



President's Cancer Panel • 2009-2010 Annual Report

# AMERICA'S DEMOGRAPHIC AND CULTURAL TRANSFORMATION: Implications for Cancer

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES • National Institutes of Health • **National Cancer Institute**





## THE PRESIDENT'S CANCER PANEL

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This report is submitted to the President of the United States in fulfillment of the obligations of the President's Cancer Panel to appraise the National Cancer Program as established in accordance with the National Cancer Act of 1971 (P.L. 92-218), the Health Research Extension Act of 1987 (P.L. 99-158), the National Institutes of Health Revitalization Act of 1993 (P.L. 103-43), and Title V, Part A, Public Health Service Act (42 U.S.C. 281 *et seq.*).

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# AMERICA'S DEMOGRAPHIC AND CULTURAL TRANSFORMATION: Implications for Cancer

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The President's Cancer Panel

March 2011

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
National Institutes of Health  
**National Cancer Institute**



The President  
The White House  
Washington, DC 20500

Dear Mr. President:

The United States is in the midst of a demographic transformation that is changing the cultural landscape of the nation. The current wave of immigration, which began in earnest in the 1960s, continues to accelerate. Minorities, now roughly one-third of the U.S. population, are expected to become the collective majority before the middle of the century. Differing subpopulation rates of immigration, aging, and birth and mortality are driving this transformation.

The nation's changing sociocultural composition has implications for virtually every aspect of American life, especially public health and the delivery of health care. Factors such as educational attainment, economic status, age, household composition, health insurance status, and cultural factors—all of which vary among and within population subgroups—can influence disease risk, affect the extent and quality of interactions with the health care system, and increase or decrease the extent to which individuals enjoy long and healthy lives.

Cancer incidence among minority populations is projected to nearly double between 2010 and 2030, while increasing 31 percent among the non-Hispanic white population. Minority and other underserved populations are disproportionately affected by certain cancers, are often diagnosed at later stages of disease, and frequently have lower rates of survival. These factors, coupled with the expected rise in cancer incidence nationwide owing to aging of the mainly Caucasian population, raise concerns about the future cancer burden. The impact of these increases on overall cancer incidence and mortality is uncertain, in large part because of limitations in the ways in which data are collected. Currently available data, which are based primarily on socially derived definitions of race and ethnicity, are notoriously imprecise and must be used with an understanding of their considerable limitations when attempting to project the cancer burden of the increasingly diverse U.S. population.

The current understanding of cancer risk, progression, and outcomes is based largely on studies of non-Hispanic white populations. The risk factors, screening guidelines, and treatment regimens identified through research are not necessarily appropriate for individuals of non-European descent. As a result, our understanding of the influences of key factors within and across subpopulations—regardless of individuals' socially defined race or ethnic group—is limited. Indeed, the "one-size-fits-all" approach to cancer screening guidelines and prevention and treatment strategies is no longer appropriate. A more robust understanding of risk factors associated with cancer in diverse populations would provide new opportunities to reduce the national burden of cancer through culturally appropriate interventions.

To energize efforts to address these troubling issues, the President's Cancer Panel (the Panel) focused its 2009–2010 inquiry on the changing population demographics in the United States and how this shift may affect the future cancer burden, cancer screening and education, and the delivery of cancer care. The Panel examined the complex interaction of sociocultural, environmental, biological, and genetic factors that contribute to the unequal cancer burden experienced by diverse U.S. subpopulations.

The attached report includes recommendations to the research and health care communities to help propel the nation toward effective cancer education and treatment services that reach beyond traditional ideas of race, ethnicity, and culture. The report also highlights the urgent need for new approaches to characterizing populations and assessing potential effects of changing demographics on cancer incidence and mortality in the coming decades.

Mr. President, we urge you to take action now to ensure that funding for research on cancer and other health disparities is a priority and to address the serious data deficiencies that undermine efforts to tackle these issues. As our nation continues to thrive and change, we must ensure that the cancer enterprise has the tools, data, and skills needed to support ongoing efforts to eradicate cancer for all Americans.

Sincerely,



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



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# Acknowledgements

The President's Cancer Panel is grateful to the Panel staff and support staff who provided valuable input and information for this report. This report would not have been possible without their hard work and dedication.

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# Executive Summary

Cancer incidence among minority populations is projected to nearly double between 2010 and 2030 while increasing 31 percent among the non-Hispanic white population. Minority and other underserved populations are disproportionately affected by certain cancers, are often diagnosed at later stages of disease, and frequently have lower rates of survival once diagnosed.

Racial and ethnic differences in cancer incidence, presentation, and prognosis are well documented. However, the current understanding of cancer risk, progression, and outcomes is based largely on studies of non-Hispanic white populations. The risk factors, screening guidelines, and treatment regimens identified through research are often not appropriate for individuals of non-European descent.

Regardless of race/ethnicity, each individual has a unique complement of cultural, environmental, biological, and genetic risk factors that coalesce to determine cancer risk. Insights into the interactions between multiple variables (e.g., gene-neighborhood interactions) and biological markers of cancer risk and prognosis can be gained through thoughtfully designed research and should ultimately help health care providers more effectively treat patients.

Between September 2009 and February 2010, the President's Cancer Panel (the Panel) convened four meetings to assess the factors that contribute to the unequal cancer burden shouldered by diverse U.S. subpopulations. The Panel received testimony from 39 invited experts from the academic, government, and cancer advocacy communities and from the public.

This report summarizes the Panel's findings and conclusions based on the testimony received and additional information gathering. The Panel's recommendations describe concrete actions that the research and health care communities can take to propel the nation toward effective cancer education and treatment services across the cancer continuum that reach beyond traditional ideas of race, ethnicity, and culture.

## AMERICA'S DEMOGRAPHIC SHIFT

The United States is in the midst of a demographic transformation that is changing the cultural landscape of the nation and is creating new challenges for the delivery of health care. Racial and ethnic minority groups represented roughly one-third of the U.S. population in 2008 but are projected to become the collective majority before the middle of the century. Notably, the Hispanic/Latino population is projected to nearly triple between 2008 and 2050. Slower growth is expected for other minority groups over the same timeframe, and it is expected that the segment of the population whose members identify as being of two or more races will increase dramatically. Despite modest net growth, by 2050 only 38 percent of the U.S. population is expected to identify as single-race, non-Hispanic white, a group that comprised nearly three-quarters of the U.S. population as recently as 1995.

The changing sociocultural composition of the United States has implications for virtually every aspect of American life, including public health and the delivery of health care. Factors such as educational attainment, economic status, age, household composition, health insurance status, and cultural factors—all of which vary among and within racial and ethnic groups—can influence disease risk, affect the extent and quality of interactions with the health care system, and increase or decrease the extent to which individuals enjoy long and healthy lives.

## ASSESSING THE CANCER BURDEN OF A DIVERSE POPULATION

Populations may be defined and classified in many ways: by gender, age, geographic region, urban or rural residence, and other parameters, including race and ethnicity. Census, vital statistics, cancer surveillance, and other health and employment data that include racial and ethnic categories are used to assess the cancer burden of America's increasingly diverse population. These data also influence numerous important decisions that affect cancer and other biomedical research, public policy, and programs and services available to the population.

Currently available data on race and ethnicity are, however, substantially flawed and must be used with an understanding of their considerable limitations when attempting to assess or project the cancer burden of the ever more diverse U.S. population.

### Challenges in Data Collection and Analysis

The U.S. population has become more diverse due principally to immigration, differing subgroup birth and death rates, and the growing number and social acceptance of marriages and other partnerships among individuals from population groups that previously seldom intermixed. This diversity challenges national efforts to identify population groups by race, ethnicity, or culture in order to monitor compliance with civil rights legislation and for other legal, social, health care, research, and political purposes. Further, definitions of the terms "race," "ethnicity," and "culture" used both for data collection purposes and in social interaction are not consistent and the terms often are confused or used interchangeably. Commonly used definitions of these terms vary and often do not make clear distinctions between them. In particular, culture tends to be viewed as a component of race, ethnicity, or both.

Three key factors complicate data collection concerning race and ethnicity: self-report of race and ethnicity, racial and ethnic classification by others, and lack of standardization in data collection related to race and ethnicity.

## The Use of Race, Ethnicity, and Culture in Research

Observers from diverse disciplines share the view that disagreement about the meaning and appropriate use of race, ethnicity, and culture in research is one of the most contentious subjects in science.

Many researchers believe that focusing on socially constructed definitions of race and ethnicity may minimize attention to and evaluation of cultural, social, environmental, and economic influences on lifestyles, attitudes, and behaviors that are likely to have more direct effects on cancer and other disease outcomes. For example, race and ethnicity often are used as proxies for poverty, poor housing/living conditions, lower educational attainment, poor diet and obesity, low physical activity levels, high-risk behaviors (e.g., tobacco use), environmental exposures, and limited access to health care. Yet these factors predict poorer health status and outcomes regardless of individuals' socially defined race or ethnic group.

It has been noted that scientists need to be more aware of their uncritical acceptance of social concepts of race and ethnicity when developing study questions and defining and analyzing different populations. The insidious influence of institutionalized and unrecognized racial bias can have profound effects on the direction and conclusions of scientific inquiry by affecting what questions are deemed worthy of study; who receives funding, mentoring, and training; and how the merits of study findings are judged.

Weaknesses in data resources are of particular importance to researchers and may thwart efforts to characterize populations in a scientifically meaningful way. Importantly, current data sets generally do not capture the variability within groups that is relevant for studies of disease vulnerability and treatment response (e.g., African Americans and immigrants of African origin are all categorized as black; great diversity also exists within both Asian and Hispanic populations related to country of origin). Further, it has been noted that in both research and health care, it is a fallacy to presume that experiences or characteristics of subpopulations are relevant only as they compare to those of non-Hispanic whites, who are as ancestrally and culturally diverse as Asians, Hispanics/Latinos, or other government-defined populations. Aggregating all non-Hispanic whites into a single group does them the same disservice of masking important health-related differences among subgroups as is the case with the other defined racial/ethnic populations.

Because national data sets are not always reliable or truly representative of geographic or sociocultural subpopulations, national surveys may yield conflicting and/or misleading results. Researchers need to integrate information from local providers who interact with communities and local registries to improve the validity of national data sets.

## FACTORS INFLUENCING CANCER RISK, INCIDENCE, SURVIVAL, MORTALITY, AND OUTCOMES

Cancer risk and outcomes result from the complex interplay of numerous socioeconomic, cultural, environmental, biological, behavioral, and genetic factors. Different populations—however defined—have differing patterns of risk factors and risk factor combinations that are reflected in cancer incidence, survival, and mortality rates. Moreover, even within defined population groups, no two individuals have the exact same risk factor profile. To reach the goal of personalized medicine for all, it will be necessary to identify and tease apart the interactions of various risk factors that contribute to disease. Understanding these relationships and their impact on human health will inform the development of strategies to prevent and treat cancer in all populations.

As the United States experiences its ongoing demographic shift, the research community will have to consider how to expand the current understanding of factors that influence cancer risk and outcomes, and how to apply this knowledge for the benefit of all subpopulations.

## Genetic and Biologic Factors

The emergence of molecular biology has led to the recognition that genes play an important role in cancer susceptibility, as well as in the effectiveness and side effects of available treatments. Less clear are the contributions of biology and genetics to the disparities in cancer burden and outcomes between different racial and ethnic populations, although ongoing research is attempting to shed light on this issue. While genetic and biologic processes are rooted in the DNA inherited from one's ancestors, they can be modified—sometimes dramatically—by external factors. Thus, genetic studies focus both on the inherited genome and changes to the genome acquired over the course of a

lifetime. These acquired changes, which include DNA sequence mutations as well as epigenetic modifications that can alter DNA structure and function, are likely due to a combination of genetic susceptibility, lifestyle factors, and environmental exposures. Similarly, the biological traits of individuals and their tumors—such as which genes are expressed and the levels of various proteins present within a cell—are a function of both the inherited and acquired attributes of the DNA as well as cellular responses to the environment.

## Socioeconomic and Sociocultural Determinants of Health

The impact of socioeconomic position, or class, on health outcomes has long been recognized. Yet research has focused primarily on trying to identify health differences according to race and ethnicity rather than on socioeconomic differentials. In many studies, race and ethnicity are used as proxy measures for socioeconomic position, but doing so typically fails to account for specific socioeconomic factors, the interaction of specific combinations of socioeconomic variables, or the socioeconomic heterogeneity within government-defined racial and ethnic groups. Further study of these complex relationships is needed to gain a better understanding of the effects of socioeconomic factors on cancer and other health outcomes.

In addition, cultural and lifestyle factors can have independent and sometimes profound effects on cancer susceptibility and outcome in both native and foreign-born Americans. For example, culture and lifestyle may influence how individuals and population groups perceive health and disease, the priority of obtaining cancer screening and prevention services compared with other demands of daily life, and willingness to trust and engage the health care system.

Limited access to health care has long been a formidable barrier to the most effective known disease prevention and treatment interventions and optimal health status for minorities, immigrants, and other often underserved populations such as the poor and rural residents. Presently, these populations are less likely to receive standard and/or high-quality treatment for cancer. Numerous factors, both individually and in varying combinations, such as lack of health insurance and language differences, may limit access to quality cancer and other health care.

## MOVING FORWARD TO IMPROVE CANCER CARE AND RESEARCH

To improve cancer care and reduce cancer outcome disparities for immigrant, poor, minority, and other disadvantaged people in the nation's rapidly changing population, it will be necessary to expand health care access and improve the quality of patient-provider interactions. In addition, myriad important research questions need to be answered. Many activities are already under way to generate new knowledge and approaches to providing more effective and accessible care for all across the cancer continuum, but significant challenges remain.

### Improving Access to Care and Interaction with the Health Care System

Recent legislative and related health care policy changes, together with (1) greater attention to patient and public education and communication needs and (2) a more diverse and culturally competent cancer care and research workforce, have significant potential to improve both health care access and quality. However, as promising as these actions are for expanding health care access, many of the social determinants that negatively affect health—such as poverty, low educational attainment, inadequate housing, high-risk occupations, toxic exposures, and poor diet—will persist into the foreseeable future for many people in America. Numerous initiatives and interventions are being pursued to ameliorate the health impact of these factors.

### Advancing Research to Reduce the Cancer Burden of a Diverse Population

Much of the progress against cancer in recent decades is the result of research, and continued investment in research will be necessary to further diminish the burden of cancer. Although the use of race and ethnicity as variables or to define study populations in biomedical research is controversial, the concepts are ingrained in society and in research and will likely

continue to be used for the foreseeable future. As such, researchers must consider proper use and context when applying ethnicity, ancestry, or race as variables to ensure that these concepts enhance the value of the research and do not undermine translation of the research to improved human health. It has been suggested that variables describing ethnicity, ancestry, or race should be constructed with regard to the specific research setting and hypothesis and should be clearly explained in published reports; in addition, if these concepts are being used as proxies, researchers should consider whether more specific measures could be developed.

Greater community involvement in research, the development of population-based guidelines, advances in molecular and genetic research, and increasing clinical trial participation are examples of key activities aimed at advancing research designed to prevent, detect, and treat cancer among underserved groups and the U.S. population as a whole.

## Learning from the Rest of the World

An understanding of the social, cultural, environmental, and biological factors that contribute to cancer in countries greatly affected by the disease would likely improve understanding of the cancer burden of populations that have recently immigrated to the United States, but very few of these nations have the resources or capacity to conduct rigorous biomedical research.

Collaborations in which the United States shares its research and technological capability may yield returns both abroad and in this country. These partnerships also may provide insights into social and cultural factors that allow the United States to engage minorities in biomedical research and also may result in medical knowledge that enhances the delivery of appropriate preventive and treatment interventions to diverse populations.

Both commitment and leadership are needed on many fronts to meet the cancer-related needs of America's rapidly changing population. It will be critically important to build upon and contribute to such endeavors both at home and abroad.

## TAKING ACTION TO REDUCE THE CANCER BURDEN FOR ALL

The demographic changes facing the United States raise important questions about how best to conduct cancer research and deliver health care that will reduce the burden of cancer for all of America's people.

The President's Cancer Panel believes several fundamental issues must be addressed to move science, the health care community, and the nation toward effective cancer education and services across the cancer continuum that reach beyond traditional ideas of race, ethnicity, and culture to embrace and honor our true similarities, differences, and humanity.

The Panel concludes that:

### **New Approaches to Data Collection Are Needed to Better Characterize Populations**

Existing vital statistics, census, public and private insurer, and cancer surveillance data are seriously compromised in their ability to accurately characterize populations in ways that would support improvements in cancer prevention, treatment, and population research and cancer care. New approaches to characterizing populations and data collection are urgently needed, as are standardized definitions and data sets.

### **Biologic and Sociologic Factors Must Both Be Examined to Truly Understand the Heterogeneity of Populations and Resulting Health Disparities**

Historically, sociologic factors underlying health disparities have been largely ignored in favor of biologic factors. More recently, there has been a shift away from considering biologic factors for fear that this approach will be equated with or reinforce racism and race-based research and medicine, yet socioeconomic factors still have been inadequately addressed. Race and ethnicity are poor proxies for complex socioeconomic variables because they mask the true heterogeneity of populations and reinforce unproductive generalizations. Relatively recent genetic research has produced evidence that relevant biologic factors may exist in cancer and other diseases, particularly as specific genes or gene products may be affected by interaction with environmental factors. An evidence-based approach to health disparities is needed that includes consideration of both biologic and sociologic factors.

### **In the Quest for Personalized Medicine for All, More Research Is Needed**

Personalized medicine for all is the ultimate goal in cancer care, but is not universally feasible or affordable in the near future. Personalized medicine already is being provided to a limited extent. It needs to be institutionalized to the maximum extent possible, beginning with current knowledge (e.g., lymphoma and colorectal cancer subtyping, targeted anticancer drugs and biologics). Until personalized medicine is a reality for all, research is needed to identify subpopulations at high risk of disease due to genetic/ancestral, biologic, sociocultural, and other factors that directly relate to risk or response to therapy, and then apply findings to each subpopulation.

### **Common Risk Factors Should Inform Cancer Screening Recommendations**

Current one-size-fits-all approaches to cancer screening guidelines are no longer useful, nor are guidelines based on racial differences, however defined. It is essential to consider the universe of patients and identify common genetic and environmental risk factors on which to base screening recommendations.

### **Trained Interpreters Should Be Essential Members of the Health Care Team**

Patient-provider language differences are a significant barrier to the provision of quality cancer and other health care. Trained interpreters, therefore, should be considered essential members of the health care team. Funding to support interpreter training and the crucial communication services they provide is seriously deficient.

### **Health Care Providers Should Incorporate Patient Sociocultural and Socioeconomic Characteristics into Patient Care**

The majority of health care providers do not adequately understand, inquire about, or integrate patient sociocultural and socioeconomic characteristics into cancer and other disease prevention and treatment. This information is critical to providing the best care for each individual.

### **To Eliminate Health Disparities, Social Determinants of Poor Health Outcomes Must Be Addressed**

Poverty, low educational attainment, substandard housing and neighborhoods, and insufficient access to quality health care are the most important determinants of poor health outcomes. Cancer and other health disparities will only be eliminated when these problems are adequately addressed.

## RECOMMENDATIONS

Although the focus of the Panel's meetings was the impact of changing demographics on cancer research and cancer care, many of the identified key issues and recommendations have implications for health

care in general. In light of the pressing imperative to address current and future cancer-related needs of all Americans, the Panel recommends the following:

Infrastructure	RESPONSIBLE STAKEHOLDERS AND OTHER ENTITIES*
<p>1. Action must be taken to address the serious data deficiencies that undermine efforts to better understand and address cancer disparity issues. Specifically:</p> <ul style="list-style-type: none"> <li>▪ The President should direct the Secretary of the Department of Health and Human Services to convene an ongoing, multidisciplinary working group of stakeholders and other interested parties to develop more accurate, representative, and useful ways of characterizing populations and collecting population data so as to improve the quality of research and health care to reduce the cancer burden and ensure social justice. Ethnogenetic layering concepts and methods hold considerable potential for understanding important differences in disease susceptibility and outcome.</li> <li>▪ Until these changes can be made, researchers and other users of existing data sources must be explicit about definitions used, assumptions made, and data weaknesses in research on or underlying policy affecting subpopulations in the United States.</li> </ul>	<p>The President</p> <p>Department of Health and Human Services:</p> <ul style="list-style-type: none"> <li>▪ National Cancer Institute</li> <li>▪ Centers for Disease Control and Prevention</li> <li>▪ National Center for Health Statistics</li> <li>▪ Centers for Medicare and Medicaid Services</li> <li>▪ Indian Health Service</li> <li>▪ Health Resources and Services Administration</li> </ul> <p>U.S. Census Bureau</p> <p>Department of Justice</p> <p>Office of the National Coordinator for Health Information Technology</p> <p>Veterans Administration</p> <p>Civilian Health and Medical Program of the Uniformed Services</p> <p>Population scientists</p> <p>Anthropologists</p> <p>Behavioral scientists</p> <p>Statisticians</p> <p>Advocates</p> <p>Other organizations concerned with ensuring social justice</p> <p>Insurance industry</p> <p>Pharmaceutical and biotechnology industries</p> <p>Biomedical research community</p> <p>Health care provider community</p>
<p>2. Data sharing among government agencies at all levels must be improved. Issues of data compatibility must be addressed and a culture of openness and focus on common goals must be fostered.</p>	<p>Federal government</p> <p>State governments</p> <p>Local governments</p>

\* The Panel recognizes that entities other than those listed may have a vital role or interest in implementation of the recommendations.

<p>3. Outreach and training must be better supported to increase the diversity of the cancer research and care workforces. This outreach must begin very early (K-12 educational level) to ensure that students have the educational foundation for careers in science and health care.</p>	<p>National Cancer Institute Department of Education National Science Foundation</p>
<p>4. Cultural competency must become an integral part of medical school, other medical, and research training curricula, and also should be included in continuing education requirements for all health care providers and administrative personnel.</p>	<p>Association of American Medical Colleges American Medical Association National Medical Association  Primary care, medical specialty, subspecialty, nursing, allied health and other licensure, certification, and training organizations</p>
<p><b>Research</b></p>	<p><b>RESPONSIBLE STAKEHOLDERS AND OTHER ENTITIES*</b></p>
<p>5. Basic, translational, clinical, population, and dissemination research on cancer health disparities must be increased, with a focus on identifying and developing evidence-based interventions to address sociocultural and/or biologic factors underlying the disproportionate burden of cancer experienced by medically underserved, socially disenfranchised, and other identified populations at high risk for cancer incidence and poor outcomes. Specifically:</p> <ul style="list-style-type: none"> <li>▪ Continued research is needed on genetic ancestry and the interaction of specific genetic characteristics with identified risk factors.</li> <li>▪ Funding for research on risk factor variation and interaction should be increased.</li> <li>▪ Social science research as it pertains to cancer health disparities should be increased.</li> </ul>	<p>Public- and private-sector research funding organizations</p>
<p>6. Exploration and evaluation of the benefit of patient navigation models and patient-centered medical home models of care in decreasing cancer and other health disparities should be continued. Attention should be paid to how models can be optimized for various populations.</p>	<p>Department of Health and Human Services:</p> <ul style="list-style-type: none"> <li>▪ National Cancer Institute</li> <li>▪ Agency for Healthcare Research and Quality</li> <li>▪ Health Resources and Services Administration/ Community Health Centers</li> <li>▪ Indian Health Service</li> </ul> <p>State health care commissions American Academy of Family Physicians Medical centers and physician practices Community health centers Health policy evaluators</p>

<p>7. Current cancer screening guidelines should be evaluated to determine their accuracy in assessing disease burden in diverse populations.</p>	<p>Department of Health and Human Services:</p> <ul style="list-style-type: none"> <li>▪ National Cancer Institute</li> <li>▪ Centers for Disease Control and Prevention</li> <li>▪ Agency for Healthcare Research and Quality</li> <li>▪ Centers for Medicare and Medicaid Services</li> <li>▪ Food and Drug Administration</li> </ul> <p>U.S. Preventive Services Task Force</p> <p>Public and private health providers</p>
<p><b>Cancer and Other Health Care</b></p>	<p>RESPONSIBLE STAKEHOLDERS AND OTHER ENTITIES*</p>
<p>8. Policies, including reimbursement policies, should be developed so that health care can be delivered in a manner that enables clinicians adequate opportunity to gather relevant sociocultural and medical information about their patients. This change would result in the provision of more personalized care for patients and improve the quality of patient-provider interactions.</p>	<p>Centers for Medicare and Medicaid Services</p> <p>Other public payors</p> <p>Private-sector payors</p>
<p>9. The importance of language translation services must be appreciated. Providers and hospitals should ensure that professionally trained translators are available and utilized. However, translation services cannot be an unfunded mandate. Mechanisms must be developed to fund this essential component of care.</p>	<p>Physicians and other health care providers</p> <p>Hospitals and health care facilities</p> <p>Joint Commission</p> <p>Department of Health and Human Services:</p> <ul style="list-style-type: none"> <li>▪ Centers for Medicare and Medicaid Services</li> <li>▪ Health Resources and Services Administration</li> </ul> <p>Other public health care payors</p> <p>Private-sector payors</p>
<p>10. Funding for reservation-based and urban Indian health care should continue to increase to improve access to cancer preventive, diagnostic, and treatment services, as well as the primary care services that are the gateway to appropriate cancer care.</p>	<p>The President</p> <p>Congress</p> <p>Indian Health Service</p>



# Preface

The President's Cancer Panel (PCP, the Panel), established in 1971 by the National Cancer Act, is charged to monitor and appraise the development and execution of the National Cancer Program and report directly to the President of the United States regarding barriers or impediments to the fullest and most rapid execution of the Program. The Panel meets at least four times per year and reports its findings annually or more frequently, as needed.

Rapid changes in the demographic composition of the U.S. population have been tracked closely in recent decades. Both experts in and observers of political, economic, and sociocultural patterns and numerous other aspects of American life have studied, predicted, and speculated as to changes that now and in the future will be driven in whole or in part by population trends. Health care arguably has been among the areas of greatest interest, particularly in recent years as the debate about how best to provide and finance health care—and for whom—has grown increasingly strident.

In previous meetings addressing other topics, the Panel noted the growing body of research on cultural, linguistic, socioeconomic, and other differences that may affect the cancer and other health care that individuals receive and the outcomes of their disease. Further, public and governmental awareness of cancer and other health disparities has grown substantially, as has scientific understanding of genetic, molecular, environmental, and sociocultural factors in human disease. The Panel concluded that an examination of population trends, factors that influence cancer risk and outcomes, and efforts to address current and emerging challenges to conducting necessary cancer research and providing quality cancer care would be of value.

Four meetings were convened between September 2009 and February 2010, on the dates and at the locations indicated below:

September 22, 2009	Seattle, Washington
October 27, 2009	Los Angeles, California
December 9, 2010	Wilmington, Delaware
February 2, 2010	Miami, Florida

The Panel received testimony from 39 experts from academia, government, industry, the voluntary/nonprofit sector, and the cancer advocacy and health care provider communities; public comment also was invited.

This report begins with an overview of demographic changes under way in the United States, followed by a discussion of current challenges in measuring the burden of cancer borne by the U.S. population. Subsequent parts of the report focus on factors that influence cancer risk, incidence, survival, mortality, and outcomes and opportunities for improving cancer care and research. The Panel's conclusions, based on the testimony received and additional information gathered prior to and after the meetings, are followed by recommendations for assessing and mitigating cancer risk in a diverse populace. Appendices include a roster of meeting participants (Appendix A), an overview of cancer incidence and mortality trends (Appendix B), and other supplemental information (Appendices C–E).

# Population Data and Descriptive Terminology Used in This Report

In preparing this report, the President's Cancer Panel faced a conundrum concerning data on American subpopulations and the terminology used to describe them. The Panel is acutely aware that labels used by government, the scientific and medical communities, the media, and the public to describe segments of the U.S. population are social constructions not based in science that are used inconsistently and without clarity as to their meaning. Further, consensus and clarity are lacking as to the meanings of race, ethnicity, and culture, from which the population group labels are derived. In addition, these labels have widely varied levels of public acceptability, affecting the extent to which individuals are willing to identify with these artificial population groupings and, therefore, the accuracy of available data. These labels are, however, firmly embedded in existing demographic and scientific data.

The limitations of available data describing population groups in the United States are discussed in depth in Part 2 of this report, as well as in the Panel's conclusions and recommendations. However, these data are the best currently available and of necessity have been used to describe, to the extent possible, population trends, health disparities, and research findings. Readers are encouraged to keep these data limitations in mind when considering statistical data contained in the report.

In this report, the following terms are used interchangeably unless specifically noted otherwise:

- African American, black
- Non-Hispanic white (NHW), white, Caucasian
- Hispanic, Latino/a
- Native American, American Indian/Alaska Native (AI/AN)
- Asian, Asian American
- Hawaiian, Native Hawaiian
- Pacific Islanders, Hawaiians and Other Pacific Islanders



## *part 1*

# **America's Demographic Shift**

The United States is in the midst of a demographic transformation that is changing the cultural landscape of the nation and is creating new challenges for the delivery of health care. This section provides data on demographic trends for various U.S. subpopulations to the extent these trends can be discerned from currently available data. (See page xiii regarding population data limitations.)

## A CHANGING POPULATION

Racial and ethnic minority groups (as currently defined by the U.S. Census Bureau; see Part 2) represented roughly one-third of the U.S. population in 2010, but are projected to become the collective majority before the middle of the century (Figure 1). Notably, the Hispanic/Latino population is projected to nearly triple between 2008 and 2050. As a share of the total U.S. population, Hispanics/Latinos will increase from approximately 15 percent to about 30 percent. Slower growth is expected for other minority groups over the same timeframe, and it is expected that the segment of the population whose members identify as being of two or more races will swell from 5.2 million to 16.2 million, or 3.7 percent of the U.S. population by 2050. Despite modest net growth, by 2050 only 38 percent of the U.S. population are expected to identify as single-race, non-Hispanic white, a group that comprised nearly three-quarters of the U.S. population as recently as 1995.<sup>1,2</sup>

...whether we think that it's only the elderly or only the young or whatever, the fact of the matter is that there are egregious deficits in survival rates and outcomes for those people who are in the minority population and those who are isolated. This clearly can't go on.

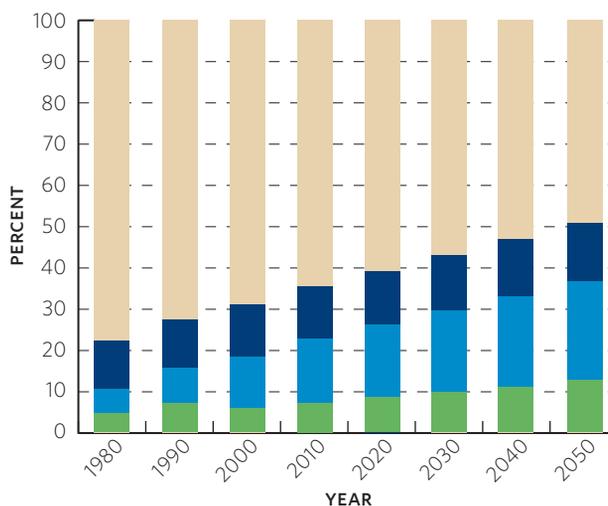
*Derek Raghavan, American Society of Clinical Oncology*



Differing birth and death rates among the various racial/ethnic groups are a major driver of the population shifts now under way. Slow net growth in the non-Hispanic white population over the next several decades will be due to high death rates among the Baby Boomer generation (those born between 1946 and 1964<sup>3</sup>), which is disproportionately white, and relatively low fertility rates among non-Hispanic whites compared with those of other population groups. Conversely, birth rates are expected to increase among many minority groups, with the most dramatic increases among Hispanics/Latinos and Asians. According to the Census Bureau, between July 2008 and July 2009 there were nearly nine births for every one death in the Hispanic/Latino population, compared with a nearly one-to-one ratio among whites.<sup>4</sup>

Immigration also is an important contributor to America's changing demographics. The Census Bureau estimates that by the mid-21st century, individuals who have immigrated since the mid-1990s and their offspring will comprise one-quarter of the U.S. population. Immigration is a significant contributor

**FIGURE 1 » U.S. MINORITIES ARE BECOMING THE MAJORITY (PERCENT DISTRIBUTION, HISTORIC AND PROJECTED)**



\* White non-Hispanic.

\*\* May include black Hispanics.

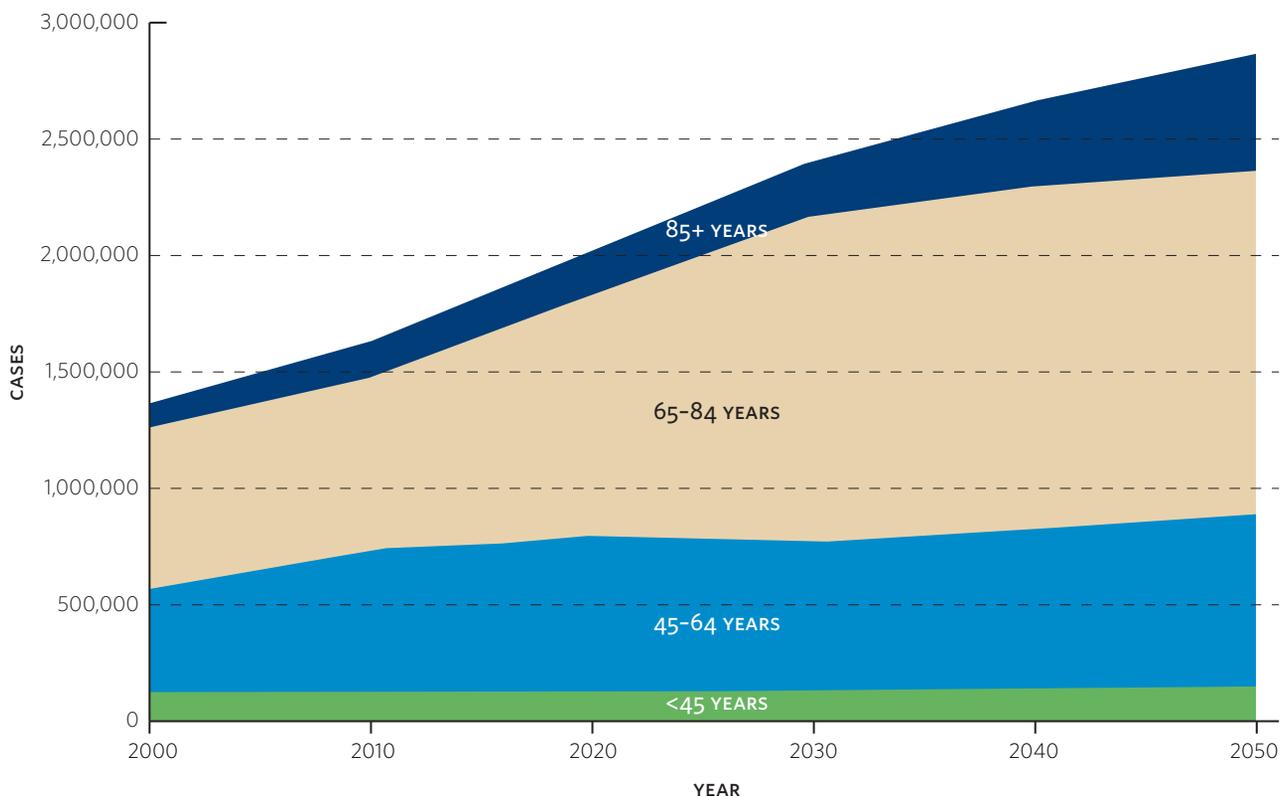
Note: Because small numbers of individuals are listed as both black and Hispanic, totals are slightly greater than 100 percent.

Sources:

U.S. Census Bureau. U.S. interim projections by age, sex, race, and Hispanic origin: 2000–2050 [Internet]. Washington (DC): the Bureau; 2004 [cited 2010 Jun 25]. Available from: <http://www.census.gov/population/www/projections/usinterimproj/>

Gibson C, Jung K. Historical census statistics on population totals by race, 1790 to 1990, and by Hispanic origin, 1970 to 1990, for the United States, regions, divisions, and states [Internet]. Washington (DC): U.S. Census Bureau; 2002 Sep [cited 2010 Jun 25]. Available from: <http://www.census.gov/population/www/documentation/twps0056/twps0056.html>

FIGURE 2 » PROJECTED NUMBER OF CANCER CASES FOR 2000–2050 BY AGE GROUP  
BASED ON PROJECTED CENSUS POPULATION ESTIMATES AND  
DELAY-ADJUSTED SEER-17 CANCER INCIDENCE RATES\*



\* Projections based on approximate single-year delay adjusted SEER-17 incidence rates for 1998–2002 and population projections from the U.S. Census Bureau.

Source: Hayat MJ, Howlander N, Reichman MC, Edwards BK. Cancer statistics, trends, and multiple primary cancer analyses from the Surveillance, Epidemiology, and End Results (SEER) program. *The Oncologist*. 2007;12(1):20-37.

to the surge in the Hispanic/Latino population.<sup>2</sup> An analysis<sup>5</sup> of U.S. domestic and international migration patterns indicates that, due in part to the economic downturn and a reduced flow of immigrants from Mexico,<sup>6</sup> international migration to the United States was nearly static between 2007 and 2008 after increasing by about a half million in the preceding year and by an average of one million annually between 1990 and 2006.

The changing sociocultural composition of the United States has implications for virtually every aspect of American life, including public health and the delivery of health care. Of particular concern, new cancer cases are projected to nearly double from 1.36 million in 2000 to almost 3.0 million in 2050 (Figure 2) as population aging, growth, and diversity progress (see additional discussion of cancer incidence and mortality trends, Appendix B).

Factors such as educational attainment, economic status, age, household composition, health insurance

status, and cultural factors—all of which vary among and within racial and ethnic groups—can influence disease risk, affect the extent and quality of interactions with the health care system (see discussion, Part 3),

...by 2050 there is really going to be no majority population in the United States, and this is what we should be thinking about in terms of demographic changes—the fact that we are really going to be a multiracial and multiethnic population. And this really has implications for the kinds of cancers and the kinds of cancer care and research that I believe we need to address.

