

**MEETING SUMMARY  
PRESIDENT'S CANCER PANEL  
AMERICA'S DEMOGRAPHIC AND CULTURAL TRANSFORMATION:  
IMPLICATIONS FOR THE CANCER ENTERPRISE**

February 2, 2010  
Miami, Florida

**OVERVIEW**

This meeting was the fourth in the President's Cancer Panel's (PCP, the Panel) 2009-2010 series, *America's Demographic and Cultural Transformation: Implications for the Cancer Enterprise*. 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

***Speakers***

Linda Burhansstipanov, M.S.P.H., Dr.P.H., Director, Native American Cancer Initiatives, Inc.  
Venus Ginés, M.A., CEO, Founder, Dia de la Mujer Latina, Inc.  
Marjorie Kagawa-Singer, Ph.D., M.A., M.N., R.N., Professor, University of California, Los Angeles (UCLA) School of Public Health and Department of Asian American Studies  
Eliseo J. Pérez-Stable, M.D., Director, Medical Effectiveness Research Center for Diverse Populations, University of California, San Francisco  
Samir Khleif, M.D., Head, Cancer Vaccine Section, Center for Cancer Research, NCI  
Wizdom Powell Hammond, Ph.D., Assistant Professor, Health Behavior and Health Education, Gillings School of Global Public Health, The University of North Carolina at Chapel Hill  
Sanya Springfield, Ph.D., Director, Center to Reduce Cancer Health Disparities, NCI  
Jeffrey D. White, M.D., Director, Office of Cancer Complementary and Alternative Medicine, NCI

**OPENING REMARKS—DR. LaSALLE D. LEFFALL**

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.

Dr. Kripke reported that the Panel held a Working Group meeting on December 14, 2009, to discuss the Panel meeting held in Wilmington, Delaware, earlier that month. The Working Group recommended that the Panel's 2010-2011 series examine the state of cancer research 40 years following the passage of the National Cancer Act. Dr. Kripke's motion to accept the Working Group recommendation was unanimously passed.

## **PANEL I**

### **DR. ELISEO J. PÉREZ-STABLE:**

#### **CANCER HEALTH DISPARITIES IN LATINOS**

##### **Background**

Eliseo J. Pérez-Stable, M.D., is a professor of medicine; Chief of the Division of General Internal Medicine, Department of Medicine; Director of the Medical Effectiveness Research Center for Diverse Populations (MERC); and Associate Director for Health Disparities at the Helen Diller Family Comprehensive Cancer Center, all at the University of California, San Francisco (UCSF) School of Medicine. He earned his B.A. and M.D. degrees from the University of Miami, trained in primary care general internal medicine at UCSF, and completed a Henry J. Kaiser Family Foundation fellowship in general internal medicine before being appointed Assistant Professor at UCSF in 1983. Dr. Pérez-Stable follows a panel of about 200 patients in primary care general internal medicine and teaches residents and students in the ambulatory setting and the hospital. Dr. Pérez-Stable's research focuses on risk factor reduction interventions for Latino populations, tobacco use and cessation, minority aging, and health care disparities.

##### **Key Points**

- There are dramatic differences in cancer incidence among women of different racial/ethnic groups. For the most common cancers—breast, lung, and colorectal—rates are lower among Latina and Asian women than among whites. African American women have the highest rates of lung and colorectal cancers while white women have the highest incidence of breast cancer. On the other hand, the cancers caused by infectious agents (e.g., cervical, stomach, liver) are most common among Latinas and Asians.
- Among men, African Americans have the highest incidence rates of prostate, lung, and colorectal cancers; rates for these cancers are lowest among Latinos. Similar to the trends observed among women, stomach and liver cancer are more common among non-white racial/ethnic groups in the United States.
- U.S. Latinos are a very diverse group, with numerous countries represented, but there are more similarities than differences between the subgroups. The Spanish language and other cultural elements unify Latinos, who—at 14 percent of the population—comprise the largest ethnic minority in the U.S.
- The genetic ancestry of Latinos is a mix of African, European, and indigenous American. The admixture that has been ongoing over the past 500 years has resulted in substantial genetic variation within Latino populations. Studies have shown that the genetic makeup of Mexican Americans is 45 percent European, 52 percent indigenous, and 3 percent African, while Puerto Ricans are 60 percent European, 24 percent indigenous, and 15 percent African.
- Despite having an adverse demographic profile, Latinos have significantly lower rates of death than non-Hispanic whites for the three leading causes of death in the United States: heart disease, cancer, and stroke.
- On average, Hispanics have lower household incomes, educational attainment, and rates of health literacy than do non-Hispanic whites. Approximately one-quarter of U.S. Latinos do not speak any English. Latinos have the lowest rates of health insurance coverage of any racial/ethnic group in the U.S.; 40 percent of Latinos between 18 and 64 years old are uninsured.
- There have been several studies comparing cancer incidence and mortality rates among Latinos of different national origins. One large study found that both foreign- and U.S.-born Latinos had lower

rates of cancer mortality than the general U.S. population. A study in Florida found that cancer incidence rates were higher among non-Mexican Latinos than among those of Mexican ancestry, suggesting that there may be differences between Latinos of different national origin.

- The term *epidemiological paradox* refers to the finding that health outcomes for Latinos are better than expected based on known or standard predictive risk factors (e.g., social class, socioeconomic status [SES]). This indicates that SES does not always translate to worse outcomes. The mechanisms behind this paradox remain unclear, although a number of hypotheses have been proposed. One of the most common explanations is the “healthy immigrant effect” (i.e., immigrants tend to be healthier than those who do not leave their home country). A second possibility—sometimes called the “salmon hypothesis”—is that immigrants return to their home country to die, so their deaths are not registered in the United States. Misclassification of Latinos at diagnosis and death may also contribute to the paradox. However, it is also possible that differences in behavior, genetics, and other undefined factors drive the lower rates of disease observed among Latinos.
- SES does influence cancer risk within Latino populations. Latinos living in counties with more than 20 percent poverty have higher cancer mortality rates than those living in counties with less than 10 percent poverty.
- A case-control study in the San Francisco Bay area found that among Latinas, lower acculturation was protective against breast cancer. Later genetic analyses of this cohort revealed that higher levels of European ancestry were associated with increased risk for breast cancer. This suggests that biology and environment may interact to influence breast cancer risk.
- A large study in the early 1990s found that, compared with non-Hispanic whites, Latinos are 2 to 2.5 times more likely to believe that breast feeding, antibiotics, bruises, eating pork, microwave ovens, and drinking coffee cause cancer. They are also twice as likely to believe that cancer is a punishment from God or a death sentence, and 50 percent more likely to believe that cancer can be spread by touch. Despite these misconceptions and less access to care, Latinas have similar rates of mammography and Pap testing as non-Hispanic whites. Colon cancer screening rates, however, are lower among Latinos.
- Data from the National Health Interview Survey (NHIS) show that Latinos have relatively low rates of smoking. A National Hispanic Leadership Initiative on Cancer study found that Latino men are less likely to smoke if they are more highly acculturated, while the opposite trend was observed for Latino women. In addition, women of Puerto Rican or Cuban national origin were more likely to smoke than were women of Mexican origin.
- Latinos who do smoke tend to be light smokers and many do not smoke every day: nearly 8 percent of Latino men and 7 percent of Latino women are nondaily smokers. NHIS data revealed that Latinos make up 17 percent of nondaily smokers but only 6 percent of the daily smoking population.
- Nondaily and light smokers (1-5 cigarettes per day) are most likely not physiologically addicted to tobacco. This population is not well understood because it has been excluded from clinical trials, including those for cessation interventions. Efforts must be made to adapt programs to help nondaily and very light smokers quit.
- In order to develop effective cessation strategies, it is important to understand cultural views on tobacco and cessation. Latinos tend to place importance on social smoking and focus on emotional and habitual cues to smoke. Reasons that motivate Latinos to quit smoking include family pressure, criticism from family, bad breath, wanting to set a good example, concern about children’s health, and risk of burning clothes. Latinos seem to be less concerned than whites about gaining weight after discontinuing use of cigarettes.
- *Guía para Dejar de Fumar* is a Spanish-language self-help guide that is available on the NCI Cancer Control PLANET Web site. The guide has been used as an intervention component in community studies and is culturally and linguistically tailored.

