

## MEETING SUMMARY PRESIDENT'S CANCER PANEL

### AMERICA'S DEMOGRAPHIC AND CULTURAL TRANSFORMATION: IMPLICATIONS FOR THE CANCER ENTERPRISE

September 22, 2009  
Seattle, Washington

#### OVERVIEW

This meeting was the first in the President's Cancer Panel's (PCP, the Panel) 2009-2010 series, *America's Demographic and Cultural Transformation: Implications for the Cancer Enterprise*. During this meeting, speakers discussed changes in the proportion of ethnic populations expected to occur in the United States over the next several decades and how this shift may affect the national cancer burden. Underlying causes of and strategies for addressing disparities in health outcomes among ethnic groups were also presented. The agenda for the meeting was organized into two discussion panels.

#### PARTICIPANTS

##### ***President's Cancer Panel***

LaSalle D. Leffall, Jr., M.D., F.A.C.S., Chair  
Margaret Kripke, Ph.D.

##### ***National Cancer Institute (NCI), National Institutes of Health (NIH)***

Abby Sandler, Ph.D., Executive Secretary, PCP  
Gwen Darien, Chair, NCI Director's Consumer Liaison Group

##### ***Speakers***

Paula Braveman, M.D., M.P.H., Director, Center on Social Disparities in Health, Department of Family and Community Medicine, University of California, San Francisco  
Wylie Burke, M.D., Ph.D., Professor and Chair, Department of Bioethics and Humanities, University of Washington School of Medicine  
Brenda K. Edwards, Ph.D., Associate Director, Surveillance Research Program, Division of Cancer Control and Population Sciences, NCI  
Harold P. Freeman, M.D., Senior Advisor to the Director, NCI  
Mark Hayward, Ph.D., Director, Population Research Center, University of Texas at Austin  
Cara V. James, Ph.D., Senior Policy Analyst, Henry J. Kaiser Family Foundation  
Lovell A. Jones, Ph.D., Founding Co-Chair, Intercultural Cancer Council  
Derek Raghavan, M.D., Ph.D., F.A.C.P., Immediate Past Co-Chair, Health Disparities Advisory Group, American Society of Clinical Oncology  
The Hon. Martha Farnsworth Riche, Ph.D., Fellow, Center for the Study of Economy and Society, Cornell University  
Daniel J. Weisdorf, M.D., Director, Adult Blood and Marrow Transplant Program, Division of Hematology, Oncology and Transplantation, University of Minnesota

## **OPENING REMARKS—LaSALLE D. LEFFALL, JR., M.D., F.A.C.S.**

On behalf of the Panel, Dr. Leffall welcomed invited participants and the public to the meeting. He introduced Panel members, provided a brief overview of the history and purpose of the Panel, and described the aims of the current series of meetings.

Welcoming remarks from Congressman Jim McDermott (D-7, WA) were read by Mr. David Loud, Community Liaison for the Representative.

Dr. Kripke reported that the President's Cancer Panel Environmental Factors Development Working Group met on August 14, 2009, to review the first draft of the upcoming report on environmental factors, which is based on the Panel's 2008–2009 series of meetings. The Working Group recommended that the report be significantly reorganized to better reflect the information presented during those meetings. Dr. Kripke's motion to accept the Working Group's recommendations was unanimously passed.

## **PANEL I**

### **THE HON. MARTHA FARNSWORTH RICHE:**

#### **DEMOGRAPHIC DYNAMICS AND THE “CANCER ENTERPRISE”**

##### **Background**

The Hon. Martha Farnsworth Riche is a Fellow of the American Statistical Association and a Fellow of the Center for the Study of Economy and Society at Cornell University. She is also affiliated with the Cornell Population Program. Through Farnsworth Riche Associates, she lectures, writes, and consults on demographic changes and their effects on policies, programs, and products. From 1994 to 1998, she served as Director of the U.S. Bureau of the Census. Dr. Riche began her career in 1961 as an economist with the Bureau of Labor Statistics. In 1978, she took her analytical and communications skills to the private sector, where she was a founding editor of *American Demographics*, the nation's first magazine devoted to interpreting demographic and economic data for corporate and public executives. In 1991, she became Director of Policy Studies for the Population Reference Bureau (PRB), a nonprofit organization devoted to educating the public about the demographic component of policy issues. At PRB, she focused on building a bridge between the research and policy-making communities.

##### **Key Points**

- There are three factors that cause populations to change: birth, death, and migration. All three of these factors are making the U.S. population more racially and ethnically diverse. The trend toward greater diversity is caused not only by higher birth rates among immigrants (especially Hispanic Americans), but also by higher death rates among white, non-Hispanic Americans. The current economic downturn is temporarily slowing the pace of demographic change but is not affecting its general direction.
- Minorities are becoming the majority in the United States. The number of Asians, African Americans, and Hispanics combined will exceed 50 percent of the U.S. population by 2050. The proportion of African Americans will be slightly reduced due to higher immigration and fertility rates among other minority groups. Projections of declines in the number of white non-Hispanics in the decades between 2030 and 2050 are based on expected deaths among the “baby boom” generation; this will not be a long-term trend.
- When discussing projections of demographic data, it is important to remember that definitions of racial and ethnic groups change over time. Almost every U.S. Census report since 1790 has been based on a different set of categories. The fastest growing category today is people who identify themselves with multiple racial or ethnic categories. As this group expands, differences between

groups are likely to become less distinct. The Hispanic category is likely to evolve because this group is defined by ethnicity rather than race. Many Hispanics self-identify as white when forced to select from a list of racial categories.

- There are significant differences among white, African American, Hispanic, and Asian/Pacific Islander/Native American populations in terms of age. Young people comprise larger proportions of all minority groups compared with whites. The average age for whites is 39; for Asians, 33; for African Americans, 30; and for Hispanics, 26. Continuing immigration will increase age differences between whites and minorities, since immigrants tend to be young adults who have children after they arrive in the United States.
- Differing population growth rates and age profiles, along with cultural differences, have resulted in variations in household composition between minority groups and whites. Decreases in the number of traditional households (married couples with children) have been accompanied by increases in the numbers of single-parent households, “empty nest” couples, people living alone, and other nontraditional living arrangements. The question most relevant to cancer is whether a household contains or lacks a potential caregiver. White adults are less likely than minority adults to live in a household with other adults.
- Another demographic variable relevant to cancer is education level. Education levels of African-American and Hispanic populations are much lower than those of whites and Asian Americans. This difference reduces diversity in the healthcare workforce and affects interactions between providers and their patients. Barriers to educational attainment for African Americans and Hispanics are related to family income levels.
- Census data provide useful information for planning healthcare services. Data on English language ability can help identify areas containing populations with potential communication problems. Geographic location data can help identify medically underserved populations.
- Experience with the census demonstrates that in collecting data on U.S. populations, one size does not fit all. Assumptions implicit in surveys developed by the majority population (e.g., the existence of stable households located at identifiable addresses) do not always apply to minority populations. Planning must include input from the populations being targeted in order to address their unique concerns.
- In the past, two groups have not been well served by the U.S. Census: the economically disadvantaged and hard-to-reach populations. Both are disproportionately composed of members of minority groups who live in underserved communities and are affected by crowded housing, linguistic isolation, and below-average educational levels. In 2000, the Census Bureau achieved the most accurate count in its history by establishing more than 9,000 partnerships with organizations trusted in their communities that helped target hard-to-reach populations.
- There is empirical evidence that the growing diversity among patients makes a business case for increasing diversity among medical professionals in order to provide greater access to care and improve patient/provider interactions. In a U.S. Health Resources and Services Administration (HRSA) study published in 2006, diversity among health practitioners was shown to improve health outcomes for minorities. Another study found that race concordance between patients and providers was associated with longer visits and measurably better communication.

## **DR. BRENDA K. EDWARDS:**

### **NCI'S SURVEILLANCE RESEARCH PROGRAM**

#### **Background**

Dr. Brenda K. Edwards has been Associate Director of the NCI Surveillance Research Program and its predecessor organizational unit since 1989. She has been involved in cancer prevention and control since its formative days early in the 1980s. Dr. Edwards began her affiliation with NCI in 1978 as a researcher in cancer treatment clinical trials, and four years later joined the team conducting some of the first cancer prevention trials. Prior to coming to NCI, she was on the faculty of a Midwestern medical school, where she was involved in community-based and environmental/occupational studies. Her research has focused on the full spectrum of cancer surveillance research, including risk factors, patterns of care, behavioral studies and survivorship, statistical methodology, and analytic activities. The surveillance system at NCI provides the research resource base for monitoring the nation's cancer burden, interpreting cancer data, and measuring progress in cancer control. During the past few years, the focus has been directed toward enhancing coordination of the U.S. public-private cancer surveillance enterprise and integrating systems to measure progress in cancer control, maintain the integrity and quality of the SEER Program as a national research resource, disseminate cancer surveillance data, and improve the quantitative assessment of health disparities.

#### **Key Points**

- A national framework for cancer surveillance was published by NCI in 2005. This plan for measuring the cancer burden includes a collection of data on healthy populations, diagnosis, treatment, survivorship, and mortality. Factors addressed include race, ethnicity, socioeconomic status, and culture; healthcare costs; individual, social, and biologic factors; and provider knowledge, attitudes, and practices. Surveillance data collected, analyzed, and published by the NCI Surveillance, Epidemiology, and End Results (SEER) program are widely used to support cancer research and to provide a context for planning and evaluating public health programs.
- Numerous studies and reports have focused on the fact that people from low-income populations are often diagnosed with cancer at late stages and have less favorable outcomes. Improved cancer prevention and early detection programs are needed to address this issue.
- In order to better represent the entire U.S. population, SEER has expanded to encompass more than a quarter of the nation. The program oversamples racial and ethnic minority populations. Percentages of the SEER population representing individuals below the poverty level and with less than a high school education are comparable to those in the 2000 Census.
- An analysis of trends from 1975 to 2006 shows clearly that African Americans have higher cancer incidence and mortality than other U.S. populations. Trends differ among all groups, with greater variability for minority groups whose numbers are comparatively low. Since the early 1990s, a trend toward lower incidence and mortality has been seen among whites and African Americans and, to a lesser extent, among other groups, with the exception of American Indians/Alaska Natives (AI/AN).
- Breast cancer is the most common cancer diagnosed in the United States, and for this disease the incidence rates are highest in the white population. Recent years have seen a downturn in incidence among whites but not among African Americans. Mortality rates for both groups were similar until the 1980s, when mortality began to increase for both groups, with a sharper increase for African-American women. In the 1990s, mortality began to decline, first for whites and, more recently, for African Americans; however, the disparity between the two groups remains significant.
- Prostate cancer is the most commonly diagnosed cancer among men, with substantially higher incidence and mortality among African Americans. This group's mortality rate has begun to decline, but remains much higher than for all other populations.