*Moon Chen, University of California Davis Cancer Center*

and increase or decrease the extent to which individuals enjoy long and healthy lives. However, as discussed throughout this document, the mechanisms by which myriad combinations of these factors influence cancer risk is poorly understood at this time.

TABLE 1 » EDUCATIONAL ATTAINMENT FOR  
U.S. POPULATION AGED 25 YEARS AND OLDER

	HIGH SCHOOL GRADUATE OR MORE	SOME COLLEGE OR MORE	BACHELOR'S DEGREE OR MORE	ADVANCED DEGREE
Population ≥25 years	84.5	54.4	27.5	10.1
<b>Race and Hispanic Origin</b>				
White alone (including Hispanics)	87.0	56.6	29.1	10.7
Non-Hispanic white alone	89.4	58.8	30.5	11.3
Black alone	80.1	45.8	17.3	5.8
Asian alone	85.8	68.0	49.5	19.6
Hispanic (any race)	60.6	32.4	12.5	3.9
<b>Nativity Status</b>				
Native-born	87.6	56.3	27.6	9.9
Foreign-born	68.0	44.1	26.9	10.9

Adapted from: Crissey SR. Current population reports. Educational attainment in the United States: 2007. Washington (DC): U.S. Census Bureau; 2009 Jan.

## EDUCATIONAL ATTAINMENT

Educational attainment varies significantly by race and ethnicity in the United States. According to 2009 Census Bureau data shown in Table 1, Hispanics/Latinos have considerably lower levels of educational attainment compared with those of other racial/ethnic groups. Only 61 percent of Hispanic/Latino adults have completed high school, compared with 84 percent of the overall U.S. adult population. Hispanics/Latinos also are the least likely to have completed some college or to have earned a college or advanced degree. Asians are more likely to have at least some college education, a bachelor's degree or more, and an advanced degree than are members of the overall U.S. population.

...widely documented barriers to education for blacks and Hispanics begin at early ages and worsen as education progresses. And we all know these barriers mostly reflect family income levels....People who need to earn or borrow money to finance professional education are more likely to be discouraged.

*Martha Farnsworth Riche, Cornell University*

Significant educational differences also exist between native- and foreign-born adults, with nearly one in three foreign-born adults lacking a high school diploma compared with only one in eight native-born adults. Foreign-born Hispanics/Latinos, fewer than half of whom have graduated from high school, account for much of this discrepancy.<sup>7</sup> However, a

notable dichotomy exists within the foreign-born population. Although a large fraction have not finished high school, similar proportions of native- and foreign-born populations have earned a bachelor's degree or more, and the percentage of individuals who have an advanced degree is higher among the foreign-born population than among those born in the United States.

## INCOME, WEALTH, AND POVERTY

As with educational attainment, the financial resources of U.S. racial and ethnic groups also vary widely. Census data indicate that Asians and non-Hispanic whites have median annual household incomes higher than the 2009 national median of \$49,777, while median annual earnings for African Americans/blacks and Hispanics/Latinos are substantially lower (\$32,584 and \$38,039, respectively).<sup>8</sup> Moreover, even at equivalent income levels, members of minority groups typically have fewer assets (e.g., savings/investments, home ownership) and, therefore, lower total net worth.<sup>9,10</sup> This difference is extremely important because it reflects financial stability and access to financial resources such as business capital and mortgage or other loans.

Similar trends are observed with respect to populations living at or below the federal poverty level (\$10,830 for an individual; \$22,050 or less for a family of four in the 48 contiguous states and District of Columbia).<sup>11</sup> The national poverty rate was 13.2 percent in a 2006–2008 three-year survey, but this statistic masks the fact that African Americans/blacks, Hispanics/Latinos,



and Native Americans (American Indians and Alaska Natives) are two to three times more likely to live in poverty than are non-Hispanic whites and Asians.<sup>12</sup> The poverty endured by Native Americans is particularly striking. In Ziebach County, South Dakota, the poorest county in the United States, more than half of the inhabitants live in poverty; Ziebach County lies almost entirely within the Cheyenne River Indian Reservation.<sup>13</sup> While ethnic and racial minorities comprised just over one-third of the total U.S. population in 2009, they accounted for 57 percent of those in poverty.<sup>8</sup>

Patterns of poverty by race/ethnic group have been relatively unchanged for decades, even though population definitions have shifted over time.<sup>8</sup> The poverty rate of white Americans continues to be the lowest of all subpopulations, while the poverty rate of Native Americans—25.3 percent—continues to exceed all others.<sup>12</sup> The black population suffers the second highest poverty rate, only slightly lower than that of Native Americans. Data on poverty among Hispanics have been available only since 1972; in recent years, the poverty rate among this group has been nearly equal to that of the black population.<sup>8</sup>

## HEALTH INSURANCE

The percentage of people in the United States who were not covered by any type of health insurance for the entire year was estimated to be 16.7 percent in 2009, but rates of insurance varied considerably among racial and ethnic groups. While nearly 12.0 percent

People who are poor should not die because they are poor.... Today, we're seeing people who were middle class yesterday who are poor today. So the circle of poverty is not a closed circle. People are in and out of poverty, and it's something that we should not accept as a cause of death.

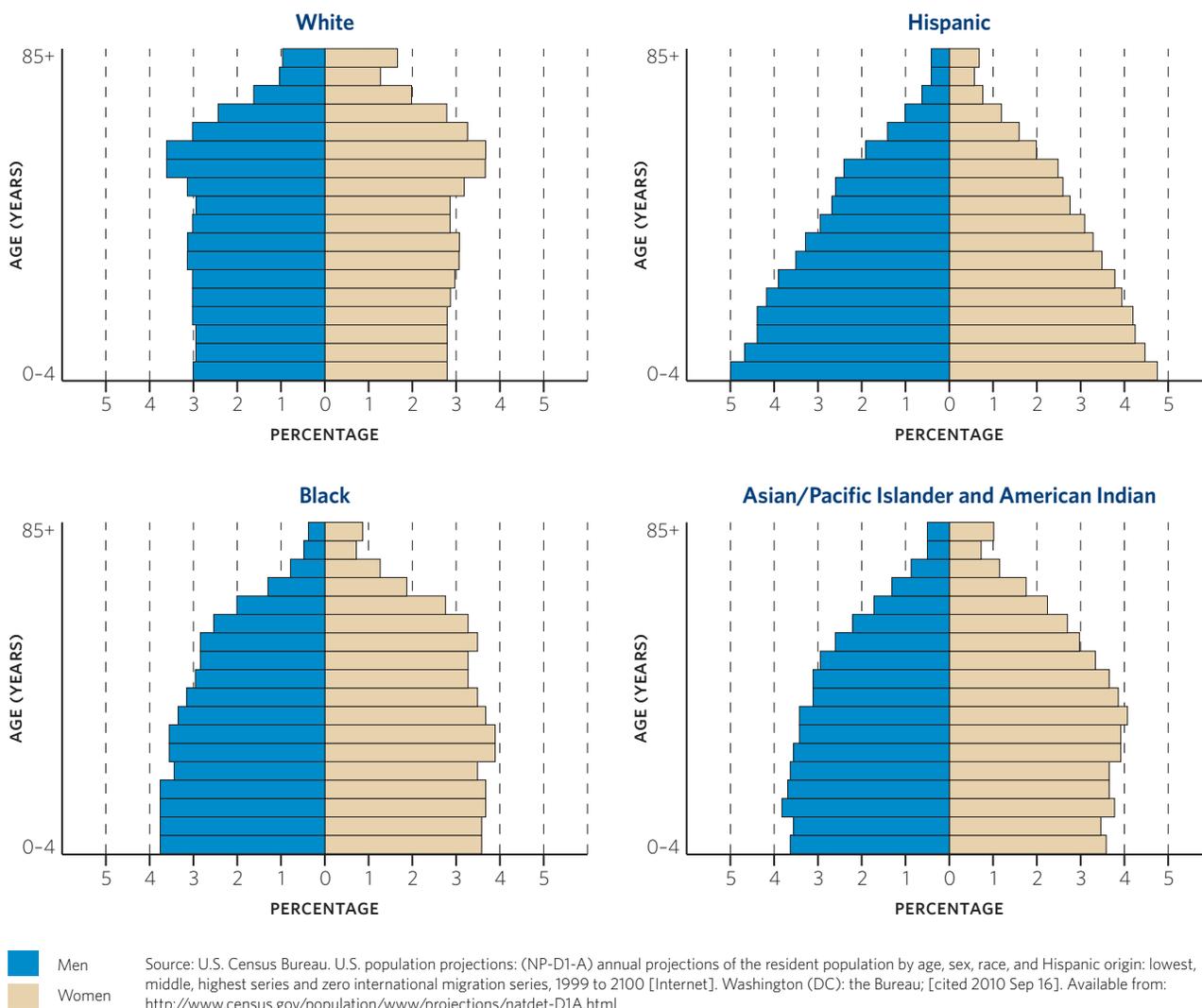
*Harold Freeman, National Cancer Institute*

of non-Hispanic whites were without insurance, uninsured rates were 17.2, 21.0, and 32.4 percent among Asians, African Americans/blacks, and Hispanics/Latinos, respectively.<sup>8</sup> Other estimates indicate that 29.2 percent of Native Americans and 17.3 percent of Native Hawaiian and other Pacific Islanders do not have health insurance.<sup>14</sup> Immigrants are among the least likely to have insurance—only two-thirds of foreign-born people in the United States are insured, and among those who are not citizens, nearly 46 percent lack insurance.<sup>8</sup>

Insurance rates also vary considerably by age across all subpopulations. According to U.S. Census data, young adults (ages 18 to 24) have the highest uninsured rate—30.4 percent. Among adults aged 45 to 64 years, 16.1 percent are uninsured.<sup>8</sup>



FIGURE 3 » AGE DISTRIBUTION OF SELECTED U.S. POPULATION SUBGROUPS  
(PERCENTAGE OF POPULATION, 2020, PROJECTED)



## AGE AND HOUSEHOLD FACTORS

Members of minority groups are younger on average than are members of the non-Hispanic white population. In 2008, the median age of non-Hispanic whites was 41.1 years compared with 27.7 years for Hispanics, 35.8 years for Asians, 29.8 years for Native Hawaiians and other Pacific Islanders, 31.4 years for blacks, and 29.5 years for Native Americans.<sup>15</sup> Figure 3 illustrates how the different age profiles of America's major subpopulations are likely to be reflected in population distributions by age in 2020.

In addition to age differences, variations exist in household composition among racial/ethnic populations that have implications for health care and cancer because they provide insight into the proportion of households that may contain or lack a potential caregiver if an individual becomes ill. Some of these

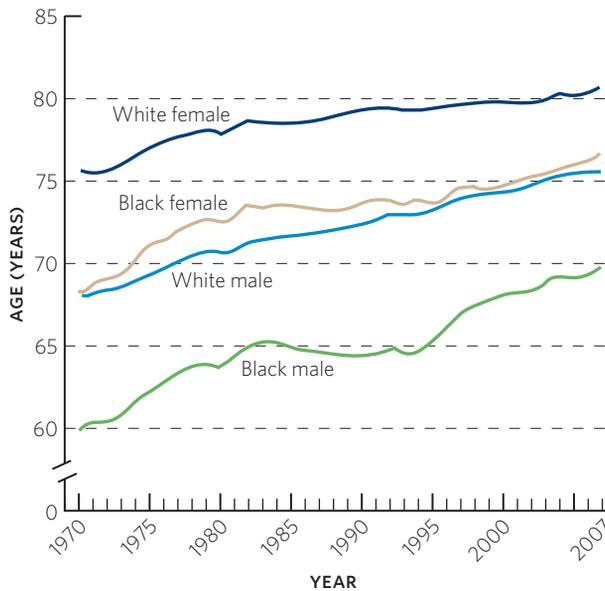
differences stem from variations in age distribution as well as cultural norms. One projection suggests that in 2020, 30 percent of non-Hispanic white and 33 percent of non-Hispanic black households will consist of individuals living alone, compared with only 18 percent of Hispanic households. Further, compared with non-Hispanic households, Hispanic households are more likely to include extended family members.<sup>16</sup>

## MORTALITY, LIFE EXPECTANCY, AND HEALTHY LIFE EXPECTANCY

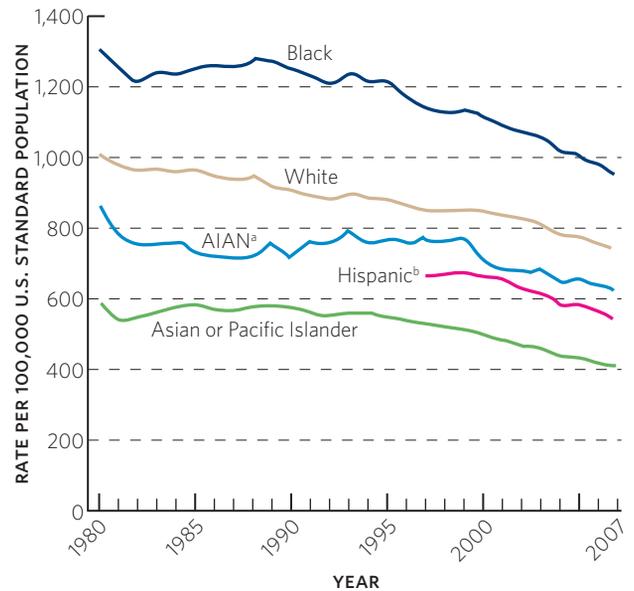
Life expectancy for babies born in the United States in 2007 reached a record high of 77.9 years.<sup>17</sup> Declines in many of the major causes of death—including cancer—contributed to this improvement. Although life expectancy increased among both blacks and whites, blacks continue to have shorter life expectancy

FIGURE 4 >>

LIFE EXPECTANCY BY RACE AND SEX



AGE-ADJUSTED DEATH RATES BY RACE AND ORIGIN



a American Indian or Alaska Native

b Mortality data for the Hispanic population of the entire United States became available in 1997.

Source: Xu J, Kochanek K, Murphy S, Tejada-Vera B. Deaths: final data for 2007. Natl Vital Stat Rep. 2010 May; 58(19):1-135.

compared with whites. As shown in Figure 4, (through 2007), life expectancy among the white population exceeded that of the black population by five years and the age-adjusted death rate for blacks was 30 percent higher than for whites.<sup>18</sup>

The historical lack of high-quality mortality data across the life span has limited the ability to produce

sound calculations of life expectancies for Hispanics/Latinos. The underreporting of Hispanic origin on death certificates is one of several data quality problems that have long precluded accurate estimations of life expectancy by Hispanic origin.<sup>17</sup> More recent data, which have been adjusted to account for some of these quality issues, indicate that the Hispanic population has a higher life expectancy at birth and at nearly all subsequent ages than the non-Hispanic white and the non-Hispanic black populations.<sup>19</sup> Other data indicate better health of recent Hispanic/Latino immigrants compared with the health of those born in the United States or with many years of U.S. residence (i.e., the “healthy migrant” effect)<sup>20</sup> and support the speculation that an unknown percentage of older members of this population choose to return to their countries of origin to die or when ill (i.e., the “salmon” bias).<sup>17</sup> Some research suggests that these same factors also may skew data showing longer life expectancy among other immigrant populations compared with the



Why is Hispanic mortality so low despite low education and income? Now, as demographers, we get possessed about little things like data quality. Can we really believe what we see in the data?

Mark Hayward, University of Texas at Austin

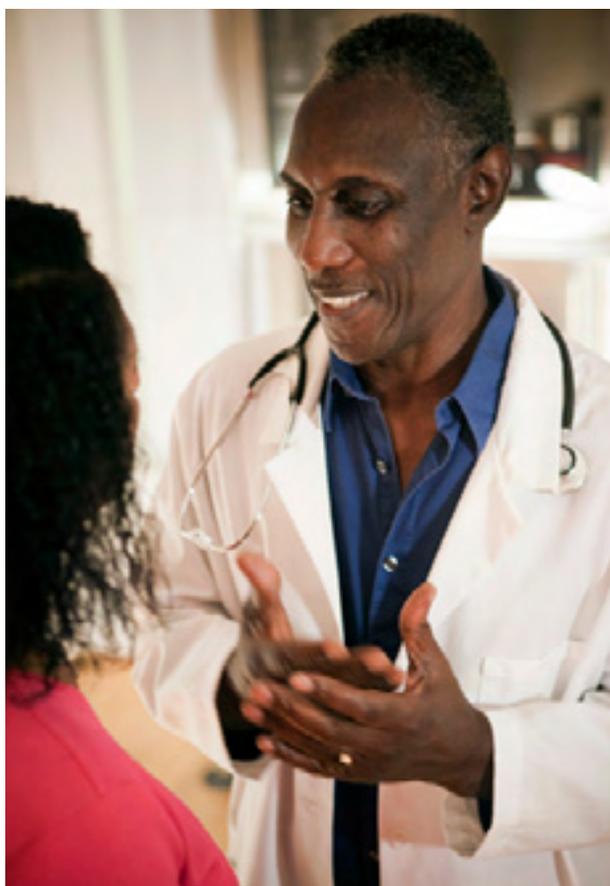
general U.S. population, U.S.-born whites, and U.S.-born individuals of the same racial/ethnic group.<sup>21</sup>

Age-adjusted mortality rates for American Indians and Alaska Natives, Asians and Pacific Islanders, and Hispanics are available and are generally lower than those reported for blacks and whites, but it is well recognized that underreporting of these racial/ethnic groups on death certificates reduces the reliability of these estimates.<sup>18</sup>

Native [Americans] were the only racial/ethnic group that did not experience a decline in cancer mortality from 1975 to 2004. Northern Plains American Indians suffer a 30 percent higher cancer mortality rate compared to the overall U.S. population. And in the Northern Plains area, the mortality rate for cancers for which an effective screening test exists is 80 percent higher compared to whites.

*Daniel Petereit, Dakota West Radiation Oncology,  
John T. Vucurevich Cancer Care Institute*

Another informative demographic indicator is healthy life expectancy, which integrates both morbidity and mortality. It assesses whether one group's lower mortality is brought about by postponing illness or by better survival following disease diagnosis. Data from the Health and Retirement Study<sup>22</sup> suggest that black men and women not only have shorter life expectancies, but also spend more months of their shortened lives enduring health problems than do their white counterparts. At 55 years of age, black men on average are likely to experience less than 16 additional years



of healthy life compared with nearly 21 years for white men (Figure 5). Hispanics also experience fewer years of healthy life than do whites (Figure 5), although they have marginally longer life expectancies.<sup>19</sup> The difference between Hispanic and white women is particularly striking. As Figure 5 also shows, Hispanic women experience on average 6.1 years of unhealthy life—2 years more than their white counterparts experience.

In addition, a recent study<sup>23</sup> that examined life expectancy differences of major American subpopulations by state determined that Asian Americans in New Jersey live the longest lives, and Native Americans in South Dakota live the shortest lives—the gap between the two is an astounding 26 years (Figure 6). Further, Native Americans in California outlive Native Americans in South Dakota by more than a decade. The authors note that life expectancy differences by state may reflect, among other factors, state-level policy, political culture, investment in key human development areas (e.g., public education and health infrastructure, health insurance coverage, housing), the overall economic condition of the state, acculturation and other characteristics of specific groups, and degree of residential segregation.



FIGURE 5 » YEARS OF UNHEALTHY AND HEALTHY LIFE EXPECTANCY AT AGE 55 BY RACE AND ETHNICITY

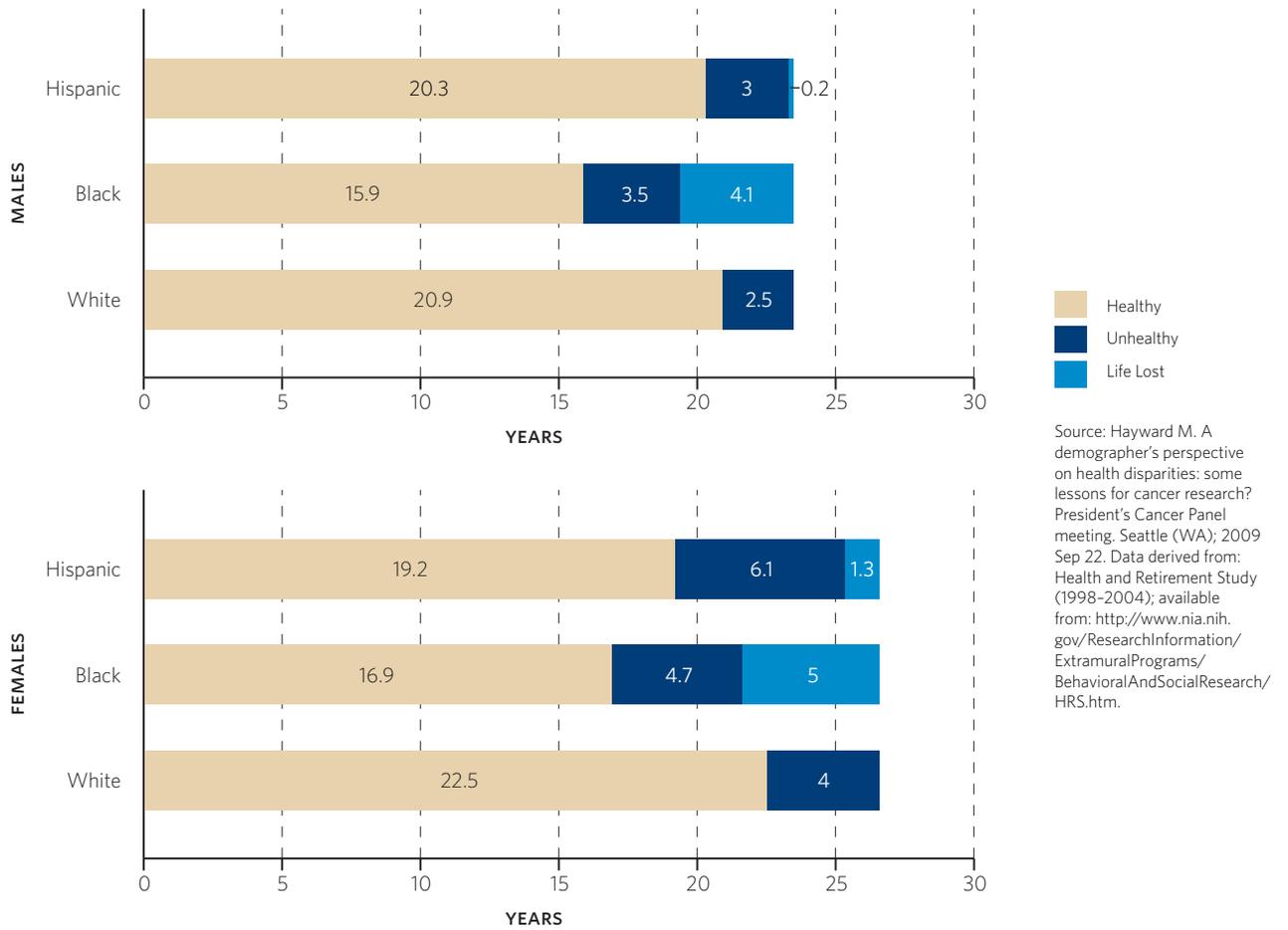
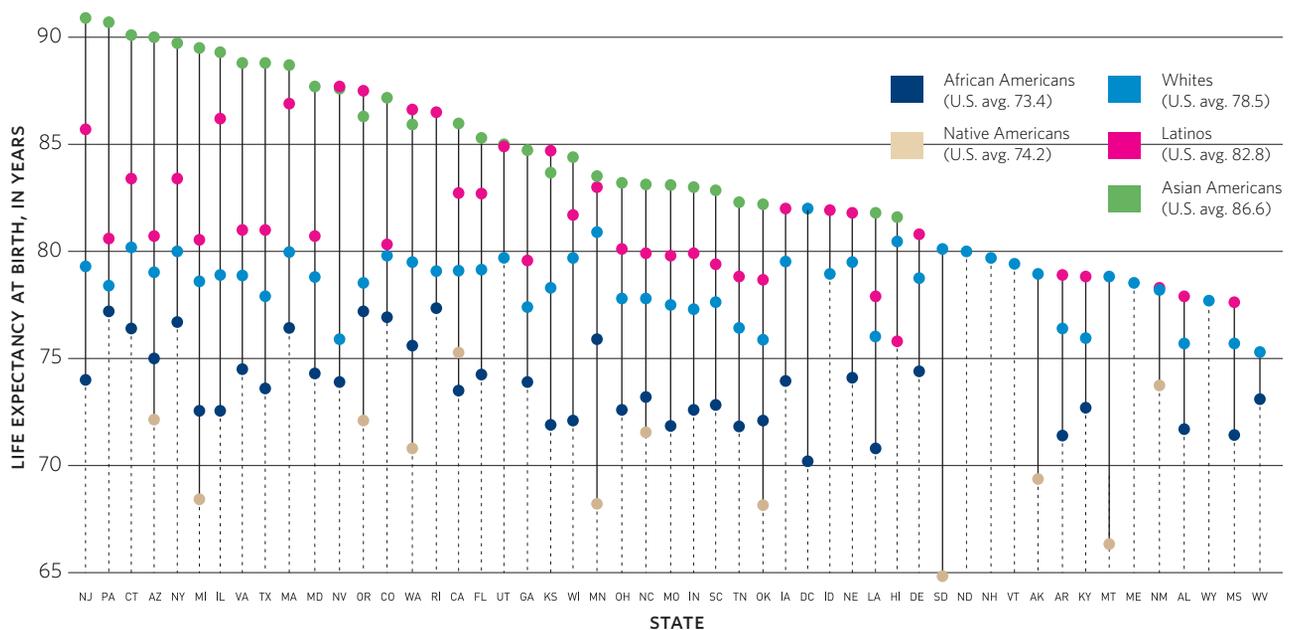


FIGURE 6 » LIFE EXPECTANCY BY STATE AND RACE/ETHNICITY\*



\* Life expectancy at birth calculated by the American Human Development Project using 2006 data from the Centers for Disease Control and Prevention. Source: Lewis K, Burd-Sharps S. A century apart: new measures of well-being for U.S. racial and ethnic groups. Brooklyn (NY): American Human Development Project, Social Science Research Council; 2010.



## *part 2*

# **Assessing the Cancer Burden of a Diverse Population**

Populations may be defined and classified in many ways: by gender, age, geographic region, urban or rural residence, and other parameters, including race and ethnicity. Census, vital statistics, cancer surveillance, and other health and employment data that include racial and ethnic categories are used to assess the cancer burden of America's increasingly diverse population. These data also support numerous important decisions that affect cancer and other biomedical research, public policy, and programs and services available to the population. Examples of such decisions are listed in Table 2.

As the following paragraphs demonstrate, however, currently available data on race and ethnicity are substantially flawed and must be used with an understanding of their considerable limitations when attempting to assess or project the cancer burden of the ever more diverse U.S. population.

## TABLE 2 » EXAMPLES OF DECISIONS THAT RELY ON POPULATION CLASSIFICATION AND ENUMERATION

### RESEARCH

Across the research spectrum, data on populations and individuals are used to:

- Develop and refine research agendas, emphases, and priorities.
- Develop specific research questions and study designs.
- Distribute public and private research funding consistent with established priorities.
- Select study subjects or populations.
- Interpret study results.
- Recruit and train research workforce.

### POLICY

Public policy often is based wholly or in part on available population statistics and research results to:

- Identify population needs.
- Develop science and health care policy.
- Develop education, housing, and workforce policies.
- Monitor to ensure social justice.
- Distribute public resources.

### PROGRAMS AND SERVICES

Based on research results and other data about population trends and characteristics, public and nongovernmental officials:

- Target populations for interventions related to health, housing, education, and employment.
- Design disease prevention, health promotion/wellness, surveillance, and treatment programs.
- Make medical treatment decisions.
- Recruit and train program personnel.
- Distribute public and private resources.

## CHALLENGES IN DATA COLLECTION AND ANALYSIS

The U.S. population has become more diverse due principally to immigration, differing subgroup birth and death rates, and the growing number and social acceptance of marriages and other partnerships among individuals from population groups that previously seldom intermixed. This diversity challenges national efforts to identify population groups by race, ethnicity, or culture in order to monitor compliance with civil rights legislation and for other legal, social, health care, research, and political purposes.

### Defining Race, Ethnicity, and Culture

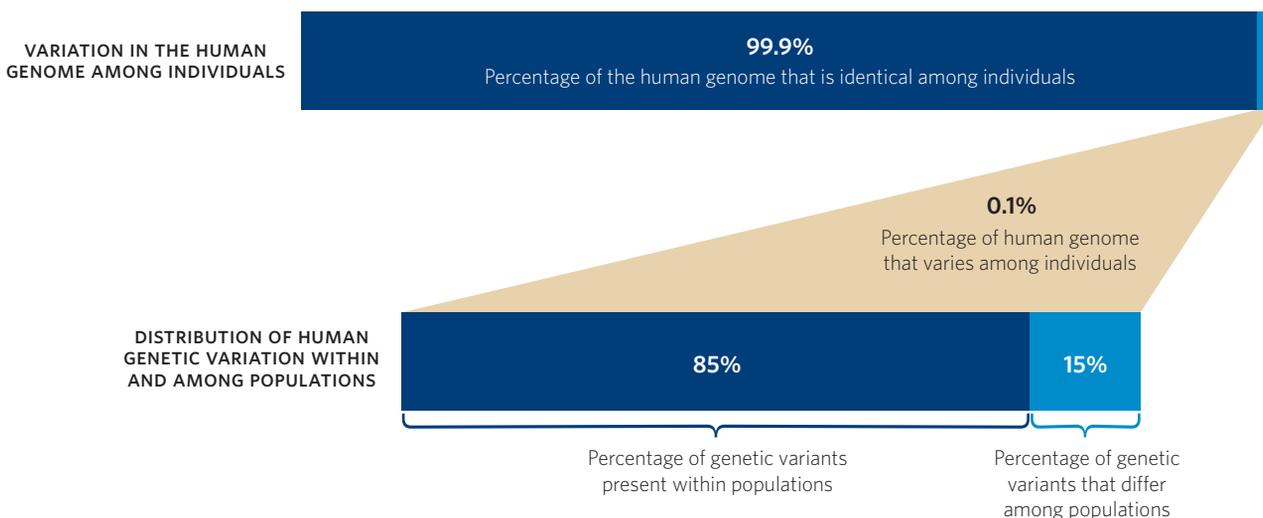
Throughout its history, the United States has placed enormous importance on discerning and assigning individuals' race and ethnicity. American concepts of race and ethnicity developed from the earliest interactions among Native Americans, African slaves, and European settlers and were reinforced by purported scientific inquiry in the 18th and 19th centuries that sought to prove biological differences among groups to support existing economic and social structures.<sup>24-27</sup> Contemporary ideas about race and ethnicity have been defined socially and culturally, and now are believed by most scientists and the lay public—though certainly not all—to have no basis in biology.<sup>28-30</sup> Research has shown that regardless of appearance or geographic region of origin, anatomically modern humans are all descended from the same ancestral group and that individual human genomes are by far more alike than they are different.<sup>31</sup> As Figure 7 illustrates, to the extent that differences exist, the vast majority of genetic variation (approximately 85%) exists within so-called racial and ethnic groups, while differences in genetic variation among populations account for a much smaller proportion (approximately 15%) of all human genetic variation.<sup>32-34</sup>

Further, alleles (one of two or more alternative forms of a gene) that influence external characteristics such as the shape of facial features, hair texture and color, eye color, and skin pigmentation are not inherited as a group, nor are any of these single features associated with specific cancers or other diseases. However, certain of these external characteristics, either singly or in combination, have incorrectly been deemed immutable indicators of "race" that reflect not just appearance but the entirety of an individual's genome. Yet pure races do not exist, and likely never

Race is possibly the most defining issue in the history of American society.

Harold Freeman, National Cancer Institute

FIGURE 7 » GENETIC VARIATION WITHIN POPULATIONS FAR EXCEEDS GENETIC VARIATION AMONG POPULATIONS



did. In admixture studies, people classified as African American have been found to have between 7 and 23 percent Caucasian admixture,<sup>35-39</sup> while people classified as white have been found to have between 0.7 and 6 percent African admixture.<sup>35,40</sup>

Common American beliefs about race would be of little consequence had assumptions about corresponding

innate capacities (e.g., intellect, athletic prowess), nonbiological attributes (e.g., trustworthiness, industriousness), and social values not been attached to them. These values, though rooted in debunked thinking,<sup>24-26,41</sup> have nonetheless remained the basis of a social hierarchy of assumed superiority or inferiority of individuals and groups based on their outward appearance. Socioeconomic position continues to be greatly influenced by this hierarchy, with profound effects on virtually every aspect of people's lives, including health.

Genetics is important, but we should try to focus more on the person and the family than on the race...

*Otis Brawley, American Cancer Society*

Further complicating the issue, definitions of the terms "race," "ethnicity," and "culture" used both for data collection purposes and in social interaction are not consistent and the terms often are confused or used interchangeably. As Table 3 indicates, commonly used definitions of these terms vary and often do not make clear distinctions between terms. In particular, culture tends to be viewed as a component of race, ethnicity, or both.

A peculiarity of American concepts of race involves who is considered black. It has been noted that only in the United States can a "white" mother have a "black" child, but a "black" mother cannot have a "white" child.<sup>42</sup> Many in the United States, either explicitly or implicitly, still adhere to what is known as the hypodescent, or



TABLE 3 » SAMPLE DEFINITIONS OF RACE, ETHNICITY, AND CULTURE

TERM	DEFINITIONS	SOURCE
<b>Race</b>	A distinct ethnic group characterized by traits that are transmitted through their offspring; a vague unscientific term for a group of genetically related people who share physical characteristics.	Mosby's Dictionary of Medicine, Nursing and Health Professions, 2009
	A family, tribe, people, or nation belonging to the same stock; a class or kind of people unified by shared interests, habits, or characteristics.	Merriam-Webster Dictionary Online
	An ethnic stock, or division of mankind; in a narrower sense, a national or tribal stock; in a still narrower sense, a genealogic line of descent; a class of persons of a common lineage. In genetics, races are considered as populations having different distributions of gene frequencies.	Dorland's Illustrated Medical Dictionary, 1988
	A sociocultural concept wherein groups of people sharing certain physical characteristics are treated differently based on stereotypical thinking, discriminatory institutions and social structures, a shared worldview, and social myths. A term developed in the 1700s by European analysts to refer to what is also called a racial group.	IOM, Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare, 2003  Byrd and Clayton, 2003
<b>Ethnicity</b>	Of or relating to large groups of people classed according to common racial, national, tribal, religious, linguistic, or cultural origin or background.	Merriam-Webster Dictionary Online
	(Ethnic) Pertaining to a social group who share cultural bonds (religion, national, etc.) or physical (racial) characteristics.	Dorland's Illustrated Medical Dictionary, 2007
	A shared culture and way of life, especially reflected in language, folkways, religious and other institutional forms, material culture such as clothing and food, and cultural products such as music, literature, and art.	IOM, Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare, 2003  Byrd and Clayton, 2003
	Ethnic group—a population of individuals organized on the basis of an assumed common cultural origin.	Mosby's Dictionary of Medicine, Nursing and Health Professions, 2009
<b>Culture</b>	The integrated pattern of human behavior that includes thought, speech, action, and artifacts and depends upon the human capacity for learning and transmitting knowledge to succeeding generations; the customary beliefs, social forms, and material traits of a racial, religious, or social group.	Medline Plus, 2010 and Merriam-Webster Dictionary Online
	That complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society.	Tyler, Primitive Culture, 1924
	Culture comprises four elements—values, norms, institutions, and artifacts—that are passed on from one generation to another. Cultures are dynamic and constantly evolving.*	Office of Multicultural Interests, Government of Western Australia, 2009
	A set of learned values, beliefs, customs, and behavior that is shared by a group of interacting individuals.	Mosby's Dictionary of Medicine, Nursing and Health Professions, 2009

\* Working definition.

Sources:

Merriam-Webster Dictionary [Internet]. [cited 2010 Apr 9] Available from: <http://www.merriam-webster.com/dictionary/>.

Mosby's Dictionary of Medicine, Nursing and Health Professions, 8th ed. St. Louis (MO): Mosby Elsevier; 2009.

Dorland's Illustrated Medical Dictionary, 27th ed. Philadelphia (PA): W.B. Saunders Co.; 1988.

Dorland's Illustrated Medical Dictionary, 31st ed. Philadelphia (PA): W.B. Saunders Co.; 2007.

Tyler EB. Primitive culture. 2 vols. 7th ed. New York (NY): Brentano's; 1924 [orig. 1871].

Office of Multicultural Interests, Government of Western Australia. Working definitions of terms [Internet]. 2009 [cited 2010 Apr 22]. Available from: <http://www.omi.wa.gov.au/publications/terminology.pdf>

Institute of Medicine. Unequal treatment: confronting racial and ethnic disparities in healthcare [Internet]. Washington (DC): The National Academies Press; 2003 [cited 2010 Apr 23]. Available from: <http://www.nap.edu/openbook.php?isbn=030908265X>

Byrd MW, Clayton LA. Racial and ethnic disparities in healthcare: a background and history. In: Institute of Medicine. Unequal treatment: confronting racial and ethnic disparities in healthcare [Internet]. Washington (DC): The National Academies Press; 2003 [cited 2010 Apr 23]. Available from: <http://www.nap.edu/openbook.php?isbn=030908265X>

one-drop rule (i.e., that a person with any ancestor of African descent, regardless of how distant, is considered black).<sup>27,43</sup> Despite current knowledge regarding genetics and mechanisms of inheritance, the archaic reference to “blood” as the determinant of genetic makeup or race/ethnicity continues to be used freely. Well into the 20th century, numerous states had laws defining how individuals’ race was to be determined; the Virginia statute addressing this issue was not repealed until 1975<sup>44</sup> and Louisiana’s statutory definition was part of its legal code until 1993<sup>45,46</sup> (Table 4).

By contrast, other individuals of mixed ancestry (e.g., Asian/Hispanic) generally are more simply considered biracial, multiracial, or multiethnic, without the need to quantify the extent of genetic contribution of any group. However, consistent with the hypodescent rule—the purpose of which was to establish and maintain European white (specifically, English) superiority—persons of mixed ancestry still are typically assigned to the group with the lower social position depending on their appearance, regardless of their actual genetic admixture.<sup>47</sup>



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, and yet we continue to use them and try to define them.