- The University of California San Francisco has developed a Web-based smoking cessation intervention that is available in English and Spanish at <http://stopsmoking.ucsf.edu>. To date, most of the users of the Spanish-language site have been from Latin America and Spain; efforts are under way to increase use by U.S. Latinos. One study found that after one year of follow-up, 20 percent of site users (both English and Spanish) had successfully quit smoking.
- Among Mexican Americans who report being smokers, nearly 30 percent have serum cotinine levels below 15 ng/ml, which is the traditionally used biochemical indicator of tobacco use. The National Health and Nutrition Examination Survey found that this cutoff underestimates smoking behavior of all groups. The survey suggested that serum levels of 6 ng/ml were sufficient to indicate smoking among whites while levels of 5 ng/ml and 1 ng/ml are indicative of smoking in African Americans and Latinos, respectively. The differences in informative cutoff values may be due in part to differences in the metabolism and clearance of cotinine as well as differences in smoking behavior (i.e., light smoking).
- The Multiethnic Cohort Study examined relative risk of lung cancer by race/ethnicity within each of four smoking levels (i.e., 1-10, 11-20, 21-30, or  $\geq 31$  cigarettes per day). Racial/ethnic differences in risk of lung cancer were observed among those who smoked 30 or fewer cigarettes per day, with Latinos generally having the lowest risk and African Americans demonstrating substantially higher risk. For example, among those who smoked 11 to 20 cigarettes per day, Latino risk of lung cancer was 64 percent lower than that of African Americans. However, racial/ethnic differences largely disappeared among heavy smokers (i.e.,  $\geq 31$  cigarettes per day). These data support the idea that interactions between genetics/biology and environment influence lung cancer risk.
- Standard questions should be used to identify patients with limited English proficiency. The U.S. Census question, “How well do you speak English?” with possible responses of “very well,” “well,” “not well,” and “not at all,” is quite predictive of English proficiency. In addition, patients should be asked to indicate the language in which they prefer to receive their medical care. Many patients will decline if simply asked whether they need an interpreter.
- Patients who speak the same language as their physicians feel better and report less pain, better health outlook, and fewer symptoms than those who do not have a language-concordant physician. Language concordance allows patients to ask more questions and better understand provider instructions and is also associated with better medication adherence. However, there is limited evidence that language concordance has an effect on clinical outcomes.
- Patients using interpreters tend to ask fewer questions and say less during encounters with clinicians. Time limitations often mean that less is covered during appointments in which a translator is used. Thus, language concordance between patients and clinicians is preferable. Language certification should be offered for clinicians, including physicians, physician assistants, nurses, and others. Clinicians should be encouraged to learn the language spoken by patients in their region, but it would also be helpful to train physicians who already speak these languages.
- Professional translators should be required for all important medical interactions, as they are more accurate than family members or other nonprofessional interpreters. Although face-to-face interpretation is preferable, video and telephone translation technologies are improving.

## **DR. SANYA SPRINGFIELD:**

### **CANCER HEALTH DISPARITIES RESEARCH AND RESEARCH CAPACITY: ADVANCING THE VISION TO LESSEN THE BURDEN OF CANCER**

#### **Background**

Dr. Springfield is Director of the NCI Center to Reduce Cancer Health Disparities (CRCHD, the Center). She is responsible for overseeing CRCHD's mission to coordinate and strengthen the NCI cancer research portfolio in basic, clinical, translational, and population-based research to address cancer health disparities. CRCHD also leads NCI's efforts in the training of students and investigators from diverse populations who will be part of the next generation of competitive researchers in cancer and cancer health disparities. Dr. Springfield received her Ph.D. in physiology and biophysics from Howard University in Washington, DC. She was awarded a National Research Service Award (F32) for postdoctoral studies in the Department of Pharmacology at the Robert Wood Johnson School of Medicine. Dr. Springfield served as a Program Director in the National Science Foundation's Division of Integrative Biology and Neurosciences. She also serves as an advisor to a number of committees aimed at finding effective ways to recruit and retain underrepresented minorities in biomedical research.

#### **Key Points**

- The biomedical challenge of the 21<sup>st</sup> century is personalized medicine—a new style of health care based on the individual patient and targeted therapies. Each patient is different, from both a biological and a socioeconomic standpoint, yet a “one size fits all” standard of care is currently followed. The key to achieving personalized medicine for all populations is understanding patient differences due to biology, behavior, and environment.
- In order to achieve personalized medicine in underserved communities, CRCHD is focusing its efforts on four main areas: research; research capacity building; applied research; and outreach, dissemination, and education.
- CRCHD is working to increase understanding of genetic, molecular, and biological variations in cancer. In partnership with the Division of Cancer Biology, CRCHD has two small grant programs that support basic cancer research by ethnic minority investigators as well as research on cancer health disparities by investigators of all ethnic backgrounds. CRCHD is also funding research on the biology of estrogen receptor-negative breast cancer, which frequently occurs in African-American women. Another partnership with the NCI intramural program is focused on genome-wide association studies of lung cancer in African Americans. Future basic research areas to be supported by the Center will include cancer stem cells, oncometabolomics, epigenetics, and the tumor microenvironment.
- Research capacity building includes both training and resource support (e.g., databanks, equipment). Training is a high priority of CRCHD. The Center's model training program is Continuing Umbrella of Research Experiences (CURE), which supports individuals from high school all the way through their first academic appointment. CURE started in 1997 and has grown tremendously over the past ten years. There are CURE trainees supported throughout the country and NCI receives more applications to this program than it can fund each year.
- The Center developed a partnership with the National Science Foundation and the NCI Centers for Proteomics and Nanotechnology to provide trainee funding in emerging technologies.
- The Minority Institution/Cancer Center Partnership (MI/CCP) program was developed in 2001 to enable minority-serving institutions and NCI Cancer Centers to train scientists from diverse backgrounds in cancer research and effectively deliver cancer advances to racially and ethnically diverse communities.

- Geographic Management Program (GMaP) pilot projects are being launched on a regional level to build critical resource hubs needed to realize personalized medicine. These hubs will provide support and efficient management of cancer health disparities research, training, and infrastructure programs.
- Global partnerships are being developed to work toward the globalization of cancer health disparities reduction. Initial efforts will focus on Africa.
- The Community Networks Program (CNP) is the Center's flagship program for community-based research interventions. The Request for Applications for the program has recently been reissued. The goal of Community Networks Program II (CNP-II) is to provide an education base for biospecimen collection and clinical trials, as well as to test evidence-based interventions that were developed by the initial CNPs.
- The Patient Navigation Research Program aims to develop and test the efficacy and cost-effectiveness of innovative patient navigation interventions to reduce or eliminate cancer health disparities. Individuals from the lay community who act as patient navigators would be particularly effective in addressing the language barrier aspect of health disparities that many ethnic minority populations face.
- NCI is successful at attracting minorities into cancer research and encouraging mainstream investigators to explore cancer health disparities, but more funding is needed to retain these investigators.
- To continue to conduct research in low-resource and high-poverty regions, public-private partnerships will need to be developed. Government funding is limited, but the pharmaceutical industry has the capacity to provide much-needed resources. Collaborations and partnerships with community organizations are also needed to address inequities and advance the science of cancer health disparities.

## **DR. JEFFREY WHITE:**

### **COMPLEMENTARY AND ALTERNATIVE MEDICINE AND CANCER: CULTURAL AND DEMOGRAPHIC PERSPECTIVES**

#### **Background**

Dr. White graduated from Cornell University with a B.S. in 1979 and received an M.D. from Howard University in 1984. He completed a residency in Internal Medicine in 1987 and fellowships in oncology and hematology in 1990 at The Washington Hospital Center in Washington, DC. Dr. White joined the Metabolism Branch of NCI in 1990, where he served in various positions culminating as Director of the Clinical Trials and Clinical Care Program. While in the Metabolism Branch, he performed laboratory-based immunology research as well as clinical trials of monoclonal antibody approaches to cancer treatment. Dr. White also served as an oncology consultant to the Director of the NIH Office of Alternative Medicine. In 1998, he was chosen as the director of the new NCI Office of Cancer Complementary and Alternative Medicine (CAM). This Office seeks to promote and support research in the various disciplines and modalities associated with the field of complementary and alternative medicine as they relate to the diagnosis, prevention, and treatment of cancer.

