast cancer among women ages 50 and older, screening for cervical cancer among all sexually active women with an intact cervix, and screening for colorectal cancer among adults ages 50 and older. • The U.S. Congress should increase support for programs that provide primary care to uninsured and low-income people (e.g., Community and Migrant Health Centers and family planning programs of Title X of the Public Health Service Act). These programs increase the use of cancer prevention and early detection services among medically underserved populations. • Support for the Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program should be increased so that the program can reach all uninsured women using innovative delivery strategies. Support is also needed for a similar program at the CDC to provide screening for colorectal cancer for uninsured and low-income men and women.

Table C-1. Implementation of PRG Priority Recommendations Will Help Meet the Goals, Objectives, and Recommendations Set Forth by HHS and Previous Expert Panels (cont.)

PRG Priority Recommendation	Affected Goals, Objectives, and Recommendations
Delivery (cont.)	
Support culturally, linguistically, and literacy specific approaches for eliminating cancer health disparities. These should include evidence-based "best practices," proven interventions, and outreach strategies. *(For Initiation within 2 Years)*	**HHS Cancer Health Disparities Goals** • Ensure unbiased access to continuous quality preventive care, early detection, and treatment of cancer for every American. ***Healthy People 2010* Objectives** • Increase the proportion of local health departments that have established culturally appropriate and linguistically competent community health promotion and disease prevention programs. • Increase the proportion of persons who report that their health care providers have satisfactory communication skills. **Committee on Cancer Research among Minorities and the Medically Underserved Recommendations** • NCI should continue to work with other appropriate Federal agencies and institutional review boards to explore creative approaches to improving patients' understanding of research and encouraging them to provide consent to participate in research. These approaches should address cultural bias, mistrust, literacy, and other issues that may pose barriers to the participation of ethnic minority and medically underserved groups.
Ensure that every cancer patient has access to state-of-the-science care. *(For Initiation within 3 Years)*	**HHS Cancer Health Disparities Goals** • Ensure unbiased access to continuous quality preventive care, early detection, and treatment of cancer for every American. ***Healthy People 2010* Objectives** • Increase the proportion of persons who have a specific source of ongoing care. **President's Cancer Panel Recommendations** • Extend state-of-the-art cancer care to rural, frontier, and other underserved areas by expanding the use of telemedicine and providing a reimbursement system that facilitates expansion of telemedicine to geographically underserved areas.
Collaborate with the private and voluntary health sectors to ensure that all Americans receive the full range of lifesaving information, services, and quality care from cancer prevention to screening to diagnosis to treatment. *(For Initiation within 3 Years)*	**HHS Cancer Health Disparities Goals** • Ensure unbiased access to continuous quality preventive care, early detection, and treatment of cancer for every American. ***Healthy People 2010* Objectives** • Increase the proportion of persons with health insurance. • Increase the proportion of insured persons with coverage for clinical preventive services. • Increase the proportion of persons appropriately counseled about health behaviors. • Increase the proportion of persons who have a specific source of ongoing care. • Increase the proportion of persons with a usual primary care provider. • Reduce the proportion of families that experience difficulties or delays in obtaining health care or do not receive needed care for one or more family members. • Increase the proportion of health care organizations that provide patient and family education. • Increase the proportion of patients who report that they are satisfied with the patient education they receive from their health care organization. **Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care Recommendations** • Avoid fragmentation of health plans along socioeconomic lines. • Apply the same managed care protections to publicly funded HMO enrollees that apply to private HMO enrollees. • Structure payment systems to ensure an adequate supply of services to minority patients, and limit provider incentives that may promote disparities.

Table C-1. Implementation of PRG Priority Recommendations Will Help Meet the Goals, Objectives, and Recommendations Set Forth by HHS and Previous Expert Panels (cont.)