*Lovell Jones, Intercultural Cancer Council*

#### TABLE 4 » EXAMPLES OF STATE LAWS DEFINING RACE

##### STATE OF VIRGINIA CODE OF VIRGINIA, 1950 (VA. CODE ANN. S1-14 (1960 REPL.VOL.), REPEALED 1975)

“Every person in whom there is ascertainable any Negro blood shall be deemed and taken to be a colored person, and every person not a colored person having one-fourth or more of American Indian blood shall be deemed an American Indian....” White people have “no trace whatever of any blood other than Caucasian; but persons who have one-sixteenth or less of the American Indian and have no other non-Caucasic blood shall be deemed to be white persons....”

##### STATE OF LOUISIANA (LA. REV. STAT. ANN. § 42:267, REPEALED BY ACT NO. 441, § 1, 1993 LA. ACTS 97)

“In signifying race, a person having one thirty-second or less of Negro blood shall not be deemed, described or designated by any public official in the State of Louisiana as ‘colored,’ a ‘mulatto,’ a ‘black,’ a ‘negro,’ a ‘griffe,’ an ‘Afro-American,’ a ‘quadroon,’ a ‘mestizo,’ a ‘colored person’ or a ‘person of color.’” La. Rev. Stat. Ann. § 42:267, repealed by Act No. 441, § 1, 1993 La. Acts 97.

## Principal Sources of National Data on Race and Ethnicity

### U.S. Census

The first census of the United States population was conducted in 1790. As Table 5 shows, racial and ethnic census categories have evolved over time; nearly every U.S. census report since 1860 has been based on a different set of categories. Racial and ethnic categories and related definitions (Table 6) are developed by the Office of Management and Budget (OMB), with the most recent revision occurring in 1997.<sup>48,49</sup> The categories, to be applied to all federal population data collection, were intended to characterize the population for a variety of purposes not related to health, and in its revisions to Directive Number 15,<sup>49</sup> OMB explicitly states that “the categories represent a social-political construct designed for collecting data on the race and ethnicity of broad population groups in this country, and are not anthropologically or scientifically based.”

The 2010 census form (Appendix C) expanded some of the ethnic and racial categories. Respondents were asked to indicate Hispanic, Latino, or Spanish ethnicity, with space provided to write in a country of origin or other ethnicity. The form stated explicitly that for the

**TABLE 5 » CHANGES IN U.S. DECENNIAL CENSUS RACE  
AND ETHNICITY CATEGORIES, 1860–2010**

1860	1890	1930	1960	1970	1980	1990	2000	2010
<b>Race</b>								
White	White	White	White	White	White	White	White	White
Black	Black	Black	Negro	Negro or Black	Black or Negro	Black or Negro	Black, African American, or Negro	Black, African American, or Negro
Mulatto	Mulatto							
	Chinese	Chinese	Chinese	Chinese	Chinese	Chinese	Chinese	Chinese
	Indian	Indian	American Indian	Indian (American)	Indian	Indian (American)	American Indian or Alaska Native	American Indian or Alaska Native
	Quadroon							
	Octoroon							
	Japanese	Japanese	Japanese	Japanese	Japanese	Japanese	Japanese	Japanese
	Filipino	Filipino	Filipino	Filipino	Filipino	Filipino	Filipino	Filipino
	Hindu				Asian Indian	Asian Indian	Asian Indian	Asian Indian
	Korean			Korean	Korean	Korean	Korean	Korean
	Mexican							
			Aleut		Aleut	Aleut		
			Eskimo		Eskimo	Eskimo		
			Hawaiian	Hawaiian	Hawaiian	Hawaiian	Native Hawaiian	Native Hawaiian
			Part Hawaiian					
					Vietnamese	Vietnamese	Vietnamese	Vietnamese
					Guamanian	Guamanian	Guamanian or Chamorro	Guamanian or Chamorro
					Samoan	Samoan	Samoan	Samoan
					Other Asian/Pacific Islander		Other Asian	Other Asian
							Other Pacific Islander	Other Pacific Islander
		Other	Other	Other	Other	Other	Other	Other
<b>Hispanic Ethnicity</b>								
				Mexican	Mexican, Mexican American, Chicano			
				Puerto Rican	Puerto Rican	Puerto Rican	Puerto Rican	Puerto Rican
				Central/S. American				
				Cuban	Cuban	Cuban	Cuban	Cuban
				Other Spanish	Other Spanish/Hispanic	Other Spanish/Hispanic	Other Spanish/Hispanic/Latino	Other Spanish/Hispanic/Latino
				(None of these)	Not Spanish/Hispanic	Not Spanish/Hispanic	Not Spanish/Hispanic/Latino	Not Spanish/Hispanic/Latino

census, Hispanic origins are not races. Respondents also were required to designate the race(s) that best describe their ancestry, including “one or more races” and “some other race,” with space provided to write in another choice.

The OMB categories are intended to be minimum categories; agencies can collect more granular data by adding categories provided they can be aggregated (“rolled up”) into the six standard categories.<sup>50</sup>

A number of such roll-up systems have been developed; Appendix D provides the CDC/HL7 Code Set developed by the Centers for Disease Control and Prevention.

Some populations are not captured by current census categories, such as Brazilians, other non-Spanish-speaking South Americans, and people with Middle Eastern origins. According to a former head of the U.S. Census Bureau who provided testimony to the Panel,<sup>16</sup> it should be expected that census categories for race and ethnicity will continue to evolve, particularly regarding individuals who identify with more than one race or ethnic group. The Census Bureau already has identified the racial and ethnic categories as a topic for research prior to the 2020 census.<sup>51</sup>



...it's important to be aware that racial and ethnic categories are always changing. I've looked at every census starting in 1790 and there has been a change just about every time. It is not likely that in 2050 we'll be using the same ones [we use now].

*Martha Farnsworth Riche, Cornell University*

## Vital Statistics

Vital statistics (births and deaths) are compiled at the national level by the National Vital Statistics System at the National Center for Health Statistics (NCHS) using hospital discharge and birth and death registry data reported from each state. The national data are reported using the OMB race/ethnicity categories. However, some states do not adhere to the OMB categories in their data collection and/or the data are of poor quality.<sup>52</sup> Standard birth, death, and fetal death certificates revised in 2003 now include the OMB race/ethnicity categories plus 13 additional categories, but as of April 2009 only 56 percent of jurisdictions had adopted the standard birth and death certificates and 39 percent had adopted the standard fetal death certificates.<sup>52</sup>

...someone who was born in Bombay, India, in 1948 and moved to the United States before the 1950 Census has been three different races in his or her entire life.

*Otis Brawley, American Cancer Society*

The National Death Index (NDI)<sup>53</sup> is a central computerized index of death record information on file in the state vital statistics offices. Working with these state offices, NCHS established the NDI as a resource to aid epidemiologists and other health and medical investigators with their mortality ascertainment activities. As such, it is available to investigators solely for statistical purposes in medical and health research. It is not accessible to organizations or the general public for legal, administrative, or genealogical

### Table 5 Notes:

In 1890, mulatto was defined as a person who was three-eighths to five-eighths black. A quadroon was one-quarter black and an octoroon, one-eighth black.

American Indians have been asked to specify their tribe since the 1900 census.

Prior to the 1970 census, enumerators wrote in the race of individuals using the designated categories. In the 1970 and subsequent censuses, respondents or enumerators filled in circles next to the categories with which respondents identified.

Also beginning with the 1970 census, persons choosing American Indian, Other Asian, Other Race, or (for the Hispanic question) Other Hispanic categories were asked to write in a specific tribe or group. Hispanic ethnicity was asked of a sample of Americans in 1970 and of all Americans beginning with the 1980 census.

Beginning with the 1990 census, respondents could select more than one race category.

Adapted from:

Bohme FG. 200 years of U.S. census taking: population and housing questions, 1790–1990. Washington (DC): U.S. Census Bureau; 1989.

U.S. Census Bureau. Form D-61(9-25-2008). Washington (DC): the Bureau; 2008 [cited 2010 Jun 25]. Available from: [www.census.gov/schools/pdf/2010form\\_info.pdf](http://www.census.gov/schools/pdf/2010form_info.pdf)

**TABLE 6 » RACIAL/ETHNIC CATEGORIES AND DEFINITIONS—  
OMB AND U.S. BUREAU OF THE CENSUS**

OMB CATEGORY	OMB DEFINITION OF CATEGORY	CENSUS DEFINITION OF CATEGORY
<b>American Indian or Alaska Native</b>	A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment	People having origins in any of the original peoples of North and South America (including Central America), and who maintain tribal affiliation or community attachment including, for example, Rosebud Sioux, Chippewa, or Navajo
<b>Asian</b>	A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam	People having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, people who have indicated their race as Asian Indian, Chinese, Filipino, Korean, Japanese, Vietnamese, Burmese, Hmong, Pakistani, or Thai
<b>Black or African American</b>	A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American"	People having origins in any of the black racial groups of Africa including, for example, Black, African American, Negro, Nigerian, or Haitian
<b>Hispanic or Latino</b>	A person of Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race. The term "Spanish origin" can be used in addition to "Hispanic or Latino"	A person of Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race
<b>Native Hawaiian or Other Pacific Islander</b>	A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands	People having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands, including people who identify as Native Hawaiian, Chamorro, Tahitian, Mariana Islander, or Chuukese
<b>White</b>	A person having origins in any of the original peoples of Europe, the Middle East, or North Africa	People having origins in any of the original peoples of Europe, the Middle East, or North Africa, including Irish, German, Italian, Lebanese, Near Easterner, Arab, or Polish
<b>Some Other Race</b>		All other responses not classifiable in the White, Black or African American, American Indian or Alaska Native, Asian, and Native Hawaiian or Other Pacific Islander race categories; respondents providing write-in entries such as multiracial, mixed, interracial, "American," or a Hispanic/Latino group (e.g., Mexican, Puerto Rican, Cuban)

Sources: Institute of Medicine. Race, ethnicity, and language data: standardization for health care quality improvement [Internet]. Washington (DC): The National Academies Press; 2009 [cited 2011 Feb 11]. Available from: <http://www.iom.edu/Reports/2009/RaceEthnicityData.aspx>

purposes. NDI records (beginning with 1979 deaths) are compiled from computer files submitted by state vital statistics offices. Death records are added to the NDI file annually, approximately 12 months after the end of a particular calendar year. Because it is based on data submitted by the states, NDI suffers from the same weaknesses as nationally reported vital statistics. Further, NDI does not conform to the OMB categories for race and does not include ethnic designation; these differences from other data sources may compromise the comparability of NDI and other population data.

## Factors That Complicate Data Collection about Race and Ethnicity

Three key factors complicate data collection concerning race and ethnicity: self-report of race and ethnicity, racial and ethnic classification by others, and lack of standardization in data collection related to race and ethnicity.

### Self-Report of Racial or Ethnic Background

Individuals' criteria for identifying with a particular racial, ethnic, or cultural group are varied and a

person's preferred affiliation(s) may change over time based on experiences and changes in his or her social and political environment (e.g., multiracial adolescents may change their self-identification at school compared with how they identify within their homes).<sup>54-56</sup> In many cases, self-classification probably does not reflect actual genetic admixture, since a considerable percentage of people have limited knowledge of their ancestral background.

Identification with a particular group may be driven in part by a desire for particular rights, benefits, or recognition that accrue to group members. For example, Native American tribal membership and rights are accorded based on "blood quantum" (percent Indian ancestry), which may lead some individuals with very little Indian ancestry to self-identify as Native American.

People also may identify with a particular group to avoid discrimination. For example, individuals from Middle Eastern/Arab countries are classified as white in the U.S. census. This decision was made because Arab immigrants a century ago petitioned to be classified as white to avoid discrimination.<sup>57</sup> According to one writer,<sup>58</sup> the Arab community now recognizes that this decision has been costly in terms of lost federal aid and political power. In contacts with the health care system, some individuals who are not Caucasian or have mixed ancestry and do not appear Caucasian may self-identify as white because they believe they will receive better care.

One author asserts that many Hispanics/Latinos in the United States think of their ethnicity not just in cultural terms, but also in a racial context.<sup>58</sup> In the 1990 census, about 15.4 million people (5.5% of the U.S. population) reported themselves to be "some other race"; of these, more than 97 percent were Hispanic.<sup>59</sup> Similarly, in the 2000 census, approximately 42 percent of Hispanics (nearly 14.9 million/5.3% of the population) reported themselves to be "some other race."<sup>60</sup> In the 2009 National Survey of Latinos, 37 percent of respondents volunteered "Hispanic/Latino" as their race.<sup>61</sup> These results suggest that in the 2010 census, many respondents who indicate Hispanic ethnicity are likely to have again reported "some other race" or write in "Hispanic" or "Latino" as a racial affiliation.

### Racial or Ethnic Classification by Others

Misclassification of individuals' racial or ethnic background by others, resulting in lack of concordance with self-identification or actual genetic admixture, has been a common occurrence in the United States. For

example, until the late 19th century, immigrants and their descendants from many non-English European countries, such as Italy and Ireland, were not accepted as white.<sup>62</sup> Census information on race was obtained primarily by enumerator observation through 1950, by a combination of direct interview and self-identification in 1960 and 1970, and by self-identification alone beginning only in 1980. However, with enumerator observation, a person of mixed white and other parentage usually was classified with the other race. A person of mixed race other than white usually was classified by the race of the person's father through 1970 and by the race of the person's mother in 1980 and 1990.<sup>63</sup>

These changes notwithstanding, misclassification by others remains a significant issue that can result in substantial undercounting of minority populations. Racial misclassification of Native Americans may be

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*Just because someone checks a box and says "I'm of African descent,"—there's a huge amount of variability in what that means in terms of where those people's African ancestry came from.*

*Timothy Rebbeck, University of Pennsylvania*

as high as 40 to 60 percent.<sup>64</sup> It has been observed by Native Americans in previous testimony to the President's Cancer Panel that often "you are born Indian, but die white" (i.e., many Native Americans are classified as white on death certificates based on the observation of health care providers).<sup>65</sup> This may occur because hospital or other health care personnel hesitate to add to the stress experienced by the family of a dying patient by asking if he or she is Native American and instead make assumptions based on appearance or surname.<sup>66</sup> Such instances affect accuracy in ascertaining Native American cancer mortality rates, a particularly important problem in a small population. Similarly, funeral directors who rely on personal observation to ascertain and record the race and ethnicity of deceased persons are likely to be inaccurate, particularly for racial and ethnic groups with many multiracial/multiethnic individuals.<sup>67,68</sup> One assessment of death rates found they were underestimated by 11 percent for Asians and Pacific Islanders and by about 21 percent for American Indians and Alaska Natives.<sup>69</sup>

Assignment of the race of newborns and in the case of fetal death also has changed over time. The process

for ascertaining infant race or ethnicity is reviewed every 10 to 15 years. Before 1980, the National Vital Statistics System assigned the race of the newborn or fetus according to the race of both parents. As with the census, if the parents were of different races and one parent was white, the child was classified according to the race of the other parent. If neither parent was white, the child was classified according to the father's race. The only exception was that if either parent was Hawaiian, the child was classified as Hawaiian.

A lot of what we do as we walk through the world is we apply concepts. So, for example, we will look at an apple, [and] we will immediately, rapidly, and without effort have tremendous amounts of information about that object....We apply this process to the social world, and it's efficient and it streamlines a person's perception, [but it]....can go wrong in the case of social categories that have been historically stigmatized or discriminated against.

*Michelle van Ryn, University of Minnesota*

Beginning in 1989, newborns and fetal deaths were classified according to the race of the mother only.<sup>70</sup> In the case of an infant's death, his or her race or ethnicity could be determined based on observation by the individual completing the death certificate (e.g., physician, funeral director). Yet, medical record information as to the race of infants and mothers, compared with the mother's report, has been shown to be poorly correlated.<sup>71</sup> The most recent revisions, approved in 2003 by the Secretary, HHS, are still being implemented in some states. The U.S. Standard Certificates of Live Birth were revised to again obtain data on both the mother's and father's race in order to capture multiple race identification. Only the mother's race is captured on fetal death certificates. Racial categories are the same on both the live birth and death certificates and conform to the OMB categories defined in 1997. However, as noted earlier, state vital health data do not necessarily reflect the OMB categories, reducing the comparability and reliability of national vital statistics information.

### Lack of Data Standardization

A 2009 Institute of Medicine (IOM) report<sup>52</sup> states that many national data sets do not adhere to federal standards for collection of race/ethnicity data. The report identifies both system and patient-provider barriers to collection of race, ethnicity, and language data. System-level barriers include: lack of standardized categories, lack of understanding as to

why data are collected, response categories that are not sufficiently descriptive of local populations, health information technology limitations, insufficient space on data collection forms, and discomfort on the part of the data collector. Identified barriers related to patient-provider encounters include: lack of standardized categories, lack of understanding as to why data are collected, response categories that are not sufficiently descriptive for local populations to self-identify with, and privacy concerns.

The authors recommend a framework for collecting race and ethnicity data that retains the current OMB categories but adds granular ethnicity data to include locally relevant choices from a national standard list of approximately 540 categories with CDC/HL7 codes (additional codes would need to be added to the existing list); an "Other, please specify" option with write-in space; and the ability to roll up the granular data to conform to the OMB categories.

## Race and Ethnicity in Health-Related Data

Although the OMB racial classifications were not intended to be scientific or used for health-related purposes, they are used as the basis for collecting and reporting race and ethnicity data at both national and local levels, with census data providing the denominators for calculating disease incidence, morbidity, and mortality rates.

### National Data Sets

Among the national health-related data sets available to policy makers and researchers, the following tend to be most frequently utilized:

#### Cancer Surveillance Data

National cancer surveillance data are aggregated from state and local sources and reported by three principal programs:

- *Surveillance, Epidemiology, and End Results Program (SEER)*. A program of the National Cancer Institute, SEER<sup>72</sup> collects data on U.S. primary cancer incidence, stage at diagnosis, first course of treatment, mortality, prevalence, and survival through 17 population-based registries covering 26.2 percent of the U.S. population. Relative to percentage of the total U.S. population covered, SEER oversamples minority groups to improve the power of analyses of smaller subpopulations

(Figure 8).<sup>73</sup> According to a speaker representing the SEER program, SEER works with the Census Bureau to obtain decennial and intercensal data that are used as denominators in the computation of SEER cancer incidence, prevalence, survival, and mortality data. Mortality data reported by SEER are provided by the NCHS. SEER attempts to adjust for changing census categories and inconsistencies in regional-, state-, and hospital-level data collection on race and ethnicity. Although SEER collects data on more than 50 population groups, data are reported according to the population definitions established by OMB. Thus, SEER data have significant limitations due to classification issues described above and do not capture heterogeneity within ethnic and racial groupings.

SEER has, however, provided important insights about some cancer patterns in the United States. For example, SEER linkage with the Medicare database has provided opportunities to study cancer patterns in older Americans. Similarly, the NCI Cancer Research Network of Health Maintenance Organizations and researchers using SEER-Medicare linked data have conducted studies to assess cancer recurrence for specific cancers. A speaker noted that SEER was developed as a research tool, but is now used (inappropriately) as a policy tool.<sup>74</sup>

- **National Program of Cancer Registries (NPCR).**<sup>75</sup> Administered by CDC, the congressionally

When SEER started, it was started as a research tool and not a policy tool. We have converted it into a policy tool....It was never meant to set our agenda at the local and state levels. It was to give national trends.

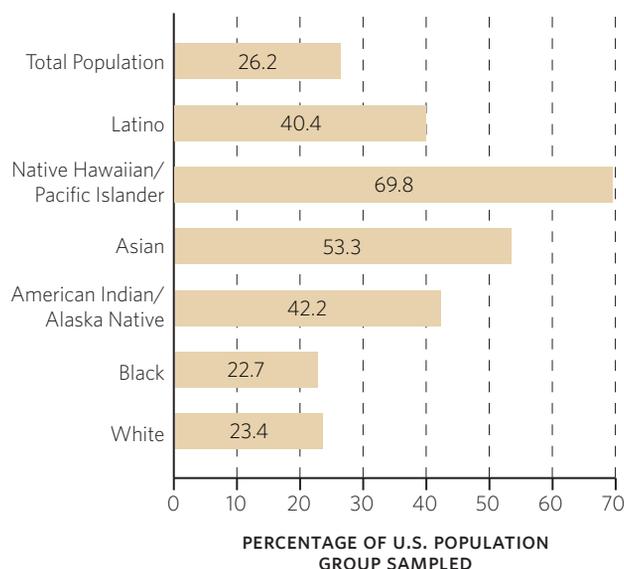
*Lovell Jones, Intercultural Cancer Council*

mandated NPCR supports central cancer registries in 45 states, the District of Columbia, Puerto Rico, and the U.S. Pacific Island jurisdictions. NPCR data represent 96 percent of the U.S. population. With the implementation of NPCR, cancer became a reportable condition in every state. SEER provided the model for NPCR registry development and data standards.

Like SEER, NPCR collects data on cancer incidence; the type, extent, and location of the cancer; and the type of initial treatment. Neither SEER nor NPCR collect data on cancer treatment after the first course of treatment following diagnosis, and neither program collects data on recurrences. NPCR data typically are reported using the OMB race and ethnicity definitions, but like SEER, the data are subject to inaccuracies due to variations in the quality of data collected from regional and state registries and medical records. NPCR and SEER pool their cancer surveillance data to produce annual assessments of the U.S. cancer burden.

- **National Cancer Data Base (NCDB).**<sup>76</sup> NCDB, a joint program of the American College of Surgeons Commission on Cancer (CoC) and the American Cancer Society (ACS), is a nationwide oncology outcomes database for more than 1,400 Commission-accredited cancer programs in the United States and Puerto Rico. Approximately 70 percent of all newly diagnosed cases of cancer in the United States are captured at the institutional level and reported to the NCDB. Established in 1989, the NCDB now contains approximately 25 million records from hospital cancer registries across the United States. These data are used to explore trends in cancer care, create regional and state benchmarks for participating hospitals, and serve as a basis for quality improvement. Data submitted to the NCDB are collected from CoC-accredited cancer program registries using nationally standardized data item and coding definition, and nationally standardized data transmission format specifications coordinated by the North American Association of Central Cancer Registries. Data elements include patient characteristics, including race categories similar to those used by the U.S. Census Bureau,<sup>77</sup> cancer

**FIGURE 8 » RACIAL/ETHNIC  
COVERAGE IN SEER**



Source: National Cancer Institute. SEER Surveillance, Epidemiology, and End Results Program. Bethesda (MD): NCI; 2005 Sep [cited 2010 Sep 16]. NIH Publication No. 05-4772. Available from: [http://seer.cancer.gov/about/SEER\\_brochure.pdf](http://seer.cancer.gov/about/SEER_brochure.pdf)

staging and tumor histological characteristics, type of first-course treatment, and outcomes information. Unlike other cancer surveillance databases, the NCDB collects data on cancer recurrences.

### *Selected Other National Health-Related Data Sources*

Race/ethnicity data collected in medical records can become part of large health information databases that researchers, health plan administrators, policy makers, and others rely upon to conduct studies and develop policies. In addition, periodic government surveys of population health collect data on the race and ethnicity of respondents. The issues of misclassification and lack of standardized data collection described above are infused into these databases when information on individuals is aggregated. In addition, surveys

(approximately 8.3 million<sup>80</sup>) and veterans and their dependents (more than 5 million<sup>81</sup>), respectively. The military shares these data for its own analyses and to facilitate continuity of care for military and veteran personnel and dependents.<sup>82</sup>

- *Private Health Insurer Databases.* Private-sector health insurers maintain robust demographic, health status, and claims payment databases on current and former subscribers. The data are drawn principally from medical records and claim forms. Some of the larger insurers (e.g., Kaiser) have their own research components and use these data to examine clinical, health services delivery, patient outcome, and cost-effectiveness issues, among other topics. Historically, insurers have seldom shared these data with public or academic researchers.

The question is: Who are the Hispanics in our [national] surveys? We don't know....Should you be confused? I am.

*Mark Hayward, University of Texas at Austin*

(including medical history forms used by health care providers) developed by the majority (Caucasian) population may have underlying assumptions (e.g., that the definition of a stable household is limited to two-parent families at an identifiable address) that may not always apply to minority, poor, and other disadvantaged populations.

Major national health-related data sources include:

- *Medicare and Medicaid Databases.* The Centers for Medicare and Medicaid Services (CMS) is the largest health care payor in the United States, funding care for an estimated 43 million Medicare beneficiaries aged 65 years and older<sup>78</sup> and, in conjunction with states, approximately 47 million Medicaid enrollees in 2009.<sup>79</sup> CMS maintains extensive patient databases using OMB race/ethnicity categories. In addition to conducting its own analyses of these data, CMS also permits linkage of its database to other federal partners under established agreements. As noted earlier, numerous cancer-related studies have been conducted by linking the SEER and Medicare databases.
- *Military and Veterans' Demographic and Health Data.* The Department of Defense (DoD) and Department of Veterans Affairs (VA) each maintain massive health-related and other databases on active-duty military personnel and retirees and their dependents
- *National Health Interview Study (NHIS).*<sup>83</sup> First conducted in 1957, NHIS is a national survey on a broad range of health topics. Data are collected through personal interviews conducted by U.S. Census Bureau personnel. The survey results, which are analyzed and published by the NCHS, have been used to track health status, health care access, and progress toward achieving national health objectives. Similar studies, such as the California Health Interview Study, are conducted at the state level.
- *National Health and Nutrition Examination Survey (NHANES).*<sup>84</sup> NHANES began in the early 1960s and has been conducted as a series of surveys focusing on different population groups or health topics. It combines interviews and physical examinations. The interviews include demographic, socioeconomic, dietary, and health-related questions. The examination component consists of medical,



dental, and physiological measurements, as well as laboratory tests administered by trained medical personnel. Information about the distribution of health problems and risk factors in the population give researchers important clues to the causes of disease. Data collected from the current survey are compared with information collected in previous surveys. Findings from NHANES are used to assess the prevalence of major diseases, disease risk factors, and nutritional status and its association with health promotion and disease prevention. NHANES findings also are the basis for national standards for such measurements as height, weight, and blood pressure. Survey data are used in epidemiological studies and health sciences research to help develop public health policy, direct and design health programs and services, and expand knowledge about health in the United States.

- **Youth Risk Behavior Surveillance System (YRBSS).**<sup>85</sup> This national survey monitors priority health-risk behaviors and the prevalence of obesity and asthma among youth and young adults. The YRBSS includes a national school-based survey conducted by CDC and state, territorial, tribal, and local surveys conducted by state, territorial, and local education and health agencies and tribal governments. Six categories of priority health-risk behaviors among youth and young adults are monitored, including: behaviors that contribute to unintentional injuries and violence; tobacco use; alcohol and other drug use; unhealthy dietary behaviors; physical inactivity; and sexual behaviors that contribute to unintended pregnancy and sexually transmitted infections (STIs), including human immunodeficiency virus (HIV) infection. Some data are reported by racial/ethnic subgroup.

### Local Data

While data on race, ethnicity, and culture always should be used with care in developing public policy and related programs, national trends may be particularly misleading in developing state or local policy. SEER develops State Cancer Profiles<sup>86</sup> to help state policy makers and researchers identify local cancer trends. However, suboptimal data sharing among federal agencies has precluded some potentially informative analyses of state/local data.

National statistics may mask important variations in health disparities. Many demographic and disease trends are only apparent when local (state and/or county level) data are considered. For example, a 2009

*We need more local data because, without it, it's hard to measure what's improving.*

*Cara James, Henry J. Kaiser Family Foundation*

Kaiser Family Foundation study<sup>87</sup> found that women of color in every state continue to fare worse than white women on more than two dozen indicators of poor health and disease risk, as well as overall health, health care access, and other social determinants of health (e.g., education, income). Disparities varied by state and by population group, both as a whole and depending on state of residence; for example, in some states, white women fared worse than minority women on certain indicators. However, some of the disparities were stark. American Indian and Alaska Native women, with the exception of those living in Alaska, had among the worst outcomes on many health indicators and challenges related to socioeconomic factors (e.g., high rates of obesity and smoking, lack of cancer screening, higher number of days women reported poor health). In many instances, the rate of poor outcomes for this population of women was twice as high as that for white women. In states where disparities were smaller, the difference often was due to the fact that both white women and women of color were doing poorly.

Analyses of local data also may refute conclusions based on national data. A recent study<sup>88</sup> suggests that race and genetics may not be as big a factor in surviving some cancers as previously thought. The researchers found that supposed racial disparities were far less apparent or disappeared entirely when smaller populations, such as towns or neighborhoods, were studied. The findings suggest that modifiable factors such as socioeconomic status, cancer stage at diagnosis, treatment, and other aspects of an individual's health may be more important than biology in determining cancer survival.

## THE USE OF RACE, ETHNICITY, AND CULTURE IN RESEARCH

Observers from diverse disciplines share the view that disagreement about the meaning and appropriate use of race, ethnicity, and culture in research is one of the most contentious subjects in science.<sup>89-92</sup> Rather than focusing on socially constructed definitions of race and ethnicity, some scientists maintain that studying areas of geographic origin or ancestral populations more accurately reflects genetic admixture over time and is a valid approach to identifying genetic variation

within and across socially defined populations that may be relevant to disease susceptibility, prevention, and response to treatment.<sup>91</sup> One meeting participant noted that when groups migrate, some people stay behind, and those who leave do not take all of the population's genetic variation with them.<sup>93</sup> This ongoing process results in a continuous overlapping of genetic variation, explaining in part why members of a socially constructed racial or ethnic group do not have identical disease susceptibilities.

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*Because the U.S. health data have historically been reported by race or ethnic group and not by socioeconomic factors like income or education, I think when people do see disparities by income or education, the first thought in their minds is, "Oh, that must be about race or ethnic group."*

*Paula Braveman, University of California, San Francisco*

In addition, many researchers believe that focusing on socially constructed definitions of race and ethnicity may minimize attention to and evaluation of cultural, social, environmental, and economic influences on lifestyles, attitudes, and behaviors that are likely to have more direct effects on cancer and other disease outcomes. For example, race and ethnicity often are used as proxies for poverty, poor housing/living conditions, lower educational attainment, poor diet and obesity, low physical activity levels, high-risk behaviors (e.g., tobacco use), environmental exposures, and limited access to health care. Yet these factors predict poorer health status and outcomes regardless of individuals' socially defined race or ethnic groups. Focusing on race and ethnicity also may perpetuate negative stereotypes about minorities or reinforce racist beliefs, particularly the one-drop rule.<sup>27,47</sup>

It has been noted that scientists need to be more aware of their uncritical acceptance of social concepts of race and ethnicity when developing study questions and defining and analyzing different populations.<sup>89</sup> Some studies suggest that researchers are ill-equipped to deal with and tend to defer to medical ethicists on difficult questions regarding race and ethnicity.<sup>94,95</sup> Researchers also need to be alert to embedded and internalized bias in scientific and medical institutions, including their structure and hierarchy. Figure 9 illustrates the circular impact and distortion of such racialization (i.e., the extension of racial meaning to a previously racially unclassified relationship, social practice, or group)<sup>96</sup> on scientific inquiry, health care, and social history. The insidious influence of institutionalized and unrecognized

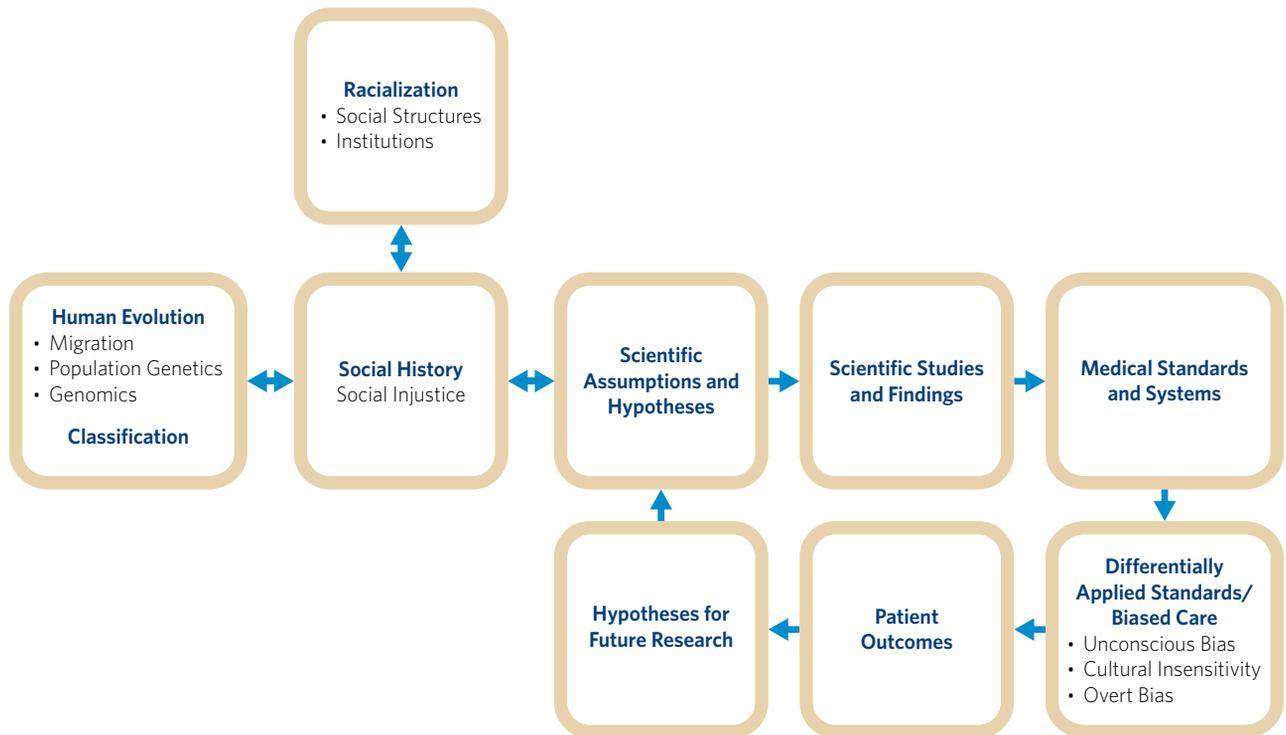
racial bias can have profound effects on the direction and conclusions of scientific inquiry by affecting what questions are deemed worthy of study; who receives funding, mentoring, and training; and how the merits of study findings are judged.

In general, researchers recognize that guarding against the attachment of a value system to differences in random genetic markers, genes that lead to disease susceptibility or variations in drug response, or other health-related genetic variants is crucial to avoid discrimination and exacerbation of existing health disparities.<sup>91,97</sup> In an attempt to minimize the extent to which racial and ethnic bias infiltrates biomedical research, the International Committee of Medical Journal Editors (ICJME) established uniform requirements for manuscripts submitted to biomedical journals.<sup>98</sup> Regarding the selection and description of study participants, the requirements state, "when authors use such variables as race or ethnicity, they should define how they measured these variables and justify their relevance."

However, weaknesses in data resources described earlier are of particular importance to researchers and may thwart efforts to characterize populations in a scientifically meaningful way. For example, racial and ethnic misclassification affects sample population selection in research and may skew results in ways that are not apparent to or accounted for by researchers. Changes in population group definitions also change the numerators and denominators used to determine population size, growth, and disease rates. Accounting for evolving census definitions of race/ethnicity and fluidity of individuals' self-reports from one decennial census to another may be especially important for computing and interpreting data from longitudinal studies that span two or more decades. In addition, in many surveys, respondents self-report racial/ethnic affiliations; these responses may differ from the way the individuals answer race/ethnicity questions in the census. Collecting more granular race and ethnicity data, however, poses challenges with respect to sample size and adequate powering of studies.

Importantly, current data sets generally do not capture the variability within groups that is relevant for studies of disease vulnerability and treatment response (e.g., African Americans and immigrants of African origin are all categorized as black; great diversity exists within both Asian and Hispanic populations related to country of origin). Further, it has been noted that in both research and health care, it is a fallacy to presume that experiences or characteristics of subpopulations are

FIGURE 9 » IMPACT OF RACIALIZATION\* ON SOCIAL HISTORY, SCIENCE, AND HEALTH CARE



\* Racialization is the extension of racial meaning to a previously racially unclassified relationship, social practice, or group.

Adapted from: Reuben SH, 2002 (unpublished).

relevant only as they compare to those of non-Hispanic whites, who are as ancestrally and culturally diverse as Asians, Hispanics/Latinos, or other OMB-defined populations.<sup>99</sup> Aggregating all non-Hispanic whites into a single group does them the same disservice of masking important health-related differences among subgroups as is the case with the other defined racial/ethnic populations.

In addition, many data sets only capture a snapshot of individual or population health at a single point in time, which fails to account for important events taking place earlier in peoples' lives that may affect disease susceptibility. Ideally, information would be captured about exposures and events throughout the life span. Such data may be particularly informative in understanding disease patterns in immigrant populations.

Because national data sets are not always reliable or truly representative of geographic or sociocultural subpopulations, national surveys may yield conflicting and/or misleading results. Researchers need to integrate information from local providers who interact with communities and local registries to improve the validity of national data sets such as SEER and NHIS. However, a common set of data elements will

We don't really like to think that we have all these implicit processes going on, but there's incontestable evidence that we do. So we're frequently not aware that we're activating implicit prejudice and stereotypes. We're not aware of the impact on our perceptions, emotions, or behavior....And many cognitive processes result in confirmation of expectancies; that is, we process information in ways that support our implicit beliefs.

*Michelle van Ryn, University of Minnesota*

be needed to optimize such efforts and improve the comparability of data.

Further, people who self-identify as multiracial are largely lost to research as it currently is conducted, yet these individuals may comprise an especially important (and rapidly growing) group for identifying disease-relevant genomic characteristics that are common across so-called racial and ethnic categories. With changing demographics and greater recognition of racial/ethnic group heterogeneity, the opportunity exists to more usefully compare a group of people against a reference group with either the worst or the best outcomes in order to identify not only the risk factors of diverse cultures but their most protective and health-promoting beliefs and practices.<sup>99</sup>



## *part 3*

# **Factors Influencing Cancer Risk, Incidence, Survival, Mortality, and Outcomes**

Cancer risk and outcomes result from the complex interplay of numerous socioeconomic, cultural, environmental, biological, behavioral, and genetic factors. It is important to keep in mind, however, that different populations—however defined—have differing patterns of risk factors and risk factor combinations that are reflected in cancer incidence, survival, and mortality rates. Moreover, even within defined population groups, no two individuals have the exact same risk factor profile.