- Lung cancer is the leading cause of cancer deaths in the United States. Incidence and mortality are much higher for men than for women, and much higher among African-American men than among white men. There have been downward trends in incidence and mortality among men, but incidence rates for women continue to increase. African-American women have somewhat higher incidence rates than whites, but the most significant increases have been among AI/AN; the increase in women's lung cancer mortality has stopped, except among AI/AN.
- Colorectal cancer is the nation's second leading cause of cancer deaths. Substantial declines in incidence and mortality have been reported for a number of years. However, declines for African Americans began much later than for whites and a gap between rates for these groups persists. Rates for most other groups also began to decline recently, but colorectal cancer does not appear to be decreasing among AI/AN.
- Cervical cancer incidence has declined sharply for all population groups. The highest incidence rates for this cancer are found among Hispanic women. Mortality is highest among African-American women but is also high among AI/AN. The decline in cervical cancer mortality may be flattening.
- Incidence and mortality for liver and intrahepatic bile duct cancers have been increasing since 1975. The highest rates are seen among Asians and Pacific Islanders. High rates are also found among Hispanics and AI/AN.
- Data collection on cancer in the United States has improved significantly since 1975. SEER has collected data on 10 percent of the U.S. population over the past 30 years. Expansions in 1995 and 2000 extended SEER's coverage. The program now collaborates with the CDC-funded North American Association of Central Cancer Registries, Inc. (NAACCR, Inc.) to pool data from around the nation. These combined efforts have produced over 10 years of data for more than 70 percent of the population and 5 years of data for more than 85 percent of the population.
- Pooled data have been used to produce an Annual Report to the Nation. The 2006 Annual Report presented comprehensive data on cancer incidence, mortality, and disparities in the U.S. Latino population. The report noted that this population is disproportionately affected by infection-related cancers and more likely than other groups to lack health insurance. The relationship between poverty and cancer incidence varies among cancer types.
- The 2007 Annual Report to the Nation focused on AI/AN. Collecting data on this population is difficult because medical records often do not include this category as an option. NCI has teamed with the Indian Health Service (IHS) to utilize that agency's administrative records and delivery system data. All 50 states were asked to link their population-based registries with the IHS database. This helped NCI find unidentified AI/AN in other state-based cancer registries. American Indian and Alaska Native cancer mortality rates have remained level while overall rates have declined, but mortality for this population is lower than for whites and African Americans. American Indians and Alaska Natives are more likely to be diagnosed with late-stage cancer. Other concerns with this population include elevated risk factors for some cancers (e.g., smoking, obesity, alcohol use), susceptibility to infection-related cancers, and lack of access to care and insurance coverage.
- The cancer surveillance community conducts and supports health disparities research by focusing on the changing dynamics of the immigrant population. A new SEER project is creating a data set on the large populations of Asians and Latinos in California. Area-based data are being used to enhance cancer registry data. The SEER Small Area (Ecological) Data Set focuses on attributes such as age, housing, educational attainment, poverty, and language isolation.
- NCI works closely with the U.S. Census Bureau. Census data are used to develop denominators for the populations being studied and to support ecologic analysis efforts.
- NCI also uses data from the National Health Interview Survey (NHIS). NHIS data on cancer screening have shown that racial and ethnic minority populations have much lower utilization of

cancer screening methods than whites. In addition, utilization of colorectal cancer screening is low for the total population.

- Data from the California Health Interview Survey (CHIS) provide important information at the regional level. For example, the survey has found that large percentages of women in some ethnic groups have never had a Pap test. The CHIS is using a multiracial category to capture data on individuals who do not identify themselves as belonging to a single category.
- NCI communications staff have developed a series of *Briefs* to disseminate data from the Health Information National Trends Survey (HINTS). One *Brief* pointed out that Hispanics are less likely to seek cancer information than non-Hispanics; when they do seek such information, they often report low levels of satisfaction. Hispanics are less well informed than the general population about cancer risk factors such as smoking. Another *Brief* addressed factors associated with low levels of physical activity, which include non-white status, low income, obesity, lack of health insurance, and low education levels.
- In 2005, NCI published *Measures for Measuring Cancer Disparities: A Review Using Data Relevant to Healthy People 2010 Cancer-Related Objectives*. This monograph raises conceptual issues involved in measuring disparities and reviews different methodological approaches. It discusses 22 potential measures of absolute and relative differences between populations. A beta version of a new Health Disparities Calculator (HD\*Calc) has been added to SEER\*Stat for review and comment.
- The emerging U.S. cancer surveillance program is using linked data sets to conduct rapid-response studies to explain cancer trends, understand cancer disparities, assess technologies and therapies, and provide ideas for new research.

## **DR. PAULA BRAVEMAN:**

### **REDUCING DISPARITIES IN CANCER WILL REQUIRE MORE THAN EQUITABLE HEALTHCARE**

#### **Background**

Dr. Paula Braveman is Professor of Family and Community Medicine and Director of the Center on Social Disparities in Health at the University of California, San Francisco (UCSF). She received her degrees in medicine and epidemiology from UCSF and UC Berkeley, respectively, and practiced medicine in a range of settings serving diverse, disadvantaged populations. For more than two decades, Dr. Braveman has studied and published extensively on social disparities in health and healthcare and is actively engaged in bringing attention to this field in the U.S. and internationally. Her research focuses on measuring, documenting, and understanding socioeconomic and racial/ethnic disparities, particularly in maternal and infant health and healthcare. During the 1990s, she worked with World Health Organization staff in Geneva to develop and implement a global initiative on equity in health and healthcare. Throughout her career, she has collaborated with local, state, federal, and international health agencies to see research translated into practice, with the goal of achieving greater equity in health. Dr. Braveman has been a member of the Institute of Medicine (IOM) of the National Academy of Sciences since 2002.

#### **Key Points**

- Despite spending far more on medical care than any other country, the United States consistently ranks at or near the bottom among industrialized nations when it comes to standard measures of health.
- Reducing health disparities in cancer will require more than reducing disparities in the healthcare system. Race/ethnicity, along with social factors such as income and education, are major causes of health disparities. Some types of disease, including different types of cancer, are more heavily

influenced by these social factors than other types. Genetics, behavior, nutrition, climate, and natural physical environment also influence health and healthcare.

- Racial/ethnic differences in health are prominent, but do not account for health disparities by income or education. There are distinct differences in life expectancy between socioeconomic groups in the U.S., with a correlation between higher income and longevity in both men and women. The difference between those at or below poverty and those in the highest income bracket (more than four-times the federal poverty level [FPL]) is the starkest, but there are also differences between the observed life expectancy of middle-class Americans and those of the upper class. This pattern is strikingly similar within all U.S. racial/ethnic groups. Level of education similarly correlates with life expectancy among all groups. Although not all health indicators correlate with income and education, most do.
- In non-Hispanic whites, overall cancer death rates decrease with greater education level. However, this pattern is not consistent across all racial/ethnic groups. For the most part, cancer death rates are inversely related to years of education for black men; but there is no direct relationship between cancer death rate and years of education for black women. Mortality trends differ by cancer type—some cancers are more heavily influenced by social factors than others.
- Education affects health through myriad complex pathways. The most obvious is that educational attainment influences health knowledge, literacy, and behaviors. Education can also affect health through psychosocial factors, including social standing and support and sense of control.
- Low educational attainment can result in poor health due to inability to obtain a good job. Low income leads to unhealthy housing, poor nutrition, stress, and living in an unhealthy neighborhood. Poor working conditions can result in physical hazards, lack of health insurance and sick leave, and a lack of control over one's life.
- Recent data show persistent and widening gaps in smoking by educational attainment. The more education an adult has received, the less likely he/she is to be a smoker.
- Race/ethnicity often captures unmeasured socioeconomic differences that can influence health. At a given income level, blacks and Hispanics live in unhealthier neighborhoods than whites with a similar income. Poor neighborhoods greatly affect the health of children living in them. Physical danger (e.g., crime and pollution), limited access to healthy food, lack of positive peer role models, low-quality schools, limited access to good jobs, and stress, fear, and anxiety are all issues faced by children living in poor neighborhoods. At a given educational level, whites have a higher income and are more likely to have grown up in an advantaged family than blacks and Hispanics. These factors are rarely assessed in health studies.
- Income directly shapes medical care, housing, nutrition, physical activity, neighborhood conditions, stress, and social support. The effect of income on health is also multigenerational; parents' income affects the next generation's education, working conditions, and income level.
- Data from an annual population-based postpartum survey conducted in California show that the number of major stressors experienced during pregnancy decreases as income level increases. Only about 12 percent of women whose income levels are over four times the FPL experience major stressors; and 10 percent of those women only experience one stressor. These stressors include food insecurity, financial hardship, separation or divorce, homelessness, job loss, domestic violence, and incarceration.
- Income and education are important mediators of health, but the legacy of racism can harm health in other ways. Structural racism, evidenced by residential racial segregation, tracks people by race into different socioeconomic opportunities. People are born into a family and neighborhood with particular educational and job opportunities; and it is often hard to break free from this predestined path.

- In addition, living in a society with a legacy of discrimination can harm health through physiological pathways involving stress. Awareness of racism can undermine self-esteem and confidence; it can also affect school and work performance.
- Lack of socioeconomic data is an obstacle to understanding and addressing health disparities. When health data identify race/ethnicity but not socioeconomic factors, racial/ethnic stereotypes are reinforced. However, information on race is still essential since socioeconomic factors will not capture experiences of racism. Data are needed on both race/ethnicity and key socioeconomic factors such as income, education, and neighborhood conditions in order to understand disparities.
- Social disparities generate and perpetuate health disparities. Differences in race or class—commonly measured by levels of education or income—lead to differences in exposure to health-harming or health-promoting substances or experiences. Depending on biological vulnerability, specific exposures may lead to disease, the outcome of which is further affected by social position.
- Differences in race/ethnicity, income, and education can be seen as differences in underlying resources and opportunities for good health. Too many Americans face barriers to these opportunities that cannot be removed by personal responsibility; this is where societal action is required.

## **DR. WYLIE BURKE:**

### **GENOMIC RESEARCH: CHALLENGES OF REACHING MINORITY POPULATIONS**

#### **Background**

Dr. Wylie Burke is Professor and Chair of the Department of Bioethics and Humanities at the University of Washington (UW) and Director of the UW Center for Genomics and Healthcare Equality. She received a Ph.D. in genetics and an M.D. from UW; completed a medical residency in internal medicine; and was a Medical Genetics Fellow. She is an Adjunct Professor in the Departments of Medicine and Epidemiology, a member of the Fred Hutchinson Cancer Research Center, and a member of the UW Institute for Public Health Genetics. Her academic work addresses the ethical and policy implications of genetic information in research, medicine, and public health. Dr. Burke is a member of the Institute of Medicine and the Association of American Physicians, and is a Fellow of the American College of Physicians. She served on the Secretary's Advisory Committee on Genetic Testing and the National Human Genome Advisory Council, and is a past President of the American Society of Human Genetics.

