



President's Cancer Panel • 2009-2010 Annual Report

## America's Demographic and Cultural Transformation: Implications for Cancer

### Addendum: How the Patient Protection and Affordable Care Act and Other Recent Legislative Activity May Impact the Panel's Recommendations

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





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How the Patient Protection and Affordable Care Act  
and Other Recent Legislative Activity  
May Impact the Panel's Recommendations

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# Addendum

## How the Patient Protection and Affordable Care Act and Other Recent Legislative Activity May Impact the Panel's Recommendations

### INTRODUCTION

The Patient Protection and Affordable Care Act (PPACA, P.L. 111-148), also known as the Affordable Care Act, is the most significant health care legislation to be signed into law since the Medicare and Medicaid programs were created in the 1960s.

During the period in which this report of the President's Cancer Panel, *America's Demographic and Cultural Transformation: Implications for Cancer*, was being prepared and finalized, implementation of PPACA provisions and associated appropriations were being debated in Congress. As a result, the report does not address extensively how the PPACA may apply to meeting the challenges of rapidly changing demographics in the United States and the health care needs of all of the American population.

Though the PPACA has been signed into law, specific provisions of the PPACA continue to be the subject of debate in the House of Representatives and the Senate, and the full impact of the legislation on both the health of Americans and the performance and efficiency of the U.S. health care system has yet to be realized. Provisions of the PPACA are to be implemented in stages through 2018.

Due to the importance of numerous PPACA provisions either in directly enabling or potentially facilitating implementation of recommendations contained in this report, the Panel is providing this addendum as further guidance for policymakers and the public. Specific provisions of PPACA related to Panel recommendations are discussed herein. In addition, the Panel provides further discussion concerning PPACA provisions and recent federal investments in health information technology (HIT) as they apply to recommendations contained in this report. A list of the report recommendations is included in this addendum.

### HEALTH CARE ACCESS

This Panel report does not make an explicit recommendation regarding increased access to health care, though several previous reports<sup>1-6</sup> have done so. However, the need of all Americans for access to quality and affordable health care is a central theme of the Panel's current report.

Certainly, many provisions of the PPACA respond to the public's strong desire<sup>7,8</sup> and need for greater access to necessary health services, greater continuity of care, and finally, freedom from fear—of losing health insurance in the event of job loss, of having to stay in unsuitable jobs simply to retain health coverage, and of being unable to get affordable health insurance due to preexisting conditions. The PPACA provisions that will increase access to affordable health care will provide millions of uninsured individuals an option for securing health coverage for themselves and their families, including lower-wage employees who cannot afford employer-offered benefits and workers at small businesses that have been unable to offer health insurance due to cost. A great many of these workers and families are members of vulnerable population subgroups discussed in the Panel's report. PPACA addresses the needs of these Americans by creating health insurance exchanges and a temporary insurance program until the exchanges are implemented in 2014.

Many PPACA provisions are particularly important to newly diagnosed cancer patients and those with a history of cancer. As advances continue to be made in cancer treatment and care, and as Americans are expected to live longer, the population of cancer survivors can be expected to expand. The elimination of annual limits and lifetime caps on care, as called for in the PPACA, is crucial to cancer survivors who may require treatment more than once over the course of their lives to control disease recurrence or spread, as

well as to manage health conditions resulting from cancer treatments (e.g., second primary cancers, cardiac problems, fatigue). The PPACA prohibition on denial of coverage due to preexisting conditions has enormous implications for cancer survivors, particularly childhood cancer survivors, many of whom have difficulties obtaining adequate health coverage.

In June 2000, President Clinton issued an Executive Memorandum<sup>9,10</sup> mandating coverage of the routine costs of cancer care for Medicare beneficiaries who participate in clinical trials. Through the PPACA amendment to the Public Health Service Act, this coverage is now required for insured cancer patients of all ages. The importance of this provision cannot be overstated. Currently, it is estimated that of all adult cancer patients in the United States, less than 3 percent to not more than 5 percent participate in clinical trials,<sup>11</sup> a level far too low to accelerate the pace at which new therapies can be tested or answer key questions regarding the efficacy of treatment interventions for diverse populations. Patients may not enroll in clinical trials for a number of reasons (e.g., not offered this option, poor communication about trials, inability to travel to receive care), but chief among these has been lack of insurance coverage of treatment costs and untenable out-of-pocket expenses. Thus, the PPACA requirement for coverage of many clinical trials costs may have the added benefit of markedly advancing cancer treatment research progress.