#### **Key Points**

- Complementary and alternative medicine is defined by the National Center for Complementary and Alternative Medicine as medical and health care practices that are not an integral part of conventional (Western) medicine. The World Health Organization defines CAM as a broad set of health care practices that are not part of a country's own tradition and are not integrated into the dominant health care system. Complementary medicine refers to interventions used in combination with conventional treatment, while alternative approaches are those used instead of conventional treatment.

- Major domains of CAM research include alternative medical systems (e.g., traditional Chinese medicine, homeopathy, acupuncture); energy therapy (e.g., electromagnetic therapy); exercise, including both Western forms and other types (e.g., yoga); manipulative and body-based therapies (e.g., therapeutic massage, chiropractic); mind-body interventions (e.g., hypnosis); nutritional therapeutics (e.g., diet modification, bioactive food components); off-label use of drugs not traditionally used as cancer therapy; and spirituality and spiritual healing.
- In 2007, 38.3 percent of U.S. adults reported using CAM for a specific illness or for health promotion within the past 12 months; this represents an increase from 36 percent in 2002. Many patients do not disclose CAM use to their health care providers.
- It is unclear whether conventional health care practitioners can influence patient decision making about CAM use. There are limited data regarding why patients decide to use CAM and why they tend not to disclose CAM use to their providers. There is an ongoing study at M.D. Anderson Cancer Center that is training health care practitioners to talk about CAM approaches with their patients.
- Results of a large study about preferred sources of health information indicated that Caucasian patients preferred information from medical journals, newsletters from research institutions, and the Internet. Japanese patients relied on media and commercial sources, including television, newspapers, books, magazines, and CAM providers. Non-Japanese Asians and Pacific Islanders used information sources involving person-to-person communication with physicians, social groups, and other cancer patients. Higher educational level was closely associated with use of health information based on objective, scientific, and updated information, while lower educational level was associated with interpersonally communicated information; however, the effect of patients' ethnicity overrode their educational level with respect to their choices of health information.
- Data from the 2002 National Health Interview Survey (NHIS) indicate that cancer survivors use CAM more frequently than those who have not been diagnosed with cancer. An American Cancer Society survey found that cancer survivors use a number of CAM approaches, with prayer/spiritual practice, relaxation, and nutritional supplements/vitamins being among the most commonly used.
- Among breast cancer patients, 12.9 percent report using herbal remedies, but rates vary by racial/ethnic group. Only 8 percent of whites and 9 percent of blacks report herbal remedy use, but rates among Latinas and Chinese women are 14 percent and 22 percent, respectively.
- There are several potential drawbacks of CAM use by cancer patients, including delay in receiving effective conventional care or adverse interactions with conventional care.
- A qualitative interview study of multiethnic cancer survivors who reported having declined all or part of recommended conventional treatment revealed that the primary reason for declining conventional treatment was to avoid damage or harm to the body. The majority of these patients felt that conventional treatment would not make a difference in their disease outcome and some participants perceived CAM as an effective and less harmful alternative to conventional treatment. Some participants also reported that their discovery of CAM contributed to their decision to decline conventional treatment.
- Nearly 80 percent of patients receiving chemotherapy in one study were found to be using herbs or vitamins. Nearly 30 percent were at risk of detrimental chemotherapy-herb/vitamin interaction. Most of the patients in this study expressed willingness to discontinue their CAM use if a detrimental interaction was suspected. Although most of the patients in the study discussed herb/vitamin use with their oncologists, the majority also relied on friends and naturopathic physicians for information about CAM. Methods to improve communication regarding CAM use are needed to identify and minimize the risk of chemotherapy-CAM interaction.
- In a case study of a Korean woman with lung cancer, an herbal mixture was found to interfere with the efficacy of gefitinib. Once use of the herbal mixture was discontinued, the woman's cancer

responded well to the drug. It is suspected that some components of the herbal mixture can modulate the activity of enzymes responsible for the metabolism of gefitinib.

- Some potential benefits of CAM use include symptom relief, cost-effectiveness, and cultural familiarity. Acupuncture has been shown to be effective for reducing chemotherapy-induced nausea and vomiting as well as hot flashes. Yoga has been shown to help patients with sleep disorders. Hypnosis can support recovery from breast surgery.
- There are some indications that lifestyle modifications may improve outcomes for cancer patients. The Women's Intervention Nutrition Study found that women on low-fat, high-fruit/vegetable diets had better relapse-free survival rates than other women. The Women's Healthy Eating and Living Study did not replicate this finding, but did identify a survival advantage for patients on the low-fat diet who had the highest levels of physical activity.
- Self-reported exposure to racism has been associated with behaviors such as tobacco use and alcohol consumption, which supports the idea that racism takes a physiological toll on those who experience it. Future research is needed to examine whether energy imbalance may stem in part from racism-related stress.
- The Institute of Medicine Committee on Use of Complementary and Alternative Medicine recommended in 2005 that NIH and other public agencies provide the support necessary to develop and implement a sentinel surveillance system to collect and report data on patterns of CAM use; include CAM-relevant questions in federally funded health care surveys; and implement periodic comprehensive, representative national surveys to assess changes in prevalence, patterns, perceptions, and cost of both CAM and conventional therapies, with an oversampling of ethnic minorities.
- The National Center for Complementary and Alternative Medicine has an Office of Special Populations Research that is addressing some issues related to CAM use by various racial/ethnic groups. In addition, SEER (Surveillance, Epidemiology and End Results) has collected some data on CAM use. The NCI Center to Reduce Cancer Health Disparities is collaborating with the Office of Cancer Complementary and Alternative Medicine to examine CAM use among cancer patients in American Samoa.
- CAM is extensively used by native-born Americans and U.S. immigrants, but there are important differences in the types of CAM used by different subpopulations. Over time, the profile of CAM use may change as U.S. racial/ethnic patterns shift. Health care practitioners need to be educated regarding herbal therapies; in particular, those approaches commonly used by some ethnic groups.

## **DR. LINDA BURHANSSTIPANOV:**

### **AMERICAN INDIAN/ALASKA NATIVE ISSUES AND IMPLICATIONS FOR THE CANCER ENTERPRISE**

#### **Background**

Linda Burhansstipanov, M.S.P.H., Dr.P.H., CHES (Cherokee Nation of Oklahoma) has worked in public health since 1971, primarily with Native American issues. She taught full-time for a total of 18 years at California State University, Long Beach and the University of California, Los Angeles. She developed and implemented the Native American Cancer Research Program at the National Cancer Institute from 1989 to 1993. She is the current Grants Director and President of Native American Cancer Research (NACR)—a community-based and American Indian-operated nonprofit corporation initiated in 1998—and President of Native American Cancer Initiatives, Inc. (NACI), a for-profit technical assistance, training, and public speaking organization initiated in 1997. She is the founder of both NACR and NACI, and currently is the principal investigator and subcontractor for multiple NIH grants. Dr. Burhansstipanov serves on national boards such as the Susan G. Komen for the Cure American Indian and Alaska Native



National Advisory Council and Mayo Clinic's Spirit of Eagles Community Network Programs Advisory Board. She has over 100 peer-reviewed publications, most of which address Native American cancer, public health, and data issues.