#### **Key Points**

- The field of genetics holds huge promise for improving cancer care and outcomes. Genetics can be used to identify individuals at high risk for disease who may benefit from targeted prevention activities. It is also being used to improve disease classification; for example, gene expression profiling is used to determine whether women with early-stage breast cancer would benefit from chemotherapy. Genetics research also provides insight into disease biology, which can lead to development of innovative drugs.
- There is concern that the benefits of genomic research enjoyed by the majority population will take longer to reach minority populations, or not reach them at all. One example of this is seen in analysis of the BRCA genes. Certain mutations in the BRCA genes are associated with higher risk of both breast and ovarian cancer and are present in all population groups. Current testing of these genes can reveal the presence or absence of known high-risk mutations but may also identify gene variants of unknown clinical significance (i.e., variations in gene sequence that are not normal but for which there are no data regarding their association with increased disease risk). Receiving a result that is of unknown clinical significance can be very frustrating for women, and these results are much more common among minority women; women of European ancestry have a 5 percent likelihood of carrying a variant of unknown clinical significance, but African-American and Hispanic women are at

least twice as likely to receive these uninformative results. Thus, the benefit of undergoing BRCA gene testing is much lower for minority women.

- There are several reasons why the benefit of genetic research to minority populations may lag behind benefits to their white counterparts. Minority populations are less likely to participate in biomedical research; specifically, in genomic research. This may be in part because of minority community mistrust of researchers, and genetic researchers in particular; for example, some Native American communities express concern that researchers may focus on genetic determinism rather than consider genetics as one of many factors that contribute to complex disease.
- Current genetic research involves analysis of very large data sets built from large data repositories. Efficient use of these resources would involve sharing of data and samples among studies; however, there are concerns among minority communities and others that data sharing and appropriate use of samples are inadequately controlled. One conspicuous case in the United States involved the Havasupai Tribe, which provided samples for a study of the genetic basis of diabetes, an area of interest for the Tribe. Without permission from the Tribe, the samples were loaned to another researcher for different studies. This was viewed by the Tribe as a serious breach of trust, and the effects of this action reverberated among Native American communities.
- Minority populations are less likely to have access to genetic services. These services currently are poorly reimbursed by both public and private insurance and tend to be offered in tertiary care centers that may be difficult for some patients to access. Furthermore, there is a lack of diversity among both researchers and genetic services providers.
- In order to ensure that the benefits of genetic research reach all populations, a robust clinical research agenda must be established and pursued. In particular, research is needed to determine the implications of the information generated through genetic testing; public funding of this type of research is currently inadequate. Establishing the value of genetic services will help secure reimbursement for these services, including genetic counseling, which is often critical for helping individuals determine whether genetic testing may be helpful and supporting them as they consider what steps to take once they receive test results. Research is also needed on healthcare delivery (i.e., how people get the healthcare they need and how they experience outcomes).
- It is important to develop mechanisms for people to access genetic services. Urban tertiary care centers should consider ways in which they can partner with community healthcare centers to reach more people. Currently, some people travel several hours for a genetic consultation, which can be a tremendous burden. In some cases, it may be possible for the geneticist to provide a community physician with information over the telephone and for the physician to in turn provide this information to the patient. This would avert the need for the patient to travel a significant distance. However, different reimbursement models may be necessary to support these types of partnerships.
- It is important for genomic researchers to engage communities to learn about community concerns. This may help address the lack of trust among minority communities for the research enterprise. Building these relationships may help researchers understand the types of oversight minority communities would like to see for large databanks. This, in turn, may increase participation of minorities in efforts such as the NIH dbGAP (database of Genotypes and Phenotypes), in which minorities are currently underrepresented.
- In addition to revealing fundamental disease biology, genomics and other molecular studies have the potential to provide insight into how environmental exposures interact with genes to influence disease risk. This type of research may help identify which exposures experienced disproportionately by minorities are most important for disease.
- Training should be an important component of efforts to ensure that genetic research benefits minority populations. Although programs that provide incentives for minorities to enter the healthcare and biomedical research workforces have been somewhat successful, there is still a lack of diversity

among researchers and healthcare workers. This is particularly notable among genetics healthcare workers. Outreach programs that enable students from minority communities to see the commitment of the research enterprise to the well-being of their communities should help motivate these students to engage in research and healthcare activities.

- Many in the healthcare and research fields express concern over the educational “leaky pipeline” (i.e., the fact that many minority students do not complete high school, college, or graduate training). Although it would be preferable to have these students complete their training and become researchers and healthcare workers, the “leaky pipeline” should not necessarily be viewed as a failure. Rather, it should be thought of as an “irrigation system.” If minority students have positive educational experiences, they will carry these back to their communities and become potential links between these communities and the research/healthcare system.

## **DR. DANIEL WEISDORF:**

### **DIVERSITY INITIATIVES IN BLOOD AND MARROW TRANSPLANTATION: CHALLENGES AND PROGRESS**

#### **Background**

Dr. Daniel Weisdorf is Professor of Medicine and Director of the Adult Blood and Marrow Transplant Program at the University of Minnesota. He had Internal Medicine training in Chicago and a subsequent Hematology/Oncology Fellowship at the University of Minnesota, where he remained on the faculty. He also serves as Scientific Director of the National Marrow Donor Program and Senior Research Advisor of the Center for International Blood and Marrow Transplant Research. His research interests include complications of hematopoietic stem cell transplantation and immunotherapy for hematologic malignancies.

#### **Key Points**

- Hematopoietic cell transplantation (HCT), which encompasses bone marrow transplantation and transplantation of other blood cells, is a potentially curative therapy for a variety of diseases, including several cancers (e.g., leukemias, lymphomas, myeloma), marrow disorders (e.g., sickle cell anemia, thalassemia, aplastic anemia), immune deficiency, and metabolic storage diseases.
- HCT for cancer treatment requires pretransplant conditioning, which involves chemotherapy or radiation to reduce the number of cancer cells and suppress the immune system in order to prevent rejection of the transplanted cells. Hematopoietic stem cells from bone marrow, growth-factor stimulated adult blood, or umbilical cord blood are then infused into the patient. If successful, HCT restores bone marrow function, allowing generation of new blood cells, and also improves immune function, which helps the patient recover from therapy and may help prevent recurrent cancer. When used to treat nonmalignant disease, HCT can replace missing or defective immune functions, enzyme-producing cells, or tissue cells.
- When a patient requires HCT, cells can be provided by a family member, but only about one-third of patients have a suitable tissue-type-matched family member. When a related donor is not available, a search is done for an unrelated donor using the National Marrow Donor Program (NMDP) or another registry. NMDP is licensed by the U.S. Health Resources and Services Administration to provide bone marrow and umbilical cord registry services for patients within the United States and link to registries around the world to identify potential donors. NMDP is also charged with collecting outcome data on a variety of patient experiences and providing educational materials to patients.
- It is estimated that in 2009, 4,700 people will receive transplants using cells from donors identified through NMDP. When the program began in 1987, only bone marrow transplants were facilitated. In the mid-1990s, growth-factor-stimulated circulating peripheral blood cells from adult donors began to

be offered as an alternative. In the late 1990s, umbilical cord blood units from unrelated donors also became a part of the registry.

- Over the past 20 years, there have been significant advances in the ability to identify well-matched donors and provide supportive care for HCT patients. This has resulted in significant improvement in patient outcomes. For example, two-year post-HCT survival rates for adult acute myeloid leukemia patients have increased from approximately 20 percent to nearly 40 percent. Survival rates for pediatric acute lymphoblastic leukemia have also nearly doubled over this time frame.
- A multivariate statistical analysis of NMDP data from 2000 to 2005 was conducted to assess the impact of tissue-type matching on outcomes and determine why some patients are able to find a well-matched donor while others are not. Tissue-type matching is done using a series of human leukocyte antigens (HLAs). The current multicenter analysis, which evaluated eight HLAs, found that a higher number of matched HLAs correlated with better outcomes in patients with relatively early-stage disease; patients with fully matching HLAs (8 of 8) exhibited a survival rate twice that of patients receiving a transplant with only six of eight HLAs matched. However, patients with advanced disease exhibited similarly low survival rates regardless of HLA matching, illustrating the importance of access to HCT at an early stage of disease.
- The analysis further delved into which patients are most likely to receive well-matched transplants. Across all age groups, between 80 and 90 percent of patients receive well-matched or partially matched transplants. Patients older than 50 years of age are more likely than younger patients to receive well-matched transplants; this is in part because physicians are less willing to proceed with HCT in older patients unless a strong match is identified since this population often experiences increased morbidity and mortality upon receipt of an incompletely matched transplant.
- Analysis across racial/ethnic groups revealed that well-matched donors are available for about 60 percent of Caucasian patients but only 30 percent of African-American patients and less than 40 percent of Asian and Hispanic patients. In total, 90 percent of Caucasians received a well-matched or partially matched HCT while only 70 percent of individuals from other ethnic groups were able to find well- or partial-matched donors. It is important to note that these data represent only those patients who underwent transplantation and, thus, do not include patients without access to HCT.
- The percentage of patients who receive well- or partial-matched HCTs has been increasing over time. This number was less than 80 percent in 2000-2001 and increased to almost 95 percent by 2004-2005.
- Caucasians comprised 69 percent of the U.S. population in 2000, but received 85 percent of HCTs in the United States between 1994 and 1998. This trend is beginning to change—between 2004 and 2008 Caucasians received only 72 percent of HCTs, with blacks receiving 5 percent (up from 4 percent in 1994-1998) and Hispanics receiving 9 percent (up from 7 percent in 1994-1999). The percentage of transplant patients identified as multiracial or other increased from 3 percent in 1994-1998 to 8-10 percent in 2004-2008.
- An interesting trend becomes evident when NMDP data for the 10 months prior to July 2009 are analyzed. During this time period, nearly 88 percent of adult donor transplants were given to Caucasian patients, with Hispanics and African Americans receiving less than 5 percent and less than 4 percent, respectively. However, Hispanics received nearly 16 percent and African Americans received just under 10 percent of umbilical cord blood transplants, while Caucasians received just under 70 percent. These numbers reflect the different biology of adult and newborn cells—newborn cells are more flexible and can yield good transplant results even when their tissue type is not perfectly matched to the recipient. Because of this flexibility, cord blood cells are better able to serve individuals from racial and ethnic minority populations who may not have a perfectly matched NMDP donor.