Because cancer and other health disparities are associated with lower socioeconomic status, provisions in the PPACA that expand Medicaid eligibility for low-income individuals can be expected to have a positive impact on the disease burden experienced by vulnerable populations. Other provisions related to increasing health care access for vulnerable populations include:

- Narrowing the prescription drug coverage gap for Medicare beneficiaries.
- Assisting rural hospitals in testing new care delivery models and other delivery system reforms.
- Establishing school-based health programs designed to provide services to low-income children and families.

In addition, the PPACA reauthorizes in perpetuity the Indian Health Improvement Act. This action, first recommended by the Panel in its 2002 report,<sup>2</sup> is an important step toward providing the health

care guaranteed to Native Americans by the U.S. Government, and must be accompanied by appropriations that will enable the provision of quality care.

## DIRECT AND POTENTIAL IMPACT OF PPACA PROVISIONS ON PANEL RECOMMENDATIONS IN THIS REPORT

In addition to increasing health care access, numerous other provisions of PPACA either directly address or potentially facilitate implementation of the Panel's recommendations in this report. Provisions related to data quality and sharing, research to improve health care services, and improved diversity and capacity of the health care workforce are discussed in the following sections.

### Data Quality and Data Sharing

Effectively addressing disparities in cancer incidence, mortality, and outcomes will require a clearer understanding of the factors that contribute to cancer among diverse segments of the U.S. population. However, for a variety of reasons, current data do not provide a comprehensive or accurate picture of these causative and contributory factors; data that are available often are not optimally utilized by researchers or health care providers. Panel Recommendations 1 and 2 call for action to address these data deficiencies, specifically emphasizing the need to develop more accurate, representative, and useful ways to characterize populations and noting the need for improved data sharing among government agencies at all levels. Several PPACA provisions acknowledge the need for enhancements in data collection, analysis, and reporting in health care and have the potential to facilitate progress in efforts to understand, and hopefully eventually eliminate, health disparities in the United States.

"Understanding Health Disparities: Data Collection and Analysis," a section within Title IV of the PPACA, amends the Public Health Service Act to require all federally conducted or supported health programs or surveys to collect and report, to the extent practicable, data on race, ethnicity, sex, primary language, and disability status by 2012. Of note, any data collected for racial and ethnic minority groups also must be collected

for underserved rural and frontier populations. In addition, the provision states that data on the smallest possible geographic level (e.g., state, local, institutional) must be collected if such data can be aggregated. The Panel believes data on occupational and other environmental exposures also should be collected, as these exposures increasingly are understood to have important influences on cancer risk.<sup>12</sup>

The Secretary of the Department of Health and Human Services (HHS) is charged with overseeing the development of standards for these data, which, at a minimum, must adhere to the standards for data on race and ethnicity set forth by the Office of Management and Budget (OMB). This undertaking provides an opportunity to improve the quality of data on populations and on disparities in cancer and other areas of health care. Particular insight may be gained from data on primary language, which is not encompassed by current OMB standards. As referenced in the report, populations that prefer communicating in languages other than English often have suboptimal interactions with health care providers and systems. Thus, the Secretary should be encouraged to adopt standards that go beyond those set forth by OMB to enable meaningful evaluation of trends and analysis within the broad OMB categories. Such data will support efforts to measure progress, as detailed in the HHS action plan to reduce racial and ethnic health disparities.<sup>13</sup>

Further, the Secretary is directed to work with the National Coordinator for Health Information Technology to develop strategies for management of health disparities data and to ensure that these data are interoperable and secure. These efforts should facilitate the data sharing among stakeholders (e.g., federal agencies, nongovernmental entities) that is mandated by PPACA for programs covered through this provision.

The PPACA also amends the Social Security Act to promote data sharing across federal agencies. This provision—which requires the Centers for Medicare and Medicaid Services (CMS) integrated data repository to include claims and payment information from not only Medicare, Medicaid, and the Children's Health Insurance Program, but also from health-related programs administered by the Departments of Veterans Affairs and Defense, the Social Security Administration, and the Indian Health Service—was adopted primarily as a means to identify fraud, waste, and abuse. However, the data sharing agreements among the

agencies involved may be an important first step in fostering a culture of openness that will benefit health disparities data collection and research.