PRG Priority Recommendation	Affected Goals, Objectives, and Recommendations
Delivery (cont.)	
Collaborate with the private…(cont.)	**National Cancer Policy Board Recommendations** • Public and private organizations (e.g., the National Cancer Institute and the American Cancer Society) should take steps to improve the public's understanding of cancer prevention and early detection with a focus on promoting healthy lifestyles and informed decision making about health behaviors and cancer screening. • Public and private initiatives to reduce disparities in the cancer burden (e.g., initiatives of the National Cancer Institute and the American Cancer Society) should be supported. **Committee on Cancer Research among Minorities and the Medically Underserved Recommendations** • NIH and other Federal agencies (particularly the Health Care Financing Administration) should coordinate to address funding for clinical trials, particularly to address the additional diagnostic and therapeutic costs associated with prevention trials and third-party payment barriers associated with clinical treatment trials. • NCI should continue to assess its dissemination practices to identify effective cancer information delivery strategies among ethnic minority and medically underserved populations, revise and implement the strategic dissemination plan on the basis of the results of that research, and institute an ongoing system of monitoring to assess its effectiveness. **President's Cancer Panel Recommendations** • Provide immediate medical coverage for the uninsured—84 percent of whom are workers and their dependents—upon a diagnosis of cancer to help ensure that no person with this disease goes untreated. • Address health coverage issues that contribute substantially to the financial devastation of people underinsured for cancer care costs: – Provide reimbursement for anti-cancer agents, supportive medications (e.g., antiemetics and pain medications), and proven chemopreventive agents regardless of method of administration. – Within 2 years, public and private payers should reach consensus on and implement a standard health benefit package for cancer care. This benefit package should be based on the best available medical evidence and should be updated regularly to reflect advances in the standard of care. The reports and deliberations of the Institute of Medicine, other groups, and consumers should be used to inform this effort. • Address patient and public needs for cancer information and for assistance in accessing services: – Provide funding to help communities coordinate, promote, and support community-based programs, including patient navigator programs, that help people obtain cancer information, screening, treatment, and supportive services. – Recognize that the services of non-physician personnel who are trained to conduct cancer screening, and provide cancer education and case management in varied settings are an important component of cancer care that should be reimbursed. • Sustain cancer care in the community by providing consistent and realistic health care provider reimbursement across states, and between urban and rural locations within states, for the cost of chemotherapy drugs and their administration.

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Appendix D
Glossary of Terms and Acronyms

AHRQ	Agency for Healthcare Research and Quality (Department of Health and Human Services)
AoA	Administration on Aging (Department of Health and Human Services)
Best Practices	Strategies, activities, or approaches that are thought, by experts, to be most effective for achieving an intended goal.
Cancer Care Continuum	The medical and nonmedical services associated with cancer prevention, detection, diagnosis, treatment, and survivorship.
CBPR	Community-Based Participatory Research
CDC	Centers for Disease Control and Prevention (Department of Health and Human Services)
CHP	Child Health Plus
CMS	Centers for Medicare and Medicaid Services (Department of Health and Human Services)
Consumers	Individuals, including accompanying family members, guardians, or companions, seeking physical or mental health care services, or other health-related services.[1]
CRCHD	Center to Reduce Cancer Health Disparities (National Cancer Institute)
Cultural and Linguistic Competence	A set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. "Culture" refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. "Competence" implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities.[1]
Culturally and Linguistically Appropriate	Respectful of and responsive to cultural and linguistic needs.[1]
DCCPS	Division of Cancer Control and Population Sciences (National Cancer Institute)
Ethnicity	A concept of shared origins and/or culture in which social, religious, linguistic, dietary, and other variables are common among individuals or populations.
Evidence	Tested in peer-reviewed research with findings published in a peer-reviewed journal.
FDA	Food and Drug Administration (Department of Health and Human Services)
FSC	Federal Steering Committee
Health Services Research	A multidisciplinary field of inquiry, both basic and applied, that examines the use, costs, quality, accessibility, delivery, organization, financing, and outcomes of health care services to increase knowledge and understand the structure, processes, and effects of health services for individuals and populations.[2]
HHS	Department of Health and Human Services