- As of 2008, NMDP had over 100,000 cord blood units. Although this number is very small compared with the approximately 8 million volunteer adult donors registered with NMDP, it is a substantial resource because of the flexibility of cord blood cells.
- Concerted efforts by NMDP to recruit minority donors have paid off; in 2008, the program received more donations from minorities than from Caucasians. Of note, 84 percent of the minority adult donors recruited are under 45 years of age. This is beneficial because younger donors remain in the donor pool longer than older donors and are more often healthy, which means they will be more likely to be able to donate if a matching patient is identified.
- Efforts to increase the number of cord blood units from minority donors have also been successful. As of June 2009, there are nearly as many minority as Caucasian cord blood units in the NMDP bank. Because of this, cord blood transplants comprise an increasing percentage of the total number of HCTs facilitated by NMDP. The rising number of available cord blood units is increasing minority patient access to HCT because these patients are able to undergo transplantation with cord blood cells that may be an imperfect tissue-type match.
- Several studies have compared outcomes among white, Hispanic, and black patients undergoing HCT. When patients undergo HCT with cells from a sibling donor, Hispanic patients exhibit higher toxicities and lower survival, and black patients exhibit higher mortality than white patients. Similarly, black and Hispanic patients experience higher mortality than white patients when an unrelated donor is used. However, autotransplantation (when cells collected from the patient prior to treatment are given back to the patient) is associated with equivalent outcomes for blacks and whites. This may be because adherence to post-transplant therapy and the need for follow-up care are particularly important for patients receiving allogeneic transplants (i.e., from sibling or unrelated donor), as these procedures are frequently associated with late complications. Several factors (e.g., socioeconomic status, insurance, geography) may pose barriers for minority patients in obtaining the follow-up care necessary to optimize outcomes following allogeneic transplant. Additionally, minority patients tend to undergo transplantation at smaller centers that may be less experienced and less able to recognize the complexities of care necessary to support patients following HCT.
- Future opportunities to improve outcomes for minority HCT patients include improving access to care, timely referral, and insurance coverage for these populations. It is also important to identify tools to facilitate adequate support and follow-up for all patients undergoing treatment.

## **DISCUSSION AND CONCLUDING COMMENTS:**

### **PANEL I**

#### **Key Points**

- A change was made with the 2000 U.S. Census regarding how race and ethnicity data are collected. The decision to do this was made by the Office of Management and Budget (OMB) based on a 12-year process that included collection of information about peoples' preferences as well as other Census Bureau research. There were two perspectives on how data should be collected about multiracial individuals—one was that people should simply indicate that they are multiracial, while the other held that it was important for individuals to provide specific information about their background. The final decision was that individuals would be able to select “more than one race” and then select two or three categories if desired; it is not known if and how the data about the racial makeup of multiracial individuals will be tabulated. Determining the process to capture information about multiracial individuals had a political component because existing racial/ethnic classifications “lose” the people who identify themselves as “more than one race.” Research revealed that the Asian American classification lost the largest proportion of respondents.

- SEER collects information about patient age at the time of diagnosis, so it is possible to determine whether different racial/ethnic groups tend to be diagnosed with cancer at an earlier age. However, because of population shifts over time and differences in the average ages of racial/ethnic groups, it is important to calculate and compare age-specific rates in order to assess whether there are differences in age of disease onset.
- There was skepticism about the idea that cancer is biologically different among racial/ethnic groups. Genetic variants associated with cancer risk may exhibit different prevalence patterns among different populations; however, in the case of BRCA1, women with the same mutation exhibit similar disease risk regardless of racial background. It is important to note that differences in disease progression may also be due to differences in exposures (i.e., gene-environment interactions). Finally, it was pointed out that there is extensive genetic variation within racial/ethnic groups that should not be overlooked.
- Environmental exposure likely plays a more important role in cancers that occur in older people, such as leukemias and myelomas. However, current understanding of the genetics of these diseases does not allow robust assessment of how differences in exposure among racial/ethnic groups might influence disease occurrence and progression.
- When considering how to address cancer in the future, it is important to recognize that culture and demographics will continue to evolve. For example, the categories for the 2050 Census will likely be different from those used in 2010. Additionally, there are cultural differences between generations— younger people view things in a fundamentally different way than older people and also use different modes to access information. It is important to consider these types of differences when making recommendations about the future.
- There is a need for a cultural transformation in the sciences. Future generations of scientists should be trained to think about the context of their research and understand why it is important to consider factors such as race, income, education, and neighborhood. Viewing research questions through a social disparities lens rather than focusing on racial disparities will help prevent excessive attention to the idea that differences in disease outcomes among racial/ethnic groups are due to differences in biology.
- Oncologists are beginning to use gene expression profiling to characterize early-stage breast cancer in order to gain insight into the risk of disease recurrence; this can aid the decision of whether a woman should receive adjuvant chemotherapy. Recent research has also shown that patients with lung, gastrointestinal, or colorectal tumors that harbor a specific mutation are less likely to respond to certain types of therapy. Although examples of clinical applications of cancer genetic research such as these are currently somewhat limited, genetic analysis has the potential to guide therapy.
- The hematopoietic stem cells used for HCT are adult cells capable of repopulating blood and immune cells; bone marrow cells, which are one type of hematopoietic stem cell, have been available for therapy for over 40 years. Other types of stem cells include adult organ-specific stem cells, which are capable of repopulating a specific organ, and embryonic stem cells, which have received extensive political attention over the last several years because they may be able to repopulate any organ. The value of harnessing the stem-cell-like properties of adult cells for repair and replacement of tissues has been shown and these approaches have applications in cancer (e.g., blood and marrow transplantation), cardiovascular disease, and some other areas. However, additional genetic and cell biology research is needed to reveal how the different types of stem cells might be used to treat a broad variety of diseases.
- Advances in medical science are important, but do not necessarily ensure significant improvements in public health, particularly related to health disparities. Even if universal health insurance coverage is achieved in the United States, many of the social determinants that negatively impact health will persist. Health care reform will not be affordable or sufficient unless social factors such as poverty,

low-quality education, and neighborhood conditions are also addressed. This was observed in the United Kingdom; a report in the 1980s revealed that socioeconomic disparities in mortality actually widened following implementation of the National Health System. Subsequent policy changes in the U.K. shifted resources toward low-income families with children and early childhood development programs in an attempt to reverse this trend. Concerns about the potential of universal health insurance coverage to exacerbate disparities should not impede healthcare reform efforts, however, because access to healthcare should be viewed as a human rights issue.

- SEER requires a significant investment of resources, but it is a relatively small portion of the NCI budget and provides researchers with substantial data about cancer in the United States. The linkage of SEER to other Federal data systems, such as the Medicare database, has enhanced its value. NCI has also made available the resources and techniques developed in conjunction with SEER, which has benefited others in the United States and around the world who have an interest in registries.
- Cancer patients tend to be older, and these patients—particularly white patients—are becoming more likely to live alone and, thus, less likely to have caregivers within the home. In these instances, patients and families often enlist the services of paid caregivers, who are disproportionately minority. The cultural differences between patients and caregivers should be recognized and explicit effort taken to deal with the communication issues and conflict that may arise because of these differences. It will not be productive to ignore these issues or write them off as personal conflicts.
- The President should be urged to promote a change in the way the nation understands how various factors work together to influence health and cancer risk and emphasize what is already known about cancer. Attention must be paid to social inequities that contribute to poor health outcomes among underserved populations. The President should also be encouraged to make resources available for community-based participatory research and the development of strategies to build meaningful community-university partnerships. Finally, he should promote a robust research agenda that improves understanding of how to prevent and treat cancer as well as deliver interventions in culturally appropriate ways.

## **PUBLIC COMMENT**

### **Key Points**

- The published literature should be examined to identify practices used internationally that may help improve cancer care for patients in the United States. Research on some techniques that have been successful in other countries is not being adequately supported in the United States. Some physicians and researchers believe that implementing best practices from around the world could help substantially reduce healthcare spending. Some doctors are testing patients' immune systems and correcting identified deficiencies, which may help prevent diseases such as cancer; U.S. doctors should be encouraged to do this. Legislation that would promote FDA approval of best practices used abroad for use in the United States should be considered.
- Cancer could be prevented by reducing exposure to environmental toxins. A study in Asia identified changes in people's genetic profiles after exposure to relatively low levels of toxins (e.g., heavy metals, organochlorines).
- Personalized medicine is now a possibility for cancer and other diseases. It is now possible to rapidly develop a patient's genetic profile and use the information to develop a personalized treatment strategy.
- Access to care involves more than insurance coverage. It is also influenced by nonmedical factors, such as the need to relocate to receive treatment, lost income, doubled living expenses, and the need for a caregiver to leave the workforce. Also, some minority patients are not informed of the possibility of a bone marrow transplant as a treatment option. The MAVIN Foundation created a Web

site—BMTbasics.org—designed to educate mixed-heritage patients and their families about hematopoietic stem cell transplantation. The MAVIN Foundation has had some difficulty obtaining relevant age- and race-related data regarding HCT.

- Opportunities for donation of umbilical cord blood should be expanded; not all states have cord blood donation programs and those that do exist are underfunded. This allows the private cord blood industry to perpetuate misinformation to the public. A public agency should offer solid information and opinions to counteract the efforts of the private cord blood industry. Additionally, it is difficult to obtain information from centers regarding who donates bone marrow and cord blood.
- Analysis of donor pools for HCT should not necessarily be based on the racial/ethnic classifications used by OMB and the Census Bureau. Ancestral origins are more important than self-reported race with regard to matching donors and patients.
- Although investment in disease prevention is essential, access to screening is also important. The Washington Breast, Cervical, and Colon Health Program, a demonstration program funded through the Centers for Disease Control and Prevention, targets traditionally underserved populations such as the poor and working poor, ethnic minorities, sexual minorities, and people living in rural communities. Colorectal cancer screening is generally less utilized than screening for breast and cervical cancer.
- The Panel should urge the President to ask Congress to provide Federal support for mandated health programs.

## **PANEL II**

### **DR. HAROLD FREEMAN:**

#### **HEALTH DISPARITIES: A UNIVERSAL MARKER FOR SOCIAL AND ECONOMIC INEQUITY**

##### **Background**

Dr. Harold Freeman is President and Founder of The Ralph Lauren Center for Cancer Care and Prevention in New York City and Founder of The Harold P. Freeman Patient Navigation Institute. He is also a Senior Advisor to the Director of the National Cancer Institute and the NCI Center to Reduce Cancer Health Disparities. Dr. Freeman is a past National President of the American Cancer Society (ACS). He served for 11 years as Chairman of the President's Cancer Panel. In 2003, Dr. Freeman received a Special Recognition Award from the American Society of Clinical Oncology (ASCO). This award recognizes a person or persons who have had a major impact in areas of clinical oncology, cancer research, clinical trials, reimbursement, and patient advocacy.