In addition to focusing attention on the overall categorization framework for U.S. populations, PPACA also directs HHS to establish a comprehensive methodology and criteria for designating Medically Underserved Populations (MUPs). MUP designations—along with those for Health Professions Shortage Areas—are used to determine eligibility for several federal programs, including the Health Resources and Services Administration (HRSA)-supported Health Centers. Existing criteria for designation of MUPs are now significantly outdated. HRSA has been trying to develop a methodology and procedure that would, at a minimum, define consistently the indicators used to designate MUPs and allow for updating designations on a regular basis. As directed by PPACA, a Negotiated Rulemaking Committee on the Designation of Medically Underserved Populations and Health Professions Shortage Areas was created in July 2010.<sup>14</sup> The Committee, composed of stakeholder representatives and experts in health care access issues and statistical methods, indicated in a preliminary report that its proposed methodologies, to be released by October 2011, will incorporate factors reflecting the health status of a population, its socioeconomic characteristics, and barriers to care.<sup>15</sup>

## Research to Improve Health Care Services

Panel Recommendations 5 through 8 address research needed to better understand meaningful differences among subpopulations that affect overall health status and variations in cancer risk and outcomes. The Panel also highlights research needed to identify best practices for meeting the cancer prevention, early detection, treatment, and support needs of a diverse population.

PPACA establishes the Patient Centered Outcomes Research Institute (PCORI) that is tasked to identify priorities and provide for the conduct of comparative outcomes research. PCORI is specifically required to ensure that subpopulations are appropriately accounted for in research designs. The Panel believes it will be important for PCORI to go beyond OMB subpopulation definitions to identify populations with characteristics that are the true causes of or contributors to patient outcome differences.

The PPACA also establishes the Center for Medicare and Medicaid Innovation within CMS. The Center will research, develop, test, and expand innovative payment and delivery arrangements with the goal of improving the quality and reducing the cost of care provided to patients participating in these crucial health programs. PPACA authorizes dedicated funding for testing models that require benefits not currently covered by Medicare. Successful care models identified through these research activities may then be expanded nationally. Moreover, PPACA provides for the development of medical home models and grants to develop medication management services for chronic disease.

Related directly to the Panel's Recommendation 6, PPACA reauthorizes patient navigation demonstration programs; as noted in the report, patient navigation services appear to be particularly critical to timely, effective care for typically underserved subpopulations. Of further note, PPACA requires the new health care exchanges to award grants to navigators to educate the public about qualified health plans, facilitate enrollment, and provide referrals on grievances, complaints, and questions. While not directly aimed at exploring and evaluating navigation models, the law nonetheless recognizes the value of the navigator role.

The PPACA requirement that all new group and individual health plans provide free preventive care for proven preventive services and free preventive care coverage (including wellness visits) under Medicare supports the Panel's Recommendation 7 for evaluating cancer screening guidelines to determine their accuracy in assessing disease burden in various U.S. subpopulations. As research further elucidates the screening services and schedules most beneficial to populations with varying levels of risk, this provision will ensure that persons requiring earlier or more frequent screening will be able to receive those services.

The wellness visit and preventive services available under Medicare as provided by the PPACA can be expected to have a positive effect on individuals whose cultural norm is to visit the doctor only when they are sick. Under the PPACA provision, such individuals will be more likely to have cancers diagnosed at earlier, more curable stages.

Further, PPACA provides for the potential to address specific disparities, such as the longstanding disparity in pain management.<sup>16,17</sup>

## Improved Diversity and Capacity of the Health Care Workforce

As the Panel discusses at length in its full report, meeting the cancer and other health care needs of the changing U.S. population will depend in considerable measure on the ability to grow and diversify the health care workforce. Recommendations 3, 4, 8, and 9 address various aspects of these workforce issues, and the PPACA contains provisions that will directly enable or facilitate their implementation. To guide overall health care workforce development, PPACA establishes a national commission tasked with reviewing the health care workforce, projecting workforce needs, and providing timely information on workforce needs to Congress and the Administration.

The Panel has noted that to increase the diversity of the cancer research and care workforces, outreach and training must begin early to ensure that students, particularly from populations underrepresented in medicine and science, receive the education and support needed for careers in science and health care. This issue is addressed by provisions in Title V of PPACA.

Additionally, several sections of Title V respond to the worsening shortage of nurses and nurse educators, a looming problem about which the Panel has reported frequently over the past decade.<sup>14,6</sup> These provisions provide for nursing student and nurse faculty loan repayment programs, grants to nursing schools to strengthen nurse education and training programs and improve nurse retention, and a graduate nurse education demonstration program.