## Key Points

- Many of the American Indian/Alaskan Native (AI/AN) issues surrounding inadequate cancer care stem from miscommunication. The AI/AN population comprises 565 federally recognized tribes, each with a unique culture and way of communicating. For many AI/ANs, English is a second, third, or fourth language. Because of these communication differences, many misunderstandings about the AI/AN population arise (e.g., they are uneducated, they will not understand scientific terms, they will be noncompliant with health care instructions, they are uninterested in clinical trials).
- AI/ANs may need to translate English and Western medicine concepts into their Native language and determine the cultural implications of treatment options such as genetic treatment regimens. AI/AN patients may also need to discuss treatment logistics with their families or loved ones to determine how treatment will impact their lives. Additionally, AI/ANs may need to integrate spiritual healing and time for ceremony into clinical protocols.
- A high proportion of AI/AN cancer patients practice traditional Indian and other complementary medicine along with Western medicine. However, traditional healers have never been a barrier to patients receiving timely care.
- The goal of Native American Cancer Research is to reduce Native American cancer incidence and mortality, and to increase survival from cancer among Native Americans. To accomplish this goal, NACR implements cancer research projects involving prevention, health screening, education, training, control, treatment options, and support among Native Americans. NACR studies are primarily supported by federal agencies (e.g., NIH) and national organizations (e.g., Susan G. Komen for the Cure).
- One NACR project is an interactive, Web-based, culturally relevant Native American cancer survivorship program, Native American Cancer Education for Survivors (NACES). The focus of this community-driven educational intervention is to improve quality of life (QOL) for Native American cancer survivors.
- In addition to a multifaceted intervention tailored to individual patients, NACES includes a four-part survey that collects or assesses: (1) personal information (such as where the survivor lives), (2) physical and spiritual QOL, (3) mental, emotional, and social QOL, and (4) the survivor's personal experience with cancer (e.g., distances to travel to obtain cancer care). Fourteen trained Native patient advocates located in AI/AN communities throughout the country delivered the survey to survivors via a laptop computer. Nearly half of patients who completed the survey were from the Southwest region of the U.S. and 46 percent lived on a reservation.
- More than half (59%) of survey participants were diagnosed more than five years ago and most were breast cancer survivors. The overrepresentation of breast cancer is because NACES was originally developed to study these patients; however AI/ANs with cancers other than breast also started using the intervention and completing the survey, so the scope of the effort was expanded.
- Although more than half of participants were diagnosed with cancer more than five years ago, they reported experiencing excessive problems a few days each week or every day. In addition, survivors reported having several comorbidities, the most common of which was diabetes; one-fifth also reported problems with obesity.
- More than half (54%) of the survivors reported difficulty getting cancer treatment. The majority of survey participants had to drive over 100 miles one way to receive care; travel time for treatment took more than 4 hours for 51 percent of participants. Only 13 percent of AI/AN survivors reported using Indian Health Service (IHS) as their primary provider. Higher numbers said they relied on Medicare

or Medicaid to pay for their care. A small number of respondents—only 6 percent—reported that they had no health insurance, but it is important to note that many AI/AN consider IHS to be health insurance, which it is not. Eighty-one percent of survivors reported spending personal money on their cancer treatment. The cost of treatment is at least \$30,000, but survivors reported spending less than \$10,000. Survivors used the Centers for Medicare and Medicaid Services and the U.S. Department of Veterans Affairs for help with payment.

- Although the NACES survivors documented many challenges, they also reported a message of hope and productivity. Most survivors (92.6%) reported that their spiritual QOL was good or excellent. Similarly, 82 percent reported their mental and emotional health as good or excellent.
- AI/ANs are from very diverse tribal Nations and they communicate and interact differently. Health care providers and AI/AN patients frequently experience challenges when interacting with one another. These challenges include, but are not limited to, AI/ANs not being able to recall hearing the phrase “clinical trials.” This may be due to not understanding what the provider was saying or the provider not having explained the possibility of clinical trials. Among NACES respondents, 20 percent had participated in a clinical trial, which illustrates the willingness of AI/ANs to take part in trials if they are given adequate opportunity.
- Behavioral patterns also contribute to communication challenges between providers and AI/AN patients. AI/ANs are more likely to be oral learners in comparison with other populations. Additionally, AI/AN patients tend to be very stoic and do not show pain, resulting in the undermedication of pain in AI/AN cancer survivors.
- Providers have many stereotypes that contribute to disparities. These include misinformation about IHS and how AI/ANs access or fail to access cancer care through the IHS Contract Health Service. Patients and providers alike erroneously refer to IHS as “health insurance,” which it is not. IHS is significantly underfunded by Congress and does not have the resources to provide comprehensive, quality cancer care.
- An additional provider misconception is that Indian gaming profits are available to most tribes. However, most tribes do not have casinos. And even for those that do, profits are used for tribal infrastructure and rarely for health care.
- Having trained Native patient advocates or navigators accompany patients to appointments with providers reduces many types of miscommunication. Such positions need to be paid rather than voluntary.

## **DR. JEFFREY HENDERSON:**

### **TOWARD A FUTURE OF GOOD HEALTH AND WELLNESS: THE CURIOUS CASE OF CANCER IN AMERICAN INDIANS AND ALASKA NATIVES**

#### **Background**

Dr. Jeffrey Henderson is a Lakota and an enrolled member of the Cheyenne River Sioux Tribe of north-central South Dakota. He acquired both his bachelor’s (1985) and medical (1989) degrees from the University of California, San Diego. After a residency in Internal Medicine at the University of Washington in Seattle, Dr. Henderson served as Clinical Director of the Indian Health Service hospital and clinic for two years. He then earned his M.P.H. from the University of Washington. In 1998, Dr. Henderson founded the Black Hills Center for American Indian Health (BHCAIH), a community-based, nonprofit organization whose mission is to enhance the wellness of American Indians through research, service, education, and philanthropy. Since receiving its first grant funding in the fall of 2001, BHCAIH has met with considerable success, garnering over \$18 million through eight NIH and numerous state and private foundation grants and contracts. In 2009, Dr. Henderson finished a three-year term serving as

Chair-designee on the Secretary's National Advisory Council for Minority Health and Health Disparities. He currently serves on the National Advisory Council for the Centers for Disease Control and Prevention's Breast and Cervical Cancer Early Detection Program.

## Key Points

- Of the 217 traditional languages still spoken by AI/ANs today, there is no indigenous word for cancer. For a long time, cancer was not thought to be a problem for AI/ANs because data were either unavailable or inaccurate. However, it has become clear that racial misclassification of AI/ANs on death certificates and in disease registries is common, with some retrospective studies finding that up to one-third of AI/ANs were not designated as such. New methods have allowed a much clearer picture of the burden of cancer among Native people to emerge; for example, linkages between the NACR cancer registries, SEER, and the IHS fiscal intermediary databases have helped ensure that AI/ANs are appropriately categorized when they are diagnosed with or die from cancer.
- Compared with non-Hispanic whites, AI/ANs have a slightly lower overall rate of cancer incidence at all sites combined. However, AI/ANs have higher rates of kidney, stomach, cervical, liver, and gallbladder cancers.
- Data on AI/AN cancer incidence have been aggregated into six geographic regions: Alaska, Pacific Coast, Southwest, Southern Plains, Northern Plains, and East Coast. Cancer rates among AI/ANs in these regions vary considerably, much more than regional rates for non-Hispanic whites. These data reveal that although AI/ANs overall have relatively low rates of cancer, AI/AN cancer rates in some regions are considerably higher than those of non-Hispanic whites. Among men, Northern Plains AI/ANs have the highest rates of many types of cancer, while Southwest AI/ANs often exhibit low incidence; in some cases, cancer incidence rates are five times higher in one region compared with another. Highly variable rates are also observed among AI/AN women: Northern Plains women have a nearly tenfold higher incidence rate of lung cancer than Southwest women. This may be in part because more than 50 percent of Northern Plains women smoke, while the smoking rate for Southwest women is around 17 percent.
- SEER is considered the gold standard for cancer registries, but it covers only approximately 12 percent of the AI/AN population. This has skewed perceptions of the AI/AN burden of cancer because the AI/ANs represented in SEER are largely from the Southwest.
- AI/ANs have high rates of poverty. Of the ten poorest counties in the U.S., eight are AI/AN communities. Half of these are in western South Dakota and are occupied by Northern Plains Natives.
- Efforts are under way to integrate the regional AI/AN cancer data with social and economic data. This will contribute to the development of a multilevel model of disease causation that evaluates individual and population health by taking into account social and economic policies, institutions (including medical care), neighborhoods and communities, living conditions, social relationships, individual risk factors, genetic/constitutional factors, pathophysiologic pathways, and the physical environment.
- Indian Health Service (IHS) spends considerably less per capita than other Federal health care programs. While the VA spent nearly \$4,800 per person in 2001, IHS spent only \$1,776. Approximately 40 percent of the IHS budget is set aside for contract health services (i.e., services not delivered through IHS facilities). These contract funds are usually depleted several months before the end of the IHS fiscal year, which results in many people having their health care delayed.
- Several recent and ongoing initiatives have been attempting to address the cancer burden among AI/ANs. The Centers for Disease Control and Prevention Breast and Cervical Cancer Early Detection Program has been serving tribal communities for ten years. NCI provided funding for Education and Research Towards Health (EARTH), a long-term study investigating how lifestyle, diet, physical activity, and other factors influence the health of AI/ANs. IHS is launching a new colorectal cancer

screening initiative to try to increase screening among AI/ANs. There are also a number of community-based interventions being carried out to try to lower cancer risk among AI/ANs.