To reach the goal of personalized medicine for all, it will be necessary to identify and tease apart the interactions of various risk factors that contribute to disease. Understanding these relationships and their impact on human health will inform the development of strategies to prevent and treat cancer in all populations. This section provides a discussion of recent research and other data presented by meeting participants, as well as information gathered subsequent to the Panel's meetings, related to the diverse factors that affect the cancer burden.

TABLE 7 » EXAMPLES OF FACTORS THAT MAY AFFECT  
INDIVIDUAL AND POPULATION CANCER RISK

GENETIC/BIOLOGIC FACTORS	SOCIOECONOMIC FACTORS	ENVIRONMENTAL/OCCUPATIONAL FACTORS	CULTURAL/LIFESTYLE FACTORS	HEALTH CARE ACCESS
Ancestral genetic contribution	Income/wealth	Toxins	Beliefs, customs, and values	Insurance
Acquired gene mutations	Education/literacy	Radiation	Comfort with health care system	Out-of-pocket health costs
Tumor biology	Social position/class	Geographic location	Language	Non-medical costs of care
Cell signaling	Housing/neighborhood	Built environment	Tobacco use	Proximity to services
Infection			Diet/physical activity	Regular source of care
				Quality of care
				Cultural acceptability of services
				Provider bias

So the first thing that pops into most people's minds on what influences health [is] going to be "medical care"....genetic makeup....the climate and natural physical environment....health related behaviors....Nutritional effects, too....[when] we think of these influences, we need to ask ourselves the question, "What influences the influences?"

*Paula Braveman, University of California, San Francisco*

As the United States experiences its ongoing demographic shift, it is important that the research community considers how it will expand the current understanding of factors that influence cancer risk and outcomes, and how it will apply this knowledge for the benefit of all American subpopulations. The latter portion of Part 3 highlights key aspects of what is known about the influence of numerous factors on cancer and issues that remain to be addressed.

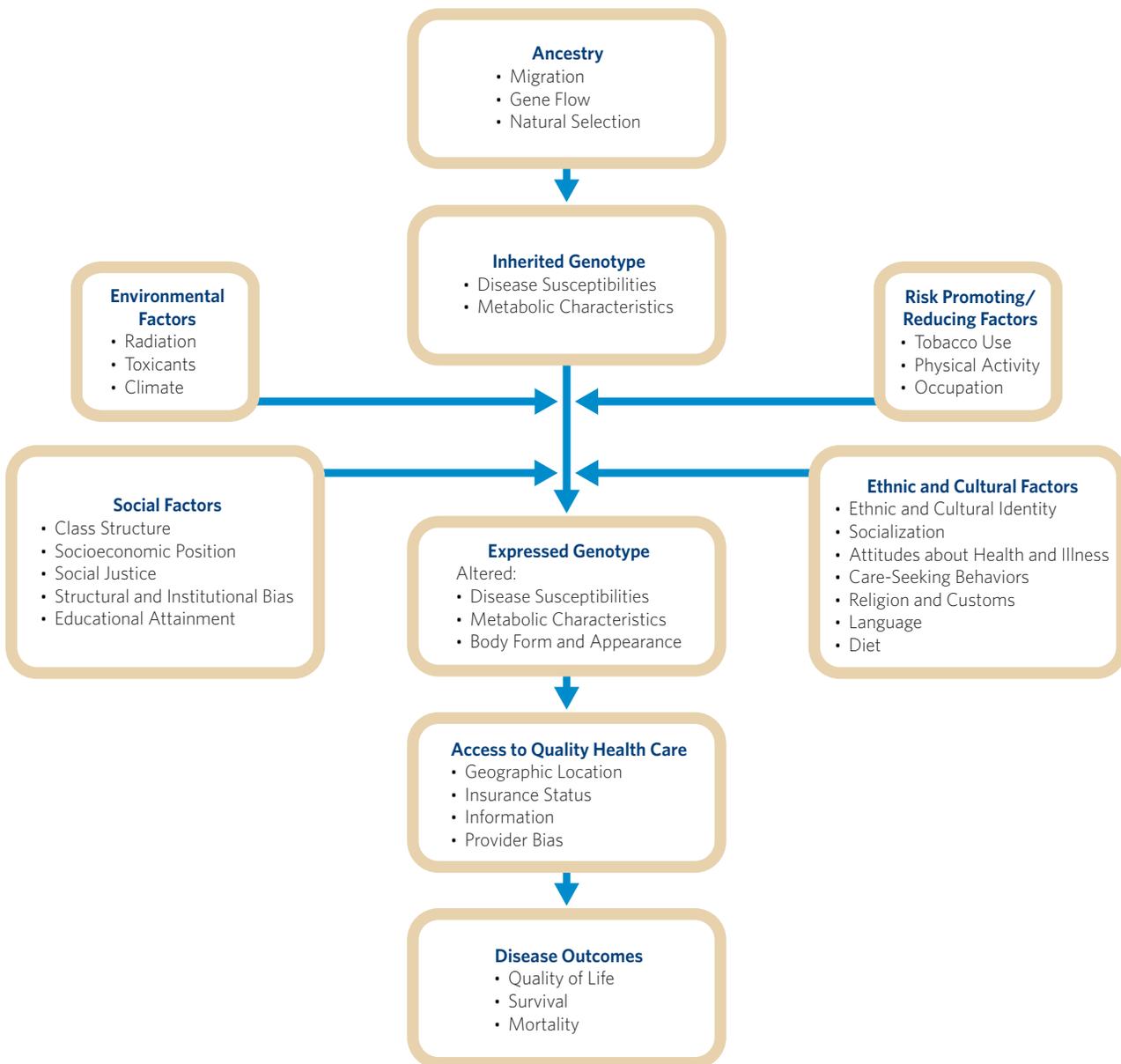
Table 7 lists examples of the diverse factors that may affect individual and population cancer risk, incidence, survival, and mortality. These factors often are interdependent and may manifest in clusters. Similarly, demarcations between various factor categories may not be distinct.

Some factors that affect cancer risk and outcomes are modifiable (e.g., access to care) while others are not (e.g., ancestry). Information about some factors (e.g., age at menarche, parity) may be useful for cancer risk

stratification but less amenable to intervention. In addition, all risk factors are not always relevant, or equally relevant, to all populations. For example, the National Cancer Institute-funded SHINE study, also known as the 4-Corners Breast Cancer Study,<sup>100,101</sup> found that several factors associated with breast cancer risk in non-Hispanic white women (e.g., height, postmenopausal obesity, alcohol consumption, use of hormone replacement therapy, younger age at menarche) were not associated with breast cancer risk among Hispanic women, while other risk factors (e.g., parity, age at first birth, breast feeding) did not differ by ethnicity. In general, risk factors mediated by estrogen were associated with increased risk for breast cancer among non-Hispanic white women but not among Hispanic women. In addition, SHINE and other studies<sup>102-105</sup> detected considerable variation in the proportion of ER-positive to ER-negative tumors between these two populations. This variability may be due to differences in estrogen metabolism.

The extent to which various risk factors are relevant for diverse populations and differences in gene-environment interactions among populations or subpopulations are important subjects for research. Currently, most known risk factors and their interactions have been identified through research conducted only on the majority population. Guidelines for minimizing cancer risk are based on this research and may likewise have limited relevance for other groups. Figure 10 provides a framework for understanding how external

FIGURE 10 » EPIGENETIC FACTORS AFFECTING EXPRESSED GENOME AND DISEASE OUTCOMES



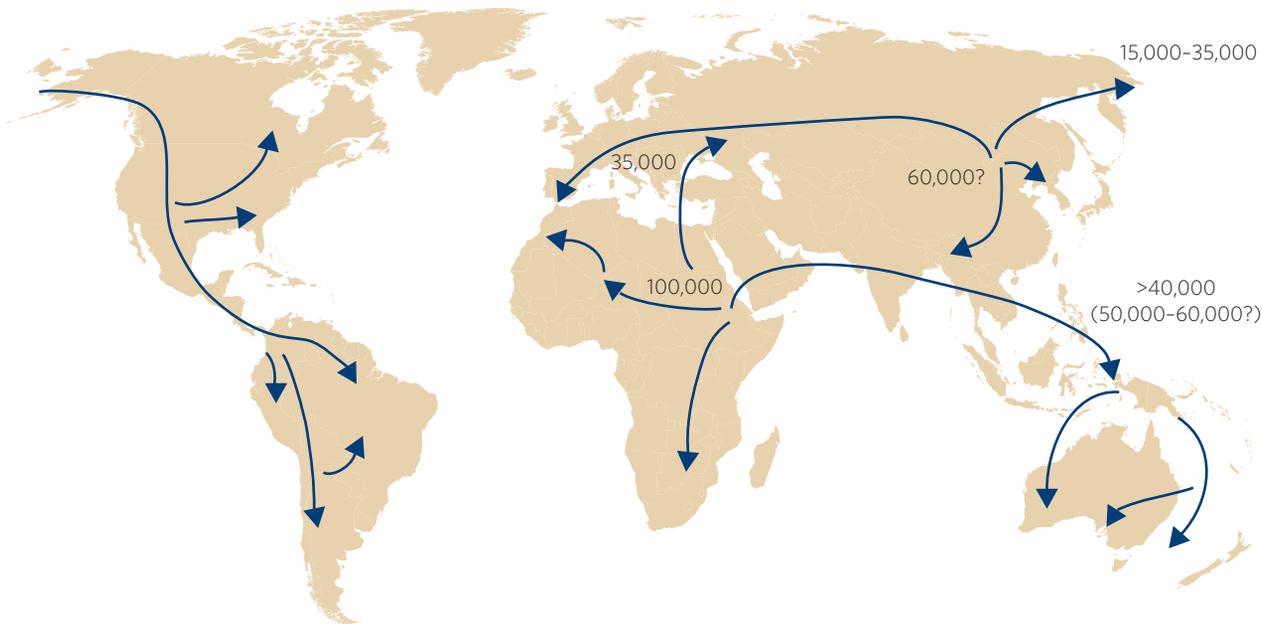
Adapted from: Jackson FLC. *Ann Hum Biol.* 2008 Mar-Apr;35(2):121-44.

factors may act as filters that alter expression of an individual's genome, potentially changing disease susceptibilities, response to interventions across the cancer continuum, access to cancer and other health care, and, ultimately, health status and disease outcomes. These interrelationships are described in the following sections.

## GENETIC AND BIOLOGIC FACTORS

The emergence of molecular biology has led to the recognition that genes play an important role in cancer susceptibility, as well as in the effectiveness and side

effects of available treatments. Less clear are the contributions of biology and genetics to the disparities in cancer burden and outcomes between different racial and ethnic populations, although ongoing research is attempting to shed light on this issue. It is helpful to keep in mind that while genetic and biologic processes are rooted in the DNA inherited from one's ancestors, they can be modified—sometimes dramatically—by external factors. Thus, genetic studies focus both on the inherited genome and changes to the genome acquired over the course of a lifetime. These acquired changes, which include DNA sequence mutations as well as epigenetic modifications that can alter DNA structure and function, are likely due to a combination

FIGURE 11 » MIGRATION PATTERNS OF *HOMO SAPIENS*\*

\* Numbers indicate approximately how many years ago various migrations occurred.

Source: Cavalli-Sforza LL, Menozzi P, Piazza A. *The history and geography of human genes*. Princeton (NJ): Princeton University Press; 1994.

of genetic susceptibility, lifestyle factors, and environmental exposures. Similarly, the biological traits of individuals and their tumors—such as which genes are expressed and the levels of various proteins present within a cell—are a function of both the inherited and acquired attributes of the DNA as well as cellular responses to the environment.

Geneticists believe that anatomically modern humans originated in Africa approximately 100,000 years ago and migrated from there to the Middle East and Asia before moving into Europe and the Americas (see Figure 11). These migrations occurred over tens

Most of the ethnic variation probably reflects different levels of exposures to causal factors. The migrant data certainly support that. At least some variation, though, probably reflects differences in genetic susceptibility...

Laurence Kolonel, Cancer Research Center of Hawai'i

of thousands of years and genetic diversity emerged among geographically separated populations through a variety of mechanisms. As previously noted, because migrant populations do not carry with them all of the genetic diversity of their parent populations, subsequent generations in the new settlements will have a different genetic complement than the parent population. This phenomenon, called the founder effect, is the result

of a genetic “bottleneck,” and can result in different frequencies of genetic variants and disease between the offspring of the parent population and offspring of the migrant populations. In addition, migrating populations are often relatively small, which makes them more likely to experience random changes in their allele frequencies over time; this phenomenon is known as genetic drift. New patterns of genetic variation also may arise in response to new environmental pressures experienced by migrants, or as a result of natural selection.<sup>106</sup>

Despite the many forces of genetic evolution that have been acting over thousands of years, it is estimated that humans are 99.9 percent identical to each other at the DNA level and that the vast majority of the 0.1 percent variation in the human genome—approximately 85 percent—can be observed among individuals within the same population (see also Figure 7, p. 13). However, the remaining small proportion of the genome can be used to distinguish populations with divergent ancestry using ancestry informative markers, genetic variants whose frequencies have been shown to vary globally among human populations.

In the past few centuries, populations that had been geographically separated for thousands of years have been brought together, resulting in genetic admixture. Members of these admixed populations have genetic ancestry from two or more groups. For example, in



the United States, many Hispanics/Latinos have European, Native American, and African ancestry. Ancestry informative markers can be used to assess the proportion of genetic ancestry derived from each of multiple parent populations. This relatively new capability has provided interesting insight into the genetic makeup of individuals who are categorized into a single racial or ethnic group. For example, one study of ten populations of African descent in the United States and Jamaica found considerable variation in their levels of European genetic ancestry, ranging from a low of 6.8 percent in Jamaica to more than 20 percent in New Orleans.<sup>36</sup>

In addition to underscoring an inherent weakness in assigning biological meaning to socially defined racial and ethnic categories, genetic analysis of admixed populations provides a unique opportunity to gain insight into genetic components of disease risk. Ancestry informative markers can be used to identify whether inherited DNA at one or more specific sites from a particular ancestral population is associated with a disease trait. The markers can then be used to home in on the genetic culprit of the disease, although achieving this final step can be challenging.

Such studies have been conducted to evaluate assertions of a genetic basis for some of the observed differences in cancer incidence and mortality among racial/ethnic populations. Breast cancer has received significant attention in this regard. In the United States, breast cancer incidence rates are highest among

...[measures of] self-reported race are not adequate by today's science. I believe what we should be doing in very large population cohorts are these somewhat simple experiments of racial and genetic admixture tied to outcome. We spend so much money in our science dealing with targeted therapies and genetic abnormalities that if we don't really understand the racial and genetic admixture of our population group, those studies become somewhat out of context.

*Cheryl Willman, University of New Mexico Cancer Center*

non-Hispanic white women and lowest among Native American and Alaska Native women (Figure 12). In a genetic admixture study<sup>107</sup> of U.S. Latinas of mixed European and Native American ancestry, analysis of more than 100 ancestry informative markers indicated that higher proportions of European ancestry were associated with increased risk of breast cancer, even after adjusting for known breast cancer risk factors. The magnitude of the effect was substantial—for every 25 percent increase in European ancestry, a 40 percent increase in breast cancer risk was observed. These results are consistent with the notion that genetic factors underlie the high incidence of breast cancer among those with European ancestry; however, a specific offending genetic variant (or variants) was not identified. Absent this finding, it remains possible that unmeasured and/or unknown nongenetic risk factors also may contribute to the breast cancer trends observed among U.S. women.

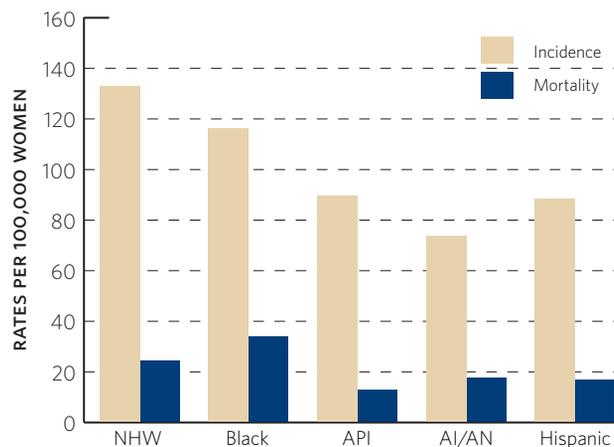
Speculation regarding biological differences between the breast tumors of non-Hispanic and Hispanic/Latina women also has been spurred by the discovery that many risk factors are not equally important to these populations. Use of hormone replacement therapy and younger age at menarche—which are well-characterized risk factors for postmenopausal non-Hispanic white women—were either weakly or not associated with breast cancer risk in Hispanic/Latina women.<sup>101</sup> Overall, the study found that 62 to 75 percent of breast cancers among non-Hispanic white women were attributable to evaluated risk factors compared with only 7 to 36 percent of cases in Hispanic/Latina women. Many of the risk factors found to differ by ethnicity relate to estrogen exposure, suggesting that genetic regulation of hormone signaling could play a role in the different disease etiologies in these populations, although it also is possible that the endocrine system could be altered by environmental factors.<sup>101</sup> A companion study found that Hispanic/Latina women have a higher ratio than non-Hispanic

white women of two estrogen metabolites—2-hydroxyestrone and 16 $\alpha$ -hydroxyestrone—which are thought to be inversely associated with breast cancer risk.<sup>108</sup>

Other studies have investigated the genetic and biologic basis of disparities in breast cancer mortality. As shown in Figure 12, African American women experience higher mortality due to breast cancer than any other racial/ethnic group despite the fact that non-Hispanic white women are more likely to be diagnosed with the disease. Although inadequate access to and utilization of care account for much of this difference, a meta-analysis of 20 studies found that African American women continue to experience increased mortality and decreased survival even after adjusting for stage at diagnosis and socioeconomic data.<sup>109</sup> In addition, survival disparities between some African American and white clinical trial participants have been shown to persist even when patients are treated according to the same protocol. African American race has been associated with significantly increased mortality among patients with gender-specific cancers (e.g., early-stage premenopausal breast cancer, early-stage postmenopausal breast cancer, advanced-stage ovarian cancer, advanced-stage prostate cancer) but not among patients with other cancer types (e.g., lung and colon cancers, lymphoma, leukemia, myeloma).<sup>110</sup> Adjustments for socioeconomic status did not substantially change these observations.

Differences in the expression of tumor markers between African American and European American women with breast cancer have been well documented. For example, African American women are more likely than European American women to be diagnosed with breast tumors that lack expression of estrogen receptor (ER) and/or progesterone receptor (PR).<sup>111,112</sup> These women also are more likely than European American women to be diagnosed with triple-negative tumors (i.e., tumors that lack expression of ER, PR, and human epidermal growth factor receptor 2 [HER2]) and are associated with poorer prognosis.<sup>103,113</sup> It remains unclear, however, whether the different patterns of ER expression among African American and European American women are based in genetics. A study in the relatively homogeneous white Scottish population found that women of lower socioeconomic status were more likely than affluent women to develop ER-negative tumors,<sup>114</sup> suggesting that environment, not genetics, is responsible for the observed differences in tumor biology. Evidence also indicates that genetic ancestry may play at least some role. An admixture analysis of nearly 1,500 African American women

FIGURE 12 » BREAST CANCER (FEMALE)  
INCIDENCE AND MORTALITY RATES



Key: NHW=Non-Hispanic white; API=Asian and Pacific Islander; AI/AN=American Indian/Alaska Native.

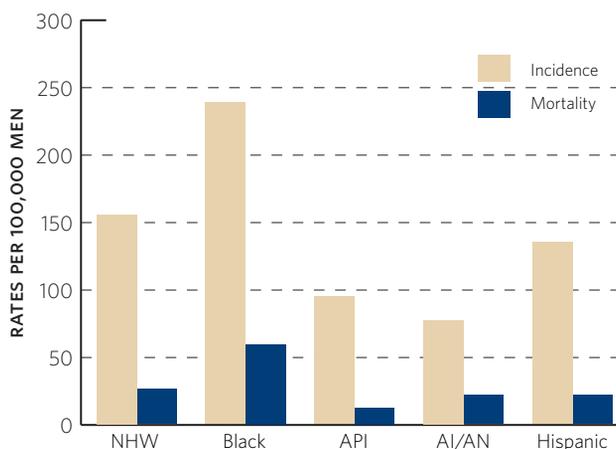
Source: Horner MJ, Ries LAG, Krapcho M, Neyman N, Aminou R, Howlander N, et al. (eds). SEER Cancer Statistics Review, 1975–2006 [Internet]. National Cancer Institute. Bethesda (MD) [http://seer.cancer.gov/csr/1975\\_2006/](http://seer.cancer.gov/csr/1975_2006/). Based on November 2008 SEER data submission; 2009.

using approximately 1,500 ancestry informative markers found that African American women with higher proportions of European ancestry were more likely to have tumors that expressed ER and PR, even after adjusting for several known risk factors.<sup>115</sup> In addition, several of the susceptibility loci identified through genome-wide association studies are more strongly associated with ER-positive than ER-negative disease, suggesting that genetic variation can influence biological features of breast cancer.<sup>116,117</sup>

Researchers also are investigating whether genes and biology may underlie the striking disparities in prostate cancer incidence and mortality between African American men and men of other racial/ethnic groups (Figure 13).

A study<sup>118</sup> of men with prostate cancer found no difference between African American and European American men in the expression of previously recognized diagnostic and prognostic markers for the disease. However, analysis of their gene expression profiles found variations in the activities of certain signaling pathways, including immune response, stress response, cytokine signaling (regulatory immune system factors that convey signals between cells), and chemotaxis (movement of a cell or organism toward or away from certain chemicals). These differences suggest that tumors in African American men may elicit an immune response distinct from that elicited by tumors in European American men. The variability in signaling pathway activity could be due to

FIGURE 13 » PROSTATE CANCER  
INCIDENCE AND MORTALITY



Key: NHW=Non-Hispanic white; API=Asian and Pacific Islander; AI/AN=American Indian/Alaska Native.

Source: Horner MJ, Ries LAG, Krapcho M, Neyman N, Aminou R, Howlander N, et al. (eds). SEER Cancer Statistics Review, 1975–2006 [Internet]. National Cancer Institute. Bethesda (MD) [http://seer.cancer.gov/csr/1975\\_2006/](http://seer.cancer.gov/csr/1975_2006/). Based on November 2008 SEER data submission; 2009.

environmental factors, genetic factors, or a combination of both. Immune signaling variations also have been observed in the microenvironments of breast tumors from African American and European American women.<sup>119</sup> Some studies have supported the hypothesis that genes involved in host defense may have evolved differently in geographically separated populations to enable the immune system to respond to infections unique to a given environment.<sup>120,121</sup>

Evidence also is emerging that genetic ancestry influences the prognosis of children with acute lymphoblastic leukemia (ALL). Extensive molecular analysis of children with high-risk ALL found that genetic ancestry was the most significant predictor of patient outcome, with patients of Hispanic/Latino ancestry having a higher rate of relapse following standard therapy. Strikingly, even among self-reported non-Hispanic whites, patients with higher levels of Hispanic genetic admixture were more likely to relapse.<sup>122</sup> Additional genetic analysis revealed that Hispanic ancestry was strongly associated with rearrangements in a gene called *CRLF2*.<sup>123</sup> This observation suggests that ethnic background may predispose individuals to the acquisition of specific genetic abnormalities that could influence tumor biology.

These examples and others provide some support for the idea that there may be genetic differences among racial and ethnic populations that contribute to disease risk and prognosis, but it is clear that genetic contributions can be modified by and must be considered in concert with the numerous other factors that can influence the integrity and expression of the genome. Ethnogenetic layering is a methodology that attempts to integrate these factors to gain insight into the disease susceptibilities of various subpopulations.<sup>124</sup> It rejects traditional race categories and focuses instead on geographically defined microethnic groups,



each of which includes members who are genetically related and share traits—such as cultural practices, environmental exposures, demographic status, and historical background—that influence the functional manifestation of the genome. Among other things, this approach acknowledges heterogeneity that exists within racial groups. For example, one ethnogenetic layering study<sup>125</sup> suggests that the high incidence of aggressive breast cancer among African American women in the Chesapeake Bay area may be due to the ancestral ties of this population to the Bight of Bonny, a region in Africa from which a large proportion of enslaved Africans arriving in the Chesapeake Bay area during the 18th century were brought. Early-onset, aggressive breast cancer occurs with unusually high frequency among modern populations in the Bight of Bonny. Such information may assist in identifying breast cancer susceptibility genes present in both African and African American microethnic groups.

As one speaker noted in his testimony to the Panel,<sup>126</sup> it is important to remember that any differences in genetics, tumor biology, or any other risk factor identified among racial, ethnic, or microethnic groups will not be fully generalizable. Rather, it is likely that certain factors are more prevalent in one group than in another. Research on racial and ethnic populations may help identify genetic and biological factors that increase risk or alter outcomes, but future clinical interventions targeting these factors have potential to benefit individuals with a particular trait across all populations.

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*I think in the future we need to not argue about whether it's nature or nurture, but do a better job of describing both nature and nurture and how those interplay in cancer risk and outcomes.*

*Tim Byers, University of Colorado Denver*

## SOCIOECONOMIC AND SOCIOCULTURAL DETERMINANTS OF HEALTH

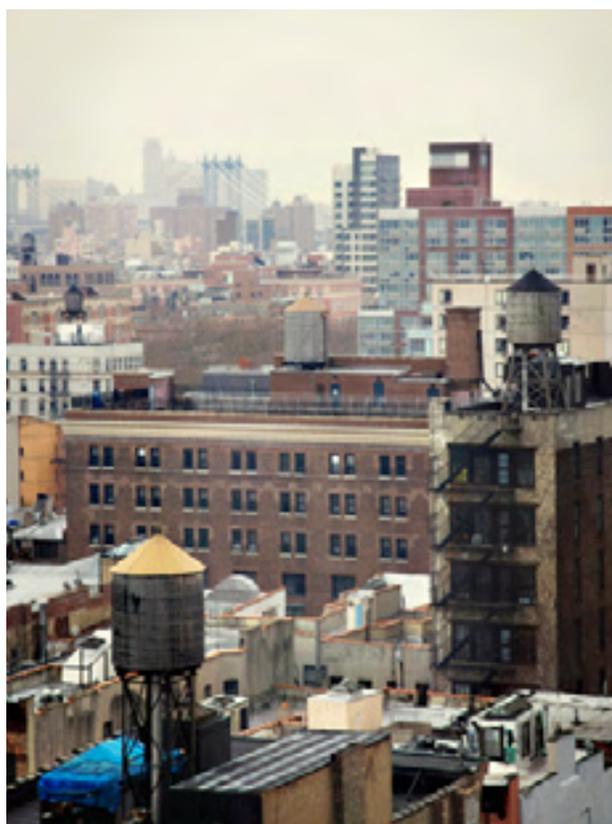
Figure 10 (p. 29) arrayed the multitude of possible influences—environmental, social, lifestyle, cultural, and health care access factors—that may alter the expression of an individual's genes and biologic processes, leading to differences in disease susceptibility and health outcomes. In this respect, these influences may be considered determinants of health.

## Socioeconomic Status

It has been observed that as with many phenomena, the more closely one looks at any aspect of socioeconomic status, the more complicated the picture becomes.<sup>127</sup> In addition, no consensus exists on how best to measure socioeconomic effects, and the scales and other tools that exist are subject to varying interpretation, creating additional problems in understanding the impact of these factors.<sup>128</sup> Similar problems exist regarding the measurement of cultural influences on health.

The impact of socioeconomic position, or class, on health outcomes has been recognized for at least 165 years in the United States and also has been documented in other nations.<sup>129–132</sup> Yet in the United States, research has focused primarily on trying to identify health differences according to race and ethnicity rather than socioeconomic differentials. In many studies, race and ethnicity are used as proxy measures for socioeconomic position, but doing so typically fails to account for specific socioeconomic factors, the interaction of specific combinations of socioeconomic variables, or the socioeconomic heterogeneity within OMB-defined racial and ethnic groups. Several speakers at the Panel's meetings underscored emphatically the importance of studying the impact of socioeconomic factors on cancer and other health outcomes.

Stress is believed to be a central concept for understanding how social disadvantage produces ill





health, but there is no standard measure of stress.<sup>127</sup> Allostatic load refers to the cumulative physiologic effect of chronic, multiple stressors that cause fluctuating or heightened neural or neuroendocrine responses that in turn increase morbidity and mortality risk.<sup>133</sup> The stressors that together comprise allostatic load occur at the individual, household, neighborhood, and broader social levels. The physiological cost of allostatic load associated with socioeconomic stress on aging<sup>134</sup> and disease—including cancer progression<sup>135</sup>—has been a subject of research for more than a decade.

Mortality differences by socioeconomic position are not fully explained by individual health behaviors (e.g., tobacco use) but they do reflect societal patterns of risk in that lack of power and resources and fewer life chances increase vulnerability to health problems, including cancer risk.<sup>136</sup> As noted in Part 1, poverty and educational attainment are correlated with life expectancy among all racial/ethnic groups, and mortality rates for some cancers have been found to correlate with income and education within OMB-defined racial/ethnic subpopulations. However, for many people in America, higher income and better education alone are insufficient to eliminate differences in cancer incidence and outcome, due to the intertwined effect of racism on patterns of social and economic inequality and disadvantage.<sup>137</sup>

...it is surprising that there actually aren't a lot more data like this looking at how stress is distributed by income and other social markers, but the data that are there show this pattern with a gradient. It has almost, you might say, a dose-response look to it.

*Paula Braveman, University of California, San Francisco*

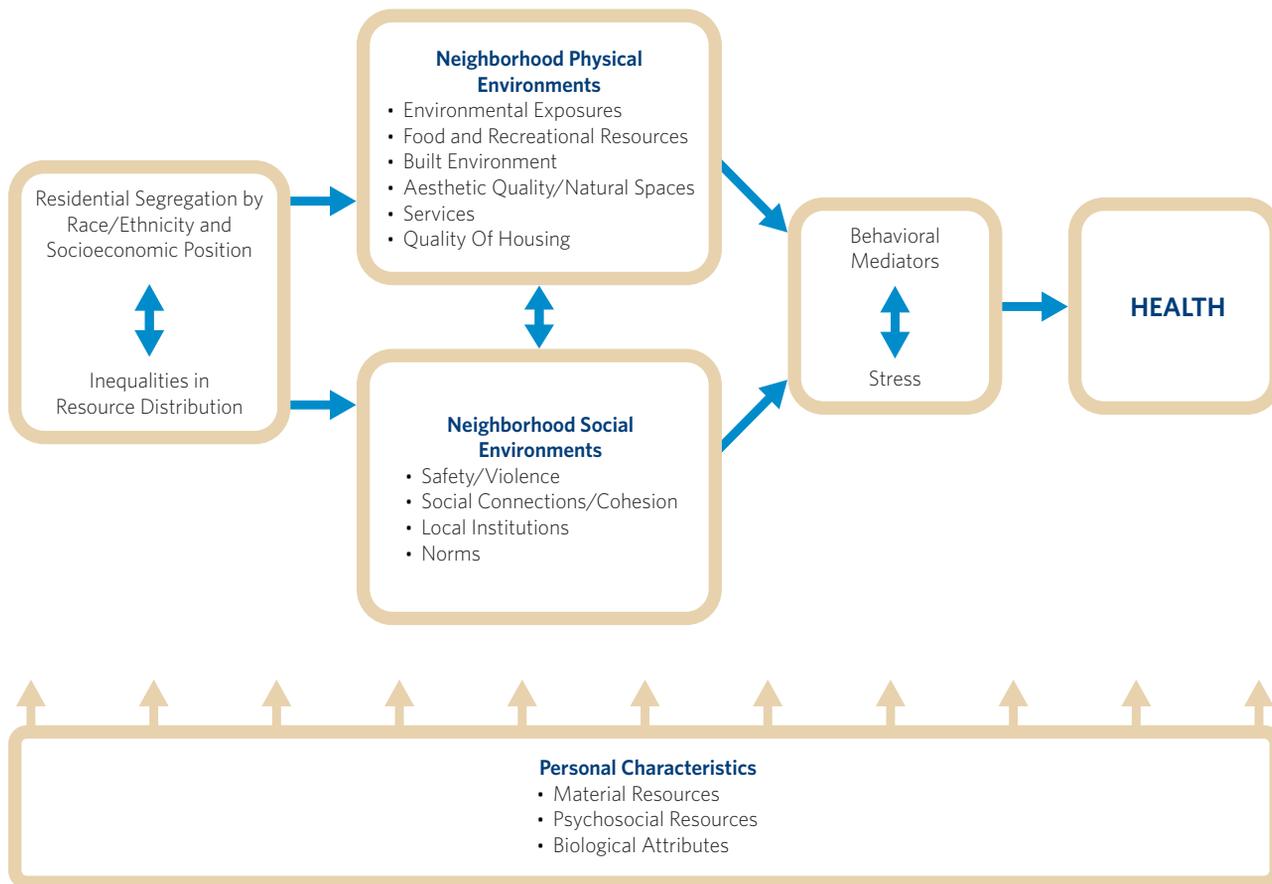
## Environment and Occupation

Environmental and occupational factors can have significant effects on individuals' cancer risk. The President's Cancer Panel's 2008–2009 report<sup>138</sup> describes in detail the myriad exposures to known and suspected carcinogens that may affect people in their home and work environments.

Others have noted that where an individual lives may better predict his or her health than access to good-quality health care.<sup>139</sup>

Interest in the multilevel influence of neighborhood on health and well-being has intensified among public health scientists, epidemiologists, and social scientists seeking to better understand persistent racial/ethnic differences across a range of health outcomes.<sup>140</sup> Approaches to understanding the mechanisms and importance of neighborhood context vary among disciplines, but efforts to understand these differences

FIGURE 14 » THE CONTRIBUTIONS OF NEIGHBORHOOD ENVIRONMENTS TO HEALTH INEQUALITIES



Source: Diez Roux AV, Mair C. Neighborhoods and health. *Ann NY Acad Sci.* 2010 Feb 16;1186:125-45.

using data at the individual level and nationally have failed to fully explicate the dynamics that result in observed morbidity and mortality differences.

As Figure 14 indicates, poor and racially/ethnically segregated neighborhoods are associated with low-quality schools, limited access to good jobs, substandard housing and health care, physical danger (e.g., crime), limited access to healthy food, lack of positive peer role models, poor transportation and other services, and the psychological distress associated with these factors. Characteristics of the built environment also affect health; urban neighborhoods in particular often lack recreational facilities and safe places to walk or engage in other exercise outdoors.

The cancer risk of immigrants to the United States tends to increase the longer they are in the country. While a substantial part of this increase appears to be related to adoption of a Western diet and more sedentary lifestyle (discussed further in the following section), occupational, neighborhood, and other environmental influences likely also contribute to increased risk.

## Culture and Lifestyle

Cultures are not static; they are ever-evolving, dynamic phenomena.<sup>141,142</sup> Like the terms “race” and “ethnicity,” “culture” has been variously defined (see examples, Table 3, p. 14). Cultural beliefs (including religion), values, customs, and norms often dictate lifestyle choices such as dietary practices, tobacco use, excess sun exposure, level of physical activity, and sexual or reproductive choices. Conversely, if members of a cultural group adopt lifestyle choices that differ from practices that are traditional or accepted by the group, such choices, over time, may alter the culture of that population group. This process of cultural change and adaptation resulting from continuous firsthand contact between groups—acculturation—occurs across time and generally is considered to be irreversible.<sup>143-146</sup>

In the United States, full acculturation (assimilation) has been said to take three generations to occur.<sup>147</sup> However, when immigrants have distinguishing physical characteristics (e.g., skin color, clothing), they are more

likely to experience xenophobia and discrimination and may limit interaction with the host culture to avoid rejection.<sup>142,148</sup> It should be noted that the same dynamic may occur when U.S.-born minority group members relocate to an area of the country where there are few other members of the group.

Many think of acculturation only as it concerns the assimilation of immigrant cultures into the culture of their new country of residence. However, acculturation is a two-way process wherein the “dominant” or host culture also adopts features of the immigrant, minority, or “weaker” culture, although the groups remain distinct in numerous respects.<sup>149,150</sup> Frequently, immigrants seek to maintain their native culture in their private lives, but participate with the host culture in their public lives. In some instances, groups (e.g., Amish, Orthodox Jews, conservative Muslims) choose to remain almost entirely separate from the host culture, usually due to conservative religious practices, including dietary restrictions, prescribed manner of dress, and rules limiting social interaction.<sup>151</sup>

Earlier sections of this report described how diverse aspects of culture and lifestyle may interact with an individual’s genetic makeup to affect cancer and other disease susceptibility and outcome. Cultural and lifestyle factors also can have independent and sometimes profound effects on cancer susceptibility and outcome in both native and foreign-born

Americans. For example, culture and lifestyle may influence how individuals and population groups perceive health and disease, the priority of obtaining cancer screening and prevention services (e.g., vaccinations for cancer-related infectious agents such as human papillomavirus and hepatitis B and C) compared with other demands of daily life, and willingness to trust and engage the health care system.

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I sometimes jokingly say [that] people who say that the biology is different between blacks and whites and that accounts for these disparities must [think] that black people mutated around 1980. The reality is the biology did change, but it wasn't genetic biology.... It's fast food and dietary changes of the 1960s. It's the fact that 15 percent of Americans were obese in 1970 and 35 percent were obese in 2005. It's the fact that we learned how to screen for colorectal cancer around 1980 and whites got the screening and got the treatment and blacks did not. It's a number of factors, very few of them having to do with genetics.