##### **Key Points**

- Disease occurs within the context of human circumstances—socioeconomic status, culture, and environment—which determine survival and quality of life. Human circumstances also account for the disconnect between discovery and delivery—a key determinant of the unequal burden of cancer in the United States.
- In order to understand health disparities, there needs to be a clear understanding of social issues such as class, culture, race, and social injustice. Class is determined by economic status and access to resources. Culture encompasses behavior, values, belief systems, traditions, and worldviews, and is a powerful determinant of health outcomes. Although race is thought by some to be a biological classification, it is more appropriately considered an indicator of a people's social history. Social injustice, culture, and poverty/low economic status are the three major causes of disparities across the health spectrum, from prevention to survivorship.

- Health disparities can be measured by incidence, mortality, and survival, but the fundamental element of disparities measure is longevity. People who live in communities with resources and opportunities have a higher survival rate from cancer than people who live in communities with fewer resources. In the U.S., white females have the longest lifespan and black males have the shortest.
- Disparities in cancer care are caused by the complex interplay of low economic class, culture, and social injustice, with poverty playing the dominant role. Residents of poorer communities, irrespective of race, have higher death rates from disease. Within each race/ethnic group, viewed separately, those living in poor counties have lower disease survival. Poverty should not be an offense punishable by death.
- According to a 2005 survey, 25 percent of African Americans, 22 percent of Hispanics, and 9 percent of whites in the U.S. live in poverty. About one-third of Hispanics, 20 percent of blacks, and 11 percent of whites in the U.S. have no health insurance. A 2008 ACS study found that people insured with Medicaid do not have a better cancer survival outcome than the uninsured, revealing that lack of health insurance is not the primary driver of health disparities.
- Poverty results in substandard housing, less education and social support, a tendency towards risk-promoting behavior, and inadequate access to healthcare. Culture and poverty often overlap; culture can diminish or accentuate poverty's negative effects. For example, Seventh Day Adventists do not smoke or drink alcohol, based on their religious beliefs. Consequently, Seventh Day Adventists have the lowest cancer rate and longest lifespan of all cultural groups studied in the U.S. Even when Seventh Day Adventists are living in poor economic conditions, they will not develop diseases related to tobacco or alcohol.
- In 1986, ACS produced a report on cancer in the economically disadvantaged. Some findings of significance were that poor people face barriers when they attempt to seek diagnosis and treatment of cancer, and they often do not even seek care if they cannot afford it. Poor people also experience more pain, suffering, and death because of late-stage disease. Fatalism about cancer is prevalent among the poor and prevents them from seeking care. Cancer education programs are often culturally insensitive and irrelevant to many people.
- In order to eliminate healthcare disparities, the healthcare community must apply what is known at any given time to all people, irrespective of their ability to pay. Universal access to healthcare is necessary, but a comprehensive, unified approach must also be developed to improve conditions rooted in poverty.
- In the U.S., people see, value, and treat one another through a powerful lens of race. This lens can create false assumptions that may result in serious harm to members of some racial and ethnic groups.
- A 1999 *New England Journal of Medicine (NEJM)* study showed that black patients were much less likely than white patients to be evaluated for renal transplantation. Another *NEJM* paper in the same year reported that black patients were substantially less likely than white patients to receive curative surgical treatment for lung cancer. The same investigators found that 80 percent of black patients received care from one-fifth of all physicians; black patients faced obstacles in accessing tertiary treatment centers and were less likely to have access to board-certified specialists. After reviewing data like these, in 2003, the Institute of Medicine concluded that bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers might contribute to racial and ethnic disparities in healthcare.
- Systems for monitoring treatment equity according to standards of care need to be established and implemented in order to diminish bias in the provision of healthcare.
- Targeted approaches to providing culturally relevant education; appropriate access to screening, diagnosis, and treatment; and improved social support are needed in areas with the highest cancer

mortality rates. These approaches must also encompass a high level of awareness among medical trainees and professionals regarding their role in eliminating bias in medical care delivery.

- ACS found that there is a critical window of opportunity to save lives from cancer between the point of an initial suspicious finding and resolution of the finding by further diagnosis and timely treatment. The Patient Navigation Program was created to target this window of opportunity and eliminate barriers to diagnosis and treatment of cancer. ACS is now recommending expansion of the program to include outreach navigation. Outreach navigators work in communities and bring people from the neighborhood to care facilities. Underserved communities should receive funding for patient navigation programs to provide personal assistance in obtaining adequate diagnosis and treatment.
- Health disparities are fundamentally an issue of inequities. To eliminate disparities, biomedical science must proceed with consideration of social sciences, history, and civil and human rights. The unequal burden of disease in society is a challenge to science and a moral dilemma. Health disparities exact an extraordinarily high human cost and a significant economic cost to the United States.

## **DR. LOVELL JONES:**

### **REDUCING RACIAL AND SOCIAL CLASS INEQUALITIES IN HEALTH: THE NEED FOR A NEW APPROACH**

#### **Background**

Dr. Lovell Jones is a founding cochair of the Intercultural Cancer Council, the nation's largest multicultural health policy group focused on minorities, the medically underserved, and cancer. He has edited *Minorities and Cancer*, one of the few comprehensive textbooks on this subject. He is the founding chair of "Minorities, the Medically Underserved and Cancer," the nation's largest multicultural conference, which provides a forum for exchanging the latest scientific and treatment information. This biennial conference brings together people from all ethnic communities and social strata to share strategies for reducing the incidence of cancer among these populations. Dr. Jones also has spearheaded regional hearings on cancer and the poor for the American Cancer Society. In 2002, Dr. Jones, along with Dr. Armin Weinberg, cofounder of the Intercultural Cancer Council, received the Humanitarian Award from ACS. He has served on the Breast Cancer Integration Panel for the Department of Defense and published over 100 scientific articles on subjects ranging from hormonal carcinogenesis to health policy.

#### **Key Points**

- Health in minority and underserved communities cannot be approached as a single issue; it has to be considered in a holistic manner. A holistic approach must take into account all factors that influence health, including the perceived need for healthcare and community attention to health concerns, knowledge, attitudes, and practice. No one center, institution, or profession can solve the problem of health disparities. The minority and underserved communities must be involved in determining the solutions to the problems they face. All health is local. If health disparities are going to be addressed, local health data are needed.
- To ensure long-term success, efforts to address health disparities should not focus on a single disease. Comprehensive solutions to health disparities will revolve around six key elements: trust, respect, partnership, communication, flexibility, and knowledge.
- Health disparities continue to persist in America because health is not a national priority.
- The Joint Center for Political and Economic Studies released a press statement that brought to light the billions of dollars in excess cost from racial disparities in health access and outcomes. Researchers at Johns Hopkins University and the University of Maryland found that over 30 percent of direct medical expenditures for African Americans, Asian Americans, and Hispanics were excess

costs linked to health inequalities. Between 2003 and 2006, these excess healthcare costs amounted to \$229.4 billion. Eliminating these inequalities would have saved the U.S. economy \$1.24 trillion.

- The IOM report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* concluded that racial and ethnic minorities tend to receive lower quality healthcare than nonminorities, even when access-related factors, such as patients' insurance status and income, are controlled.
- Health is probably the best indicator of the failure of the U.S. to address the issue of race/ethnicity and social class. The existence of health disparities is not just a scientific issue but also a moral and ethical issue. Racial and ethnic categories used in the census have been socially and politically determined and were never intended to be scientific or anthropological in nature; yet, these categories continue to be used.
- Some diseases do tend to cluster within certain populations: obesity is more common in African-American women and Native American and Hispanic populations; Type 2 diabetes occurs more often in Native American, Hispanic, and African-American populations; and hypertension is greater among African-American populations. However, this does not necessarily mean that there are genetic differences between these groups. Among other things, a multitude of gene-environment interactions impact an individual's disease risk. Of the genetic variation observed in humans, only 15 percent occurs between "races."
- African Americans in some areas of the U.S. (Virginia, North and South Carolina, Georgia, Florida, Alabama, Mississippi, Louisiana, and parts of Arkansas, Texas, and Tennessee) have a high rate of mortality due to stroke, leading to designation of this region as the "Stroke Belt." The largest component (40 percent) of Africans brought to this area during the slave trade came from Angola, Equatorial Guinea, Gabon, and the Congo—regions with very low dietary salt intake.
- Race, racism, and racialism are not resolved issues. Unconscious discrimination occurs even among those who are not prejudiced. Stereotype-linked bias is an automatic and unconscious process.
- The solution to health disparities requires no new laws, but a willingness to change the way the problem is addressed. A dramatic increase in new funding is not necessary; rather, changes in the way current funds are allocated should be made.
- In order for the scientific community to accurately assess health disparities, the metrics of how academic scientists are rewarded need to be modified. Currently, scientists are rewarded based on the number of grants they receive or the number of papers they publish. However, publishing papers on health disparities is not really addressing the issue. There have been numerous publications on health disparities, but these disparities persist. Academic scientists need to be more connected to the community. They should be less concerned about publications and more focused on eliminating disparities. It should be remembered that what is publishable may not be relevant, but what is relevant can always be made publishable.
- A medical model that effectively deals with the complex nature of health disparities must take into account more than access to care. It must include the social context of a community and the complementary systems devised by society to deal with the disruptive effects of illness on the lives of people in the community.
- A syndemic is a set of linked health problems involving two or more afflictions that interact synergistically and contribute to excess burden of disease in a population. Syndemics occur when health-related issues cluster by person, place, or time.
- There are five elements, originally written for establishing an effective cancer education program, that are relevant to addressing health disparities: (1) persons representative of the target population should be included on the committee that plans to provide the program; (2) major items should refer to the local cancer/health plan; if one does not exist, a local health plan should be developed before

proceeding; (3) a wide range of health communication methods are needed to capitalize on the strengths of each; (4) procedures or instruments are needed to measure success; and (5) sufficient funds and manpower to carry out the plan are needed. Infrastructure needs to be built from within, so communities become the ultimate project owners.

- Health disparities express themselves at both the individual and group levels, and their resolution must be addressed at both levels of analysis. Successful interventions must be culturally compatible and transgenerational at the group level in order to be sustained.