- There have been some economic development activities among AI/AN tribes, most related to casinos. However, fewer than half of Native tribes have casinos and most of these do not generate meaningful profit.
- The low rates of cancer among some regional AI/AN populations may provide an opportunity to gain insight into factors that protect against cancer. These findings could have implications for other populations.
- Social inequities have a profound impact on the health status of AI/ANs. The tribes have been harmed by several ineffective and detrimental social and economic Federal policies over time. Improvements in social condition are needed to alleviate the dramatic disparities in health.

## **DISCUSSION AND CONCLUDING COMMENTS:**

### **PANEL I**

#### **Key Points**

- Regional cancer incidence rates vary much more among AI/AN populations than among whites. The degree of genetic diversity among AI/AN populations is not known because population-based genetic studies have not yet been done. A study will soon be initiated to look at genes and single nucleotide polymorphisms (SNPs) involved in smoking and nicotine metabolism among Northern Plains and Southwest AI/AN populations; this should provide some insight into genetic diversity.
- The dramatic differences in cancer incidence among different AI/AN tribes provide opportunity to examine protective factors as well as those that impart risk of cancer.
- Social and economic factors are among the most significant contributors to the poor health outcomes experienced by AI/ANs and must be addressed to eliminate health disparities. In addition, more health services are needed for these populations. Additional funding is needed for the Indian Health Service, in particular for the contract health service budget. However, enhancing patient advocate/navigation services would have a more significant impact with relation to increasing timely access of AI/ANs to high-quality cancer care. Navigators understand the logistical challenges experienced by Native people and can talk to AI/ANs about these issues, which, among other things, encourages clinical trial participation. Navigation has a role across the full continuum of cancer care, from prevention to survivorship or end of life.
- Most CAM studies examine symptom management and quality of life, but some have looked at effects on survival. Most of the alternative approaches that have been tested in the U.S. (e.g., shark cartilage, vitamin C) have not shown a positive impact on survival. The U.S. is currently trying to learn more about integrated approaches being used in Asia.
- Most data about CAM use are based on a very broad definition of CAM, which makes it difficult to distinguish the approaches being used by different populations, including racial/ethnic minorities. More granular survey instruments are needed to clarify which types of CAM are being used by which populations.
- The lack of discussion between patients and providers regarding CAM is problematic. More research is needed to determine how to promote these discussions.
- Developing a regulated herbal therapeutics market in the U.S. would increase access to these interventions for populations that prefer to utilize well-developed, evidence-based herbal therapy.
- Virtually all Native American cancer patients utilize CAM, with most using some form of traditional Indian medicine. It is important that patients be encouraged to let their physicians know what

traditional approaches they are using in a way that does not violate the sacredness of the traditional medicine. Western providers also should communicate directly with traditional healers to make sure that the traditional approaches will not interfere with the Western treatments.

- CRCHD develops outcome measures for each of its programs so they can be evaluated. NCI devotes approximately \$250 million a year to health disparities. More funding is needed to support current programs and export effective approaches to the community.
- NCI is partnering with the African Organization for Research and Training in Cancer to create training opportunities for physicians in Africa. NCI also is doing work with some Latin American countries.
- Researchers are looking at gene-environment interactions that may contribute to differences in lung cancer among different populations. Some studies are examining whether genetic ancestry can influence risk of lung cancer. It has become easier to measure exposure to tobacco-related carcinogens, which should provide insight into differences in environmental exposures to various toxins.
- Options for increasing patient-provider language concordance include training providers in languages used by their patients (e.g., medical school curriculum) and using fluency in another language as a selection for medical school. In addition, funding is needed for translation services so that professional translators can be consistently used.
- Researchers need to consider biological, social, environmental, and other individual factors that influence disease. Differences among racial/ethnic groups may help determine how these factors are operating and interacting.
- Emphasis needs to be placed on developing, implementing, and evaluating culturally appropriate interventions. Collecting data is useful, but interventions are needed to reduce disparities. In addition, although evidence-based interventions are preferable, it must be recognized that the research on these interventions has generally not been done in medically underserved communities, so the results must be interpreted cautiously.
- The solutions to health disparities largely lie within the communities that experience disparities. Researchers must use truly participatory approaches to ensure that these communities have ownership of the research projects being conducted. Much of what is currently labeled as community-based participatory research lacks many of the principles critical for this type of approach.

## **PUBLIC COMMENT**

### **Key Points**

- Many tribes prohibit or discourage members from participating in genetic research because they have been insulted by the fact that some previous studies have not involved informed consent and/or have failed to report research findings back to the community. However, there have been some examples of successfully involving Native communities in genetics research; in these cases, researchers have worked respectfully with the community over a long period of time and given the community a voice.
- People exposed to secondhand smoke have an increased risk of myocardial infarction, and light and nondaily smokers likely have at least this level of risk. Although the risk of cancer is lower among light and nondaily smokers than among heavy smokers, it should not be ignored.

## PANEL II

### DR. SAMIR KHLEIF:

## CANCER CARE: VIEWS FOR THE MIDDLE EASTERN POPULATION

### Background

Dr. Khleif earned his M.D. from the University of Jordan School of Medicine. He completed his residency in internal medicine at the Medical College of Ohio and his fellowship in medical oncology at the National Cancer Institute. Dr. Khleif carries American Board certifications in both internal medicine and medical oncology. He currently serves as Chief of the Cancer Vaccine Section at NCI and as a professor of medicine at the Uniformed Services University for Health Sciences. Dr. Khleif's research program focuses on understanding the interaction between the immune system and tumor cells and utilizing this understanding for the development of novel immune therapeutics and vaccines against cancer. Through an agreement between the U.S. Department of Health and Human Services and Jordan, Dr. Khleif was appointed Director General and Chief Executive Officer of the King Hussein Institute for Biotechnology and Cancer. Dr. Khleif led development of this unique new regional clinical and research institute, which will provide a unique environment for cancer patients and serve as a hub for biotechnology and life science research and development for the Middle East. The project is under the patronage of his majesty King Abdullah II as one of the leading projects in the region for economic development. Dr. Khleif also served as a Special Assistant to the U.S. Food and Drug Administration Commissioner from 2006-2009. During that tenure, he led a national effort to restructure the drug discovery and development system in cancer into a more efficient, innovative, and less expensive system.

### Key Points

- Jordan is a country on the eastern shore of the Mediterranean Sea with a population of approximately 7 million. Half of the Jordanian population is under the age of 15.
- The U.S. had an agreement with Jordan to build the 130-bed King Hussein Cancer Center (KHCC). KHCC is the only cancer center in Jordan and has become the referral center for the entire country as well as seven other countries in the region. Approximately 3,500 new cancer cases are seen there each year. The U.S. was also asked to help build the King Hussein Institute for Biotechnology in Cancer, a 260-bed cancer center. The insights gained through these efforts are relevant for other cancer-related efforts in the Middle East as well as for the U.S. Middle Eastern population.
- Data from the Middle East Cancer Consortium indicate that the incidence rates of cancer in Jordan, Egypt, and Cyprus are lower than overall rates observed in the United States; however, mortality rates are higher in Jordan than in the U.S. This is in part because more than 70 percent of cancer patients in Jordan are diagnosed with clinically advanced disease.
- Although the types of cancer diagnosed in Jordan are similar to those in the U.S., some cancers—such as bladder cancer and leukemia—are relatively more common in Jordan.
- Among Jordanians, there is a general lack of knowledge about cancer and a strong stigma associated with cancer diagnosis. People often do not want to use the word *cancer*, instead calling it “the other disease” or “the sneaky disease.” There is also a perception that cancer is a death sentence, and many cancer patients become socially isolated after their diagnosis. Many Jordanians think that cancer is contagious or a curse.
- The stigma associated with cancer also causes issues with truth telling. Patients often do not want to know their diagnosis or prognosis, or family members do not want the patient to be given information. This makes it challenging to provide care, particularly palliative care. It is also difficult to offer patients psychiatric care, which is considered an insult.