*Otis Brawley, American Cancer Society*

Fatalistic beliefs about cancer—that it is a death sentence, God’s will, or a punishment for wrongdoing—remain prevalent in both native and foreign-born segments of the population, and may be particularly strong among recent immigrants from countries in which cancer mortality is high due to lack of screening and treatment services. Though cancer survivor organizations in many countries are fostering greater openness about cancer,<sup>152</sup> in some cultures, cancer still is considered a shameful condition to be concealed, sometimes even from one’s family, for fear of ostracism.<sup>153</sup> These beliefs can lead people to avoid cancer screening or treatment even when they are symptomatic. In other cases, people may avoid screening or treatment because of the family financial burden a cancer diagnosis would create, or because of their perception of their own worth in their family and community.<sup>153</sup> A 2008 study of breast cancer fatalism and health care system perceptions among women in Mississippi found that, compared with the other women studied, those with a fatalistic attitude were more likely to be African American, rate their quality of care as fair or poor, have a family history of breast cancer, believe that little could be done to prevent breast cancer, believe that breast cancer could not be cured if found early, and believe that treatment could be worse than the disease.<sup>154</sup>



Cancer susceptibility also can be influenced by culturally based dietary practices. For example, gastric cancer is the most common malignancy in Japan and among Japanese immigrants to the United States who continue to consume primarily a traditional Japanese diet; research has shown that high intake of salt and traditional salt-preserved foods is associated with gastric cancer risk.<sup>155</sup> In addition, salted food intake may increase the risk of *Helicobacter pylori* infection and may act synergistically with *H. pylori* to promote gastric cancer development.<sup>156,157</sup> The typical Western diet (high fat and red meat intake, low fiber and fruit/vegetable intake) is associated with increased colorectal cancer risk.<sup>158,159</sup> Some research also has linked adoption of a Western diet to higher breast cancer risk in Asian Americans compared with those who follow a more traditional low meat and starch intake, high vegetable/legume intake diet.<sup>160</sup>

...the issue was cancer means death and when a patient is diagnosed with cancer it means that the patient is dead and, accordingly, the patient and family will be treated [as such] within the society....It's a scourge, so the patient becomes socially isolated and the attitude of giving up becomes very prominent.

*Samir Khleif, National Cancer Institute*

## Access to Care and Interactions with the Health Care System

Dating back to colonial America, limited access to health care has been a formidable barrier to the most effective known disease prevention and treatment interventions and optimal health status for minorities, immigrants, and other historically underserved populations.<sup>62</sup> In contemporary America, these populations still are less likely to receive standard and/or high-quality treatment for cancer.<sup>65,153,161</sup> Although clinical trial and other research has shown that equal treatment can result in equal outcomes,<sup>162-164</sup> not all populations receive equal treatment. Some disparities remain even when patients have the same type and stage of disease and equal insurance.<sup>165</sup> By one estimate, racial disparities in health care between 2003 and 2006 cost the United States \$229 billion in direct medical care expenses.<sup>166</sup>

Numerous factors, both individually and in varying combinations, may limit access to quality cancer and other health care. A number of these factors are described in the following paragraphs.

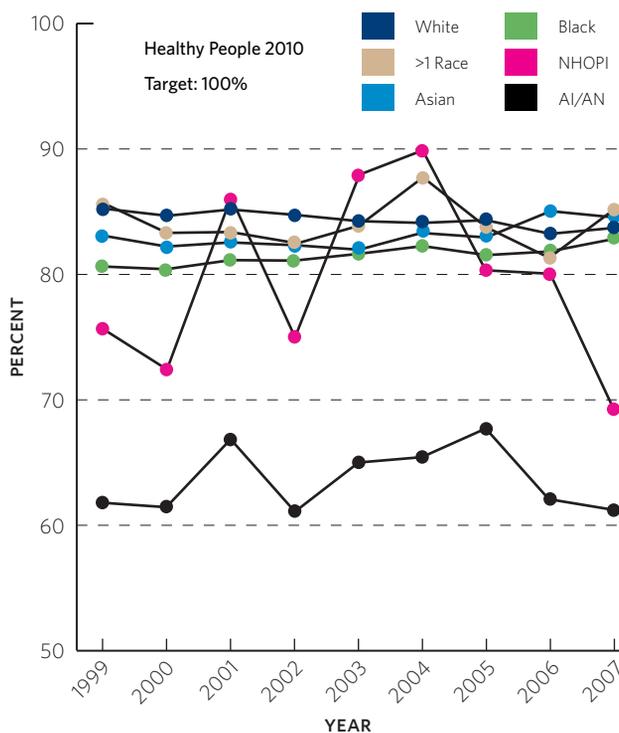
## Lack of Health Insurance and/or Financial Resources to Pay Out-of-Pocket for Care

In 2009, the percentage of people living in the United States without health insurance rose to 16.7 percent, the highest rate since the Census Bureau began collecting these data in 1987.<sup>8</sup> This rate represents a 1.3 percent increase over the 2008 uninsured rate, and represents 50.7 million people. The Census Bureau ascribes much of the change to the economic downturn as people lost full-time jobs with health benefits and either remained unemployed or took jobs without health coverage.

As described in Part 1, minorities and other underserved populations, including recent immigrants, are less likely than the non-Hispanic white population to have health insurance. They are more likely to work in low-paying jobs that do not provide health insurance benefits. Many of these workers and their families are unable to afford individual health insurance policies, but have too much income and too many assets (e.g., a car) to qualify for Medicaid. Even at equivalent salaries, most minorities have lower net worth (e.g., assets plus income less expenses) than do non-Hispanic whites.



**FIGURE 15 » PEOPLE UNDER AGE 65 YEARS WITH HEALTH INSURANCE, 1999–2007**



Key: AI/AN=American Indian or Alaska Native; NHOPI=Native Hawaiian or Other Pacific Islander.

Denominator: Analyses by race, ethnicity, and income performed for civilian noninstitutionalized population under age 65. Analyses by education performed for civilian noninstitutionalized population ages 25–64.

Note: Data from Centers for Disease Control and Prevention, National Center for Health Statistics, National Health Interview Survey (NHIS), 1999–2007. NHIS respondents are asked about health insurance coverage at the time of interview; respondents are considered uninsured if they lack private health insurance, Medicare, Medicaid, State Children's Health Insurance Program (SCHIP), a state-sponsored health plan, other government-sponsored health plan, or a military health plan, or if their only coverage is through the Indian Health Service. This measure reflects the percentage of survey respondents under age 65 who were covered by health insurance at the time of the interview.

Source: Agency for Healthcare Research and Quality. National Healthcare Disparities Report, 2009. Rockville (MD): AHRQ; March 2010. Available from: <http://www.ahrq.gov/qual/nhdr09/nhdr09.pdf>

As a result, they have fewer resources to fall back on (including financial help from family members) in the event of a major illness such as cancer.

Figure 15 shows the uneven distribution of health insurance in the population by OMB-defined racial/ethnic groups. As the figure indicates, insurance rates for the nonelderly have fallen far short of the Healthy People 2010 target of 100 percent coverage.<sup>167</sup>

Insurance rates are consistently lowest for Native Americans. Most American Indians living on reservations are served almost exclusively by chronically and severely underfunded Indian Health Service (IHS) facilities.<sup>65</sup> Care for urban Indians is even more precarious; although more than half of all

Native Americans live in nonreservation settings, only one percent of the IHS budget is allocated to their care via the Urban Indian Health Program.<sup>168</sup> It should be noted that IHS is not an insurance program. Rather, the U.S. Government agreed through numerous treaties executed in the early- to mid-1800s and in subsequent legislation enacted over 150 years to provide health care to American Indians in perpetuity in exchange for cession of most of the land that now comprises the United States.<sup>65</sup>

To offset IHS funding shortfalls, health centers serving Native Americans must aggressively seek reimbursement from all possible public and private payors, and many actively assist patients in qualifying for Medicaid, Medicare, and other coverage. Through the 2009 stimulus funding, IHS received \$590 million to support community-based health and public health projects, and the agency has received budget increases in the past two fiscal years. Through the 2010 health care reform legislation, the Indian Health Care Improvement Act was reauthorized indefinitely,<sup>169</sup> but it is unclear whether this action will translate into continued funding increases that would help to make up the funding deficits that have for decades crippled IHS's ability to uphold its commitment to providing health care to Native Americans.

**Irrespective of race, if you have no health insurance, your chances of dying from a disease such as cancer are much higher.**

*Harold Freeman, National Cancer Institute*

Lack of health insurance causes people to delay or even forgo cancer and other health care due to cost, often resulting in later stage of disease at diagnosis and shorter survival compared with insured individuals.<sup>170</sup> Table 8 demonstrates the impact of insurance on national cancer screening rates. The table also shows the impact of education, which is closely related to income and income potential, on cancer screening.

Screening rates differ substantially both between and within states. Figure 16 illustrates state-level impacts of income and insurance differences on colorectal cancer screening rates in California, a populous state with a highly diverse population that includes a large Hispanic/Latino subpopulation. Figure 16 also shows the significant differences in colorectal cancer screening among Hispanic/Latino subpopulations in the state by country of origin. These differences may be affected by

**TABLE 8 » PREVALENCE (%) OF RECENT CANCER SCREENING EXAMINATIONS AMONG U.S. ADULTS BY HEALTH INSURANCE COVERAGE AND EDUCATIONAL LEVEL**

	HEALTH INSURANCE		EDUCATIONAL LEVEL, YEARS OF EDUCATION			
	Have Health Insurance (SE)	No Health Insurance (SE)	≤11 years (SE)	12 years (SE)	13–15 years (SE)	≥16 years (SE)
<b>Colorectal cancer (men and women aged ≥50 years)</b>						
Either a flexible sigmoidoscopy or colonoscopy <sup>a</sup>	52.6 (0.7)	12.7 (2.5)	34.0 (1.4)	48.1 (1.1)	52.2 (1.2)	61.9 (1.2)
FOBT home kit <sup>b</sup>	10.3 (0.4)	8.8 (3.9)	8.1 (0.8)	8.1 (0.6)	12.9 (0.8)	10.8 (0.7)
FOBT or endoscopy <sup>c</sup>	55.7 (0.7)	19.5 (4.4)	37.3 (1.4)	50.8 (1.1)	56.3 (1.2)	64.5 (1.2)
<b>Breast cancer (women aged ≥40 years)</b>						
Mammogram <sup>d</sup>	56.2 (0.7)	26.0 (3.8)	40.1 (1.8)	49.2 (1.4)	55.2 (1.3)	64.5 (1.3)
<b>Cervical cancer (women aged ≥18 years)</b>						
Pap test <sup>e</sup>	81.0 (0.5)	60.6 (2.4)	68.3 (1.6)	73.7 (1.2)	81.1 (0.8)	84.8 (1.0)
<b>Prostate cancer (men aged ≥50 years)</b>						
PSA <sup>f</sup>	46.2 (1.0)	9.1 (2.1)	29.8 (2.0)	37.6 (1.7)	48.1 (2.1)	55.7 (1.8)

Key: NHIS=National Health Interview Survey; SE=standard error; FOBT=fecal occult blood test; Pap=Papanicolaou test; PSA=prostate-specific antigen test.

a Recent sigmoidoscopy within the preceding five years or colonoscopy test within the preceding ten years.

b Recent fecal occult blood test using a home kit test performed within the preceding year.

c Recent fecal occult blood test using a home kit test performed within the preceding year or recent sigmoidoscopy or colonoscopy test within the preceding ten years.

d Women aged ≥40 years who had a mammogram in the past year.

e Women who had a Pap test within the preceding three years.

f A prostate-specific antigen (PSA) test within the past year for men who had not been told they had prostate cancer.

Source: Centers for Disease Control and Prevention, National Center for Health Statistics. National Health Interview Survey. Atlanta (GA): CDC; 2008.

...[when] overall population decreases in mortality due to the four most prevalent cancers...[were] teased out by education...most of that decline was concentrated among people with 16 or more years of education – those likely to have college degrees. And for the less educated, in some cases the line was flat, in others there actually were worsening trends, and sometimes there was an improvement but at a lower rate than among the more educated.

*Paula Braveman, University of California, San Francisco*

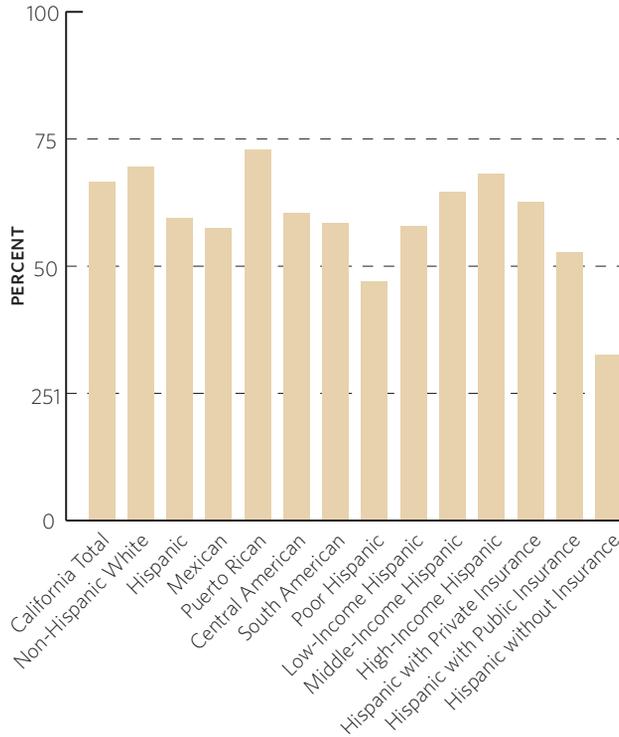
insurance and income, but also may be influenced by other factors, as described later in this section.

As Table 9 illustrates, one less obvious factor underlying cancer and other health disparities by insurance status is that the uninsured often are charged more (“list” prices) and pay more out-of-pocket for the same services compared with the insured, who pay only a small fraction of discounted prices charged to their health plans.<sup>171</sup> Research also indicates that

for a similar medical episode/encounter, total costs incurred by uninsured nonelderly cancer patients were approximately half those of privately insured patients because they received fewer services.<sup>172</sup> Yet despite their lower spending, the uninsured patients paid close to three times more out-of-pocket than their insured counterparts paid. This disparity is particularly punishing for the uninsured, since these out-of-pocket costs typically comprise a higher percentage of income than is the case for those with private insurance.

Moreover, a 2006 national study of households affected by cancer<sup>173</sup> found that compared with those always insured, uninsured individuals with cancer were two to six times more likely to experience financial problems due to the cost of cancer care. These problems included: using up all or most of savings, borrowing money from relatives, being contacted by collection agencies, seeking help from charity or public assistance, taking out loans or second mortgages, being unable to pay for basic necessities like food or heat, and declaring bankruptcy.

**FIGURE 16 » ADULTS AGE 50 AND OVER WHO RECEIVED A SIGMOIDOSCOPY, COLONOSCOPY, OR FECAL OCCULT BLOOD TEST IN THE PAST FIVE YEARS, CALIFORNIA ONLY, BY RACE, HISPANIC SUBGROUP, INCOME, AND INSURANCE STATUS, 2007**



Denominator: Civilian noninstitutionalized adults age 50 and over in California.  
 Note: Income groups are all Hispanic. For this measure, public insurance includes people with Medicare and/or Medicaid coverage.  
 Source: University of California, Los Angeles, Center for Health Policy Research. California Health Interview Survey. Los Angeles (CA): UCLA; 2007.

It is important to note that the underinsured can experience the same financial catastrophe as the uninsured. The underinsured are commonly defined as: (1) people with insurance who spend more than 10 percent of their income on out-of-pocket medical

...the different survival rates [are] an access issue about not just insurance, but ability to be able to take on the tremendous nonmedical costs that terribly impact families, including relocation, lost income, double living expenses, need for a caregiver, being out of the workforce not just months [but] often years, and so on... innovations do not help if people don't have access to them. And this includes language access, of course.

*Joanna Ramos, Cancer Survivor*

expenses related to a serious illness, (2) low-income adults who have medical expenses of at least 5 percent of income, or (3) people who have deductibles that equal or exceed 5 percent of income.<sup>174,175</sup> Many who are underinsured do not realize the extent of their financial liability until they are faced with high deductibles and copayments, time limits for covered services, and caps on monthly, lifetime, or disease-specific coverage until the bills begin to mount up. Research<sup>176</sup> has shown, and many—including President Obama<sup>177</sup>—have noted that most American families are just one serious illness away from financial ruin.

**Nonmedical Costs of Care**

The poor, those un- or underinsured, and other underserved populations are particularly vulnerable to the financial impact of nonmedical costs of care, such as child care, transportation expenses, and lost income due to time away from work while receiving care.<sup>153</sup> Those who must travel to receive needed cancer care also may incur lodging, food, and travel costs for themselves and, when needed, a spouse or companion. Those in low-paying jobs often have poor job stability and, in addition to lost income, may risk job loss if they take too much time off from work to obtain cancer care or to care for a loved one with cancer. Ultimately, the barriers to care created by these problems may result in adverse patient outcomes.

**TABLE 9 » FOR TREATMENT OF EQUIVALENT CONDITIONS, UNINSURED PATIENTS OFTEN RECEIVE FEWER SERVICES BUT PAY MORE OUT-OF-POCKET THAN THE INSURED**

	TOTAL SERVICES RECEIVED		TOTAL CHARGES FOR SERVICES RECEIVED	AMOUNT PAID BY INSURANCE	AMOUNT PAID BY PATIENT
<b>Insured Patient</b>		➔	\$\$\$\$	\$\$\$	\$
<b>Uninsured Patient</b>		➔	\$\$\$	—	\$\$\$



### Lack of a Usual Source of Quality Care

People without health insurance, who are disproportionately from poor, minority, immigrant, and other underserved groups, and those who rely on some publicly funded health providers (e.g., Medicaid, Indian Health Service) are less likely to have a usual source of medical care compared with those with private insurance or Medicare. Receiving care in low-quality settings or relying on emergency rooms for care can contribute to health disparities,<sup>178</sup> and having neither insurance nor a usual source of care has been shown to have an additive negative effect on health.

Further, even when patients have access to a source of health care such as a clinic, they may seldom see the same physician twice. Poor continuity of care, inconsistent preventive health services, and unnecessarily repeated tests are common in such situations. In recent years, growing attention has been given to strategies for improving the consistency and quality of primary care provided to poor and underserved populations. The “medical home” concept—establishing both a regular source of care and a regular practitioner—combined with patient-centered care increasingly is seen as a viable option to address the needs of these patients and reduce disparities. Patient-centered care has been defined as “respecting and responding to patients’ wants, needs

and preferences, so that they can make choices in their care that best fit their individual circumstances.”<sup>179</sup>

It has been noted, however, that for the benefits of patient-centered care to be realized, providers must be taught patient-centered communication skills.<sup>180</sup> The National Cancer Institute identifies six fundamental functions of physician-patient communication: fostering healing relationships, exchanging information, responding to patients’ emotions, managing uncertainty, making informed decisions, and enabling patient self-management.<sup>181</sup>

Patient-centered medical home (PCMH) models are being tested<sup>182,183</sup> to determine if this approach to providing primary care can improve utilization of preventive services, including cancer screening, and reduce disparities. The PCMH approach, which has been endorsed by all of the major primary care professional organizations, is generally defined as including a regular physician provider who offers and coordinates continuous, comprehensive, culturally effective care of the whole person, fosters patient engagement in care, uses information technology to monitor quality of care, and is easily accessible to the patient.<sup>184</sup> PCMHs are encouraged to seek formal recognition by the National Committee for Quality Assurance<sup>185</sup> as well as a seal of distinction in multicultural health care.<sup>186</sup> One study<sup>178</sup> of Latino

access to a PCMH found that white (57.1%) and Puerto Rican (59.3%) adults were most likely to have a PCMH, while Mexicans/Mexican Americans (35.4%) and Central and South Americans (34.2%) were least likely to have one. Patients with a PCMH had higher rates of preventive care and positive patient experiences. Further, disparities in care were eliminated or reduced for Latinos with PCMHs. Having private insurance, which is less common among all Latinos, was an important predictor of having a PCMH, suggesting that addressing health care coverage differences that block access to a PCMH will also reduce disparities.

### Geographic Isolation

Many people still live far from sources of quality cancer care. About 20 percent of Americans live in rural areas, where they have less access to care and, typically, less awareness of clinical trial opportunities.<sup>187</sup> For example, one speaker noted that many Native Americans in South Dakota live at least 140 miles from the nearest cancer center.<sup>188</sup> Distance from care of this magnitude may cause people to forgo screening, delay or fail to follow up on suspicious screening results, and if diagnosed with cancer, drop out of care due to time and expenses (e.g., child care, gasoline, time off from work) associated with travel to the clinic or hospital. Urban residents also may effectively be isolated from care if reaching the source of screening and treatment services requires walking to and from bus or subway stops and taking long or multiple public transit trips to reach a hospital, clinic, or cancer center. In both urban and rural settings, lacking reliable personal transportation, feeling too weak or ill to endure the necessary travel, lacking a companion to accompany the patient to treatment, and other factors affect the likelihood that patients will receive recommended cancer screening and prompt diagnostic services, and that they will be able to access and complete their treatment regimens.

### Distrust of Health Care Providers and the Health Care System

Trust is a critical element in all medical relationships and a key contributor to use of preventive health care services, positive therapeutic outcomes, and patient satisfaction. Conversely, lack of patient trust is associated with less provider-patient interaction, poor clinical relationships with limited continuity, less adherence to recommendations, and reduced utilization of health care services.<sup>189</sup>

Overall, interpersonal trust has been found to be stronger than trust in institutions. It depends more

on individual characteristics and actual experiences than on global attitudes, preferences, and values.<sup>190–192</sup> Among other factors, physician-patient trust requires the patient to accept the inherent imbalance of knowledge and power in the relationship and to risk making vulnerable to the physician's actions the patient's most prized possession—life.<sup>193,194</sup> The relevance of trust is believed to be particularly great in oncology care, since patients are in an extremely vulnerable position—they have to deal with complex medical information, make difficult medical decisions, and cope with uncertain prognoses and radical treatments with limited if any guarantee of improvement in their condition.<sup>195</sup>

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...the Natives in [Western South Dakota] have access to the cancer center, [but] they live on average about 140 miles away....where they come from they're not on an interstate, so it's at least a two-and-a-half to three-hour drive each way.

*Daniel Peterreit, Dakota West Radiation Oncology,  
John T. Vucurevich Cancer Care Institute*

Distrust of health care providers and the health care system is widespread in many segments of the population. These feelings have many bases, among them:

- Negative interactions experienced by the patient or a family member, friend, or other community member, including overt discrimination, disrespectful treatment, inadequate information, and lack of attendance to patient feelings, values, and preferences.
- Communication problems and lack of confidence in providers from racial, ethnic, and cultural groups or nations different from those of the patient.
- Lack of trust that the patient's best interest is the health care provider's chief concern (e.g., profit motive) or suspicion of malicious provider motives (e.g., medical experimentation).
- Fear, including fear of hospitals and medical technology, being diagnosed with cancer or other serious medical conditions, pain, loss of control, and never leaving the hospital.
- Providers' failure to convey information about diagnosis and treatment in an understandable way.
- Concern that providing race and ethnicity information will result in discriminatory treatment.

In the African American community, with very, very good historical and present reasons, there is suspicion of the medical establishment, and that isn't only in the lower socioeconomic populations.

*Derek Raghavan, American Society of Clinical Oncology*

In much of the African American community, the infamous and relatively recent Tuskegee Syphilis Study<sup>196</sup> is considered conclusive proof of continuing racist and malevolent treatment of blacks by the medical system and reinforces deep-seated community fears of genocide (e.g., that HIV/AIDS was created by the government to decimate the African American population).<sup>197-200</sup> Similarly, forced sterilization of Puerto Rican, Chicana, and Native American women,<sup>201-203</sup> in some cases during childbirth and without their knowledge, has fueled distrust of the health care system in these populations. For example, a study<sup>204</sup> of patient decisions to undergo curative surgery for early-stage non-small-cell lung cancer found that in addition to other factors (including racial discrimination), poor provider communication and patient doubt about accuracy of the diagnosis were important factors in the greater likelihood that, compared with white patients studied, black patients would choose no surgery. Without surgery, patients could expect to survive one year (median survival), compared with median survival of four years with surgery. These findings may explain in part the surgical differential between black and white patients with early-stage lung cancer that has been documented for more than a decade.<sup>205,206</sup>

In addition, research<sup>189</sup> examining the relationship of trust in the health care system and the use of preventive health services by older black and white adults found that black patients' relatively high distrust of their physicians likely contributes to health disparities by causing reduced utilization of preventive services. The findings also suggest that disseminating health information to African Americans through informal means is likely to increase utilization of preventive health services by this population.

### Cultural Acceptability of Services

Even when cancer screening and other services are available, individuals may not utilize them because doing so would be culturally unacceptable. For example, in some cultures, it is forbidden for a woman to have contact with a man other than her husband or other male family member, creating barriers to examination by a male physician.<sup>207</sup> In traditional, male-dominated

societies such as the Muslim culture, a female patient may ask a health care provider to consult with her husband or a male family member about her care.<sup>208</sup> *Machismo* is highly important among men in many cultures, including some Hispanic/Latino and African American/black subpopulations. These men often are strongly opposed to having a digital rectal examination to check for signs of prostate cancer, because they view the procedure as degrading or acceptance of a behavior they associate with homosexuality.<sup>209,210</sup> Some Native American patients may insist on incorporating traditional healing practices into the cancer treatment process.<sup>211</sup> Women may be reluctant to put their own health needs ahead of their family priorities and delay seeking care.<sup>212</sup> Moreover, people in many farming and other rural cultures consider it unacceptable to go to the doctor unless they are in significant pain and can pay the bill.<sup>153</sup> In all of these situations, tailored educational efforts, preferably implemented by members of the community, are essential (see also p. 55 regarding patient navigators and community health workers).

### Literacy, Health Literacy, and Language Issues

As the U.S. population becomes increasingly diverse, literacy, language, and other communication problems, already recognized as a barrier to effective health care,<sup>161</sup> are of growing importance.

#### Literacy and Health Literacy

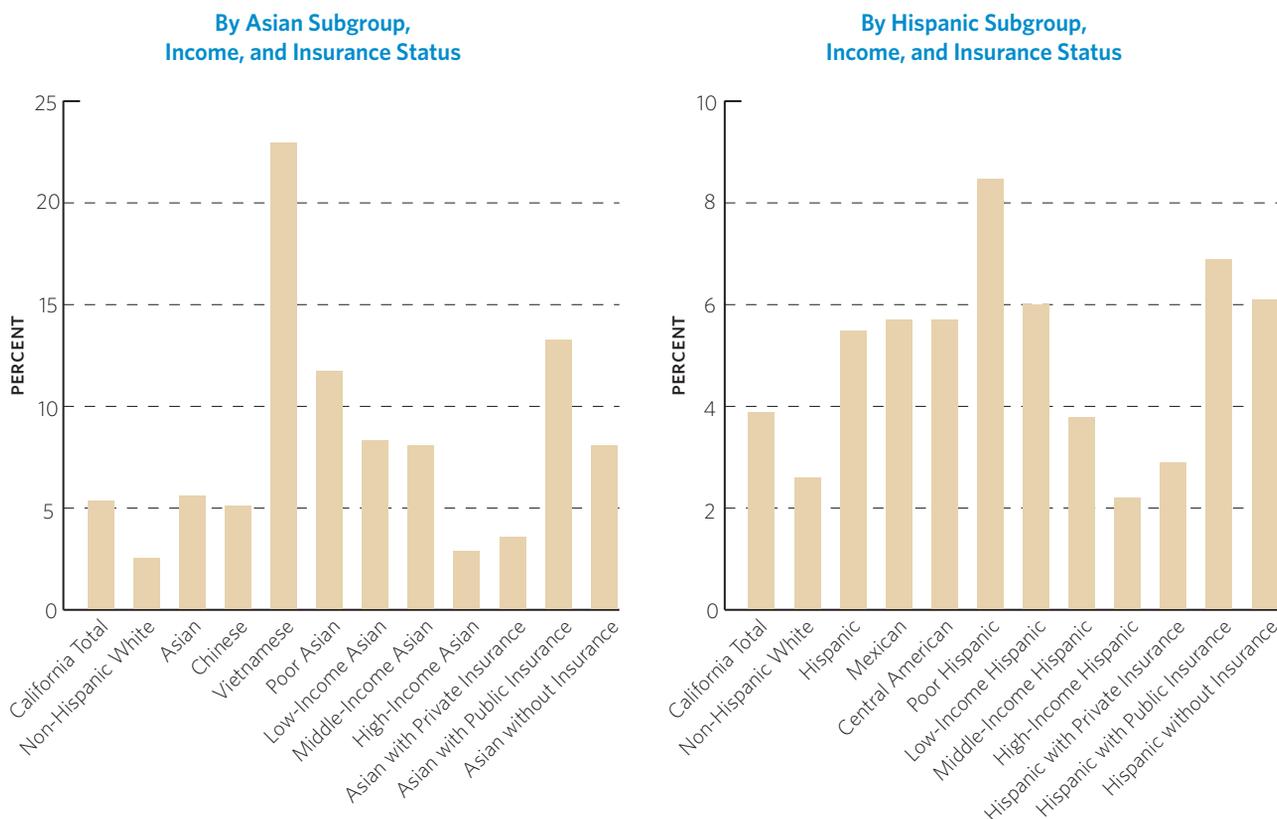
Health and medical communication problems are magnified when individuals have limited literacy. Immigrants may have limited literacy both in English and in their native languages. In such cases, literal translation of a health provider's statements or print materials in English and other languages may not improve patients' ability to understand health-related information because the translation or materials are at a proficiency level that is too high.

Health literacy also plays an important role. If we don't know how our bodies function, then the information that we're getting has no way to inform us. We can try to imagine what this could mean, and so much of a patient's response is at that level.

*Yolanda Partida, Hablamos Juntos*

Difficulty understanding medical information and communicating effectively with health care providers is not limited to minority, immigrant, and other

FIGURE 17 » ADULTS AGED 18 AND OLDER WHO REPORTED DIFFICULTY UNDERSTANDING THEIR DOCTORS DURING THEIR LAST VISITS WITHIN THE PAST TWO YEARS, CALIFORNIA ONLY, 2007



Denominator: Civilian noninstitutionalized adults in California aged 18 and older.  
 Note: Income groups are all Asian. Data did not meet criteria for statistical reliability for Filipino, Japanese, and Korean subgroups.  
 Source: University of California, Los Angeles, Center for Health Policy Research. California Health Interview Survey. Los Angeles (CA): UCLA; 2007.

Denominator: Civilian noninstitutionalized adults in California aged 18 and older.  
 Note: Income groups are all Hispanic. Data did not meet criteria for statistical reliability for Puerto Rican and South American subgroups.  
 Source: University of California, Los Angeles, Center for Health Policy Research. California Health Interview Survey. Los Angeles (CA): UCLA; 2007.

underserved populations; it is a problem also faced by most of the majority population. Health literacy is commonly defined as a person’s capability to obtain, process, and understand basic health information and services needed to make appropriate health decisions.<sup>213</sup> According to the Department of Education, only 12 percent of English-speaking adults in the United States have proficient health literacy skills.<sup>214</sup> Limited health literacy impacts communication with doctors and other health providers about health problems and concerns, medicines, tests, forms, and disease self-management. Even highly educated individuals, regardless of so-called race or ethnicity, are challenged to understand and evaluate complex medical information, particularly in stressful situations such as having a newly diagnosed cancer, or learning that a loved one has or may have cancer. Further, Americans are confused by shifting public health messages regarding dietary recommendations, the advisability and timing of PSA testing and other

cancer screening, the safety of dietary and hormone supplements, and other aspects of health.

California Health Interview Survey data (Figure 17) suggest the diversity of literacy and health literacy levels of various U.S. subpopulations. The greater frequency of difficulty understanding providers among the poor, uninsured, and publicly insured reflects the lower educational attainment associated with poverty.

*Language*

According to the U.S. Census Bureau,<sup>215</sup> 322 languages were being spoken in homes across the United States in 2000. Of these, approximately 150 were indigenous languages spoken by American Indian and Alaska Native tribes and speakers of some indigenous Central and South American languages. Census data also indicate that the distribution of non-English speakers across the United States is uneven (Figure 18).

Forty-five million people in the U.S. speak a language other than English at home. It's proportionately higher in the elderly, who are also at greater risk for having cancer. Over 175 different languages [are] spoken in the U.S., and in many cities almost a fifth of the population have limited English proficiency.

*Francesca Gany, New York University*

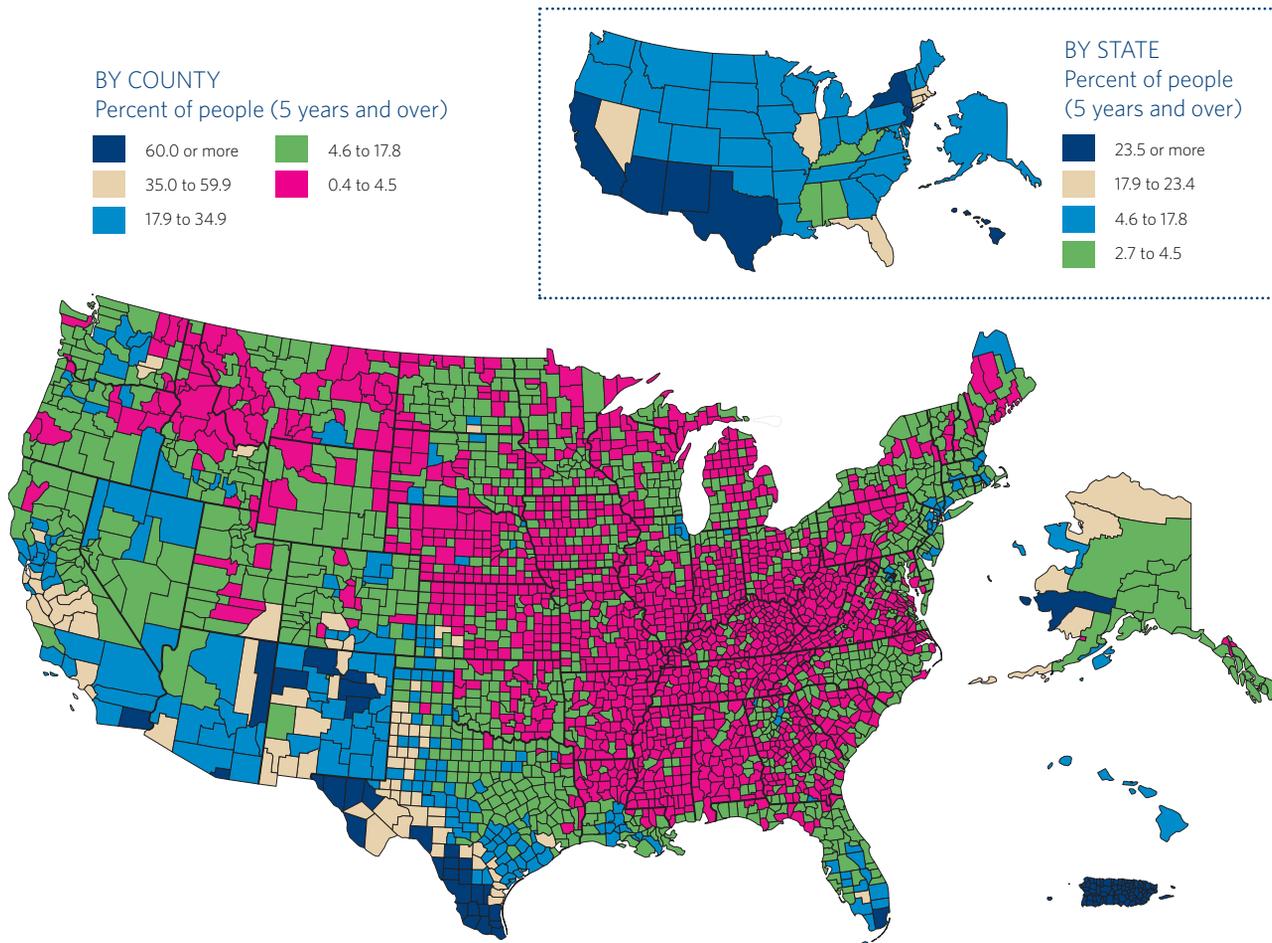
In 2000, more than a quarter of the population in seven states (CA, NM, TX, NY, HI, AZ, NJ) spoke a language other than English at home. Eight states had more than one million non-English speakers in 2000: CA (12.4 million), TX (6 million), NY (5 million), FL (3.5 million), IL (2.2 million), NJ (2 million), AZ (1.2 million), and MA (1.1 million).

In addition, increases in the number of non-English speakers have been dramatic in recent years, as Table 10 reveals. Although data from the 2010 census

are not yet available, it is relatively certain that this trend has continued between 2000 and 2010.

As the Census Bureau notes,<sup>215</sup> in the United States the ability to speak English plays a large role in how well people can perform daily activities (e.g., grocery shopping) and communicate with public officials, medical personnel, and other service providers. Individuals with limited English proficiency (LEP) who also have no one in their household to help them on a regular basis are considered linguistically isolated. A linguistically isolated household is one in which no person aged 14 years and older speaks English at least "very well." In 2000, 4.4 million households encompassing 11.9 million people were considered linguistically isolated. Like the total number of non-English-speaking U.S. residents, the numbers of linguistically isolated individuals and households increased dramatically from 2.9 million households and 7.7 million people in 1990.