## **DR. DEREK RAGHAVAN:**

### **DISPARITIES OF CANCER CARE**

#### **Background**

Dr. Derek Raghavan is Immediate Past Co-Chair, Health Disparities Advisory Group, American Society of Clinical Oncology, and a Fellow of the American Association for the Advancement of Science. His clinical and research interests are focused on genitourinary cancer, cancer in the elderly, disparities of cancer care, anticancer drug discovery and development, and comparative human oncology. Dr. Raghavan became Chair and Director of the Cleveland Clinic Taussig Cancer Center in March 2004. He is also Professor of Medicine at the Lerner College of Medicine of Case Western Reserve University. Previously, Dr. Raghavan served as Associate Director of the USC Norris Comprehensive Cancer Center; Professor of Medicine and Chair of Oncology at the USC School of Medicine, Los Angeles; leader of Solid Tumor Oncology and Investigational Therapeutics at Roswell Park Cancer Institute, Buffalo, NY; and Professor of Medicine at SUNY Buffalo. He has served as Chair of the ASCO Health Disparities Advisory Group, NCI Cancer Clinical Investigations Review Committee, and the Veterans Administration Merit Advisory Board in Oncology; a member of the NCI Cancer Centers Support Review Committee, EORTC Scientific Advisory Committee, and the Deutsche Krebschilfe International Scientific Board; and advisor to several comprehensive cancer centers.

#### **Key Points**

- The U.S. Department of Health and Human Services (DHHS) defines health disparities as differences among specific population groups in the incidence, prevalence, mortality, and burden associated with disease.
- The largest population experiencing cancer health disparities in the United States is African Americans. Smaller groups affected by cancer health disparities include other racial and ethnic minorities, impoverished whites, the elderly, Medicaid patients, and individuals with mental disorders.
- Regardless of the data set used, all comparisons of white and African-American populations demonstrate clear patterns of cancer health disparities. There is clear evidence that African Americans are more likely than whites to be diagnosed with malignant cancers. Notwithstanding overall decreases in cancer death rates over the past decade, age-adjusted total cancer mortality is still higher in African Americans. African Americans are less likely to be diagnosed with cancer at an early stage and, thus, less likely to survive five years.
- While many factors that contribute to disparities are particular to specific populations, a description of factors relevant to disparities among African Americans can provide a paradigm for discussion of cancer health disparities experienced by other minority groups. Those factors include distrust of the medical establishment, low levels of educational attainment, lack of information about cancer, and lack of financial and social resources (including lack of insurance).
- Issues within the medical establishment are important. These include the geographic distribution of physicians and lack of cultural diversity in the provider workforce. Providers who are in a position to

reach underserved populations often lack experience with cancer-related concerns. One of the most important issues related to cancer health disparities is the lack of a medical home for many members of minority groups.

- Targeted advertising contributes to disparities. For example, tobacco companies are known to target lower-socioeconomic segments of minority populations. Disparities are also associated with social patterns (e.g., diet, obesity, smoking, and occupational exposures) and access to care.
- Several years ago, the American Society of Clinical Oncology developed a Health Disparities Advisory Group. ASCO has increased the level of educational content on disparities provided at its annual meeting, which is attended by more than 30,000 oncologists and cancer researchers. ASCO has also created an editorial panel on minority populations and diversity for its Web site (<http://cancer.net>). ASCO editorial policies have been tailored to increase content on disparities in the Association's journals.
- The ASCO Diversity in Oncology Initiative was launched by the Health Disparities Advisory Group in 2007 with support from Susan G. Komen for the Cure. The initiative is a comprehensive program to facilitate recruitment and retention of underrepresented minorities in the field of clinical oncology. Phase 1 of the initiative includes three components: a medical student rotation, awards for resident travel opportunities (e.g., to ASCO meetings), and a loan repayment program. The medical student rotation program provides an eight- to ten-week clinical or clinical research rotation for U.S. minority medical students. This program will eventually be expanded to include international students. Each student is paired with a clinical oncologist mentor for academic and career guidance. Phase 2 of the initiative addresses the needs of minority oncologists at the junior faculty and senior investigator levels.
- Short-term outcome measures for this initiative include obtaining funding for the program and recruiting qualified candidates. Intermediate measures focus on the program's effect on choice of specialization, choice of practice locations, and provider retention. Long-term measures include increased diversity in oncology specialties and improved survival and reduced disparities among minorities.
- Applicants for these awards are highly qualified and committed to serving their communities and other underserved areas. Similar programs should be established at the national level to increase opportunities for minority students to become involved in reducing cancer health disparities.
- To address cancer health disparities at the community level, the Cleveland Clinic has formed a collaborative partnership with a number of professional associations, local government agencies, academic centers, and networks of healthcare providers. The initiative was launched at a continuing medical education meeting in 2006 designed to educate Ohio physicians about cancer disparities.
- Cleveland Clinic programs growing from this partnership have included a patient navigation program, outreach to barbershops and beauticians, faith-based activism, health fairs, establishment of an African American Men's Health Center, donations to schools for health education, and professional training programs. The patient navigation program—operated by coordinators, navigators, performance improvement specialists, and medical, nursing, and support staff—supports identification, screening, education, coordination, referrals, and follow-up of patients.
- The Case Comprehensive Cancer Center has launched several initiatives, including: Project T.E.M.P.L.E., a community-based program focusing on breast cancer among African-American and Latina women; a community video program to explain clinical trials to the public and educate nurses and support staff; community-based epidemiologic studies; clinical research initiatives; and efforts to increase diversity of clinical staff.
- A greater proportion of government resources should be focused on addressing the huge national problem of cancer health disparities. Vast expenditures are being dedicated to development of drugs that are likely to affect a small percentage of cancer patients, while members of underserved

populations are dying of cancer because of failure to diagnose it early enough or provide access to adequate care. Assessment of outcomes should be embedded within all cancer-related initiatives, and communities should be made part of the process of designing programs.

## **DR. CARA JAMES:**

### **PUTTING WOMEN'S HEALTHCARE DISPARITIES ON THE MAP**

#### **Background**

Dr. Cara James is Senior Policy Analyst for the Race, Ethnicity and Health Care Group and Director of the *Barbara Jordan Health Policy Scholars Program* at the Henry J. Kaiser Family Foundation. She is also one of the moderators for the Foundation's series *Today's Topics in Health Disparities*. Dr. James' research interests include racial/ethnic minority health, care for the disabled and other underserved populations, and improving doctor-patient communication. Dr. James coauthored one of the background chapters for the Institute of Medicine's report *Unequal Treatment*, and she currently serves as a member of IOM's Roundtable on Health Disparities. She was also part of the Consumer Assessments of Health Plans (CAHPS) survey team that developed the ICH CAHPS, a national survey to measure patient assessments of care at dialysis facilities. Dr. James received her Ph.D. in health policy and A.B. in psychology from Harvard University.

#### **Key Points**

- The Kaiser Family Foundation recently released a report entitled *Putting Women's Health Disparities on the Map*. This effort was undertaken to reveal state-level trends regarding health outcomes of various racial/ethnic groups, which are sometime masked when analysis of national data is done. The report focused on women because women often serve as family caregivers and play a significant role in researching healthcare issues and seeking healthcare services for their family members. There are plans to do a similar study on men in the future.
- Currently, approximately two-thirds of the U.S. population self identify as non-Hispanic white; however, minority groups are growing quickly, as is the pool of people who self-identify as two or more races. As the proportion of minorities in the population increases, the overall health status of the United States will be increasingly driven by the health status of these groups. Unless something is done to address the poor health outcomes currently experienced by many racial and ethnic minorities, the already low international standing of the United States with respect to health outcomes will likely decrease even further.
- The distribution of racial/ethnic populations varies by state. Some states, particularly those that border Mexico, already have "majority minority" populations (i.e., there is not a single racial/ethnic group that comprises over 50 percent of the population); however, many states are still almost entirely non-Hispanic white.
- Data sources used for the Kaiser study included the Behavioral Risk Factor Surveillance System (BRFSS), the Current Population Survey, the National Vital Statistics System, the Area Resource File, and other sources. The large number of data sources was necessary because no single source (or small number of sources) provided information on all of the selected indicators. The Kaiser research team found that it was difficult, and sometimes impossible, to obtain state-level data that included information about race/ethnicity. It was particularly difficult to find data for American Indian/Alaska Native and Native Hawaiian/Pacific Islander populations.
- The 25 indicators used in the study were organized into three dimensions: health status, access and utilization, and social determinants. Other policy-related variables were also analyzed, including physician diversity ratio (i.e., whether providers mirror the population they are treating), health

professional and mental health professional shortage areas, Medicaid-to-Medicare fee index, Medicaid income eligibility, family planning funding, and access to abortion.

- A disparity score was calculated for each indicator. This score reflects the ratio of the rate of women of color experiencing an indicator to the rate of white women experiencing the indicator (with the exception that white men were used as the baseline for all groups for analysis of gender wage gap). A disparity score higher than 1.0 indicates that minority women fared *worse* than white women, while a score of less than 1.0 indicates minority women fared *better* than white women. A disparity score of 1.0 means that white and minority women fared the same with respect to the indicator.
- The disparity scores for the indicators in each dimension were averaged to generate a dimension score. In order to facilitate comparisons between states, data for each indicator were adjusted based on the comparison of white women in the state to white women nationally (this correction prevented states with poor outcomes among all groups and, thus, low disparities from receiving a favorable score). The dimension scores for all of the states were ranked and states were classified as better than average, average, or worse than average.
- The Kaiser study found that disparities were evident in every state and on most indicators. Overall, the rate of new AIDS cases among women of color was more than 11 times that of white women; the disparity in new AIDS cases was greatest in Minnesota, where women of color were 37 times as likely to be diagnosed with AIDS, and lowest in Montana, where there were no new AIDS cases reported in women of color during the time frame of the study. Nationally, the uninsured rate for women of color was more than twice that of white women. However, the disparity was worse in some states—the disparity score for uninsurance in North Dakota was 4.59. On the other hand, the disparity score in Hawaii for uninsurance was less than 1.0. Women of color were more than three times as likely as white women to have no high school diploma, although rates for smoking, cancer mortality, serious psychological distress, and no routine checkup were lower among women of color than among white women (disparity score less than 1.0).
- The analysis revealed that small disparities were sometimes the result of both white women and women of color doing poorly. For example, with respect to the indicator “no Pap test,” Utah had a low disparity score, but this was because white women in Utah had the lowest rate of Pap testing among white women in the United States. On the other hand, in Massachusetts, the disparity score was high because white women in Massachusetts had higher than average rates of Pap testing. These observations have policy implications. States in which everyone is doing poorly should focus attention on improving outcomes among all women, while those with large disparities should focus on improving outcomes among the populations with poorer outcomes.
- The analysis also revealed that each racial and ethnic group faces its own particular set of health and healthcare challenges. Hispanic women consistently had problems with access to and utilization of care. Black women had among the worst rates for many indicators of health and social determinants, including cancer mortality. Asian American, Native Hawaiian, and other Pacific Islander women had among the lowest rates of cancer screenings. White women had higher rates of smoking, cancer mortality, psychological distress, and no routine checkup.
- Outcomes for American Indian and Alaska Native women were among the worst for nearly all indicators. For example, 36 percent of AI/AN women smoked, compared with 25 percent of white women, and 26 percent of AI/AN women reported serious psychological distress, compared with 17 percent of white women. With regard to access and utilization, 34 percent of AI/AN women reported no recent mammogram, compared with 25 percent of white women, and 30 percent of AI/AN had late prenatal care, compared with 11 percent of white women. Finally, nearly three times as many AI/AN as white women lived in poverty (33 percent versus 12 percent, respectively), and less than 1 in 5 AI/AN women had a high school diploma, compared with 93 percent of white women. Lack of data often makes it difficult to document the poor health outcomes experienced by AI/AN women; in fact, data were unavailable for this population for many of the indicators used in the current analysis.