HRSA	Health Resources and Services Administration (Department of Health and Human Services)
Incidence	The number of new cases of a disease that occur in a population over a period of time.
Medicaid	A program that uses Federal and state funds to pay for medical services for low-income individuals (Centers for Medicare and Medicaid Services).
Medically Underserved	Populations that have inadequate access to, or reduced utilization of, high-quality cancer prevention, screening and early detection, treatment, and/or rehabilitation services. Included are rural, low-literacy, and low-income populations. An effort to clarify and further define "medically underserved" is currently under way at NIH. (National Cancer Institute Center to Reduce Cancer Health Disparities).
Medicare	A Federal insurance program for people age 65 and older and certain disabled people (Centers for Medicare and Medicaid Services).
Minority	There are four minority racial groups: American Indian/Alaska Native; Asian; Native Hawaiian/Pacific Islander; and Black. Individuals of Hispanic origin are an ethnic minority and may be of any race. Caucasians, not of Hispanic origin, are generally considered the majority group. The minority group or subpopulation to which an individual belongs is determined by self-reporting.[3]
NBCCEDP	National Breast and Cervical Cancer Early Detection Program (Centers for Disease Control)
NCI	National Cancer Institute (National Institutes of Health)
NCMHD	National Center on Minority Health and Health Disparities (National Institutes of Health)
NHGRI	National Human Genome Research Institute (National Institutes of Health)
NHLBI	National Heart, Lung, and Blood Institute (National Institutes of Health)
NIH	National Institutes of Health (Department of Health and Human Services)
NINDS	National Institute of Neurological Disorders and Stroke (National Institutes of Health)
OMB	Office of Management and Budget (Executive Office of the President of the United States)
OMH	Office of Minority Health (Department of Health and Human Services)
OWH	Office on Women's Health (Department of Health and Human Services)
Peer Review	A system for evaluating research applications that uses reviewers who are the professional equals of the applicant.
Population	A group of people that live in a given geographic area or share common characteristics.
PRG	Progress Review Group
Promotoras	Latina community outreach workers
Quality of Life	The overall enjoyment of life. Many clinical trials assess the effects of cancer and its treatment on the quality of life. These studies measure aspects of an individual's sense of well-being and ability to carry out various tasks.

Race	The concept of race as used by the Census Bureau reflects self-identification by people according to the race or races with which they most closely identify. These categories are sociopolitical constructs and should not be interpreted as being scientific or anthropological in nature. Furthermore, the race categories include both racial and national-origin groups.
Randomized Controlled Trial	A prospective study in which participants are randomly assigned to one or more groups exposed to an experimental intervention and a control group that is not exposed to the experimental intervention.
SAMHSA	Substance Abuse and Mental Health Services Administration (Department of Health and Human Services)
SEER	Surveillance, Epidemiology, and End Results Program (National Cancer Institute)
SES	Socioeconomic status. A measure of access to social and economic resources, most commonly indicated by income, level of education, or type of occupation.
Special Populations	Those ethnic and racial minority groups designated by Office of Management and Budget standards as well as elderly, low-income, low-literate, disabled, and rural populations. The National Cancer Institute's working definition of "special populations" also includes medically underserved populations, such as rural, low-income, and low-literate individuals. These groups are generally characterized as experiencing higher cancer incidence and/or mortality rates or are relatively underserved by cancer programs.
Subpopulation	A group within a larger racial or ethnic group that can be characterized by geographic origin, national origin and/or cultural differences. The subpopulation to which an individual belongs is determined by self-reporting.
Translational Research	Research that advances findings from research studies into general clinical practice.
Tribal	Recognized as eligible for the special programs and services provided by the Federal government to Indians because of their status as Indians.
USPSTF	U.S. Preventive Services Task Force (Department of Health and Human Services)

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