FIGURE 18 » PEOPLE WHO SPOKE A LANGUAGE OTHER THAN ENGLISH AT HOME: 2000



Note: Data based on sample. For information on confidentiality protection, sampling error, nonsampling error, and definitions, see [www.census.gov/prod/cen2000/doc/sf3.pdf](http://www.census.gov/prod/cen2000/doc/sf3.pdf)

Source: U.S. Census Bureau. Census 2000 Summary File 3 [Internet]. Washington (DC): the Bureau [cited 2011 Feb 14]. Available from: <http://factfinder.census.gov>

**TABLE 10 » LANGUAGE SPOKEN AT HOME FOR THE POPULATION AGED FIVE YEARS AND OLDER WHO SPOKE A LANGUAGE OTHER THAN ENGLISH AT HOME FOR THE UNITED STATES AND REGIONS: 1990 AND 2000**

		UNITED STATES	NORTHEAST	MIDWEST	SOUTH	WEST
Spanish	1990	17,345,064	3,133,043	1,400,651	5,815,486	6,995,884
	2000	28,101,052	4,492,168	2,623,391	9,908,653	11,076,840
	Percent change	62.0	43.4	87.3	70.4	58.3
Other Indo-European Languages	1990	8,790,133	3,547,154	1,821,772	1,909,179	1,512,028
	2000	10,017,989	3,778,958	1,861,729	2,390,266	1,987,036
	Percent change	14.0	6.5	2.2	25.2	31.4
Asian and Pacific Island Languages	1990	4,471,621	845,442	459,524	715,235	2,451,420
	2000	6,960,065	1,348,621	760,107	1,277,618	3,573,719
	Percent change	55.6	59.5	65.4	78.6	45.8
All Other Languages	1990	1,238,161	298,646	238,713	229,731	471,071
	2000	1,872,489	437,584	378,311	430,859	625,735
	Percent change	51.2	46.5	58.5	87.5	32.8

Note: Data based on sample. For information on confidentiality protection, sampling error, nonsampling error, and definitions, see [www.census.gov/prod/cen2000/doc/sf3.pdf](http://www.census.gov/prod/cen2000/doc/sf3.pdf)

Source: U.S. Census Bureau. Census 2000 Summary File 3 [Internet], and Census 1990 Summary Tape File 3 (STF 3)—Sample Data [Internet]. Washington (DC): the Bureau [cited 2011 Feb 14]. Available from: <http://factfinder.census.gov>



Patients with LEP often experience more medical errors and receive lower quality of care compared with those with strong English proficiency.<sup>216</sup> Without the assistance of trained interpreters, communication between English-speaking health care providers and patients whose first or preferred language is not English can be difficult, with significant potential for inaccurate transfer of information and a reduced likelihood that the patient’s emotional and cultural needs will be met. In many instances, family members (including children) or friends, nonmedical hospital staff, or other individuals not trained in medical translation are called upon to deliver complex and emotionally difficult information to patients, often compromising the patient’s privacy. Moreover, some languages (e.g., Somali, some Native American languages) have no words for “cancer,” “smear test,” or other terms related to cancer screening and treatment.<sup>217</sup>

Although many U.S. physicians report language or cultural barriers as obstacles to providing high-quality patient care, a recent national survey of physicians in varied practice settings revealed that physician

efforts to overcome communication barriers are modest and uneven.<sup>218</sup> Physicians were asked whether their practices provide interpreter services or patient education materials in languages other than English; whether their practices have information technology for identifying patients' preferred languages; whether they receive reports containing patient demographic information or reports about the quality of care delivered to minority patients; and if they have received training in minority health issues. Table 11 shows that of the surveyed physician practices, larger practices and those with the highest percentages of minority patients were most likely to provide interpreters and patient

education materials in languages other than English. However, these practices did not consistently provide interpreter services or non-English materials. Even in practices with the information technology to access patients' demographic characteristics and preferred languages and monitor treatment quality for minority patients, few did so. Further, in practices with more than 50 percent minority patients, only about half of the physicians had been trained in minority health issues.

It also should be noted that electronic medical records (EMRs) have the potential to both help and hinder physician-patient communication. A recent study<sup>219</sup>

**TABLE 11 » U.S. PHYSICIANS AND DISPARITY REDUCTION EFFORTS, BY MINORITY PATIENT COMPOSITION AND PRACTICE TYPE, 2008**

	ALL PHYSICIANS	AVERAGE MINORITY PATIENTS <sup>a</sup>	DISPARITY REDUCTION TOOLS					
			PROVIDING INTERPRETERS <sup>b</sup>	PROVIDING ANY PATIENT-EDUCATION MATERIALS IN NON-ENGLISH LANGUAGE <sup>c</sup>	TRAINED IN MINORITY HEALTH ISSUES <sup>d</sup>	RECEIVING PATIENT DEMOGRAPHIC REPORTS <sup>d</sup>	ROUTINELY USE IT TO ACCESS PATIENTS' PREFERRED LANGUAGE <sup>b</sup>	RECEIVING QUALITY REPORTS <sup>d</sup>
All Physicians	100%	32.7%	55.8%	40.1%	40.3%	23.2%	7.3%	11.8%
<b>Percent Minority Patients</b>								
Low (<10%) (R)	17.8	3.2	39.2	24.1	35.7	17.9	4.3	8.2
Medium (10–50%)	61.4	27.3	54.5**	37.3**	37.3	22.3*	7.0**	10.8
High (>50%)	20.8	73.8	72.3**	59.9**	51.5**	28.8**	10.5**	16.8
<b>Type of Practice</b>								
Solo/2 Physicians (R)	31.2	30.9	34.4	29.8	36.1	19.7	3.1	13.9
Group (3–5 Physicians)	15.4	28.1	42.4**	32.5	31.7	18.4	4.2	9.2
Group (6–50 Physicians)	19.2	29.5	51.5**	33.3	32.5	21.0	5.0*	9.3
Group (51+ Physicians)	6.1	25.9	72.7**	46.9**	38.4	25.5	10.4**	8.8
Group/Staff HMO	3.5	35.7	90.6**	75.1**	71.3**	48.7**	33.2**	23.4
Institutional Practice <sup>e</sup>	23.6	41.6	85.7**	53.0**	52.5**	28.2**	11.9**	12.2

\* Difference from reference group, as indicated by (R), is statistically significant at p<.05; \*\* at p<.01.

a This is the percentage of patients treated who are black or Hispanic, as reported by physicians.

b Excludes physicians who report having no non-English-speaking patients.

c Population consists of physicians whose practices treat at least one of the following chronic conditions: diabetes, asthma, depression, congestive heart failure. Population excludes physicians who report having no non-English-speaking patients.

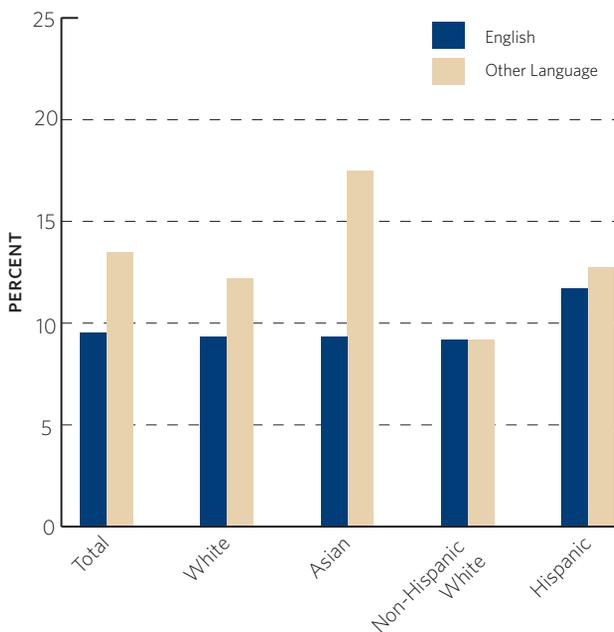
d Excludes physicians who report having no minority patients.

e Institutional practice includes community health centers, hospitals, and medical school/university.

Source: Reschovsky J, Boukus E. Modest and uneven: physician efforts to reduce racial and ethnic disparities. Issue Brief No. 130 [Internet]. 2010 Feb [cited 2011 Feb 14]. Available from: <http://www.hschange.com/CONTENT/1113/?words=au46>



**FIGURE 19 » ADULT AMBULATORY PATIENTS WHO REPORTED POOR COMMUNICATION WITH HEALTH PROVIDERS, BY RACE AND ETHNICITY, STRATIFIED BY LANGUAGE SPOKEN AT HOME, 2006**



Denominator: Civilian noninstitutionalized population aged 18 years and older.

Note: Average percentage of adults aged 18 and older who had a doctor's office or clinic visit in the last 12 months and reported having poor communication with health providers (i.e., their health providers sometimes or never listened carefully, explained things clearly, showed respect for what they had to say, and spent enough time with them). Data were insufficient for this analysis for black non-English speakers.

Source: Agency for Healthcare Research and Quality. Medical Expenditure Panel Survey. Rockville (MD): AHRQ; 2006.

You know, as a physician or a clinician, taking care of a patient who does not speak the language you speak takes twice as long, and so you either take twice as long or you do half as much. And, believe me, most of the time we do half as much because nobody gives you more time to see patients because there's no interpreter.

*Eliseo Perez-Stable, University of California, San Francisco*

found that EMRs can assist real-time communication with patients during office visits, primarily by enabling immediate access to patient information (allowing clinicians to talk with patients rather than search for information from paper records). However, EMRs also can detract from interaction during office visits when clinicians rely on EMRs for information gathering and transfer at the expense of real-time communication with patients. The study authors conclude that given the time pressures already present in many physician practices, policies promoting EMR adoption should potentially incorporate communication skills training for medical trainees and clinicians using EMRs.

Problems related to language differences between patients and providers also are illustrated in Figure 19. Surveyed patients who spoke a language other than English were more likely than those who spoke English at home to rate their communication with health providers as poor; specifically, that their health providers sometimes or never listened carefully,

When you hear...that you have a cancer diagnosis [it] is going to be somewhat traumatic; [patients] literally are going to translate it into their first language and then figure out what they want to ask the doctor, and then translate what they want to ask the doctor back into English and then say it, which means there's a very, very long pause.

*Linda Burhanstipanov, Native American Cancer Initiatives, Inc.*

explained things clearly, showed respect for what they had to say, and spent enough time with them.

A substantial percentage of respondents to the California Health Interview Survey (Figure 20) specified language difference as the reason they had difficulty understanding their doctors during recent visits. Among Asians surveyed, language difference was most commonly a problem for those with public insurance, the poor, and Vietnamese patients; these groups are not mutually exclusive. Among Hispanic/Latino respondents, communication problems related to language difference were most common among the uninsured and publicly insured, poor and low-income individuals, and those from Mexico and Central America.

Several speakers at the Panel's meetings emphasized strongly the critical importance of overcoming language barriers to minimize medical errors, enhance patient-provider understanding and trust, and improve the quality of cancer and other health care for diverse patient populations.

### Provider Bias

Unfortunately, instances of overt bias still occur in patient-provider communications, in the provision of medical care, and in society generally, but such instances have declined over time as norms condemning bias and endorsing racial equality have become stronger and more widespread.<sup>220,221</sup> As in contemporary society, most prejudicial behavior on the part of health care providers—and patients—is unintended or unconscious but can have deleterious effects on the medical encounter and patient care. For this reason, providers need to become more aware of triggers of unintended bias that can affect the care they provide to patients. Unconscious biases are "habits of mind" learned over time through repeated personal experiences and internalized cultural socialization and, as such, are highly resistant to change.<sup>222</sup> For example, people's life experiences and learned beliefs regarding the essential nature of race—either that (1) race reflects an inalterable essence and is indicative of



traits and ability or (2) that race is socially constructed, malleable, and arbitrary—create a mind-set through which individuals construe and interpret their social experiences. These interpretations in turn affect feelings, motivation, and competence in navigating between racial and cultural boundaries.<sup>223</sup>

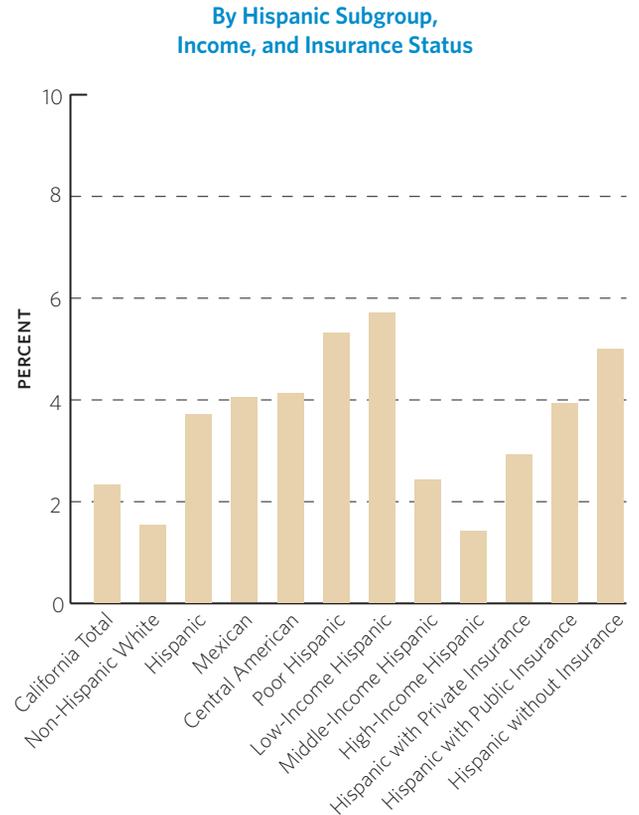
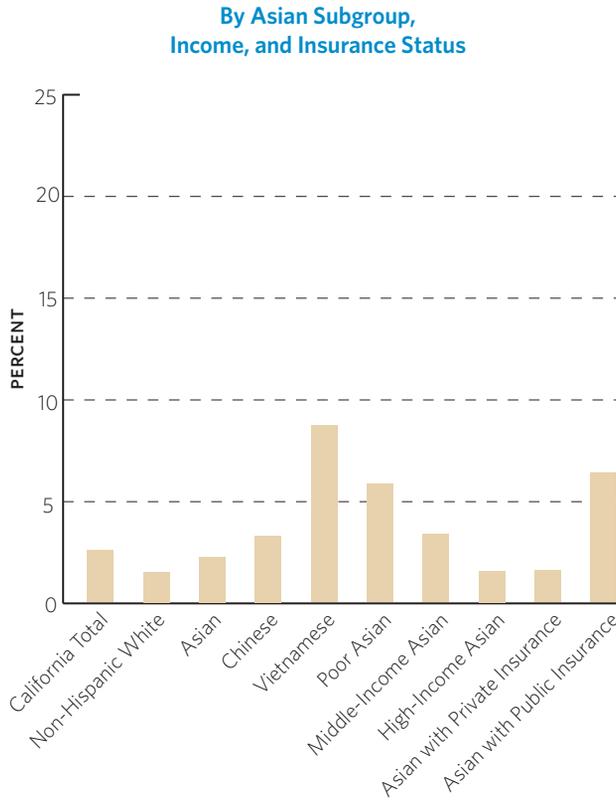
Interracial anxiety (i.e., anxiety and avoidance based on negative expectations of an interaction with a person of another race<sup>224</sup>) may be felt by both providers and patients. Although it may not be fully recognized at a conscious level during patient-provider interactions,

...we pay a lot of attention to the biases of physicians and stereotyping. Patients do the same thing in reverse.

*Yolanda Partida, Hablamos Juntos*

interracial anxiety can hamper the development of patient trust and compromise the effectiveness of patient-provider communications. Research indicates that people who are self-motivated to control prejudice tend to do so effectively across situations and strive for positive interracial interactions. In contrast, people who respond without prejudice to avoid social sanction (i.e., externally motivated) consistently fail at regulating difficult-to-control prejudice and respond with anxiety and avoidance in interracial interactions.<sup>225</sup>

**FIGURE 20 » ADULTS AGED 18 AND OLDER WHO REPORTED LANGUAGE AS THE REASON THEY HAD DIFFICULTY UNDERSTANDING THEIR DOCTORS DURING THEIR LAST VISITS WITHIN THE PAST TWO YEARS, CALIFORNIA ONLY, 2007**



Denominator: Civilian noninstitutionalized adults in California aged 18 and older.  
 Note: Income groups are all Asian. Data did not meet criteria for statistical reliability for Filipino, Japanese, Korean, and low-income subgroups, and uninsured Asians.  
 Source: University of California, Los Angeles, Center for Health Policy Research. California Health Interview Survey. Los Angeles (CA): UCLA; 2007.

Denominator: Civilian noninstitutionalized adults in California aged 18 and older.  
 Note: Income groups are all Hispanic. Data did not meet criteria for statistical reliability for Puerto Rican and South American subgroups.  
 Source: University of California, Los Angeles, Center for Health Policy Research. California Health Interview Survey. Los Angeles (CA): UCLA; 2007.



One speaker noted that providers sometimes think they understand and respond appropriately to the culture and traditions of patients that influence patients' needs and preferences. However, providers may falsely assume a homogeneity of culture, values, and experiences in so-called racial and ethnic groups that does not exist.

It was further noted that providers may unconsciously fall back on stereotyping because grouping people in this way serves the need for cognitive efficiency, particularly when providers are tired, distracted, pressed for time, or cognitively busy. Manifestations of unintended provider bias may include failing to offer all treatment options, including clinical trials; making false assumptions about a patient's ability to understand explanations of disease or care; and assuming that the patient will not adhere to the prescribed treatment regimen.



## *part 4*

# **Moving Forward to Improve Cancer Care and Research**

To improve cancer care and reduce cancer outcome disparities for immigrant, poor, minority, and other disadvantaged people in the nation's rapidly changing population, it will be necessary to expand health care access and improve the quality of patient-provider interactions. In addition, myriad important research questions remain to be answered. The following sections outline these challenges and highlight a number of activities already under way to generate new knowledge and new approaches to providing more effective and accessible care for all across the cancer continuum.

## IMPROVING ACCESS TO CARE AND INTERACTION WITH THE HEALTH CARE SYSTEM

Recent legislative and related health care policy changes, together with (1) greater attention to patient and public education and communication needs and (2) a more diverse and culturally competent cancer care and research workforce have significant potential to improve both health care access and quality.

### Health Care Reform

With the signing into law of the Patient Protection and Affordable Care Act of 2010 (P.L. 111-148, sec. 3021), important steps have been taken to make adequate health care available to a greater proportion of people in the United States. Major provisions of this legislation and the implementation schedule for major provisions are shown in Appendix E.

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*We need equitable healthcare. But it won't be affordable or sufficient without our understanding and addressing of the social factors like poverty, low-quality education, and neighborhood conditions.*

*Paula Braveman, University of California, San Francisco*

The health care reform legislation does not provide coverage to the entire population, and it is likely that all consequences of the legislation have not been anticipated. However, according to one analysis of the legislation,<sup>226</sup> more patients will be able to rely on a physician practice that is accessible around the clock and will help arrange specialist appointments. Some of this added capacity will be provided through the Department of Health and Human Services Community Health Centers program, which will be expanded both in terms of the number of centers and the ability of centers to serve more patients. Under the Patient Protection and Affordable Care Act, Congress authorized \$11 billion in new funding (effective Fiscal Year 2011) to support this expansion.<sup>227</sup> This additional funding and capacity should provide more patients with a regular source of care, which will increase the likelihood that they will receive recommended cancer screening and timely diagnostic care when indicated, and will have better access to tertiary care centers. Moreover, having a regular source of care improves the potential for patients to develop trust relationships with providers.

However, as promising as these actions are for expanding health care access, many of the social determinants that negatively impact health—such as poverty, low educational attainment, inadequate housing, high-risk occupations, toxic exposures, and poor diet—will persist into the foreseeable future for many people in America. Numerous initiatives and interventions are being pursued to ameliorate the health impact of these factors.

### Public and Patient Education and Communication Needs

Lack of accurate, appropriately targeted information is an important contributor to disparities in cancer care and in other health disparities. Information outreach to public audiences is key to promoting understanding of cancer as a disease, the value of cancer screening, lifestyle changes that promote health and decrease cancer risk, and ways to access the health care system. Cancer patients, and those who care for and about them, likewise have critical needs for accurate, understandable information and effective communication with all aspects of the health care system (e.g., care providers, administrators, pharmaceutical and equipment suppliers, social services personnel) throughout their cancer experience from screening through survivorship or end-of-life care. A continuing issue in public and patient education is the “digital divide,” the low utilization of online resources by specific populations due principally to lack of access and/or unfamiliarity or discomfort with seeking medical information in this manner. In particular, the population with the highest cancer risk—those over age 65—remain among the least likely to seek cancer and other health information online.<sup>228</sup> Other populations less likely to use the Internet to obtain cancer-related information include males, Hispanics/Latinos, those with lower income and educational attainment, persons with limited English proficiency, and those without a usual source of care.<sup>229–232</sup> In addition, both patients and the public may lack the skills to evaluate information they find online, which is of widely varied quality.

### Public Education

Several speakers at the Panel's meetings emphasized the importance of attention to cultural sensitivity and the health literacy levels of target audiences when developing and implementing cancer education and screening interventions for the public. In addition, it is important to select appropriate communication



channels that will reach diverse audiences with cancer- and other health-related messages. Some research has shown that informal networks (e.g., family, friends, faith communities), settings (e.g., barber shops, beauty salons, worksites, churches), and information sources (e.g., religious leaders, popular media) can be more effective in reaching target populations than more formal educational interventions. For example, one study<sup>189</sup> found that due to greater patient distrust of physicians and the health care system among African American adults compared with white adult survey respondents, dissemination of health information to African Americans through informal networks was likely to increase their utilization of preventive health services. Radio, particularly shows with call-in and on-air interview formats, provide an interactive forum for focusing on education, patient action, motivation, and self-empowerment among African American<sup>233,234</sup> and Hispanic/Latino<sup>235</sup> audiences.

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...bringing our mobile [mammography and cancer] screening can to these communities does not work without an appropriate accompanying education program, partly due to lack of trust and cultural differences.

*Cheryl Willman, University of New Mexico Cancer Center*

Some research suggests that while television is effective in raising awareness, it does not adequately educate or inform audiences.<sup>236</sup> However, cancer prevention and screening messages have been incorporated with apparent success in both Spanish-language daytime television dramas and mainstream (i.e., English-

language) television programming.<sup>237,238</sup> In recent years, the exploding number and variety of cable television outlets has created increased opportunities to air television drama, documentary, and talk shows focusing on cancer and other health topics.

Numerous cancer education and screening interventions have been conducted in barber shops, beauty salons, churches, and at other community sites. For example, compared with a control group that received only general health education that included cancer-related issues and screening, Korean American participants in a church-based, bilingual, and culturally appropriate colorectal cancer screening and education intervention showed significant improvement in awareness of colorectal cancer risk factors, susceptibility of Korean Americans to this disease, and the benefits of screening. In addition, at the 12-month postintervention follow-up, 77.4 percent of participants in the intervention group had obtained screening compared with 10.8 percent in the control group.<sup>239</sup>

### Patient Navigators and Community Health Workers

A principal role of patient navigators is to ensure that individuals with suspicious cancer screening results receive timely diagnosis and treatment. Navigators help cancer patients access medical, social, financial, translation, transportation, and other services as needed. Further, navigators establish and help maintain communication between patients, their families, physicians, and the health care system.<sup>240</sup> While patient navigation has not yet been shown to decrease cancer mortality directly, patient navigation programs have been shown to influence other factors (e.g., adherence to follow-up visits after a screening abnormality, improvements in screening rates, timely resolution of suspicious findings) that may affect mortality.<sup>241</sup> Patients with navigation assistance have been shown to complete prescribed treatment with fewer interruptions.<sup>242</sup> Treatment delays can decrease the effectiveness of cancer therapies and reduce patients' length of survival. For example, one speaker noted and research has demonstrated that survival rates among patients with head and neck, cervical, or non-small-cell cancers can decline if treatment is interrupted and subsequently prolonged by as little as one week due to treatment toxicities or for other reasons.<sup>188,243,244</sup> Evidence of this negative effect on patient outcome is strongest for head and neck cancers; even a one-day gap in treatment is potentially detrimental.<sup>244</sup>



...we're starting at the point of the abnormal finding, where there's a mammogram that has a suspicious finding or a breast mass, and getting those people rapidly to resolution, most of whom do not have cancer. And that is the way we get to early diagnosis through navigation.

Harold Freeman, National Cancer Institute

Most current patient navigation programs are based on the model developed in Harlem, New York, in 1990.<sup>245</sup> As part of a larger program to remove barriers to screening, diagnosis, and treatment, patient navigation was associated with a substantially lower stage at diagnosis and improved survival among African American breast cancer patients.<sup>246</sup> NCI funds nine patient navigation programs that are testing various navigation strategies tailored to specific populations. These programs, which focus on four cancers for which screening tests are available (breast, cervical, prostate, and colorectal), are being evaluated through NCI's Patient Navigation Research Program.<sup>240</sup> For example, one speaker described the navigation program in South Dakota that is improving access to radiation oncology services and other cancer care for the Native American population, as well as providing education about clinical trials with the goal of increasing participation in trials when medically appropriate.

Community health workers are trained laypersons who promote cancer screening and provide both cancer and other health information and a point of contact for people within the community. These workers are gaining recognition as important members of the health care workforce,<sup>161,247</sup> and their importance in

achieving health care reform goals is stated explicitly in the Patient Protection and Affordable Care Act. Also known as community navigators, outreach workers, community health representatives, and *promotores(as)*, a key strength of these workers is the authenticity of their connection to the neighborhood or community context, which has been shown to promote trust in the health care system.<sup>247</sup> Greater trust in turn has contributed to higher screening rates.<sup>248</sup> Peer education conducted in homes, at health fairs, and in other community settings by *promotores(as)* or other trained lay health workers from the community has proven useful in dispelling fatalism about cancer, encouraging participation in screening, and facilitating greater openness about cancer.

### Patient Education

Cancer patient education efforts are proliferating, employing diverse media, and becoming increasingly tailored to specific cancer sites and population groups (e.g., breast cancer awareness and patient services for women under age 40). Most are telephone and Internet based. Many are administered by advocacy groups such as the American Cancer Society, Komen for the Cure, the Lance Armstrong Foundation, and the National Coalition for Cancer Survivorship.

NCI's Cancer Information Service (CIS) provides accurate cancer information to the public, patients and their families, and health professionals via a toll-free telephone number (1-800-4-CANCER), email in English and Spanish, and *LiveHelp* instant messaging on NCI's Web site. Established in 1976, CIS handles nearly 125,000 inquiries annually.<sup>249</sup> CIS also provides smoking cessation counseling through NCI's Smoking Quitline (1-877-44U-QUIT). In addition, CIS has been a source of print materials for both patients and the public through local partners.

NCI has expanded community outreach through its National Outreach Network (NON, the Network), which comprises several NCI programs, including community-based oncology, research, and navigation programs and the NCI-designated Cancer Centers. The goal of NON is to build and sustain a network for education, community outreach, and research dissemination, particularly in underserved and at-risk communities. NON utilizes community health educators (CHEs) who are knowledgeable about NCI programs and experienced in communications, cancer control, training, and evaluation. CHEs interface with researchers, partners, and the community to develop, adapt, and disseminate health promotion/cancer education

materials and other culturally appropriate information and materials on cancer prevention and treatment.<sup>250</sup>

Among other NCI patient education resources, the PDQ® database<sup>251</sup> provides cancer treatment summaries by cancer site and information on complementary and supportive care written both for patients and physicians. Some of the summaries are available in Spanish. PDQ also includes a dictionary of cancer terms, another dictionary on agents used to treat cancer or cancer-related conditions, a registry of approximately 8,000 open cancer clinical trials, and a cancer genetics services directory.

The National Institutes of Health (NIH) administers [clinicaltrials.gov](http://clinicaltrials.gov),<sup>252</sup> a searchable Internet database of active clinical trials addressing numerous cancer and noncancer diseases. In September 2010, the [clinicaltrials.gov](http://clinicaltrials.gov) registry listed more than 95,000 trials with locations in 174 countries.

Most cancer centers and major medical centers serving cancer patients have dedicated patient education centers on site, and many also provide information at satellite clinics and, increasingly, online. Some researchers are exploring how best to reach various patient groups with Internet-based information tools. For example, investigators have assessed the impact of the Comprehensive Health Enhancement

Support System (CHESS) on African American and Caucasian low-income, rural women with breast cancer. The population-based study<sup>253</sup> found that these women used the system's information, analysis, and communication extensively, with positive effects on social support, negative emotions, participation in health care, and information competence. The growing use of online educational tools also is evidenced by an increasing number of clinician-moderated online communities of patients with cancer and other health conditions. However, in a discussion of how to reduce colorectal cancer incidence in African Americans, one author noted that health care providers need to become better educated about the cancer risks of specific populations, which would encourage them to promote screening, enable them to provide effective education to patients, and improve their ability to reach out to the community.<sup>254</sup>

### Translation Services

The complexity of cancer care amplifies already challenging communication problems related to informed consent, treatment regimens, and related issues. With more than 300 languages being spoken in the United States,<sup>215</sup> it is essential that medical information is translated accurately for those with limited English proficiency (LEP). Few providers, however, receive training in working with interpreters. According to one study,<sup>255</sup> only 23 percent of U.S. teaching hospitals provide any such training and in most institutions that offer it, the training is optional.

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...in the cancer clinical encounter, training matters. We should not be seeing cancer patients without trained medical interpreters.... We saw that the vocabulary precision rate was significantly worse for the untrained interpreters versus the trained interpreters.

*Francesca Gany, New York University*

As discussed previously, it is common for untrained interpreters, including family members, neighbors, friends, hospital staff, and interpreters not familiar with medical terminology, to be asked to translate complex medical information to patients with LEP when the provider does not speak the patient's preferred language(s). In addition to inaccuracies in translation, translator opinions may be transmitted inappropriately to the patient and without the provider's knowledge. Moreover, providers with limited non-English language skills sometimes attempt to communicate in the patient's language; the resulting miscommunications



can be off-putting, culturally inappropriate, and factually incorrect, all of which can increase patient mistrust of the provider and the health care system.

Efforts are under way to address some of these translation issues. For example, a three-year effort supported by the National Cancer Institute resulted in the 2010 publication of a glossary of basic cancer-related terms that includes English definitions, Navajo translations of terms, and the literal translations of Navajo back into English.<sup>256</sup> The translations focus more on the cancer cells and less on the patients to avoid the guilt, blame, or sense of doom inadvertently communicated in the past. The ultimate goal of the glossary is to educate the Navajo people about cancer and increase the likelihood that tribal members will accept cancer screening services and seek care promptly when an abnormality is suspected or detected.<sup>257</sup>

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*...of the 217 traditional languages that are still spoken today, not a one of them has an indigenous word for "cancer."*

*Jeffrey Henderson, Black Hills Center for American Indian Health*

New York pharmacists are required by state law to provide drug information to all patients, both verbally and in writing. More than one million people in New York speak a language other than English as their first language. Under a 2009 agreement with the state attorney, five major pharmacy chains agreed to print drug dosage information in five languages (Spanish, Chinese, Italian, Russian, and French) other than English at their stores in New York and to give oral assistance in 150 languages. In addition, the companies agreed to hire bilingual operators to answer phone calls.<sup>258</sup>

A Panel meeting speaker described the Remote Simultaneous Medical Interpreting System (RSMI),<sup>259</sup> an intervention conducted in New York City, where the population with LEP is approximately 25 percent overall but as high as 70 percent among Chinese immigrants, 65 percent among Russian immigrants, and 21 percent among the Filipino population. Using United Nations interpreter training as a model, a remotely located pool of trained interpreters was accessed as needed to provide translation services to LEP patients. The investigators found that compared with other translation approaches, RSMI resulted in fewer interpreting errors,<sup>260</sup> improved referral rates for screening colonoscopy,<sup>261</sup> and led to increased

patient satisfaction regarding protection of privacy and respectful treatment.<sup>262</sup> Moreover, compared with other methods, RSMI was found to be a more efficient approach to providing language services.<sup>260</sup>

In 1998, the office for Civil Rights of the Department of Health and Human Services issued a memorandum<sup>263</sup> relative to discrimination on the basis of national origin as defined in Title VI of the Civil Rights Act of 1964. The memorandum states that denial or delay of medical care because of language barriers constitutes discrimination. Recipients of Medicare and Medicaid funds are required to provide adequate language assistance to patients with limited English proficiency. As of 2009, 13 states and the District of Columbia were providing third-party reimbursement through Medicaid and the State Children's Health Insurance Program for interpreter services.<sup>264</sup> But some states with large numbers of patients with LEP have not followed suit, and there is scarce funding for translation services for other patients whose care is financed by other payors and those with neither public nor private coverage. Many providers cite cost as a significant barrier to providing translation services, although these services are widely recognized as important to reducing medical errors and disparities and improving quality of care.<sup>265</sup> However, a 2002 report<sup>266</sup> of the Office of Management and Budget estimated that providing all U.S. patients with limited English proficiency with appropriate language services for emergency department, inpatient, outpatient, and dental visits would only add an average of \$4.04 (0.5%) to the cost of a physician visit.





## The Cancer Research and Care Workforce

To provide quality care to America's changing population, the cancer research and care workforce must become more diverse, and all researchers and providers need to become more knowledgeable about the diverse cultures of their patients.

### Workforce Diversity

Racially and ethnically diverse and other underserved populations still are underrepresented in the cancer research and care workforce. For example, in 2010, only about 16 percent of first-year U.S. medical students were black/African American, Hispanic/Latino, or Native American,<sup>267</sup> but these populations (as currently defined) comprised as much as 30 percent of the total U.S. population in 2009.<sup>268</sup> The shortage of medical providers from diverse and underserved populations is of concern because evidence indicates that willingness to engage the health care system,<sup>269</sup> treatment adherence,<sup>270</sup> and patient satisfaction<sup>269,271–273</sup> are improved when there is racial/ethnic/cultural concordance between patient and provider. In addition, when patients are able to select a physician, they are more likely to choose a provider of the same race.<sup>271–273</sup> Findings regarding the association of racial/ethnic/cultural concordance between patient and provider with improved patient outcomes are, however, inconclusive.<sup>274</sup>

Funding dedicated to attracting, training, and retaining talented individuals in careers in cancer research and cancer care has been limited. For more than 15 years,

NCI has supported biomedical research training opportunities for individuals from racially and ethnically diverse and other underserved populations. NCI is the only Institute at NIH with a program dedicated to expanding the diversity of the research workforce. The centerpiece of the program, the Continuing Umbrella of Research Experiences<sup>275</sup> provides a continuum of research training and career development opportunities that begin at the high school level and extend through participants' achievement of a junior investigator position and/or independent research funding.

Responding to the need for clinical oncology workforce diversity, the American Society of Clinical Oncology (ASCO) recently developed a Diversity in Oncology Initiative.<sup>276</sup> Like NCI, ASCO recognizes the need to begin outreach and recruitment at the junior high/middle school and high school levels to encourage students to explore science through enhanced curricula and mentoring programs that extend through undergraduate and graduate education. A series of research and travel awards will be made to individuals interested in or currently practicing in the oncology field. In addition, a loan repayment program is planned for individuals who agree to practice oncology in a medically underserved region of the United States.

In addition to the need for a workforce more representative of the U.S. population, there is a need both in research and in cancer care for greater diversity in the disciplines brought to bear on the cancer problem. For example, there currently is a shortage of social and behavioral scientists with expertise in cancer-related issues who could provide valuable perspectives on research questions, clinical

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*...we have really a great track record of attracting racial and ethnic minorities into cancer research and also now bringing in mainstream investigators to explore the biology, the genetics of cancer health disparities. But we must do a better job of retaining them.*

*Sanya Springfield, National Cancer Institute*

trial and preventive intervention design, and health services organization and staffing. Similarly, social workers, cultural anthropologists, social psychologists, and other behavioral and epidemiologic specialists may be underutilized in addressing cultural and other community issues that affect the health care people receive. The Minority Training Program in Cancer Control Research (MTPCCR)<sup>277</sup> is one of a small number of programs that support underrepresented master's

level students in health sciences and master's trained health professionals to pursue doctoral degrees and careers in cancer control research. Now active for more than a decade, the program has expanded from one to three sites and recently had its 100th graduate enroll in a doctoral program. In total, a quarter of MTPCCR participants have been accepted by, been enrolled in, or have graduated from doctoral programs, and the vast majority cite the program as an important influence on their decisions to pursue this training.<sup>278</sup>

The Commonwealth Fund/Harvard University Fellowship in Minority Health Policy,<sup>279</sup> established in 1996, supports development of a cadre of physicians with an interest in minority health and health policy. The fellowship is designed to prepare physicians for leadership roles in formulating and promoting health policies and practices that improve access to high quality care at the national, state, and/or local levels for minority, disadvantaged, and other vulnerable populations. Candidates are expected to pursue public service careers in public health, health policy, health management, and clinical medicine.

### Cultural Competence

While greater diversity in the cancer workforce is sorely needed, it is neither currently feasible, nor always necessary, for all patients to receive care from someone of the same racial/ethnic group. In addition, tension can arise even between providers and patients with the

same ancestral background and culture. Therefore, all providers need to be able to provide culturally sensitive and personalized care. For example, providers (and researchers) may not adequately consider the many factors that influence health (e.g., patient-perceived race/ethnicity, educational attainment, religious beliefs, culture, health literacy, neighborhood). In addition, providers may not realize that some patients do not adhere to treatment instructions because they cannot afford medications or transportation to treatment, and patients may be too proud or feel ashamed to admit this. ASCO has noted the importance of patient-provider discussions about treatment-related costs.<sup>276</sup>

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...culture and the beliefs and values that we inherited grow roots in ways that we might not even understand, and they surface at occasions when we least expect it, and they influence how we respond to health encounters.

*Yolanda Partida, Hablamos Juntos*

In 2001, the Department of Health and Human Services developed standards for cultural and linguistic competence in health care that include training of health care providers.<sup>280</sup> Likewise, the Accreditation Council on Graduate Medical Education requires that physicians-in-training demonstrate sensitivity and responsiveness to patients' culture as part of professional competency. New Jersey was the first state to pass a law tying cultural competence



education to medical licensure.<sup>281</sup> Similar legislation has been enacted in California, Washington, Connecticut, Maryland, and New Mexico; other states are considering such legislation.<sup>282,283</sup> At least one professional society<sup>284</sup> has undertaken a culturally competent care initiative, but speakers at the Panel's meetings emphasized that cultural competency remains at the margins of provider training and must move into core curricula.

As discussed in Part 3, researchers and health care providers, regardless of ancestry, may hold negative ethnic and racial stereotypes and attitudes of which they are unaware but which may affect their professional judgments and actions.<sup>285</sup> Interventions targeting the impact of bias on decision making and characteristics of the medical encounter are a necessary component of a comprehensive approach to eliminating disparities in cancer and other health care.<sup>286</sup> Contemporary approaches to ameliorating the effects of unconscious prejudice and stereotyping focus on developing cultural sensitivity and awareness, improving multicultural knowledge, and gaining cross-cultural skills central to professionalism and quality.<sup>287,288</sup> For example, some training focuses on increasing awareness that the cognitive strategy of categorizing that gives rise to stereotyping and bias is a normal aspect of human cognition and a natural phenomenon in U.S. society. Helping providers and researchers understand this connection may enable them to approach their own biases in a more open and informed manner. Selected readings, demonstrations of unconscious stereotyping using Web-based tools, and guided discussion have proven useful in enabling individuals to recognize and address their own biases.<sup>289,290</sup> Additional models and clinical teaching strategies continue to be developed.<sup>216,291</sup>

## ADVANCING RESEARCH TO REDUCE THE CANCER BURDEN OF A DIVERSE POPULATION

The preceding paragraphs have detailed the numerous factors—including genetics, biology, culture, environment, socioeconomics, and health care access—that may mediate disease risk and progression. All of these factors must be taken into account to achieve truly personalized medicine. Much of the progress against cancer in recent decades is the result of research, and continued investment in research will be necessary to further diminish the burden of cancer. However, new methodologies, such as the ethnographic layering approach discussed in Part 3, attempt to

assimilate information on these various factors, but such integrated approaches are only beginning to be tested. Most research studies continue to investigate only one or a few variables and are unlikely to elucidate the contributions and complex interactions of all of these factors.