- State-by-state variation was evident within each racial and ethnic population. For example, there was tremendous variation in the percentage of women with no mammogram in the past two years. On average, 33.7 percent of AI/AN women had no mammogram; the state averages for AI/AN women ranged from 24.7 percent in Arizona to 39 percent in Washington. Wide ranges were also seen among women of other groups. For Hispanics, the rate of no mammogram in the past two years ranged from 14.5 percent in Massachusetts to 42.9 percent in Oklahoma. For blacks, the lowest and highest rates of no mammogram were in Delaware (12.8 percent) and Mississippi (35.8 percent). For whites, Massachusetts exhibited the lowest rate (15.9 percent) and Idaho, the highest rate (37.2 percent). For Asian American and Pacific Islander women, Hawaii had the lowest rates of no mammogram (23.9 percent), and New Jersey had the highest rate (29.9 percent).
- Few states had consistent scores across all three dimensions. Four states—Hawaii, Georgia, Virginia, and Maryland—were better than average for all three dimensions. Thirteen states scored better than average for two dimensions, 19 states and the District of Columbia scored better than average for one dimension, and 14 states failed to score better than average for even a single dimension. Six states—Arkansas, Mississippi, Louisiana, Indiana, South Dakota, and Montana—scored worse than average for all three dimensions. Nine states and the District of Columbia scored worse than average for two dimensions, 16 states scored worse than average for one dimension, and 19 states scored average or better than average for all three dimensions.
- Small disparities in one dimension did not necessarily correspond to small disparities in other dimensions. For example, Ohio scored better than average for the access to care dimension but worse than average for the health status and social determinants dimensions. The reasons for these inconsistencies are not understood. Kaiser plans to conduct structural equation modeling to determine whether health policies may help explain the observed patterns.
- This study has implications for the cancer enterprise. Regardless of race, U.S. women face challenges related to health and these challenges vary based on where women live; many women of all races are foregoing important cancer screenings. All racial/ethnic populations face challenges, but some face challenges at a considerably higher rate than others.
- Attempts to reform healthcare in the United States are ongoing. The Kaiser study reveals that one in four women live in health professional shortage areas. Even if universal health coverage is achieved, there will be challenges in delivering care to these women. Considerations regarding the Medicaid-to-Medicare fee index also have implications for disparities; if reimbursements for Medicaid patients who are part of health insurance exchanges are increased to match Medicare reimbursement rates, this may discourage providers from accepting patients with standard Medicare coverage.
- There should be discussion about state and Federal responsibilities for addressing the disparities identified in the Kaiser report. Some states are already working on their problems, but something should be done to encourage action in the other states as well.
- The current economic crisis is having an effect on cancer patients. The American Cancer Society has reported a 30 percent increase in the number of cancer patients calling because they have lost insurance coverage and do not know how they are going to continue to pay for their care.
- Some data that would have added value to the current report were not available. For example, data on late-stage cancer diagnosis and domestic violence are not available by state, race, and gender. Efforts are also needed to ensure adherence to existing guidelines regarding collection of data on race and ethnicity. A 2009 Institute of Medicine report found that many national data sets do not adhere to the OMB standards established in 1997.
- It is important to remember that statistics represent individuals and the problems they have.

## **DR. MARK HAYWARD:**

### **A DEMOGRAPHER'S PERSPECTIVE ON HEALTH DISPARITIES: SOME LESSONS FOR CANCER RESEARCH?**

#### **Background**

Dr. Mark Hayward is Director of the Population Research Center (PRC) and Centennial Commission Professor of Sociology at the University of Texas at Austin. Dr. Hayward's recent research has focused on how adult health problems develop in response to physical or social exposures during childhood, adolescence, and adult life. He is a member of TREND, the Tobacco Research Network on Disparities, which is dedicated to producing scientific evidence toward reducing tobacco-related health disparities. Dr. Hayward is also a member of REVES, an international scientific network dedicated to promoting: (1) health expectancy measures for public health policy and planning, and (2) international standards for data collection and the calculation of health expectancies. He has held a number of elected positions in major scientific professional organizations, and has served on the editorial boards of a number of major scientific journals. Dr. Hayward recently chaired the Council of the Inter-university Consortium on Political and Social Research (ICPSR), and has served on the Board of Overseers for the Panel Study of Income Dynamics and the Technical Review Board of the National Longitudinal Surveys. Presently, he serves on scientific advisory boards at LSU Medical School, the University of Texas Medical Branch, and M.D. Anderson Cancer Center.

#### **Key Points**

- In 2006, life expectancy in the United States reached a record high of 77.7 years. The increase in life expectancy was due to declines in mortality due to cancer, heart disease, stroke, and chronic lung disease. Although life expectancy increased for both blacks and whites, blacks continue to lag behind. The race gap is greatest for men—at birth, white men have a life expectancy five years longer than that of black men. These recent life expectancy data, which were presented in a report of the National Center for Health Statistics, do not include estimates for Hispanics, the largest minority group in the United States. This is in part because age-adjusted mortality rates for this group were not reported until the late 1990s and there have been concerns about the quality of data for Hispanics.
- Interestingly, age-adjusted mortality rates for Hispanics are lower than those for blacks, whites, and AI/AN. The only population with a lower mortality rate is Asian/Pacific Islanders. This presents what some researchers call the Hispanic epidemiological paradox: despite the fact that Hispanics are similar to blacks with respect to income and education, they seem to have significantly lower mortality rates.
- Some demographers question whether the Hispanic epidemiological paradox is an artifact created by poor data quality. One way to investigate this question is to look at who self-identifies as Hispanic in the census, on health surveys, and on death certificates. Reinterviews of 1970 Census respondents revealed that 98.7 percent of first-generation immigrants from Spanish-speaking countries self-identified as Hispanic. However, this percentage decreased with each generation—only 83.3 percent of second-generation, 73 percent of third-generation, 44.4 percent of fourth-generation and 5.6 percent of fifth-generation immigrants self-identified as Hispanic. Interestingly, intermarriage tends to diminish Hispanic self-identification—less than one-fourth of individuals with Hispanic ancestry on only one side identified as Hispanic. This study indicates that inheritance of Hispanic identity is fragile, which has implications for interpretation of census and other survey data.
- Another study illustrates the variability among Hispanic survey respondents. The study analyzed data regarding median years of education from four nationally representative surveys—the Asset and Health Dynamic Survey Among the Oldest Old (AHEAD), the National Health and Nutrition Examination Survey, the National Health Interview Survey, and the Health and Retirement Survey.

Interestingly, each of these surveys yielded significantly different information about the years of education of Hispanic respondents. In fact, some of the surveys indicate that U.S.-born Hispanics have more education than foreign-born Hispanics, while other surveys indicate the opposite. These variable and conflicting results beg the question: Who are the Hispanics who respond to these surveys? The answer to this question is not clear, although it does appear that these surveys queried different sets of Hispanics, despite the fact that they are “nationally representative.” It is unlikely that these types of data artifacts entirely account for the Hispanic epidemiological paradox, but these issues are important and must be taken into consideration, particularly if one wants to study health disparities.

- Migration-related issues may also contribute to low mortality rates among U.S. Hispanics. For example, it is hypothesized that immigrants tend to be healthy, while unhealthy people may be less likely to emigrate. It is also possible that unhealthy immigrants return to their origin country (so-called salmon bias). Cultural factors (e.g., country of origin, reasons for migration, acculturation) may also be important.
- SEER data indicate that Hispanics have relatively low rates of breast, prostate, and lung cancers. The low incidence of lung cancer may be because prevalence of smoking is relatively low among Hispanics and those Hispanics who do smoke are often light or intermittent smokers. However, these data must be interpreted with caution because the denominator for the SEER prevalence rates is drawn from U.S. Census data, which are not entirely reliable for Hispanics, and the numerator is based on data collected by tumor registries. Hispanic classification in both instances is based on self-identification and may not be consistent.
- Racial/ethnic disparities in health outcomes often align with socioeconomic factors, but there are exceptions. For example, there are no racial differences in incidence of heart disease in middle age, although middle-aged blacks are more likely to die from heart disease. The Hispanic paradox also illustrates the limitations of socioeconomic status explanations for disparities.
- Data from several surveys indicate that among older populations, whites actually have higher prevalence of heart disease compared with African Americans, U.S.-born Hispanics, and foreign-born Hispanics, and a higher prevalence of cancer than African Americans and foreign-born Hispanics. African Americans and Hispanics have higher prevalence of diabetes than whites. Other studies have shown that blacks have higher death rates for conditions including heart disease, several cancers, and diabetes. Interestingly, Hispanics exhibit very different death rates—they have lower death rates than whites for heart disease and several cancers, although death rates due to diabetes are higher than those of whites. It is possible that the low prevalence rates for heart disease and some cancers among older African Americans is because the frailest members of this group die from disease when they are younger. This points to limitations of using prevalence data and emphasizes the need to understand why certain trends occur.
- Healthy life expectancy is a summary indicator that integrates both morbidity and mortality. It essentially assesses whether one group’s superior mortality is brought about by postponing morbidity or by better survival among those with the condition.
- At 55 years of age, the life expectancy of white males is 23.4 years, with 20.9 years of healthy life and 2.5 years of unhealthy life remaining. Overall life expectancies for 55-year-old black and Hispanic men are lower, 19.4 years and 23.3 years, respectively. This reflects 4.1 years of life lost for blacks, who will live an average of 15.9 healthy years and 3.5 unhealthy years beyond age 55. Hispanic men will live an average of 20.3 healthy years and 3 unhealthy years beyond age 55. Thus, African-American men live shorter lives and endure more years of unhealthy life.
- The life expectancy of 55-year-old white females is 26.5 years, with 22.5 years of healthy life and 4 years of unhealthy life. Black women live, on average, 5 years less than white women, with 16.9 years of healthy life expectancy and 4.7 years of unhealthy life. Hispanic women at 55 years of age

have a life expectancy of 25.3, with 19.2 years of healthy life and 6.1 years of unhealthy life. Thus, although the overall life expectancy of Hispanic women is not significantly less than that of white women, Hispanics live an additional two years with a disability. This trend was not observed among men, illustrating that there are gender-specific issues that should be taken into account when studying health disparities.