- Jordan, like other Middle Eastern countries, has a patriarchal social structure. Families provide tremendous support for patients, including financial support, and are a source of personal identity. This structure has both advantages and disadvantages. Family and social structures influence patient-doctor relationships and must be taken into account when delivering care. Physicians are expected to deliver information about diagnosis and prognosis to the patient's father or husband or the patriarch of the family, not the patient. In addition, physicians are viewed as patriarchal figures, which means that patients do not generally question a physician's advice or decisions. Patients may be afraid that asking their physician a question would be offensive because it would be viewed as questioning the physician's judgment.
- Informed consent is not required by law in Jordan or neighboring countries, although this is changing.
- The issues of stigma, truth telling, family structure, and lack of regulation/governance must be addressed at the patient, family, and public levels.
- When the KHCC was opened in 2002, the Center designed a model for introducing the culture of truth telling. The name of the Center deliberately included the word *cancer* to increase general familiarity with the word and make it clear to patients that they were being treated for cancer. King Hussein visited the Center to increase the visibility of the name. There was initially a very negative reaction from the media and some Jordanian officials. Efforts were made to continue educating the community by sponsoring events and providing information to the media so that the name of the Center and the word *cancer* would be prominently displayed. Cancer patients were also encouraged to continue their normal lives during treatment to maintain their visibility in hopes of reducing the stigma of cancer.
- These efforts paid off; within a few years, many people began to feel it was important to face cancer openly. This illustrates that major shifts in cultural norms can be accomplished, but they must be approached with a very deep understanding of the culture.
- Prior to the changes implemented by KHCC, less than 40 percent of cancer patients knew they had cancer. This has increased to 96 percent.
- KHCC provides information to both patients and families and facilitates family participation. Disease coordinators at the Center provide education about the disease. The Center also engages clergy because faith is an important part of Jordanian culture. KHCC has implemented informed consent to empower patients, and support services, such as support groups, psychooncology services, and palliative care, are provided.
- The strong family and tribal structure of Middle Eastern cultures has implications for genetic testing, particularly in settings in which there are no regulations regarding patient confidentiality. If a family or tribe is labeled as having a genetic disease, it will be stigmatized. It is important that Middle Easterners be provided with proper counseling prior to genetic testing.
- Some Middle Easterners do not want to be screened for cancer because they do not want to find out if they have an illness. This concern must be addressed through educational campaigns. It is also important that there is infrastructure in place to follow up on positive or suspicious screening results.

## **DR. WIZDOM POWELL HAMMOND:**

### **CLINICAL EXPERIENCES OF COMMUNITIES OF COLOR**

#### **Background**

Dr. Wizdom Powell Hammond is Assistant Professor of Health Behavior and Health Education at the University of North Carolina (UNC) at Chapel Hill Gillings School of Global Public Health. She completed her Ph.D. in clinical psychology at the University of Michigan. She also completed her M.P.H. at the University of Michigan School of Public Health. Following her training, Dr. Hammond was a

Robert Wood Johnson Health and Society Scholar at the University of California, San Francisco and Berkeley. Dr. Hammond has been the recipient of numerous awards, including the American Psychological Association Minority Fellowship, the Ford Foundation Predoctoral Fellowship, and the Loren Frankel Dissertation Research Award (American Psychological Association, Division 51). Her research focuses on investigating psychological and social determinants of health—both mental and physical—for African-American men across the lifespan. She specifically focuses on the influence of gender, intergenerational transmission of health, socioeconomic status, social processes such as racial discrimination, health-related attitudes, and behavior on health status. Her work helps inform studies of health disparities and differences in cancer outcomes across the racial, gender, and economic spectrum. She is in the process of establishing a clinical practice at the North Carolina Cancer Hospital where she will provide psychooncology services to individuals and their families facing cancer diagnoses.

## Key Points

- In 1996, the President's Cancer Panel recommended that measures be taken to ensure that minorities, the poor, the elderly, the uninsured, and the underinsured not be excluded from access to appropriate cancer care as the health care system evolves. Unfortunately, over ten years later, this recommendation has gained even greater urgency in the midst of health care reform, economic crisis, and increasing population diversity.
- It is projected that by 2030 cancer incidence will have increased by as much as 45 percent for the general population and 99 percent for ethnic minorities. Rate increases of 64 percent are expected for African Americans, 76 percent for American Indians/Alaskan Natives, 132 percent for Asians/Pacific Islanders, and an astounding 142 percent for Hispanics/Latinos. These cancer incidence projections are a grave indicator of the need to intercede with effective prevention, education, screening, and care interventions.
- The clinical experiences of minority populations play a critical role in the health disparities that exist across the entire cancer continuum. These experiences are characterized and shaped by racial bias and discrimination, lower-quality patient-provider interaction, lower use of or delayed screening, and information gaps about diagnosis, treatment, and follow-up care.
- Disruptions in quality care caused or perpetuated by perceptions of racial prejudices have been extensively documented. African Americans are more likely than whites to have felt disrespected in the medical setting on the basis of race or ethnicity. Additionally, a national survey showed that 16 percent of African Americans, but only 1 percent of whites, answered affirmatively to a question of whether they felt that they would have received better medical care if they were of a different ethnicity.
- Another national survey of urban populations suggests that perceptions of unfairness in the health care system are more pronounced among African Americans, with 56 percent of African Americans and 40 percent of whites indicating that they felt that the health care system often treats people unfairly based on their race or ethnic background.
- Ethnic barriers are even more pronounced in rural populations. For example, in the rural South, African Americans are twice as likely as their white counterparts to report perceived racial barriers to health care that may influence satisfaction with care and trust for medical providers.
- Evidence suggests that these racial perceptions are grounded in an unfortunate reality. Recent experimental studies show that physicians hold unconscious racial biases and stereotypes about African-American patients, which can affect care delivery and treatment decisions.
- Patients desire provider interactions that maintain their sense of ownership over their bodies and inform their decision making. They want interactions that are built on trust that is demonstrated by the provider's honesty, patience, kindness, interest, and continuity of care.



- At the UNC Men’s Health Research Lab, researchers learned that African-American men have higher medical mistrust when they have experienced everyday racism and lower medical mistrust when they have had a recent patient-centered physician interaction. These findings indicate that medical mistrust stems from proximal social experiences and features of the patient-physician interaction; thus, medical mistrust is a barrier that can be minimized through structural intervention.
- When considering patient-provider interactions, patient preference should not be overlooked. A highly cited study indicates that African-American patients report greater satisfaction with care when they are treated by physicians of the same race. A more recent study has found that perceived similarity of physician values and beliefs with the patient’s own is just as important as race concordance.
- The best treatment advances across the cancer care continuum result from cancer clinical trials. Yet, racial and ethnic minorities are largely absent from clinical trials, with data suggesting that less than 3 percent of adult patients in these population groups participate.
- While medical mistrust is a major barrier to clinical trial participation, the most significant documented barriers relate to lack of opportunity for participation. In fact, when comprehensive clinical trial recruitment strategies are used that equally provide opportunity for participation, there is no difference in rates of participation between ethnic minority and majority population groups.
- One notable solution to the dismal clinical trial participation rates among ethnic minorities is NIH’s policy on the inclusion of women and minorities in clinical research. Established in 1993, this policy dissuades research development and methodologies that propose generalizability of results from homogeneous samples. If members of certain ethnic or social groups are systemically excluded from clinical research, there is potential for resulting harm to the entire population.
- Another solution involves making intentional efforts to engage growing underserved populations to prevent, control, and treat cancer. An exceptional national example to build upon is the Communities as Partners in Cancer Clinical Trials project, which was created by the Education Network for Advancing Cancer Clinical Trials and the Community Cancer Partnerships for Health. This initiative has produced detailed recommendations that call for the inclusion of community members on Internal Review Boards, the formation of community advisory boards, and the establishment of partnerships with patient advocacy and community-based organizations. These efforts are to ensure that clinical trial results are clearly communicated in an effective manner for all minority and non-English-speaking populations.
- Also of note is the Eliminating Disparities in Clinical Trials (EDICT) project, which was developed to make information available about clinical trials and tested strategies that have been used to eliminate disparities in recruitment and retention of minority populations.
- These national examples were taken into consideration when developing Project CONNECT—a partnership between the University of North Carolina at Chapel Hill and Shaw University. The purpose of this local-level project is to encourage more community involvement in research. The program provides technical assistance to principal investigators about how to engage the community and share local opportunities to participate in research. The Project CONNECT registry currently includes 716 community volunteers interested in possibly participating in research studies focusing on health topics such as cancer, social support, care giving, psychological well-being and mental health, and sleep disturbances.
- Also developed from these outreach efforts is a program involving community research advocates (CRAs), which uses a lay health advisor model to identify natural leaders to engage community members and generate dialogue about health research. Over a one-year period, the CRAs have reported 158 one-on-one interactions (mostly taking place in workplaces and churches), 19 group discussions, and 12 community outreach activities.