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*We need a different way of sampling the population to incorporate race/ethnic groups if we really want to understand the diversity and heterogeneity of experience within those subpopulations.*

*Mark Hayward, University of Texas at Austin*

Although the use of race and ethnicity in biomedical research is controversial, the concepts are ingrained in society and in research and will likely continue to be used for the foreseeable future. Therefore, researchers must consider proper use and context when applying ethnicity, ancestry, or race as variables to ensure that these concepts enhance the value of the research and do not undermine translation of the research to improved human health. It has been suggested that variables describing ethnicity, ancestry, or race should be constructed with regard to the specific research setting and hypothesis and should be clearly explained in published reports; in addition, if these concepts are being used as proxies, researchers should consider whether more specific measures could be developed.<sup>292</sup> For example, rather than using race as a possible surrogate for socioeconomic status, socioeconomic status should be used directly. Indeed, the knowledge and interventions that stem from biomedical science may be improved if race and ethnicity are abandoned as surrogate measures in favor of more meaningful variables that will facilitate the personalization of preventive and therapeutic interventions.

## The Need for Community Involvement in Research

In recent years, the concept of community-based participatory research (CBPR) has received significant attention from those interested in research on and interventions to improve the health of medically underserved populations. The Agency for Healthcare Research and Quality has defined CBPR as a collaborative process of research involving researchers and community representatives that engages community members, employs local knowledge in the understanding of health problems and the design of interventions, and invests community members in

the processes and products of research. In addition, community members are invested in the dissemination and use of research findings and, ultimately, in the reduction of health disparities.<sup>293</sup> One important aspect of CBPR is that community participation can help ensure that study goals are relevant to the population, the means of accomplishing them are reasonable, and the results are used for the good of the community. As such, research findings and publications should not be viewed as the endpoint of CBPR projects but should serve as opportunities for partners to reflect together on how the knowledge gained can directly, meaningfully, and sustainably benefit the community being studied.<sup>294</sup>

Although many researchers characterize their work as CBPR, one speaker expressed the view that the vast majority of research labeled as CBPR does not incorporate truly participatory practices.<sup>295</sup> Proponents of CBPR point out that it should be clearly distinguished from community-placed research, which is located in but does not significantly involve the community, with the result that community representatives are passive participants in studies, react to researchers as part of community advisory boards, or merely assist with recruitment.<sup>294</sup>

NCI's Community Networks Program represents one effort to engage communities and populations that experience a disproportionate burden of cancer. The program focuses on community-based education, research, and training in order to increase community knowledge about beneficial health care services and improve access to and utilization of such services. Applicant teams must be based on established partnerships between academic institutions and community or community-serving organizations.<sup>296</sup>

Although CBPR is often linked to the social sciences, its principles are highly relevant for all types of research—including but not limited to large-scale genetic research, clinical trials, and studies of behavioral interventions—that aim to provide insight into or improve the health of target populations.

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*We need to pay very careful attention to how we can build university-community partnerships... that enable students from minority communities to understand, to see commitment from universities and the research enterprise, in particular, to the well-being of their communities. I think this will increase motivation on the part of minority students to engage in the activities of research and healthcare.*

*Wylie Burke, University of Washington*

## Molecular and Genetic Research

Molecular biology and genetic research have tremendous potential for advancing understanding of cancer biology, facilitating risk assessment, and laying the groundwork for preventive and therapeutic strategies for cancer and other diseases. These approaches play a particularly crucial role in the movement toward personalized medicine. In addition to research on specific genes that already have been implicated in disease, the declining cost of gene sequencing has facilitated the use of genome-wide association studies (GWAS) to identify genetic polymorphisms associated with risk of disease, including risk of complex diseases such as cancer.<sup>297</sup>

There has been considerable disagreement about how race and ethnicity should be utilized in biomedical research. Although genetic differences among racial/ethnic populations are relatively small, several studies have found correlations between cancer risk and genetic variants present at different frequencies among population groups.<sup>123,298,299</sup> For example, one study found a particular variant of the *p53* tumor suppressor gene in 17 percent of African American colorectal cancer patients compared with only 7 percent of Caucasians. This variant was associated with the accumulation of disruptive mutations in the *p53* gene and poor survival in African Americans but not in Caucasians, suggesting that the variant may manifest itself differently depending on an individual's racial/ethnic background.<sup>300</sup>



However, some researchers are apprehensive that pursuing race-based genetic or biologic bases of disease will perpetuate racial stereotypes and distract from social and political factors that likely contribute more substantially to the poor health outcomes of disadvantaged populations.<sup>301-303</sup> Others claim that ignoring genetic differences among population groups will result in missed opportunities to utilize this information to benefit patients who are not well served by current treatment and prevention strategies.<sup>304</sup> It has been asserted<sup>305</sup> that diversity within genetic studies is important so that investigators can compare the spectrum of cancer-associated genetic variants across populations, estimate prevalence of susceptibility variants, and determine the relative risks of these variants in particular populations. In addition, amassing samples from populations with different backgrounds will facilitate evaluation of environmental modifiers of genetic susceptibility.

There is evidence that the benefits of genomic research have not reached minority populations. Minority-serving physicians are less likely than physicians serving fewer minorities to have ever ordered a genetic test for breast cancer, colorectal cancer, or Huntington's disease, or to have ever referred a patient for genetic testing.<sup>306</sup> Arguably the most clinically significant genetic advancement in oncology to date has been the identification of mutations in the *BRCA* genes in breast cancer, which has led to major breakthroughs in the treatment of women with inherited predisposition to breast and ovarian cancers. Although *BRCA* mutations are prevalent among Hispanic and African American women,<sup>307,308</sup> minority women are significantly less likely than non-Hispanic white women to undergo testing for *BRCA* mutations. An analysis published by the owner of the only *BRCA* test commercially available in the United States, revealed that individuals of African, Native American, Latin American/Caribbean, Asian, and Near Eastern/Middle Eastern ancestry collectively accounted for less than 10 percent of those tested over a three-year period.<sup>309</sup>

Several studies have attempted to uncover the reasons for the observed differences in utilization of *BRCA* testing. One study reported that African American women continued to be less likely to undergo *BRCA* testing than white women with similar family histories even after adjusting for probability of mutation, socioeconomic characteristics, cancer risk perception or worry, attitudes about testing, or primary physician discussion about testing.<sup>310</sup> Other studies have found a lack of knowledge about inherited risk of cancer and the availability of genetic testing among African



The technology has developed in very dramatic ways in the last few years and will continue to develop so that people will be sequencing entire genomes from cases and controls in the next few years, probably. And when that happens, as it happens, I think it's very important that knowledge be gained in all populations.

*Elad Ziv, University of California, San Francisco*

Americans and Hispanics/Latinos.<sup>311,312</sup> Other barriers to *BRCA* testing in these and other populations are socioeconomic (e.g., time, access, geography, language/culture, cost) and psychosocial (e.g., medical mistrust, perceived disadvantages of genetic services) in nature.<sup>313</sup> It also has been noted that *BRCA* testing is less likely to yield informative results for minority patients than for white patients (i.e., variants identified cannot be definitively characterized as either likely to cause disease or part of normal variation). This phenomenon stems from the fact that different *BRCA* mutation spectra are present among different populations<sup>314</sup> and the known deleterious variants of the *BRCA* genes have been identified largely based on cohorts of women of European ancestry. One study<sup>308</sup> found that 46 percent of African American women undergoing *BRCA* testing were found to have *BRCA* variants with unknown clinical significance compared with only 12 percent of white women. Another study<sup>315</sup> found variants of unknown clinical significance in approximately 23 percent of Hispanic women. Uninformative results can be emotionally difficult for patients trying to make decisions regarding whether to pursue aggressive prevention measures.<sup>316</sup>



One could argue that all personalized genetic testing at this time is imprecise.

*Susan Neuhausen, University of California, Irvine*

The lack of knowledge about variants common among minority populations is perpetuated by the low utilization of genetic testing within minority communities, which makes it difficult to characterize variants prevalent within these populations. However, there have been at least a few attempts to characterize variants among minorities. A study<sup>317</sup> of Hispanic individuals with personal or family histories of breast or ovarian cancer identified a potentially deleterious novel *BRCA1* rearrangement. Based on the family histories and genomic analyses of the affected families, the authors speculate that the rearrangement originated in a Mestizo or American Indian ancestral population. This rearrangement was not observed in previous studies, perhaps because of low inclusion of individuals of Hispanic ancestry, and was thus not assessed by commercially available *BRCA* assays.

For those who believe that race and ethnicity should be taken into account in biomedical research, trends of

[Minority communities] are eager to join us in our effort to end cancer disparities, but not as silent partners. They want us to hear their voices, to include them as equal partners, and to do nothing about them without them.

*Wisdom Powell Hammond, University of North Carolina at Chapel Hill*

minority involvement in research may be particularly troubling. Several studies have reported general mistrust of research and researchers among minority populations.<sup>318-320</sup> Although the published literature is not extensive, studies have suggested that minorities, particularly African Americans, may be more likely to have negative views of research involving genetics<sup>321</sup> and be less likely to participate,<sup>322</sup> suggesting that targeted efforts are needed to encourage enrollment.

It is widely acknowledged that building trust within communities is critical for engaging minorities in biomedical research and that community involvement in all phases of the research is an important part of this process. One speaker at a Panel meeting stated that the large cohorts and infrastructure required for genome-scale studies can make it difficult to engage in meaningful community consultation.<sup>323</sup> Nonetheless, some targeted efforts to support minority enrollment in genetic studies have shown promise. Among these are obtaining endorsement of community partners and employment of onsite, race-concordant research staff to coordinate study efforts and maintain visibility among patients and staff.<sup>305</sup>

The emergence of genetic research has raised a number of legal and ethical questions regarding ownership of biological samples and the nature of the informed consent process. Although these issues are relevant to all potential research participants, the uncertainty surrounding them does little to overcome the distrust that members of many minority populations have of research and the research community. A recent controversy surrounding genetic samples from the Havasupai tribe of Arizona illustrates the tensions that can arise between researchers and communities. Members of the small tribe provided DNA samples to researchers at Arizona State University in the hope that insight would be gained into the tribe's extraordinarily high rate of diabetes. When the Havasupai later learned that their DNA had been shared with other scientists and used for studies on topics ranging from mental illness to the tribe's geographic origins, they sued the University. Although the geneticist who led the initial study maintains that permission was obtained for a range of genetic studies and an independent investigation found no firm evidence of misconduct, Arizona State University apologized for the incident and agreed to a cash settlement in addition to returning the blood samples and providing other forms of assistance to the impoverished tribe. The incident, however, resulted in a temporary ban on the University's research involving Havasupai and will likely create challenges for other researchers hoping to engage Native

communities.<sup>324,325</sup> This incident underscores the need to develop research partnerships, both to foster trust and to increase communities' ability to engage in the research process.

## Clinical Trials

Clinical trials are essential for moving findings from basic and translational research into clinical settings where they can benefit patients. However, with the exception of pediatric patients, participation in oncology clinical trials has historically been low in the United States, with the percentage of adult cancer patients who enroll in trials estimated to be 4 percent.<sup>326</sup> Rates of participation are even lower among most minority and other medically underserved populations, with estimates showing that less than 15 percent of oncology clinical trial participants are from minority groups.<sup>326,327</sup> A survey<sup>328</sup> of patients enrolled in NCI-sponsored clinical trials over a 12-month period found that black men as well as Asian American and Hispanic adults with cancer enrolled in clinical trials at lower rates than white cancer patients of the same age. Enrollment was higher in suburban counties and in geographic areas with higher socioeconomic levels, and patients enrolled in these trials were more likely than members of the general U.S. population to have health insurance.

Numerous studies have explored the reasons underlying low rates of minority participation in clinical trials.<sup>320,329</sup> Some of these barriers are related to lack of awareness of clinical trials, which sometimes stems from low physician awareness of trials. In addition, mistrust of the research and medical systems is often pointed to as a significant factor in low minority trial participation. This mistrust has a foundation in past abuses, including the infamous Tuskegee experiments during which researchers withheld treatment known to be effective from African American men with syphilis who were participating in the study. It is also reinforced by the negative interactions that many minorities continue to experience with the health care system.<sup>330,331</sup> Logistical barriers, such as those related to transportation and child care, can also get in the way of minority trial participation.

While all of the aforementioned factors undoubtedly contribute to low minority enrollment, there is evidence indicating that lack of opportunity to participate may be one of the most critical barriers. A meta-analysis<sup>332</sup> recently found that minority patients who were eligible and invited to participate in health research were just

...how do you get onto a clinical trial? To start, you have to have really good Internet [access] with really good competency and you have to have at least a high school education, and you probably need to be pretty fluent in English, and on and on. So we see even just accessing information in these trials becomes very challenging.

*Barri Blauvelt, University of Massachusetts*

as likely as white patients to enroll in a clinical trial. But substantial differences were documented in the number of minority individuals invited to participate in a trial. In several cases, the number of minority individuals provided an opportunity to enroll was much lower than would be expected based on the proportion of the minority group within the population and the incidence of the diseases being studied. Multiple factors contributed to this missed opportunity, including protocol-related issues, such as ineligibility based on age or comorbid conditions, and low levels of provider referral.<sup>320,329</sup> In some cases, providers decline to refer patients to clinical trials because of their perceptions that the patients would not be willing to participate or would not adhere to the study protocol.<sup>333</sup> Yet, at least one study<sup>334</sup> has found that minority-serving physicians themselves harbor mistrust for and feel they are not respected by research centers, illustrating the need for the research community to build relationships not only with minority patients but also with the physicians who treat them.

NIH has several programs and initiatives that provide support for efforts to enhance recruitment and retention of underserved populations in clinical studies. NCI established the Minority-Based Community Clinical Oncology Program (MBCCOP) in 1990 to increase access of racial and ethnic minorities to cancer clinical trials. MBCCOP grantees are part of the nationwide network of Community Clinical Oncology Programs (CCOP) through which patients being treated in communities are enrolled in clinical trials through NCI-designated CCOP research bases that include cancer centers and Cooperative Groups. Between 1995 and 2003, more than half of patients accrued to Cooperative Group trials through MBCCOPs were from minority populations—more than twice the rate of minorities enrolled by other CCOPs and non-CCOP institutions.<sup>335</sup> More recently, NCI established the NCI Community Cancer Centers Program (NCCCP), which was designed to create a community-based network to support basic, clinical, and population-based research. Reduction of cancer health disparities and increased participation in clinical trials are two major

goals of NCCCP. Each NCCCP site utilizes a Clinical Trials Screening and Accrual Log, which captures information—including race and ethnicity—about patients screened for and enrolled in clinical trials, with the goal of identifying barriers to trial enrollment. An NCCCP working group also has been established to monitor issues related to minority trial accrual.<sup>336,337</sup>

The NIH Revitalization Act of 1993 (P.L. 103-43) mandated the inclusion of women and minorities in NIH-sponsored clinical trials. Since that time, NIH policy<sup>338</sup> has required that women and minorities and their subpopulations be included in all clinical research in adequate numbers to allow for valid analyses of differences in intervention effect. Cost is not considered a valid reason for excluding these groups from a study. One author suggests that NCI-designated Comprehensive Cancer Centers should conduct analyses of Hispanic/Latino population growth in their service areas with the goal of informing strategic planning in order to meet the needs of this growing population.<sup>339</sup>

The mandate on inclusion of minorities in clinical research has been somewhat controversial. Arguments against it are similar to those made against making race and/or ethnicity a central component of genetic research. There is concern that the requirement places scientific value on the sociopolitical construct of race, distracting from differences in environmental factors and access to health care that likely have a larger impact on the disparate health outcomes observed among racial groups in the United States. In addition, some claim that the oversampling of minority populations often necessary to permit subset analyses unjustly shifts a disproportionate fraction of risk associated with trials to these vulnerable groups.<sup>340</sup>

Others maintain that inclusion of diverse populations in trials is necessary to ensure that results are relevant to a broad range of patients, particularly those who carry high burdens of disease. This premise formed the foundation of the Eliminating Disparities in Clinical Trials (EDICT) Project, an effort spearheaded by the Intercultural Cancer Council that involves more than 300 stakeholders from the public, private, and nonprofit sectors. The EDICT Project resulted in the development of a series of policy recommendations designed to enhance the participation of underserved populations in clinical trials.<sup>341</sup>

In addition to the debate about whether NIH should mandate inclusion of subpopulations in clinical trials, questions have been raised about whether the

policy has yielded clinically useful information about differences among subpopulations. Reviews of the published literature have found that few reports of clinical trials include the racial/ethnic makeup of participants and even fewer present results of race/ethnicity-based subset analyses.<sup>342,343</sup> Although reporting of race and ethnicity was found to be somewhat better for epidemiologic studies as a whole, relevant subgroup analyses were found to be incomplete and inconsistent.<sup>344</sup> Perhaps even more troubling is the possibility of improperly designed or underpowered subset analyses, which could lead to erroneous conclusions and inappropriately guide clinical practice (see the following discussion on treatment of hypertension in African Americans).

## Drug Response and Approval

It has long been recognized that the responses to and side effects associated with pharmaceutical agents—including anticancer therapies—vary among individuals. One review<sup>345</sup> found that at least 29 drugs or combinations of drugs have been claimed to exhibit differences in safety or efficacy among racial or ethnic groups, although many of these findings have been controversial. Observed differences in drug safety and efficacy can be due to a combination of factors, some of which may be gene based. Increasing interest in this area has spawned the field of pharmacogenetics/pharmacogenomics, which strives to identify how genes influence responses to drugs. Genetic causes of differences in drug responses include variation in the enzymes that metabolize and transport the drug within the body and variability in the expression or structure of drug targets. In addition, some drugs may be more or less efficacious because diseases that manifest similarly in different populations may be associated with different pathophysiologies.<sup>345</sup>

Variation in the effectiveness of and side effects caused by therapeutic drugs has been observed among racial/ethnic groups for cancers including those of the lung, breast, and colorectum as well as gastric cancers.<sup>346</sup> In several cases these differences have been linked to genetic variation. For example, Chinese patients are more likely than white patients to experience myelotoxicity in response to treatment with doxorubicin for breast cancer, at least in part because of a higher prevalence of genetic variants within the Chinese population that reduce the ability of patients to clear the drug from their bodies. Genetic variation has also resulted in differences in the efficacy of recently developed molecularly targeted therapies. Inhibitors of



the epidermal growth factor receptor (*EGFR*), which are used in the treatment of lung cancer, are more effective in patients whose tumors have mutations in the *EGFR* gene. Such mutations have been found to be nearly twice as common in patients from East Asia as in those from the United States or Australia.<sup>347</sup>

Virtually all instances of pharmacogenetic differences among populations reflect differences in the prevalence of certain genetic variants rather than genetic traits that are uniformly different between members of two or more groups. It follows that the most effective approach is to make personalized treatment decisions for patients based on their individual pharmacogenetic profile rather than on their race or ethnicity. This approach already is used to determine the dosage of thiopurine drugs used to treat patients with acute lymphoblastic leukemia. Patients with certain variants of the *TPMT* gene cannot efficiently metabolize these drugs and must be given lower doses to avoid serious toxicities.<sup>348</sup> However, tests that reliably predict response are not currently available for most drugs, in many cases because the functional gene variant(s) underlying differences in effect or safety are unknown. Research in this area will be informative but it has been noted that pharmacogenetic tests may not necessarily be equally informative across all populations because the influence of a single genetic variant can be affected

by gene-gene or gene-environment interactions that may differ among racial/ethnic groups.<sup>345</sup>

In some cases, reports of drugs exhibiting varying efficacy among racial/ethnic populations have had an effect on clinical practice. Although not related to cancer, the use of angiotensin-converting enzyme (ACE) inhibitors to treat hypertension is an illustrative example. Use of ACE inhibitors to treat African American hypertensives decreased based on data showing that monotherapy with ACE inhibitors yielded less impressive results in African Americans compared with whites. Yet, subsequent studies indicate that the removal of ACE inhibitors from the therapeutic arsenal used to counteract hypertension in African Americans was unwarranted. Many African Americans respond as well or better than whites to ACE inhibitors despite the fact that there are differences if members of each of the two groups are considered as a whole. This supports the conclusion that group differences in blood pressure responses are an inaccurate means of predicting individual responses to ACE inhibitors and that other factors—such as gender, pretreatment blood pressure severity, and body size—are more informative.<sup>349</sup>

The belief that ACE inhibitors are less effective in African Americans played a role in the approval of the only drug to date approved by the U.S. Food and Drug Administration (FDA) for use in a specific race. The drug, called BiDil, is a combination therapy that was developed for treatment of congestive heart failure. Although rejected by the FDA for use in the general population in 1997 (primarily due to weaknesses in clinical trial design, not lack of drug effect), BiDil was reframed—and repatented—as a drug for African Americans based on a positive trend observed within the small number of African Americans who participated in earlier trials. BiDil's developers cited data showing the relatively low effectiveness among African Americans of ACE inhibitors—a common treatment for heart failure as well as hypertension—to argue that new drugs were needed for this population. A clinical trial that included only self-reported African Americans found that BiDil imparted a significant

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The difficulty we have, I think...is that we have a history of ignoring the sociological factors for cancer disparities in favor of a bias about biological reasons that explain differences between races and ethnicities. We're now in a situation where the pendulum has swung too far the other way, and those of us who even suggest biological differences between races are usually shot down.

Tim Byers, University of Colorado Denver



survival advantage over placebo. In June 2005, the FDA approved the drug with a race-specific label, indicating that it was for use in black patients. The move was hailed by some as an important step toward addressing the disproportionate death toll due to cardiovascular disease within the African American population, but others were dismayed that the FDA attached a race designation to the drug, particularly in the absence of strong evidence that it is more effective in African Americans than in other populations. Indeed, many, including the drug's developer, believe that it would be just as effective in nonblacks, but the clinical trials that have been conducted have not addressed this question. The controversy around the drug has been heightened by the perception of some that BiDil's "rebirth" as a drug for African Americans was financially motivated—the repatenting of the drug for use specifically in blacks extended its patent protection by 13 years.<sup>350–352</sup>

Concerns that race-based subset analyses may deprive cancer patients of potentially effective treatments have been voiced. One speaker<sup>340</sup> noted that if early clinical trial data on tamoxifen treatment of breast cancer had been subjected to race-based analysis, the drug may not have been approved for use in black women because only 10–12 percent of African

American women respond to tamoxifen compared with 30 percent of white women. Subsequent research identified estrogen receptor expression as a predictor of tamoxifen response and showed that the drug is effective in women whose tumors express this estrogen receptor regardless of their race. Had race medicine been used to guide treatment decisions in the interim, many African American women may have missed out on a potentially effective treatment for their cancer.

Some who oppose race-based medicine, however, acknowledge the value of documenting race differences in drug response.<sup>349</sup> Observations of race-based differences—such as those observed in response to ACE inhibitors—provide potential clues that may help scientists design experiments to uncover physiologically relevant factors that influence treatment efficacy and that are relevant to individuals across many populations. Once identified, these biomarkers can be used to identify molecularly or biologically defined subpopulations for clinical study and/or selection for appropriate interventions.

## Guideline Development

Rigorous population-based research and clinical trials are needed to formulate evidence-based cancer control strategies and inform the development of cancer screening and treatment guidelines. In the United States, cancer screening and treatment guidelines are routinely developed by various entities, including the National Comprehensive Cancer Network (NCCN), the U.S. Preventive Services Task Force, and the American Cancer Society. U.S. guidelines often are used by other countries around the world to inform the development of their cancer control programs. Importantly, these guidelines are based largely on research on individuals of European ancestry and may not be appropriate for other populations. According to one speaker at a Panel meeting, many leaders in the international cancer field recognize that U.S. guidelines such as those developed by NCCN simply do not work

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...the NCCN [National Comprehensive Cancer Network] guidelines...simply do not work for ethnically diverse and economically challenged populations. And the fact that they were designed to be medically appropriate based on white people's research then allows us, I think, to really do some serious challenging in terms of the appropriateness of these guidelines for diverse populations, both culturally and ethnically.

*Barri Blauvelt, University of Massachusetts*

for ethnically diverse and economically challenged populations in the developing world and do not serve similar populations in the United States.<sup>353</sup>

The recognition that cancer and other diseases sometimes manifest differently among diverse populations has led some to assert that race/ethnicity-based screening and treatment guidelines may be appropriate in some cases. The American College of Gastroenterology has recommended that African Americans begin screenings for colon cancer at age 45—five years before its guidelines call for the average-risk general population to undergo screening—because of data showing that African Americans are nearly twice as likely as whites to be diagnosed with colorectal cancer before the age of 50.<sup>354</sup> After considering the same evidence, however, the American Cancer Society, the U.S. Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology recommended in their joint guidelines that screening of average-risk individuals begin at age 50 without regard to race or ethnicity.<sup>355</sup> The American College of Gastroenterology also notes that while colonoscopy is the preferred test for all those who should be screened, it is particularly important that African Americans—who have been found in some studies to have a higher prevalence of cancerous lesions in the proximal part of the large bowel—be encouraged to have their whole colon examined using colonoscopy rather than opt for a less extensive flexible sigmoidoscopy, which examines only the distal portion of the colon.<sup>356</sup> In addition, some controversy exists as to whether minority women should begin screening for breast cancer earlier than white women

because of higher rates of the disease among young minority women.<sup>357</sup> To date, no group has issued screening guidelines for members of any specific racial/ethnic group. The Breast Cancer Education and Awareness Requires Learning Young (EARLY) Act, part of the health reform legislation package passed in 2010, will provide for public and provider education of young women at higher than average risk of breast cancer—based on race, ethnicity, level of acculturation, and family history, including the African American and Ashkenazi Jewish populations younger than age 45—to encourage early detection.<sup>357</sup>

## Social and Behavioral Science Research

As discussed in Part 3, social and cultural factors underlie a large proportion of the differences in health and health outcomes experienced by minorities and other underserved populations. It follows that the social sciences should play a key role in investigating these factors and developing evidence-based models for interventions to address them. The use of race in social sciences research is less controversial than its

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...we've all learned the cycle of science, but what we haven't learned is that it takes place within a cultural context.

*Marjorie Kagawa-Singer, University of California, Los Angeles*

use in molecular and genetic research, largely because of the recognition that racial classifications are a social construct and an indicator of peoples' social history and social experience. Panel speakers emphasized that race is not equivalent to culture and that it should not be considered a proxy for socioeconomic status or other factors that may more directly influence health.<sup>295</sup> One speaker stated that data on both race/ethnicity and key socioeconomic factors are needed—collecting only race/ethnicity data can reinforce stereotypes and fail to identify factors that more directly underlie health disparities, while collecting only socioeconomic indicators will not capture the effects of racism.<sup>358</sup>

Behavioral research in particular holds promise for addressing the burden of cancer experienced by minority and medically underserved populations. This research can help uncover connections between health behaviors—including those that vary among cultural settings—and biological processes that may contribute to cancer. Such research is particularly relevant for cancer prevention and early detection.<sup>359,360</sup>



In addition, increased research focus is needed on the role of racial/ethnic discrimination in health, including institutional racism, implicit attitudes and stereotypes, effects of exposure to discrimination on physical and mental health, and the effects of cultural incompetence and racial discordance. Encouragingly, a number of studies on these and related topics, including improved instruments and methodologies for measuring discrimination prevalence and impact, have recently received funding through an NCI Program Announcement;<sup>361</sup> findings from some of these studies are beginning to be published.

## Dissemination Research

Several studies have shown that when members of different racial/ethnic groups are provided with the same services and care, in most cases they experience similar outcomes.<sup>162,362,363</sup> All too often, however, minorities and underserved populations do not receive high quality care.<sup>161</sup> One Panel speaker emphasized that the most effective approach for addressing disparities in cancer outcomes would be to apply what is known to all people, regardless of their ability to pay.<sup>364</sup>

Past experience has shown that successful programs do not naturally diffuse into routine practice in a timely manner, suggesting that widespread adoption of evidence-based interventions and activities requires active dissemination.<sup>365</sup> Yet, current knowledge of the best ways to disseminate programs once they are found to be effective is inadequate. Thus, research is needed to identify ways to communicate research findings to and promote implementation of effective programs among all population groups and the health care professionals who provide their care.<sup>366</sup>

Dissemination research has received increasing attention within the cancer research community in recent years, with discussions emerging about the roles of various stakeholders in dissemination efforts and the need for standardized terminology.<sup>365-367</sup> In addition, a disconnect between traditional approaches to intervention research and dissemination has been noted.<sup>365</sup> The dominant paradigm in intervention research has been to establish the efficacy of an intervention with a focus on maximizing the internal validity of a study. As a result, strict eligibility criteria and other design features often favor the involvement of patients, providers, and health care delivery settings that may not represent the majority of practice-based settings. Often it is not clear if and how such interventions, even if shown to be effective, can or

should be adapted for widespread use. Dissemination researchers assert that this barrier could be addressed if potential for dissemination were explicitly considered during the planning, implementation, evaluation, and reporting of intervention research, and decisions were made based on the ultimate goal of extending the benefits of a program or activity to the broader population.<sup>365,366</sup>

Behavioral and social science research can play an important role in dissemination efforts, as these disciplines are attuned to many of the population- or community-specific features that may influence implementation and adoption of health-related behaviors and interventions. For example, it has been suggested that behavioral and social science research should be conducted in parallel with the development of new cancer screening tests and related guidelines to ensure that they will be feasible, appropriate, and effective in the contexts of the communities that will benefit from them.<sup>360</sup> The need to consider cultural context will become increasingly important as the diversity of the U.S. population continues to grow and the proportion of the cancer burden shouldered by minorities increases.<sup>368</sup>

## LEARNING FROM THE REST OF THE WORLD

Cancer is the second leading cause of death in the world, and in the past 30 years the numbers of new cancer cases and cancer-related deaths have doubled.<sup>369</sup> The majority of new cancer cases will occur in lower- and middle-income countries, including the countries of origin of many U.S. nonwhite populations.<sup>370</sup> An understanding of the social, cultural, environmental, and biological factors that contribute to cancer in these countries would likely improve understanding of the cancer burden of populations that have recently immigrated to the United States, but very few of these nations have the resources or capacity to conduct rigorous biomedical research. Collaborations in which the United States shares its research and technological capability may yield returns both abroad and in this country.<sup>353</sup> These partnerships

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...cancer is not a country issue. It's a global issue. It has to be tackled in a global sense because there's a lot of immigration and, indirectly, they are also contributing to the health care burden here in this country.

*Upendra Manne, University of Alabama at Birmingham*

also may provide insights into social and cultural factors that allow the United States to engage minorities in biomedical research and may result in medical knowledge that enhances the delivery of appropriate preventive and treatment interventions to diverse populations.

In this regard, NCI supported the establishment of the Middle East Cancer Consortium (MECC) in 1996. The MECC is a partnership among Cyprus, Egypt, Israel, Jordan, the Palestinian Authority, and Turkey and is meant to encourage cooperation among cancer researchers and practicing oncologists in the Middle East region. NIH contributed financially to help institutions in the region develop cancer registries, cancer information dissemination programs, and training programs in cancer research, education, and patient care.<sup>371</sup> NIH also helped Jordan create the 130-bed King Hussein Cancer Center and the 260-bed King Hussein Institute for Biotechnology in Cancer. As part of these efforts, public outreach and education were conducted to help remove the stigma of cancer in Jordan, with noticeable effects. Whereas only 40 percent of patients in the country were informed of their cancer diagnoses before the outreach efforts, it is now estimated that 96 percent of cancer patients are aware of their diagnoses.<sup>372</sup>

NIH also has recently established a partnership with the Wellcome Trust and African Society of Human Genetics to conduct large-scale population genetic studies



of common, communicable, and noncommunicable diseases, including cancer. One goal of the partnership will be to build African research capacity; unlike much of the research conducted in Africa to date, the new studies will be conducted by African researchers in Africa and biospecimens collected will remain in Africa.<sup>373</sup>

In 2009, NCI initiated partnerships with five Latin American countries—Mexico, Brazil, Uruguay, Argentina, and Chile—to create the United States–Latin America Cancer Research Network. The network will help partner-countries develop programs in three broad areas: basic and clinical research, training, and technology and capacity building for sustainable cancer research activities. Specific areas targeted for development include clinical trials management and biospecimen banking. It is hoped that working with Latin America will provide insight into cancer trends among the growing Hispanic population in the United States.<sup>374</sup>

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...any studies that will be conducted outside of the U.S. funded by the U.S. government... [need to be] reviewed for comments and recommendations by specialized, culturally sensitive scientists or physicians or experts.

*Samir Khleif, National Cancer Institute*

It was emphasized that research partnerships with other countries or cultures must be approached with careful consideration, as missteps could result in more harm than good. One speaker indicated that the progress achieved in Jordan was predicated on the fact that those involved developed a deep understanding of the Jordanian culture, including the importance of family and religion. It was suggested that U.S.-funded studies to be conducted outside the United States be required to undergo review by a specialized panel of culturally sensitive experts.<sup>295</sup>

As the foregoing sections of this report have emphasized, both commitment and leadership are needed on many fronts—including intensified basic, clinical, population, and health services research; expanded health care delivery, payment, and information systems; improved language services and cultural competence; and community education and outreach—to meet the cancer-related needs of America's rapidly changing population. It will be critically important to build upon and contribute to such endeavors both at home and abroad.



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## *part 5*

# Conclusions and Recommendations

Except for the diverse Native peoples who inhabited for millennia the land that now is the United States, this is a nation of immigrants. Though some have not come by choice, each wave of immigrants—whether from Europe, Africa, Asia, the Pacific, or the Americas—has brought with them the cultures, languages, ancestral history, and environmental influences of the lands they left behind. Over the past several decades, air and other modes of travel have increased the ease and accelerated the pace of human migration and population interaction. As a result, the populace of the United States is growing more diverse with each passing day. These rapid demographic changes raise important questions about how best to conduct cancer research and deliver health care that will reduce the burden of cancer for all of America’s people.

The President’s Cancer Panel believes several fundamental issues must be addressed to move science, the health care community, and the nation toward effective cancer education and services across the cancer continuum that reach beyond traditional ideas of race, ethnicity, and culture to embrace and honor our true similarities, differences, and humanity.

## CONCLUSIONS

1. Existing vital statistics, census, public and private insurer, and cancer surveillance data are seriously compromised in their ability to accurately characterize populations in ways that would support improvements in cancer prevention, treatment, and population research and cancer care. New approaches to characterizing populations and data collection are urgently needed, as are standardized definitions and data sets.
2. Historically, sociologic factors underlying health disparities have been largely ignored in favor of biologic factors. More recently, there has been a shift away from considering biologic factors for fear that this approach will be equated with or reinforce racism and race-based research and medicine, yet socioeconomic factors still have been inadequately addressed. Race and ethnicity are poor proxies for complex socioeconomic variables because they mask the true heterogeneity of populations and reinforce unproductive generalizations. Relatively recent genetic research has produced evidence that relevant biologic factors may exist in cancer and other diseases, particularly as specific genes or gene products may be affected by interaction with environmental factors. An evidence-based approach to health disparities is needed that includes consideration of both biologic and sociologic factors.
3. Personalized medicine for all is the ultimate goal in cancer care, but is not universally feasible or affordable in the near future. Personalized medicine already is being provided to a limited extent. It needs to be institutionalized to the maximum extent possible, beginning with what is now known (e.g., lymphoma and colorectal cancer subtyping, targeted anticancer drugs and biologics). Until personalized medicine is a reality for all, research is needed to identify subpopulations at high risk of disease due to genetic/ancestral, biologic, sociocultural, and other factors that directly relate to risk or response to therapy and then apply findings to each subpopulation.
4. Current one-size-fits-all approaches to cancer screening guidelines are no longer useful, nor are guidelines based on racial differences, however defined. It is essential to consider the universe of patients and identify common genetic and environmental risk factors on which to base screening recommendations.
5. Patient-provider language differences are a significant barrier to the provision of quality cancer and other health care. Trained interpreters, therefore, should be considered essential members of the health care team. Funding to support interpreter training and the crucial communication services they provide is seriously deficient.
6. The majority of health care providers do not adequately understand, inquire about, or integrate patient sociocultural and socioeconomic characteristics into cancer and other disease prevention and treatment. This information is critical to providing the best care for each individual.
7. Poverty, low educational attainment, substandard housing and neighborhoods, and insufficient access to quality health care are the most important determinants of poor health outcomes. Cancer and other health disparities will only be eliminated when these problems are adequately addressed.

## RECOMMENDATIONS

Although the focus of the Panel's meetings was the impact of changing demographics on cancer research and cancer care, many of the identified key issues and recommendations have implications for health

care in general. In light of the pressing imperative to address current and future cancer-related needs of all Americans, the Panel recommends the following:

Infrastructure	RESPONSIBLE STAKEHOLDERS AND OTHER ENTITIES*
<p>1. Action must be taken to address the serious data deficiencies that undermine efforts to better understand and address cancer disparity issues. Specifically:</p> <ul style="list-style-type: none"> <li>▪ The President should direct the Secretary of the Department of Health and Human Services to convene an ongoing, multidisciplinary working group of stakeholders and other interested parties to develop more accurate, representative, and useful ways of characterizing populations and collecting population data so as to improve the quality of research and health care to reduce the cancer burden and ensure social justice. Ethnogenetic layering concepts and methods hold considerable potential for understanding important differences in disease susceptibility and outcome.</li> <li>▪ Until these changes can be made, researchers and other users of existing data sources must be explicit about definitions used, assumptions made, and data weaknesses in research on or underlying policy affecting subpopulations in the United States.</li> </ul>	<p>The President</p> <p>Department of Health and Human Services:</p> <ul style="list-style-type: none"> <li>▪ National Cancer Institute</li> <li>▪ Centers for Disease Control and Prevention</li> <li>▪ National Center for Health Statistics</li> <li>▪ Centers for Medicare and Medicaid Services</li> <li>▪ Indian Health Service</li> <li>▪ Health Resources and Services Administration</li> </ul> <p>U.S. Census Bureau</p> <p>Department of Justice</p> <p>Office of the National Coordinator for Health Information Technology</p> <p>Veterans Administration</p> <p>Civilian Health and Medical Program of the Uniformed Services</p> <p>Population scientists</p> <p>Anthropologists</p> <p>Behavioral scientists</p> <p>Statisticians</p> <p>Advocates</p> <p>Other organizations concerned with ensuring social justice</p> <p>Insurance industry</p> <p>Pharmaceutical and biotechnology industries</p> <p>Biomedical research community</p> <p>Health care provider community</p>
<p>2. Data sharing among government agencies at all levels must be improved. Issues of data compatibility must be addressed and a culture of openness and focus on common goals must be fostered.</p>	<p>Federal government</p> <p>State governments</p> <p>Local governments</p>

\* The Panel recognizes that entities other than those listed may have a vital role or interest in implementation of the recommendations.