As with the nursing workforce, the supply of primary care providers has for some time been insufficient to provide the highest quality care, and a shortage of 35,000 to 44,000 adult primary care providers is projected by 2025.<sup>18,19</sup> Despite the projected shortage, PPACA Title V provisions have the potential to expand and strengthen the primary care, allied health, and geriatric care workforces. These steps are needed to ensure that all populations have access to primary care, which is the gateway to timely cancer care, and to providers specifically trained to understand co-occurring health conditions (including cancer) common among older individuals. Title V also encourages expanded roles for nonphysician primary care providers, such as nurse-managed health clinics and community health workers. As the Panel's

report notes, primary care (and other) physicians sometimes work under extreme time pressures. Thus, it may be the nonphysician health provider who is in a position to gather the relevant sociocultural and medical information that enables the provision of more personalized care and improved patient-provider interactions.

Title V also directly addresses the Panel's Recommendation 4 for increasing cultural competency among health care providers through health professions schools and continuing education. In addition, strengthening the community health workforce (e.g., health care ambassadors, *promotoras*, navigators) provides an opportunity to improve the availability and quality of translation services (Recommendation 9), as some of these workers, who already understand the cultures and languages of their communities, may also be trained to provide accurate and effective medical translation services.

Finally, the Panel notes in its report the importance of nursing home and home care workers in the cancer and overall health care continuum. These workers typically are minimally trained and compensated, yet provide essential care to cancer and other patients. PPACA Title V provides training opportunities for such workers, which may augment their skills, compensation, and job satisfaction.

## HEALTH INFORMATION TECHNOLOGY

Although PPACA does not include any major new initiatives related to health information technology or electronic medical records (EMRs), the legislation frequently references them as potential ways to harness information and facilitate data sharing among stakeholders. The roles of HIT and EMRs in health care reform reinforce the importance of recent federal investments in these areas, including those made

through the American Recovery and Reinvestment Act of 2009 (ARRA, P.L. 111-5). Title XIII of ARRA, referred to as the HITECH (Health Information Technology for Economic and Clinical Health) Act, established the Office of the National Coordinator for Health Information Technology within HHS to promote development of a nationwide interoperable HIT infrastructure and also provided funds to incentivize the use of HIT and EMRs by providers serving patients covered through Medicare and Medicaid.

In past reports,<sup>3,4,6,12,20</sup> the Panel has emphasized the importance of robust HIT systems to enhance numerous aspects of health care delivery and support cancer research. Of particular relevance to this report, standardized data sets that include information about socioeconomic status, language preferences, other sociocultural factors, and occupational/environmental exposures that may influence cancer risk, overall health status, and/or the quality of patient interactions with the health care system may allow providers to give their patients more personalized and effective care. In addition, collecting such information may help researchers identify variables that influence disparities in cancer incidence and outcomes more directly than do race and ethnicity. Expanding use of HIT systems also may promote the development and use of standardized, interoperable data elements leading to improved data quality and data sharing, an area addressed by Recommendations 1 and 2 of this report and discussed earlier in this Addendum.

The Panel's 2010-2011 report, scheduled for publication in spring 2012, will address issues related to HIT and EMRs in considerable detail. The Panel anticipates making recommendations at that time concerning investments in or use of HIT that may support progress in cancer research and the care of patients, including those from communities and populations disproportionately burdened by cancer.