- The UNC Community Bridges to Cancer Clinical Trials initiative extends the natural leader model to grassroots community organizations which already have an extensive history of community breast or prostate cancer education activities.
- Dr. Giselle Corbie-Smith and other colleagues at UNC are working to develop a statewide Cancer Clinical Trials Community Advisory Board to improve access to local cancer clinical trials. This community advisory board will provide a venue for survivors and advocates to voice their experiences. It will also foster meaningful participation of advocates to review study concepts and protocols, pretest study materials, and endorse messages and tools. Such efforts will increase awareness of clinical trials from the ground up.
- Policy-level support is also needed. Additional guidance and political accountability will ensure that education about clinical trials occurs in diverse communities and development and dissemination of tools and strategies for physicians, researchers and advocates persist.
- Minority communities wish to see an end to the unnecessary suffering and premature deaths caused by cancer health disparities. They are eager to join the efforts to eliminate disparities, but not as silent partners—they want their voices heard.

## **MS. VENUS GINÉS:**

### **AMERICA'S DEMOGRAPHIC AND CULTURAL TRANSFORMATION: LATINO/HISPANIC IMPLICATIONS FOR THE CANCER ENTERPRISE**

#### **Background**

Ms. Ginés earned a B.A. from California State University and an M.A. from Georgia State University, with her study focusing on the cultural and system barriers faced by Latinas with breast cancer. She presented at a Congressional Panel to promote recognition of the term “Latino” as a proper category for the new population from Latin America; all Federal programs must now include both terms. Nationally, Ms. Ginés serves on the Intercultural Cancer Council, the *Redes en Acción* Steering Committee, and the NCI Director’s Consumer Liaison Group, and as a charter member of the Susan G. Komen for the Cure National Hispanic/Latina Advisory Council. Ms. Ginés is a Leadership Atlanta Class of 2004 alumni, a research associate at Kennesaw State University, and adjunct instructor at Morehouse School of Medicine. She served on the Board of Visitors for Grady Hospital, WellStar Health System, and Emory Healthcare, and as a board member of the YMCA Metro Atlanta. She founded the Intercultural Center for Health & Wellness in 2004 and concluded the Community Voices Video, which included women from 12 Latin American countries speaking on disparities. She serves on the Texas Comprehensive Cancer Coalition, serving as Chair of the Survivorship Committee. She is currently a faculty member of the Baylor College of Medicine Chronic Disease and Prevention Center and is conducting research on Latina medical mistrust.

#### **Key Points**

- The impact of the emerging Latino population needs to be considered more seriously since it is now the fastest growing population in the U.S. Currently, there are 45 million documented Latinos in the U.S.; by 2050, Latinos will represent 25 percent of the population, with over 98 million people.
- The median age of the Latino population is 27 years—34 percent are age 18 or younger. Many are foreign born (40 percent) and multiethnic (i.e., they cannot be categorized under just one ethnic category) and may be a combination of white, African American, Asian/Pacific Islander, or Native American/Alaskan Native. Over 60 percent of Latinos are Mexican American, but over 22 countries of origin are represented among the population.
- Among Latinos, 22 percent live in poverty, 40 percent earn less than \$20,000 per year, 41 percent have less than a high school degree, 48 percent do not have health insurance, and 46 percent have

limited English proficiency. Unfortunately, Latinos are less likely to seek and receive health care and preventive services than other ethnic populations.

- The Latino/Hispanic population is diverse in terms of immigration, national origin, migration patterns, historical backgrounds, language, dialects, and cultural values/beliefs. At least 2 million of the Latinos from Mexico are seasonal/migrant workers who are not welcome to remain in the U.S. but are desperately sought after as cheap labor. Latinos from Puerto Rico are U.S. citizens and often travel back and forth. Central American Latinos are often refugees looking for asylum. Many Latinos from South America speak other languages in addition to Spanish, including Portuguese and Italian.
- It is important to understand the difference between the terms Hispanic and Latino. “Hispanic” was initiated as a category for the Spanish-speaking population in the U.S. during the Nixon administration. However, over the last 30 years, an influx of immigrants have come from Latin America, warranting a better category term for the population.
- Of all major ethnic groups, Latinos have the lowest rates of health insurance coverage. The majority are seasonally or temporarily employed, and many of their employers do not provide health insurance. Consequently, although many undocumented immigrants live, work, and pay taxes in this country, they cannot access public safety net programs, except for emergency Medicaid.
- Programs geared to reduce cancer health disparities are not reaching at-risk Latino communities because of miscommunication. Latinos do not all speak the same language and have different literacy levels. People who are cognizant of cultural barriers are needed to deliver the information at an understandable level to this population.
- Día de la Mujer Latina (Day of the Latin American Women [DML]) was formed in 1997 as the first Latina health and wellness event, with specific emphasis on breast and cervical cancer education and screening. Today, this culturally tailored health fiesta is celebrated in 30 states and in Puerto Rico. Much of the success of DML is attributed to Latino community health navigators called promotoras, who are fully knowledgeable of the disparity issues surrounding the population and provide health education and facilitate screening, follow-up care, and patient navigation for poor underserved and uninsured Latinas.
- Texas was the first state in the U.S. to implement a certified promotora/community health worker (CHW) training program. Officially, Texas law defines a promotor(a) or CHW as a person who, with or without compensation, serves as a mediator between communities and health and human services systems, provides informal counseling and social support, provides culturally and linguistically appropriate health education, advocates for individual and community health needs, ensures that people get the health services they need, builds individual and community capacity, or provides referral and follow-up services.
- The utilization of promotoras to bridge the gap that exists in educating and navigating at-risk, vulnerable Latino populations to preventive care should be explored nationally to eliminate risk factors to cancer, such as obesity, lack of insurance, and lack of culturally competent health care providers.
- Two years ago, DML developed the Medical Abuse and Medical Mistrust Awareness Survey (MAMMAS©) Instrument and pilot-tested it at the health fiestas in Puerto Rico, Houston, Miami, and Atlanta. The goal was to determine how Latinas felt about medical institutions and providers who did not speak Spanish. Specifically, promotoras asked the women if they would get the human papillomavirus (HPV) vaccine for themselves or for their daughters if their doctors recommended it. In Puerto Rico, the women responded that they did not trust American health care providers because of past historical abuse, such as sterilization without consent or being used as guinea pigs for pharmaceutical therapies or research. If the doctor was Latino, the women would consider it, but definitely not for their daughters. When 64 Latino physicians in Puerto Rico were asked if they would give the HPV vaccine to their daughters, only one responded yes.

- In Houston and Atlanta, results were centered on anti-immigrant backlash as the real deterrent to accessing health care. However, not all Latinas shared the same perspective on the U.S. medical system. The women surveyed in Miami, comprising Cubans and South Americans, reported that fear or mistrust played only a small role in access to screening or clinical trials.
- In order to determine if mistrust was an isolated issue to Latinas, the EDICT Project, initiated by the Chronic Disease Prevention and Control Research Center at Baylor College of Medicine, launched eight regional meetings and six focus groups to hear the voices of underrepresented populations in clinical trials (i.e., African Americans, American Indians, Asian Americans/Pacific Islanders, Native Hawaiians, Latinos/Hispanics). Mistrust was a theme shared by many of the community navigators as the main barrier to their specific populations' participation in clinical trials.
- Cultural factors including values, beliefs, and traditions influence health behaviors, attitudes toward illness, and trust in medical care. Traditional values such as family, respect, personal familiarity, and trust are important to Latinos and affect how they utilize health care services. The Latino/Hispanic family makes medical decisions as a unit—*la familia*. The wife/mother is the center of the unit; if Latinas are empowered with the right information, it will be spread throughout the extended family.