<p>3. Outreach and training must be better supported to increase the diversity of the cancer research and care workforces. This outreach must begin very early (K-12 educational level) to ensure that students have the educational foundation for careers in science and health care.</p>	<p>National Cancer Institute Department of Education National Science Foundation</p>
<p>4. Cultural competency must become an integral part of medical school, other medical, and research training curricula, and also should be included in continuing education requirements for all health care providers and administrative personnel.</p>	<p>Association of American Medical Colleges American Medical Association National Medical Association  Primary care, medical specialty, subspecialty, nursing, allied health and other licensure, certification, and training organizations</p>
<p><b>Research</b></p>	<p><b>RESPONSIBLE STAKEHOLDERS AND OTHER ENTITIES*</b></p>
<p>5. Basic, translational, clinical, population, and dissemination research on cancer health disparities must be increased, with a focus on identifying and developing evidence-based interventions to address sociocultural and/or biologic factors underlying the disproportionate burden of cancer experienced by medically underserved, socially disenfranchised, and other identified populations at high risk for cancer incidence and poor outcomes. Specifically:</p> <ul style="list-style-type: none"> <li>▪ Continued research is needed on genetic ancestry and the interaction of specific genetic characteristics with identified risk factors.</li> <li>▪ Funding for research on risk factor variation and interaction should be increased.</li> <li>▪ Social science research as it pertains to cancer health disparities should be increased.</li> </ul>	<p>Public- and private-sector research funding organizations</p>
<p>6. Exploration and evaluation of the benefit of patient navigation models and patient-centered medical home models of care in decreasing cancer and other health disparities should be continued. Attention should be paid to how models can be optimized for various populations.</p>	<p>Department of Health and Human Services:</p> <ul style="list-style-type: none"> <li>▪ National Cancer Institute</li> <li>▪ Agency for Healthcare Research and Quality</li> <li>▪ Health Resources and Services Administration/ Community Health Centers</li> <li>▪ Indian Health Service</li> </ul> <p>State health care commissions American Academy of Family Physicians Medical centers and physician practices Community health centers Health policy evaluators</p>

<p>7. Current cancer screening guidelines should be evaluated to determine their accuracy in assessing disease burden in diverse populations.</p>	<p>Department of Health and Human Services:</p> <ul style="list-style-type: none"> <li>▪ National Cancer Institute</li> <li>▪ Centers for Disease Control and Prevention</li> <li>▪ Agency for Healthcare Research and Quality</li> <li>▪ Centers for Medicare and Medicaid Services</li> <li>▪ Food and Drug Administration</li> </ul> <p>U.S. Preventive Services Task Force</p> <p>Public and private health providers</p>
<p><b>Cancer and Other Health Care</b></p>	<p><b>RESPONSIBLE STAKEHOLDERS AND OTHER ENTITIES*</b></p>
<p>8. Policies, including reimbursement policies, should be developed so that health care can be delivered in a manner that enables clinicians adequate opportunity to gather relevant sociocultural and medical information about their patients. This change would result in the provision of more personalized care for patients and improve the quality of patient-provider interactions.</p>	<p>Centers for Medicare and Medicaid Services</p> <p>Other public payors</p> <p>Private-sector payors</p>
<p>9. The importance of language translation services must be appreciated. Providers and hospitals should ensure that professionally trained translators are available and utilized. However, translation services cannot be an unfunded mandate. Mechanisms must be developed to fund this essential component of care.</p>	<p>Physicians and other health care providers</p> <p>Hospitals and health care facilities</p> <p>Joint Commission</p> <p>Department of Health and Human Services:</p> <ul style="list-style-type: none"> <li>▪ Centers for Medicare and Medicaid Services</li> <li>▪ Health Resources and Services Administration</li> </ul> <p>Other public health care payors</p> <p>Private-sector payors</p>
<p>10. Funding for reservation-based and urban Indian health care should continue to increase to improve access to cancer preventive, diagnostic, and treatment services, as well as the primary care services that are the gateway to appropriate cancer care.</p>	<p>The President</p> <p>Congress</p> <p>Indian Health Service</p>



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# Appendices

**Appendix A:** Participant List

**Appendix B:** Cancer Incidence and Mortality Trends

**Appendix C:** Census 2010 Form D-61, U.S. Census Bureau

**Appendix D:** CDC/HL7 Code Set,  
Centers for Disease Control and Prevention

**Appendix E:** Timeline for Implementation of  
Health Reform Provisions



## APPENDIX A » PARTICIPANT LIST

### President's Cancer Panel Meetings

*America's Demographic and Cultural Transformation:  
Implications for the Cancer Enterprise*

Meeting Dates and Locations	
September 22, 2009	Seattle, WA
October 27, 2009	Los Angeles, CA
December 9, 2009	Wilmington, DE
February 2, 2010	Miami, FL

Name	Affiliation
Stefan Ambs, Ph.D., M.P.H.	National Cancer Institute
Barri M. Blauvelt, M.B.A.	University of Massachusetts Institute for Global Health  Innovara, Inc.
Paula Braveman, M.D., M.P.H.	University of California, San Francisco
Otis W. Brawley, M.D.	American Cancer Society
Linda Burhansstipanov, M.S.P.H., Dr.P.H.	Native American Cancer Initiatives, Inc.
Wylie Burke, M.D., Ph.D.	University of Washington School of Medicine
Tim Byers, M.D., M.P.H.	University of Colorado Denver Colorado School of Public Health
Moon S. Chen, Ph.D., M.P.H.	University of California Davis Cancer Center
Gwen Darien	National Cancer Institute  Samuel Waxman Cancer Research Foundation

Brenda K. Edwards, Ph.D.	National Cancer Institute
Martha Farnsworth Riche, Ph.D.	Cornell University
Jean G. Ford, M.D.	John Hopkins Bloomberg School of Public Health
Harold P. Freeman, M.D.	National Cancer Institute Ralph Lauren Center for Cancer Care and Prevention
Francesca Gany, M.D., M.S.	New York University School of Medicine Center for Immigrant Health
Venus Ginés, M.A.	Dia de la Mujer Latina, Inc.
Jorge Gomez, M.D., Ph.D.	National Cancer Institute
Wizdom Powell Hammond, Ph.D.	The University of North Carolina at Chapel Hill Gillings School of Global Public Health
Mark D. Hayward, Ph.D.	University of Texas at Austin Population Research Center
Jeffrey A. Henderson, M.D., M.P.H.	Black Hills Center for American Indian Health University of Colorado Denver Health Sciences Center
Cara V. James, Ph.D.	Henry J. Kaiser Family Foundation
Lovell A. Jones, Ph.D.	Intercultural Cancer Council The University of Texas M. D. Anderson Cancer Center
Beth A. Jones, Ph.D., M.P.H.	Yale School of Public Health
Marjorie Kagawa-Singer, Ph.D., M.A., M.N., R.N.	UCLA School of Public Health and Department of Asian American Studies
Samir N. Khleif, M.D.	National Cancer Institute
Laurence N. Kolonel, M.D., Ph.D.	University of Hawaii at Manoa Cancer Research Center of Hawaii
Margaret L. Kripke, Ph.D.	President's Cancer Panel The University of Texas M. D. Anderson Cancer Center
LaSalle D. Leffall, Jr., M.D., F.A.C.S.	President's Cancer Panel Howard University College of Medicine
Upendar Manne, Ph.D.	University of Alabama at Birmingham
Susan Neuhausen, Ph.D.	University of California, Irvine
Yolanda Partida, M.S.W., D.P.A.	Hablamos Juntos UCSF Fresno Center for Medical Education & Research
Eliseo J. Pérez-Stable, M.D.	University of California, San Francisco Medical Effectiveness Research Center for Diverse Populations

Daniel Petereit, M.D.	Dakota West Radiation Oncology John T. Vucurevich Cancer Care Institute
Derek Raghavan, M.D., Ph.D., F.A.C.P.	American Society of Clinical Oncology Health Disparities Advisory Group Cleveland Clinic Taussig Cancer Institute
Timothy Rebbeck, Ph.D.	University of Pennsylvania Center for Population Health and Health Disparities
Wael A. Sakr, M.D.	Wayne State University School of Medicine
Abby B. Sandler, Ph.D.	President's Cancer Panel National Cancer Institute
Amr S. Soliman, M.D., Ph.D.	University of Michigan School of Public Health
Sanya A. Springfield, Ph.D.	National Cancer Institute
Michelle van Ryn, Ph.D., M.P.H.	University of Minnesota
Daniel J. Weisdorf, M.D.	University of Minnesota
Jeffrey D. White, M.D.	National Cancer Institute
Cheryl L. Willman, M.D.	University of New Mexico Cancer Center
Elad Ziv, M.D.	University of California, San Francisco



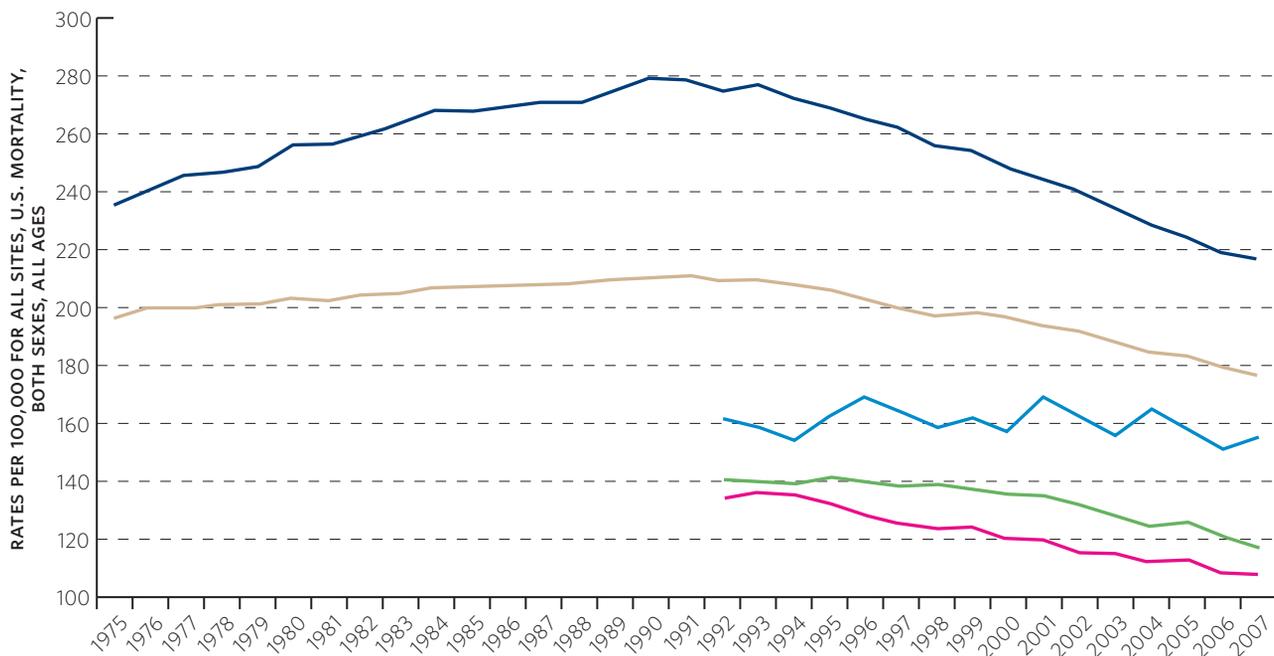
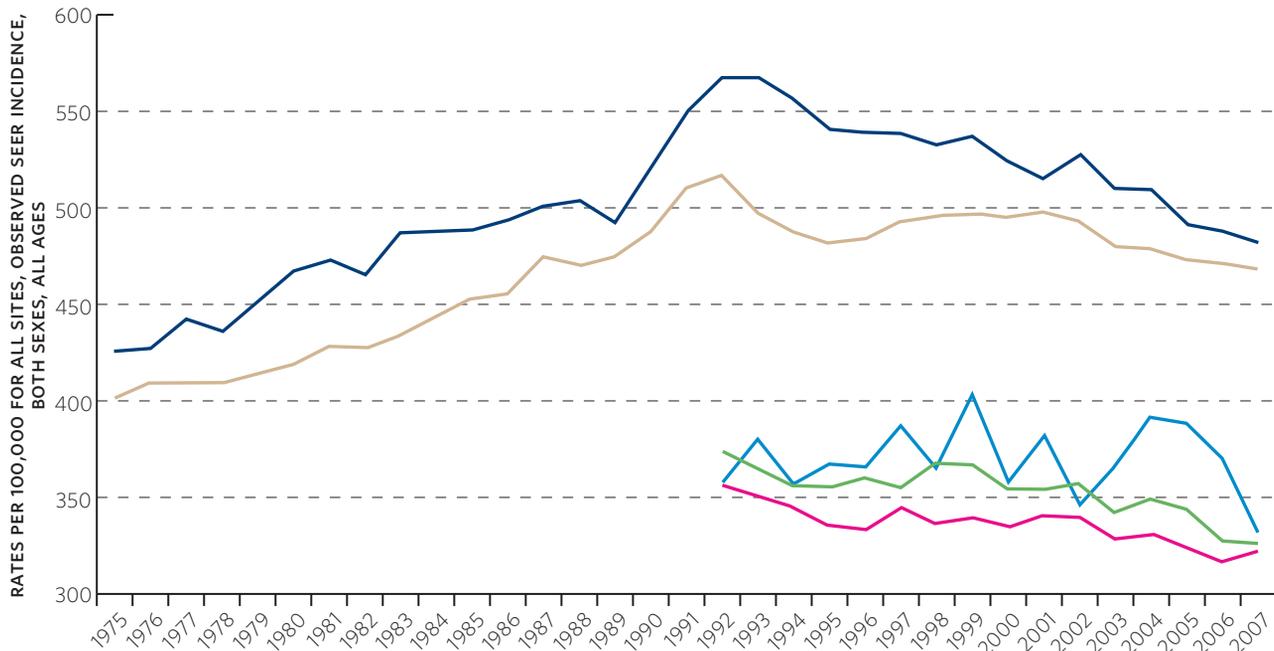
## APPENDIX B » CANCER INCIDENCE AND MORTALITY TRENDS\*

Overall age-adjusted cancer incidence and mortality rates have declined slowly in the United States in recent years.<sup>1</sup> It is estimated that more than 767,000 cancer deaths were averted between 1990 and 2006;<sup>2</sup> these improvements are attributable primarily to reductions in tobacco use among men, increased cancer screening rates, and improved treatments for specific cancers. In the coming decades, however, increases or changes in cancer rates related to demographic changes in the United States are predicted to overwhelm this progress, with a marked increase in the number of new cancer diagnoses and fatalities. Much of this increase will be attributable to aging of the U.S. population as a whole, since most malignancies occur

in older individuals. Another segment of the increase in cancer incidence will be due to a rise in cancers diagnosed among defined minority group members of all ages as defined by the Office of Management and Budget (OMB). Cancer incidence in minorities is projected to nearly double between 2010 and 2030, compared with an estimated 31 percent increase in the non-Hispanic white population.<sup>3</sup> Among the population as a whole, it is projected that new cancer cases per year will nearly double from 1.3 million in 2000 to almost 3 million in 2050.<sup>4</sup> This section provides a brief overview of cancer incidence and mortality trends in American subpopulations as they currently are understood.

\* Unless otherwise noted or cited, data on cancer incidence and mortality are based on SEER 17 data, 2002–2006, and survival data are based on SEER 17, 1999–2005.

FIGURE A-1 » SEER INCIDENCE AND U.S. DEATH RATES<sup>a</sup>, ALL CANCER SITES, BOTH SEXES  
 JOINTPOINT ANALYSES FOR WHITES AND BLACKS FROM 1975-2007 AND FOR ASIAN/PACIFIC  
 ISLANDERS, AMERICAN INDIANS/ALASKA NATIVES, AND HISPANICS FROM 1992-2007



- Black, 1975-2007
- White, 1975-2007
- American Indian/Alaska Native,<sup>b</sup> 1992-2007
- Hispanic,<sup>c</sup> 1992-2007
- Asian/Pacific Islander, 1992-2007

a Rates are age adjusted to the 2000 U.S. Standard Population (19 age groups—Census P25-1103). Regression lines are calculated using the Joinpoint Regression Program Version 3.4.3, April 2010, National Cancer Institute. Joinpoint analyses for whites and blacks during the 1975-2007 period allow a maximum of four joinpoints. Analyses for other ethnic groups during the period 1992-2007 allow a maximum of two joinpoints.

b Rates for American Indians/Alaska Natives are based on the Contract Health Service Delivery Area (CHSDA) counties. CHSDAs are geographic areas within which contract health services are made available by the Indian Health Service to members of an identified Indian community residing in the area.

c Hispanic is not mutually exclusive from whites, blacks, Asian/Pacific Islanders, and American Indians/Alaska Natives. Incidence data for Hispanics are based on the North American Association of Central Cancer Registries Hispanic Identification Algorithm and exclude cases from the Alaska Native Registry. Mortality data for Hispanics exclude cases from Connecticut, the District of Columbia, Maine, Maryland, Minnesota, New Hampshire, New York, North Dakota, Oklahoma, and Vermont.

Figure A-1 graphs cancer incidence and mortality trends for major OMB-defined U.S. subpopulations from 1975 through 2007. These trends have important implications for national efforts to prevent and control cancer. While small reductions in cancer incidence and mortality have been observed among most defined racial and ethnic groups, significant disparities persist for all cancer sites combined and for many cancer types.

Minority and other underserved populations experience disproportionate burdens from certain cancers, are often diagnosed at later stages of disease, and frequently have less favorable odds of survival once diagnosed.<sup>5,6</sup> In some cases, disparities between white and minority population groups are widening.<sup>1</sup> For example, age-adjusted colorectal cancer mortality trends by race have followed a divergent pattern for more than 20 years; while rates for Caucasians have decreased slowly but steadily, those for African Americans have been relatively stable over time. Between 1980 and 2000, the age-adjusted mortality rate dropped almost 8 percent among Caucasians, but only 0.5 percent among African Americans.<sup>7</sup> SEER data for the period 1998–2007 reveal that mortality from cancers of the lung and bronchus increased markedly for American Indian and Alaska Native women, but declined or were stable for all other women.<sup>8</sup> Figure A-2 arrays selected cancer incidence and mortality rates by cancer site for major U.S. population groups, as defined by the U.S. Census.

## African Americans

Of all U.S. population subgroups, African Americans have the highest overall cancer incidence and mortality rates (Figure A-2). For most types of cancer, they are less likely than whites to survive five years at each stage of diagnosis.<sup>5</sup> African Americans have the highest incidence and mortality rates for cancers of the prostate, colon and rectum, lung and bronchus, and esophagus, as well as for myeloma. The well-documented disparity in prostate cancer incidence and mortality affecting African American men is perhaps the most striking. Black men are 50 percent more likely than non-Hispanic white men to be diagnosed with prostate cancer, and more than three times more likely than Native American men, who have the lowest prostate cancer rate. Furthermore, black men are more than twice as likely as men of any other racial/ethnic group to die from prostate cancer.

Although white women have the highest incidence rate of breast cancer of all racial and ethnic groups in the United States, African American women are more likely to die from breast cancer once diagnosed. They are more frequently diagnosed with late-stage breast cancer and have lower five-year relative survival rates at each stage of disease.<sup>1,5,9</sup> Of note, breast cancer death rates for African Americans and whites were similar in the 1980s but began to diverge in the 1990s. During the period 2001 through 2005, the breast cancer mortality rate of African American women was 37 percent higher than that of white women.<sup>5</sup>

African American women also suffer disproportionately from cervical cancer. Although their incidence rates of this disease are not as high as those of Vietnamese or Hispanic/Latina women, African American women have cervical cancer incidence rates 45 percent higher than those of non-Hispanic white women. Black women are more than twice as likely to die from cervical cancer compared with their white counterparts. Poorer survival among African American women is due in part to late diagnosis.<sup>5</sup>

## Hispanics/Latinos

Data on the cancer burden experienced by the U.S. Hispanic/Latino population have been collected only since the early 1990s. Further, data for Hispanics/Latinos as a whole mask sharp differences in cancer burden depending on country of origin. This caveat notwithstanding, as with most other racial/ethnic groups, cancer incidence and mortality rates for Hispanics/Latinos overall have declined in recent years; in fact, between 1997 and 2006, both incidence and mortality declined at a faster pace among Hispanics/Latinos than among non-Hispanic whites.<sup>6</sup>

For all cancers combined and for the most common cancers (prostate, female breast, colorectal, and lung), incidence and death rates are lower among Hispanics than among non-Hispanic whites. Breast cancer occurs less often in Hispanic women but is likely to be diagnosed at later stages.<sup>10</sup> Hispanic women are 20 percent more likely to die from breast cancer than are non-Hispanic white women diagnosed at a similar age and stage.<sup>6</sup> A similar pattern is observed for prostate cancer—despite lower overall incidence and mortality rates, Hispanics are more likely than non-Hispanic whites to be diagnosed with advanced disease and have a lower probability of survival after diagnosis even after accounting for differences in age and stage.<sup>6</sup>

**FIGURE A-2 » INCIDENCE AND MORTALITY RATES OF SELECTED CANCERS  
(RATES EXPRESSED PER 100,000 PEOPLE)**



Incidence  
 Mortality

Note: Rates for American Indians and Alaska Natives are for Contract Health Service Delivery Area (CHSDA) counties only. CHSDAs are geographic areas within which contract health services are made available by the Indian Health Service to members of an identified Indian community residing in the area.

Source: Horner MJ, Ries LAG, Krapcho M, Neyman N, Aminou R, Howlander N, et al. (eds). SEER Cancer Statistic Review, 1975-2006 [Internet]. National Cancer Institute. Bethesda (MD) [http://seer.cancer.gov/csr/1975\\_2006/](http://seer.cancer.gov/csr/1975_2006/). Based on November 2008 SEER data submission; 2009.

Hispanics/Latinos have higher rates of acute lymphocytic leukemia and gallbladder cancers compared with the non-Hispanic white population. Hispanics/Latinos also have higher incidence and mortality rates for stomach, liver, and cervical cancers compared with those of the non-Hispanic white population.<sup>6</sup> These three cancers all are related to infectious agents and are especially prevalent among first-generation immigrants. These cancers also are more common in the Central and South American home countries of many of these immigrants. In the United States, stomach cancer incidence rates are at least 70 percent higher in Hispanics/Latinos than they are in non-Hispanic whites, due in part to two- to threefold higher *Helicobacter pylori* infection rates in this group.<sup>6</sup> The liver cancer incidence rate for Hispanics/Latinos is second only to that of Asians and Pacific Islanders and is twice as high as that of the non-Hispanic white population. The majority of liver cancers worldwide are attributable to chronic hepatitis B or C virus infections. Cervical cancer, which is almost always the result of human papillomavirus infection, afflicts U.S. Latinas more commonly than it does women of all other U.S. racial/ethnic groups except Vietnamese women.<sup>11,12</sup> The death rate from cervical cancer among Hispanic/Latina women is almost 50 percent higher than among non-Hispanic white women.

### Asians, Native Hawaiians, and Other Pacific Islanders

Asians and Pacific Islanders are the only U.S. racial/ethnic population to experience cancer as the leading cause of death.<sup>13</sup> Although they have relatively low rates of some of the most common cancers (e.g., breast, prostate, colorectal, lung), they experience a disproportionate burden from cancers associated with infectious agents. Asians and Pacific Islanders are more likely than members of any other racial/ethnic group to be diagnosed with liver or stomach cancer. The incidence of liver cancer among this population is nearly triple that of non-Hispanic whites. Compared with the non-Hispanic white population, Asians and Pacific Islanders are more than twice as likely to die from liver and stomach cancers. Vietnamese women have the highest known cervical cancer rates—about five times those of non-Hispanic white women.<sup>14</sup>

### American Indians and Alaska Natives

Native Americans' cancer incidence rate for all sites combined is lower than those of non-Hispanic whites, blacks, and Hispanics/Latinos but higher than that of Asians and Pacific Islanders.<sup>15</sup> Overall cancer mortality among Native Americans is lower than among black and white Americans but higher than among non-Hispanic whites and Asians and Pacific Islanders. Native Americans have relatively low rates of some of the most commonly diagnosed cancers, including breast and prostate.

Similar to patterns observed among other minority groups, the incidence and mortality rates of stomach and liver cancer among American Indians and Alaska Natives are approximately twice those of non-Hispanic whites. Cancers of the kidney and gallbladder are also more common among Native Americans compared with non-Hispanic whites. In addition, Native Americans have the poorest five-year survival rate for lung cancer.

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APPENDIX C » CENSUS 2010 FORM D-61,  
U.S. CENSUS BUREAU (EXCERPT)

<p><b>United States Census 2010</b></p>	<p style="text-align: right;">U.S. DEPARTMENT OF COMMERCE Economics and Statistics Administration U.S. CENSUS BUREAU</p>
<p>This is the official form for all the people at this address. It is quick and easy, and your answers are protected by law.</p>	
<p><b>Use a blue or black pen.</b></p> <p style="text-align: center;"><b>Start here</b></p> <p>The Census must count every person living in the United States on April 1, 2010.</p> <p>Before you answer Question 1, count the people living in this house, apartment, or mobile home using our guidelines.</p> <ul style="list-style-type: none"> <li>Count all people, including babies, who live and sleep here most of the time.</li> </ul> <p>The Census Bureau also conducts counts in institutions and other places, so:</p> <ul style="list-style-type: none"> <li>Do not count anyone living away either at college or in the Armed Forces.</li> <li>Do not count anyone in a nursing home, jail, prison, detention facility, etc., on April 1, 2010.</li> <li>Leave these people off your form, even if they will return to live here after they leave college, the nursing home, the military, jail, etc. Otherwise, they may be counted twice.</li> </ul> <p>The Census must also include people without a permanent place to stay, so:</p> <ul style="list-style-type: none"> <li>If someone who has no permanent place to stay is staying here on April 1, 2010, count that person. Otherwise, he or she may be missed in the census.</li> </ul> <p><b>1. How many people were living or staying in this house, apartment, or mobile home on April 1, 2010?</b></p> <p>Number of people = <input type="text"/></p>	<p><b>5. Please provide information for each person living here. Start with a person living here who owns or rents this house, apartment, or mobile home. If the owner or renter lives somewhere else, start with any adult living here. This will be Person 1.</b></p> <p>What is Person 1's name? <i>Print name below.</i></p> <p>Last Name <input type="text"/></p> <p>First Name <input type="text"/> MI <input type="text"/></p> <p><b>6. What is Person 1's sex? Mark <input checked="" type="checkbox"/> ONE box.</b></p> <p><input type="checkbox"/> Male <input type="checkbox"/> Female</p> <p><b>7. What is Person 1's age and what is Person 1's date of birth? Please report babies as age 0 when the child is less than 1 year old. <i>Print numbers in boxes.</i></b></p> <p>Age on April 1, 2010 <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/></p> <p>Month <input type="text"/> <input type="text"/> Day <input type="text"/> <input type="text"/> Year of birth <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/></p> <p>→ NOTE: Please answer BOTH Question 8 about Hispanic origin and Question 9 about race. For this census, Hispanic origins are not races.</p> <p><b>8. Is Person 1 of Hispanic, Latino, or Spanish origin?</b></p> <p><input type="checkbox"/> No, not of Hispanic, Latino, or Spanish origin</p> <p><input type="checkbox"/> Yes, Mexican, Mexican Am., Chicano</p> <p><input type="checkbox"/> Yes, Puerto Rican</p> <p><input type="checkbox"/> Yes, Cuban</p> <p><input type="checkbox"/> Yes, another Hispanic, Latino, or Spanish origin — <i>Print origin, for example, Argentinian, Colombian, Dominican, Nicaraguan, Salvadoran, Spaniard, and so on.</i> ↗</p> <p><input type="text"/></p>
<p><b>2. Were there any additional people staying here April 1, 2010 that you did not include in Question 1? Mark <input checked="" type="checkbox"/> all that apply.</b></p> <p><input type="checkbox"/> Children, such as newborn babies or foster children</p> <p><input type="checkbox"/> Relatives, such as adult children, cousins, or in-laws</p> <p><input type="checkbox"/> Nonrelatives, such as roommates or live-in baby sitters</p> <p><input type="checkbox"/> People staying here temporarily</p> <p><input type="checkbox"/> No additional people</p> <p><b>3. Is this house, apartment, or mobile home — Mark <input checked="" type="checkbox"/> ONE box.</b></p> <p><input type="checkbox"/> Owned by you or someone in this household with a mortgage or loan? <i>Include home equity loans.</i></p> <p><input type="checkbox"/> Owned by you or someone in this household free and clear (without a mortgage or loan)?</p> <p><input type="checkbox"/> Rented?</p> <p><input type="checkbox"/> Occupied without payment of rent?</p> <p><b>4. What is your telephone number? We may call if we don't understand an answer.</b></p> <p>Area Code + Number</p> <p><input type="text"/> - <input type="text"/> - <input type="text"/></p> <p>OMB No. 0607-0919-G; Approval Expires 12/31/2011.</p> <p>Form <b>D-61</b> (9-25-2008)</p>	<p><b>9. What is Person 1's race? Mark <input checked="" type="checkbox"/> one or more boxes.</b></p> <p><input type="checkbox"/> White</p> <p><input type="checkbox"/> Black, African Am., or Negro</p> <p><input type="checkbox"/> American Indian or Alaska Native — <i>Print name of enrolled or principal tribe.</i> ↗</p> <p><input type="text"/></p> <p><input type="checkbox"/> Asian Indian <input type="checkbox"/> Japanese <input type="checkbox"/> Native Hawaiian</p> <p><input type="checkbox"/> Chinese <input type="checkbox"/> Korean <input type="checkbox"/> Guamanian or Chamorro</p> <p><input type="checkbox"/> Filipino <input type="checkbox"/> Vietnamese <input type="checkbox"/> Samoan</p> <p><input type="checkbox"/> Other Asian — <i>Print race, for example, Hmong, Laotian, Thai, Pakistani, Cambodian, and so on.</i> ↗</p> <p><input type="checkbox"/> Other Pacific Islander — <i>Print race, for example, Fijian, Tongan, and so on.</i> ↗</p> <p><input type="text"/></p> <p><input type="checkbox"/> Some other race — <i>Print race.</i> ↗</p> <p><input type="text"/></p> <p><b>10. Does Person 1 sometimes live or stay somewhere else?</b></p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes — <i>Mark <input checked="" type="checkbox"/> all that apply.</i></p> <p><input type="checkbox"/> In college housing <input type="checkbox"/> For child custody</p> <p><input type="checkbox"/> In the military <input type="checkbox"/> In jail or prison</p> <p><input type="checkbox"/> At a seasonal or second residence <input type="checkbox"/> In a nursing home</p> <p><input type="checkbox"/> For another reason</p> <p>→ If more people were counted in Question 1, continue with Person 2.</p>



## APPENDIX D » CDC/HL7 CODE SET, CENTERS FOR DISEASE CONTROL AND PREVENTION\*

### OMB Race and Hispanic Ethnicity Categories



\* CDC ethnicities rolled up to the OMB minimum categories for race and Hispanic ethnicity with subcommittee annotations.



## APPENDIX E » TIMELINE FOR IMPLEMENTATION OF HEALTH REFORM PROVISIONS

OVERVIEW	
<p>Reform will unfold incrementally. Although some major elements of reform begin in 2010, others will be implemented over the course of several years. In 2014, the most substantial changes—including shared responsibility for coverage, expansion of Medicaid, insurance exchanges, and creation of an essential benefits package—will take effect.</p>	
2010	
<p><b>Early retirees:</b> A temporary reinsurance program will help offset the costs of expensive premiums for employers providing retiree health benefits.</p> <p><b>Access to care:</b> Funding will be increased by \$11 billion over five years for community health centers and the National Health Service Corps to serve more low-income and uninsured people.</p> <p><b>Small-business tax credits:</b> Small businesses (25 or fewer employees and average wages under \$50,000) that offer health care benefits will be eligible for tax credits of up to 35 percent of their premium costs for two years.</p> <p><b>High-risk pool:</b> People with preexisting conditions who have been uninsured for at least six months will have access to affordable insurance through a temporary, subsidized high-risk pool. Premiums will be based on the average health status of a standard population. Annual out-of-pocket costs will be capped at \$5,950 for individuals and \$11,900 for families.</p> <p><b>Protection for children:</b> Insurers can no longer deny health coverage to children with preexisting conditions or exclude their conditions from coverage.</p>	<p><b>Coverage for young adults:</b> Parents will be able to keep their children on their health policies until they turn 26.</p> <p><b>"Doughnut hole" rebates:</b> Medicare will provide \$250 rebates to beneficiaries who hit the Part D prescription drug coverage gap known as the "doughnut hole."</p> <p><b>Annual review of premium increases:</b> Health insurers will be required to submit justification for unreasonable premium increases to the federal and relevant state governments before they take effect, and to report the share of premiums spent on nonmedical costs.</p> <p><b>New insurance rules:</b> Insurance companies will be banned from rescinding people's coverage when they get sick, and from imposing lifetime caps on coverage. Restrictions will be placed on annual limits.</p> <p><b>Preventive care:</b> All new group and individual health plans will be required to provide free preventive care for proven preventive services. In 2011, Medicare also will provide free preventive care.</p>

## 2011

**Benefit disclosure:** Employers will be required to disclose the value of benefits provided for each employee's health insurance coverage on the employee's W-2 forms.

**New payment and delivery approaches:** A new Center for Medicare and Medicaid Innovation will test reforms that reward providers for quality of care rather than volume of services. Medicare will increase payment for primary care physicians by 10 percent for primary care services.

**CLASS Act:** A national, voluntary insurance program for purchasing community living assistance services and support (CLASS) will be established. All working adults will be automatically enrolled—unless they opt out—through payroll deductions that, after five years, will qualify them for monthly payments toward services to help them stay at home should they become disabled.

**Pharmaceutical manufacturer fee:** An annual, nondeductible fee will be imposed on pharmaceuticals and importers' branded drugs, based on market share.

**OTC drug reimbursement restrictions:** Over-the-counter drugs not prescribed by a doctor will no longer be reimbursable through flexible spending accounts or health reimbursement arrangements, or on a tax-free basis in health savings accounts.

**Physician quality reporting:** Medicare will launch a Physician Compare Web site where beneficiaries can compare measures of physician quality and patient experience.

**"Doughnut hole" discounts:** Medicare beneficiaries in the Part D prescription drug coverage "doughnut hole" will receive 50 percent discounts on all brand-name drugs. By 2020, the "doughnut hole" coverage gap will be closed.

**Premium share spending:** Health plans in the large-group market that spend less than 85 percent of their premiums on medical care, and plans in the small-group and individual markets that spend less than 80 percent on medical care, will be required to offer rebates to enrollees.

## 2012

**Medicare value-based purchasing:** Medicare will reward hospitals that provide higher quality or better patient outcomes.

## 2013

**Administrative simplification:** Health insurers must follow administrative simplification standards for electronic exchange of health information to reduce paperwork and administrative costs.

**Flexible spending limits:** Contributions to flexible spending accounts will be limited to \$2,500 a year, indexed to the Consumer Price Index.

## 2014

**Shared responsibility for coverage:** Individuals will be required to carry health insurance, and employers with 50 or more workers will be required to offer health benefits or be subject to a fine of \$2,000 per employee (not counting the first 30 employees) if any worker receives governmental assistance with premiums through the insurance exchanges.

**Insurance industry fee:** Insurers will pay an annual fee, based on market share, to help pay for reform.

**New rules for insurers:** Insurers will be banned from restricting coverage or basing premiums on health status. Annual, in addition to lifetime, limits on benefits are banned.

**Premium subsidies:** Premium and cost-sharing assistance on a sliding scale will make coverage affordable for families with annual incomes between \$30,000 and \$88,000 that buy plans through the exchanges.

**Medicare managed care plans:** Four- and five-star Medicare private plans will receive 5 percent bonuses as a reward for providing better clinical quality and patient experiences.

**Insurance exchanges:** New state-based marketplaces will offer small businesses and people without employer coverage a choice of affordable health plans that meet new essential benefit standards.

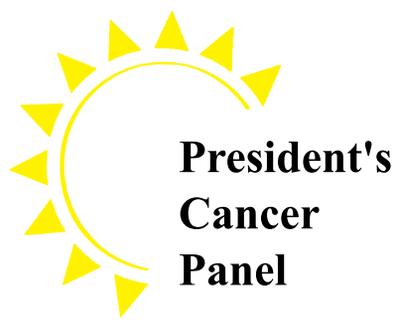
**Essential benefits package:** The Department of Health and Human Services will establish an essential standard benefits package for policies sold in the exchanges and individual and small-group markets with a choice among tiers of plans (bronze, silver, gold, and platinum) that have different levels of cost-sharing.

**Independent payment advisory board:** A new independent payment advisory board within the executive branch will work to identify areas of waste and federal budget savings in Medicare. The board's recommendations must not ration care, raise taxes, or change Medicare benefits eligibility, or cost-sharing.

**Medicaid expansion:** Medicaid eligibility will be expanded to all legal residents with incomes up to 133 percent of the federal poverty level. Currently, states have different—and in many cases very low—eligibility thresholds, and most states do not cover adults without children.

## 2018

**High-cost insurance plans:** Insurers will face a 40 percent excise tax on policies over \$10,200 for individuals or \$27,500 for family coverage.



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