

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.