## **DR. MARJORIE KAGAWA-SINGER:**

### **PUTTING CULTURE INTO “CULTURAL COMPETENCY”**

#### **Background**

Marjorie Kagawa-Singer, Ph.D., M.A., M.N., R.N., is a professor at the University of California, Los Angeles (UCLA) School of Public Health and Department of Asian American Studies. Her clinical work and research have been in oncology and the etiology and elimination of disparities in physical and mental health care outcomes for communities of color, primarily with the Asian American and Pacific Islander communities. She serves on multiple local, state, and national committees addressing the impact of culture and ethnicity on health care and health outcomes, and has published and lectured extensively on cross-cultural issues in health, cancer, pain, grief and bereavement, survivorship, end-of-life decision-making, and quality of life. She also focuses on the impact of culture and cultural competency through her research on health outcomes, and the cross-cultural validity of health behavior theories and measures in communities of color. Dr. Kagawa-Singer is the regional principal investigator in Los Angeles for the NCI-funded Asian American Network on Cancer Awareness, Research and Training, and the NCI-funded UCLA Minority Training Program for Cancer Control Research.

#### **Key Points**

- Despite years of effort to eliminate health disparities, neither the quality nor the quantity of cancer care is equally distributed among all population groups in the U.S. today.
- Ethnic “minorities”—a term historically applied to population groups of color (i.e., American Indian/Alaskan Native, Latino/Hispanic, African Americans, Asian Americans)—are predicted to be the majority population by the year 2050. Due to the aging and growth of these communities of color, a 99 percent increase in incidence of cancers is anticipated for minorities.
- Race does not equal culture and does not equal ethnicity. There is no such thing as race. It is an assumed genotype based on a phenotype—a scientific myth. A better biological term is *population group*—a population that has similar adaptive physiologic responses and cultural practice due to ecologic niche. Culture is a system of beliefs, values, lifestyles, and ecologic and technical resources and restraints. Ethnicity is a subgroup within a power structure of a multicultural society; membership in ethnic subgroups is based on self-identification.
- Scientifically, there are defined, clear measures of the social determinants of health, such as education, poverty, and income, but the concept of culture and its relationship to cancer remain

poorly understood. Cancer researchers and clinicians have ignored culture as a key variable in health disparities, and, consequently, have made no progress in eliminating these disparities.

- The impact of culture on cancer outcomes is multifactorial because culture is a multidimensional, dynamic construct that influences the meanings assigned to the threat of cancer and behavioral and emotional responses to the disease and the health care system, as well as the response of health care practitioners to diverse patients and the way health care delivery is designed.
- Culture provides common ways to find meaning and purpose in life and proscribed ways of promoting health and treating sickness. Different tools, beliefs, and practices are used by cultural groups to manipulate their environment for food and shelter; make cognitive and emotional sense of the chaos of reality around them; and find meaningful, structured modes of social interactions to support the well-being of group members.
- Too often when assessing ethnic group differences, discrete cultural beliefs and behaviors (“threads”) are removed and compared across cultural groups for their inherent characteristics. However, the usefulness of particular beliefs or behaviors cannot be judged unless seen within the pattern of the entire “cultural fabric” within which they are meant to function.
- Proper standardization of definitions and measures of culture are needed before research in health disparities can advance. A study was conducted using Medline and the World of Science search engines to look at health research studies done between 1920 and 1999. Half of the studies dealt with racial/ethnic differences but only 10 percent of those actually defined race or ethnicity in the study. Data quality becomes questionable if the cross-cultural equivalency of the study is not validated.
- The International Committee of Medical Journal Editors established guidelines for publication of studies of multiple ethnic groups that require authors to provide explicit statements about the necessity for racial/ethnic comparisons, descriptions about how the groups were identified, options provided for the respondents, and indications of how the categories were grouped for analysis. Implementation of these guidelines would enable researchers and clinicians to more confidently compare results across studies.
- Multiracial individuals comprise a growing population in the U.S. Thus, generalizations based upon racial categories should be avoided; more scientifically accurate and clinically applicable subgroups should be developed. The non-Hispanic white population is the usual comparison group for health disparities studies, yet the highly diverse subgroups of this population have their own concepts of health, lifestyles, and healing systems.

## **DISCUSSION AND CONCLUDING COMMENTS:**

### **PANEL II**

#### **Key Points**

- Patients should be treated as individuals. This approach must include understanding of a person’s background, including their country of origin. There are many studies about foreign and U.S. Middle Easterners that may provide insight to providers into how best to serve these populations.
- Researchers have the potential to do more harm than good when they study or work with special populations such as those in other countries. One way to avoid this would be to require U.S.-funded studies that will be conducted outside the United States to be reviewed by a specialized panel of culturally sensitive experts.
- Cancer patients are beginning to be diagnosed at earlier stages of disease in Jordan. It is important to ensure that there is infrastructure to accommodate increasing cancer diagnosis and treatment before undertaking efforts to increase cancer awareness and screening. It is also important to change cultural

norms so that people will be willing to seek and accept care if they are presented with a cancer diagnosis.

- One hypothesis for the high burden of bladder cancer in Jordan is the high number of smokers of black tobacco in that country. More than half of adults are smokers and nearly 25 percent of boys between 12 and 15 years old are already smoking.
- Using patient navigators is one way to connect community members with the health care system. Navigators should not be viewed as peripheral to the health care system, but should be made an integral part of the health care workforce. Each institution and system should develop a navigation plan that suits the population it serves (e.g., taking into consideration culture and gender issues).
- Community navigators, called promotoras in some communities, are also effective for reaching underserved populations. They can teach people about healthy lifestyles and preventive care and may help keep people from seeking standard medical care in emergency rooms. Community navigators should be linked with patient navigators already being funded by NCI and used by many institutions.
- Categorizing individuals by race and color can have detrimental effects. Society and science should develop more scientifically based methods for identifying and studying different populations.
- The partnership between UNC and Shaw University was built on the principles of community-based participatory research. It was important that Shaw be recognized as an equal partner and not a “little brother” to UNC. The dynamic of trust and respect between the institutions must be maintained, even as the partnership evolves over time.
- All Latinos do not fit under the definition of Hispanic developed for the U.S. Census. For example, Brazilians are Latino but not Hispanic. Not all Latinos speak the same language; even among Spanish speakers, there are different dialects and usage patterns.
- Ethnicity is very important to many individuals, but it should not be the standard by which they are judged by society. Until the U.S. recognizes that it is a race-based society, it will be difficult to make progress against health disparities.
- It is important to recognize that minority mistrust of the health care system is based on rational thought and experiences. Efforts should be made to address the elements of the health care system that drive minorities and underserved populations to be mistrustful rather than simply telling them they should trust their providers. Cultural competency needs to be a more central part of clinical training.

## **PUBLIC COMMENT**

### **Key Points**

- When personalized medicine is achieved, each patient’s genetic profile will be available to clinicians to inform the medicines prescribed, dietary instructions given, and preventive measures advised. This type of approach will supercede discussions of race and ethnicity. However, it will be decades before the benefits of personalized medicine reach the entire population, particularly minority and underserved communities. Even when personalized medicine becomes a reality, it will be important to treat people as individuals with unique backgrounds and experiences.
- It takes substantial time to build the strong relationships with communities that are necessary to do community-based participatory research. This must be recognized by NCI and other funders. NCI recently reissued the Request for Applications for its Community Networks Program, which is focused on involving the community in health disparities research.

- Funding mechanisms are needed to allow community advocates to develop an evidence base for the programs they are implementing in communities. Most mechanisms require applicants to have peer-reviewed publications, which disqualifies many knowledgeable advocates from gaining support. Advocates should team up with researchers to take advantage of the grants system. There are also some funds available for pilot projects that do not depend heavily on publication record or past research success.

### **CLOSING REMARKS—DR. LASALLE D. LEFFALL**

- Dr. Leffall thanked the panel members for their presentations.

### **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 February 2, 2010, is accurate and complete.

Certified by: \_\_\_\_\_ Date: April 23, 2010  
LaSalle D. Leffall, Jr., M.D.  
Chair  
President’s Cancer Panel