## REFERENCES

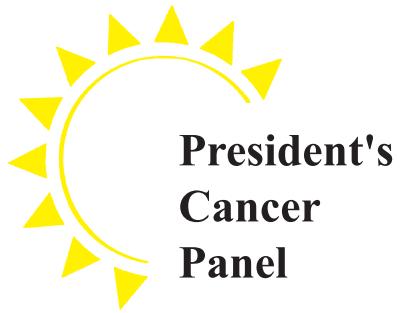
- <sup>1</sup> Freeman HP, Reuben SH. Voices of a broken system: real people, real problems. President's Cancer Panel report of the Chairman, 2000–2001. Bethesda (MD): National Cancer Institute; 2002.
- <sup>2</sup> Reuben SH. Facing cancer in Indian country: the Yakama Nation and Pacific Northwest tribes. President's Cancer Panel 2002 annual report. Bethesda (MD): National Cancer Institute; 2003.
- <sup>3</sup> Reuben SH. Living beyond cancer: finding a new balance. 2003 annual report, President's Cancer Panel. Bethesda (MD): National Cancer Institute; 2004.
- <sup>4</sup> Reuben SH. Translating research into cancer care: delivering on the promise. 2004–2005 annual report, President's Cancer Panel. Bethesda (MD): National Cancer Institute; 2005.
- <sup>5</sup> Reuben SH. Promoting healthy lifestyles: policy, program, and personal recommendations for reducing cancer risk. 2006–2007 annual report, President's Cancer Panel. Bethesda (MD): National Cancer Institute; 2007.
- <sup>6</sup> Reuben SH. Maximizing our nation's investment in cancer: three crucial actions for America's health. President's Cancer Panel 2007–2008 annual report. Bethesda (MD): National Cancer Institute; 2008.
- <sup>7</sup> Stremikis K, Schoen C, Fryer A-K. A call for change: the 2011 Commonwealth Fund survey of public views of the U.S. health system. New York: The Commonwealth Fund; 2011 Apr.
- <sup>8</sup> Schoen C, How SKH, Weinbaum I, Craig JE, Davis K. Public views on shaping the future of the U.S. health system. New York: The Commonwealth Fund; 2006 Aug.
- <sup>9</sup> The White House. President Clinton takes new action to encourage participation in clinical trials [press release; Internet]. Washington (DC): Office of the Press Secretary; 2000 June 7 [cited 2011 Apr 22] Available from: <http://clinton3.nara.gov/WH/New/html/20000607.html>
- <sup>10</sup> U.S. Department of Health and Human Services. Medicare coverage—clinical trials. Final national coverage decision. Baltimore (MD): Centers for Medicare and Medicaid Services; 2000 Sep 19.
- <sup>11</sup> Nass SJ, Moses HL, Mendelsohn J, editors. A national cancer clinical trials system for the 21st century: reinvigorating the NCI Cooperative Group Program. Committee on Cancer Clinical Trials and the NCI Cooperative Group Program. Washington (DC): Institute of Medicine; 2010.
- <sup>12</sup> Reuben SH. Reducing environmental cancer risk: what we can do now. 2008–2009 annual report, President's Cancer Panel. Bethesda (MD): National Cancer Institute; 2010.
- <sup>13</sup> U.S. Department of Health and Human Services, National Partnership for Action to End Health Disparities. A nation free of disparities in health and health care: HHS action plan to reduce racial and ethnic health disparities [Internet]. Rockville (MD): Office of Minority Health; 2011 [cited 2011 Apr 20]. Available from: <http://www.minorityhealth.hhs.gov/npa/templates/content.aspx?lvl=1&lvid=33&ID=285>
- <sup>14</sup> Negotiated Rulemaking Committee on the Designation of Medically Underserved Populations and Health Professions Shortage Areas to the Secretary of Health and Human Services. Committee charter [Internet]. Rockville (MD): Health Resources and Services Administration; 2010 [cited 2011 Apr 22]. Available from: <http://www.hrsa.gov/advisorycommittees/shortage/About/index.html>
- <sup>15</sup> Negotiated Rulemaking Committee on the Designation of Medically Underserved Populations and Health Professions Shortage Areas to the Secretary of Health and Human Services. Preliminary report [Internet]. Rockville (MD): Health Resources and Services Administration; 2011 Mar [cited 2011 Apr 21]. Available from: <http://www.hrsa.gov/advisorycommittees/shortage/>

- <sup>16</sup> Green CR, Anderson KO, Baker TA, Campbell LC, Decker S, Fillingim RB, et al. The unequal burden of pain: confronting racial and ethnic disparities in pain. *Pain Med.* 2003;4(3):277-94.
- <sup>17</sup> Anderson KO, Green CR, Payne R. Racial and ethnic disparities in pain: causes and consequences of unequal care. *J Pain.* 2009;10(12):1187-204.
- <sup>18</sup> Garibaldi RA, Popkave C, Bylsma W. Career plans for trainees in internal medicine residency training programs. *Acad Med.* 2005;80:507-12.
- <sup>19</sup> Colwill JM, Cultice JM, Kruse RL. Will generalist physician supply meet demands of an increasing and aging population? *Health Aff.* 2008;27:w232-41.
- <sup>20</sup> Reuben SH. Assessing progress, advancing change. 2005-2006 annual report, the President's Cancer Panel. Bethesda (MD): National Cancer Institute; 2006.

## **America's Demographic and Cultural Transformation: Implications for Cancer Recommendations**

1. Action must be taken to address the serious data deficiencies that undermine efforts to better understand and address cancer disparity issues. Specifically:
  - 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.
  - 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.
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.
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.
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.
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:
  - Continued research is needed on genetic ancestry and the interaction of specific genetic characteristics with identified risk factors.
  - Funding for research on risk factor variation and interaction should be increased.
  - Social science research as it pertains to cancer health disparities should be increased.
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.
7. Current cancer screening guidelines should be evaluated to determine their accuracy in assessing disease burden in diverse populations.
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.
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.
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.







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