- Better information is needed regarding the processes by which disparities arise. This would include information about the onset and duration of disparities as well as outcomes and disease sequelae associated with these processes at a population level. Many data sets only include older individuals, thus preventing collection of data about earlier events that contribute to or illustrate disparities. A study of a birth cohort determined that 95 percent of white males but only 76 percent of black males survived to age 51.
- Existing theoretical frameworks should be revised to emphasize life-course exposure and events, beginning *in utero* and continuing throughout the lifespan. These models should take into account the complex interplay between biology and social environment.
- In order to gain insight into disease etiology, data sets should include more specificity about health problems (e.g., indicate specific types of cancer rather than simply cancer).
- Data sets should be expanded to include larger samples of ethnic groups so that variability in socioeconomic and cultural factors within groups can be more accurately assessed. For example, most data sets include too few well-educated African Americans to robustly analyze the influence of education on disease risk. In addition, it is not possible to segregate Hispanic populations based on country of origin because the sample sizes would become too small. Data sets should also include information about where people live.

## **DISCUSSION AND CONCLUDING COMMENTS:**

### **PANEL II**

#### **Key Points**

- Patient navigation programs are currently being evaluated by the Center for Medicare and Medicaid Services (CMS), HRSA, and NCI. There is not yet direct evidence that patient navigation decreases mortality; however, some studies show improvements in other areas that suggest there will be a benefit. The CMS patient navigation program in Detroit has resulted in individuals coming to the hospital at an earlier stage of disease and has reduced the number of individuals who come to the hospital through the emergency room. In addition, the disparity in cancer screening rates has been eliminated at this site and patient satisfaction with care is at 98 percent.
- Long-term data regarding patient navigation comes from the program established by Dr. Freeman at Harlem Hospital. Prior to 1986, the hospital saw 606 women with breast cancer; 6 percent had Stage I disease and 49 percent had Stage III or IV disease. The five-year survival rate for these patients was 39 percent. Following implementation of screening and patient navigation programs, these numbers significantly shifted. Since 1987, 325 breast cancer cases have been seen. Of these, 41 percent have had Stage 0 or I disease, while only 21 percent have had Stage III or IV disease. The five-year survival rate for women with access to screening and intervention is 70 percent. Patient navigation is important for helping patients receive the follow-up care necessary to resolve suspicious findings identified through screening. The disparity between various ethnic groups with respect to getting a mammogram has decreased, but minority patients are still more likely to die of breast cancer.
- Part of the benefit of patient navigation is getting out into the community and delivering resources. It is essential to have a combination of universal healthcare access and programs that ensure people get

quality care in a timely fashion; universal access to care is not enough. The Harlem navigation program has started an outreach program to draw people to its screening services.

- It is important to implement navigation at the time of an abnormal finding rather than waiting until cancer has been diagnosed. Patients need the benefits of navigation to help them obtain their diagnosis in a timely manner. This makes it difficult to separate the benefits of navigation from those of increased screening and early detection.
- Researchers at M.D. Anderson have applied for American Recovery and Reinvestment Act funds to support a cost analysis of its navigation system.
- Even if patients are not diagnosed with cancer (i.e., follow-up on a suspicious finding is negative), patient navigation programs often send patients to health referral specialists who can help navigate them to receive care for other conditions (e.g., diabetes, hypertension).
- ASCO plans to follow the career development of all applicants to its Diversity in Oncology program (including those who are not selected) in order to evaluate the effectiveness of the program. However, it is recognized that there is potential bias in this type of evaluation. This program addresses the needs of minority medical students, residents, and fellows, and includes a broad mix of specialties, including family medicine, surgery, and others.
- There are data suggesting that doctor-patient race/ethnicity concordance leads to better outcomes, so it is important to increase the diversity of the provider workforce. However, it is also important to help all physicians, including those of the majority population, to provide high-quality care to minorities.
- There is tremendous heterogeneity within ethnic subpopulations. This is particularly evident in Asian and Hispanic populations. Furthermore, people of different ethnic backgrounds tend to define themselves differently (i.e., more weakly or strongly associate with their ethnic group).
- Ideally, Kaiser would have liked to analyze county-level data because there are disparities even within states. However, there were insufficient data to conduct this type of analysis.
- The Institute of Medicine recommended in a recent report that the OMB race and ethnicity categories be adopted and that more specific data be collected on race/ethnicity (e.g., subpopulations of Hispanics, Asians, blacks).
- Health disparities have a geographic component, which should be taken into account as the United States considers how to deal with its changing demographics. The Agency for Healthcare Research and Quality has identified Health Profession Shortage Areas (HPSAs), which can be rural or urban.
- It would be interesting to look carefully at cancer mortality and disease-free intervals in a way similar to the healthy life expectancy analysis presented by Dr. Hayward. However, there are currently insufficient data to conduct this type of analysis. It would be helpful if there were dialogue among those conducting large epidemiological studies to facilitate the integration of data from different studies.
- High-level demographic data can be confounded by local factors. Local variables may be confounding SEER data regarding cancer incidence and mortality among Hispanic populations. For example, during the course of a Lance Armstrong Foundation study of the late effects of testicular cancer treatment, it was discovered that the Los Angeles tumor registry, which is part of SEER, included a number of people who did not exist. This happened because immigrants used relatives' identification cards to access the healthcare system. It is important to integrate information from local providers who interact with communities and patients in order to improve the validity of national data.

- SEER was established as a research tool, not a policy tool, but it has been increasingly and inappropriately used to inform policy. State and local policy makers should be cautious about creating policy based on SEER data.
- The Intercultural Cancer Council was established to focus on the common barriers faced by populations, as well as the specific issues that need to be addressed for each population. Poor whites face many of the same barriers as minorities. Rates of cervical and lung cancers in eastern Kentucky are higher among whites than among blacks. The dialect of white people who live in the mountains of Appalachia allows others to identify them and label them as poor and unintelligent, making it less likely that they will access care.
- Culture and race are not equivalent. Culture is a powerful force that can play a significant role in disease. Race is important to the extent that people are classified by race and have been treated differently over long periods of time; this type of racism can have effects on health. However, rather than focusing on race, interventions should concentrate on lifestyles, attitudes, and behaviors that impact health.
- Increasing population heterogeneity coupled with cuts in financing for surveys will make it difficult to collect meaningful information about race and ethnicity. In many ways, it is beneficial to collect more granular ethnicity information; however, as the population becomes more heterogeneous, it is going to become increasingly difficult to classify people into a manageable number of categories.
- Health disparities reflect a problem of social injustice. Addressing inequities and social injustice is more important than working for diversity. Research should strive to more accurately identify people who experience poor health outcomes and identify ways to deliver services to these people. It is critical that interventions known to be beneficial are delivered to all people.
- Society does not yet value all human life equally. The United States needs to have an honest discussion about race and the legacy of slavery.
- Underserved populations have suffered because of the shift from an infectious disease model to a chronic disease model for addressing health. When diseases such as polio and smallpox were common, even the poorest people were vaccinated or treated for infectious diseases because these diseases could easily spread to other parts of society.
- Although it is important to address the social factors that contribute to health disparities, there should also be investment in scientific approaches. The shift in HCT to use cord blood is one example of a scientific advance that is helping minority populations receive better care.
- Additional data could help identify the mechanisms that contribute to health disparities. Data standardization is also important.
- Although more in-depth analysis on local health trends would be helpful, there is enough information to begin to address the disparities that have been documented. Programs that work with communities to improve local health are a good idea. It would be helpful to have local data in order to facilitate measurement of progress once interventions are put into place.
- NCI's dismantling of the Cancer Information Service (CIS) has reinforced the idea among underserved communities that NCI does not care. Regardless of the program that replaces it, the elimination of CIS has weakened the relationships that have been built between NCI and underserved communities.
- Although there is room for improvement in health and healthcare in the United States, it is important to recognize that the United States does a number of things well, including measuring health-related indicators. Some of the comparisons of the U.S. with other countries are misleading because not all countries measure things as well as the United States does.

- Health is determined by a confluence of many things that occur outside of the healthcare setting, including income- and education-related issues. Efforts must be made to decrease barriers to increase the access to care of underserved populations.
- Education is the most effective way to combat health disparities. There are significant differences in life expectancy—up to two or three decades—by level of education, even within racial/ethnic groups. Education helps people live in better neighborhoods and allows them to acquire more resources, but it also provides people with the cognitive ability to make decisions and be proactive about their health.

## **PUBLIC COMMENT**

### **Key Points**

- The NCI decision to halt CIS will create huge barriers to serving Americans seeking information about cancer. The President should urge Congress to mandate that funding for CIS continue.
- The barriers to recruitment and retention of minorities to clinical trials should be addressed. Research has shown that racial and ethnic minorities are less likely than whites to be offered the option to participate in a cancer clinical trial. One woman related the story of her husband, a well-educated minority, who was recently diagnosed with prostate cancer. The diagnosing physician, two surgeons, and a radiation oncologist all failed to mention clinical trials to him. Often, primary care physicians do not feel comfortable discussing clinical trials with patients and may lack information about appropriate local trials. Some providers assume that minorities will be unwilling or uninterested in participating in a trial or that they will be nonadherent. Physicians may also make assumptions about language barriers that may or may not be accurate.
- The state of Washington has a Commissioner for African American Affairs and a Governor’s Interagency Council for Reducing Health Disparities. The Council is working to develop a plan by 2012 to help residents of Washington with issues such as language barriers, communication, and information gathering.
- Veterans have higher rates of some cancers due to exposures that occur during service, and should be considered underserved populations.

## **CLOSING REMARKS—DR. LEFFALL**

- Dr. Leffall thanked the attendees and panelists for making valuable contributions and assured them that the Panel would carefully consider the information collected at the meeting.

## **CERTIFICATION OF MEETING SUMMARY**

I certify that this summary of the President’s Cancer Panel meeting, *America’s Demographic and Cultural Transformation: Implications for the Cancer Enterprise*, held September 22, 2009, is accurate and complete.

Certified by: \_\_\_\_\_ Date: December 17, 2009  
 LaSalle D. Leffall, Jr., M.D.  
 Chair  
 President’s Cancer Panel