

# Executive Summary

Between August and October 2005, the President's Cancer Panel (the Panel) convened four meetings to assess progress toward implementing key recommendations from each of its two most recent annual reports to the President of the United States:

- ***Living Beyond Cancer: Finding a New Balance*** (May 2004) described physical, psychosocial, employment, educational, financial, and legal issues that may affect cancer survivors across the lifespan. Among the recommendations contained in that report, the Panel was particularly interested in assessing improvement in the following areas:
  - Providing treatment summaries and follow-up care plans to all survivors upon discharge from treatment for their primary cancer and any secondary or recurring malignancies.
  - Expanding the body of research on adolescents and young adults with cancer.
  - Improving access to care and insurance coverage for health care services needed by survivors.
  
- ***Translating Research into Cancer Care: Delivering on the Promise*** (June 2005) examined the numerous, interrelated barriers that impede the transformation of basic research findings into better preventive, diagnostic, and therapeutic interventions and their delivery to the American public. At its meetings, the Panel revisited essential core issues related to:
  - Influencing the culture of research to encourage participation in multidisciplinary team research, which is an essential element for moving scientific discoveries forward into clinical practice.
  - Building and retaining the translational and clinical research workforce needed now and in the future to develop and test new technologies and interventions for people with cancer and those at risk.
  - Improving the dissemination of research advances and new interventions to improve patient outcomes.

A total of 75 stakeholders from government, academia, industry, the nonprofit sector, the advocacy community, and community-based health, social service, and other provider organizations participated in dynamic roundtable discussions of these topics.

The Panel asked participants to: (1) identify progress to date in implementing the selected recommendations, (2) suggest the most critical priorities for the next two years, (3) brainstorm ideas for potential partnerships, collaborations, and necessary resources, and (4) indicate explicitly how – either individually or organizationally – they could commit to advancing change.

As the sections below summarize, these productive discussions both facilitated communication among stakeholders about recent activities and generated numerous possibilities for new approaches and partnerships to address identified problems and priorities. The attached report catalogs these activities and ideas, and it is the Panel's hope that it will be used by

diverse cancer constituencies to establish new partnerships for action and to expand ongoing activities. At the same time, the meetings illuminated both uneven progress and in some cases, disturbingly diminished expectations for change related to specific survivorship and research translation concerns. These real and perceived limitations, almost without exception, could be traced directly to the impact of one or more of several longstanding, overarching issues.

## Progress on Survivorship Issues

**...the [cancer] community has an obligation to the survivor population to really take some actionable steps. And whether [for now] that's a standard treatment summary in lieu of a more rigorous guideline set, I think we should move that forward.**

– Patient advocate

The Panel was pleased with the progress made in some areas, most notably partnerships and programmatic initiatives to increase public and health provider awareness of survivorship issues. These increasingly robust activities include outreach and other programs designed to empower survivors with available knowledge about possible late effects of cancer treatment, sources of information and support, and tools to help maintain their personal health records and protect their health. Efforts to date to develop a standard treatment summary template have been productive albeit somewhat fragmented, and will benefit from collaboration among those who thus far have worked on this issue.

Progress was less encouraging in other areas, however. Lack of a solid knowledge base to support follow-up care guideline development for the many types of cancer and individual patients' circumstances is a continuing problem. However, meeting participants agreed that even while this evidence base is being strengthened, follow-up care plans must nonetheless be provided, based on best practices and the best available expert opinion.

Although research on some survivorship issues appears to be increasing, research on adolescents and young adults diagnosed with cancer continues to lag far behind the study of other age groups. This dearth of knowledge is particularly alarming given that cancer survival rates for this population have not improved appreciably for more than two decades. The Panel is optimistic that forthcoming recommendations from the recent review of research to date in this population will help stimulate and focus the national research agenda on cancer in this age group.

In addition, the vast majority of survivors of all ages continue to suffer from limited access to medical, psychosocial, and supportive care they need following cancer treatment, including in some cases, prosthetic and fertility-related services. These access barriers take two major forms. For many survivors, needed services simply are not available where they live and they cannot travel to reach them. For even more survivors, available services remain out of reach due to lack of insurance coverage for needed care and/or inability to pay for care out-of-pocket.

**The database for patients diagnosed during adolescence and young adulthood is pitiful and there's no infrastructure....because it's a rare disease, [NCI's surveillance program] is inadequate to capture that population. They are spread out between pediatric oncologists, medical oncologists, and community medical oncologists at academic centers. We have no databases to capture the on-treatment and survivorship data for [these] patients.**

– Adolescent and young adult survivorship clinic program director

## Progress Related to Research Translation

The Panel was aware that little progress was likely to have been made toward implementing its research translation-related recommendations since only a short period of time had elapsed since the report's publication. There were, however, indications of new initiatives and partnerships that can be expected over time to influence the culture of research to more fully embrace and value team science and other collaborative cancer research. For example, some Federal and other cancer research funders are revising grant award criteria to place a higher priority on team efforts. Several academic institutions and professional societies have established team science recognition awards, and scientific journal editors have begun to explore ways to improve attribution for individual contributions to team projects. Steps such as these should raise the visibility and perceived value of collaborative translational and clinical research at individual institutions and dissipate current hiring, promotion, and tenure barriers that now discourage participation in these types of research.

The promise of basic science discoveries in cancer will never be realized if we lack the cadre of translational and clinical researchers whose work turns these discoveries into better care for people with cancer. It is too soon to expect substantial progress toward implementing the Panel's research workforce recommendations, but it should be underscored that it is equally crucial to recruit young scientists to careers in translational and clinical research, and to retain them in science once they have completed training by ensuring that a viable career path exists. Greater support and protected time are needed for these investigators across their career trajectory, particularly to relieve the increasing pressure on physician-scientists to generate patient care revenue. Special initiatives may be needed to recruit and retain individuals from minority and underrepresented groups, including women.

The Panel was encouraged by new National Institutes of Health commitments to strengthen support for young investigators despite declining budgets. Similarly, other research institutions, professional societies, and foundations are providing a range of career development and new investigator awards; more are needed. Some institutions are developing innovative M.D.-Ph.D. programs, and the number of physician-scientists appears to be stabilizing after a period of significant decline. Meeting participants emphasized, however, that the scientific community must reach back to the undergraduate



**We're beginning to explore...another program that would be related to our comprehensive cancer centers but would be based in not-for-profit community hospitals where we would develop a cancer program – an NCI-designated, peer-reviewed, supported program – that would be built more on the requirements...[for] dissemination of information and quality of care, getting us ready in the community where the patients are for the new era of molecularly targeted therapies and new era of getting new therapy regimens right to the patient in the community.**

*– NCI deputy director*

population to nurture early interest in a research career. Further, it was recognized that crucial academic decisions affecting later career choices are made as early as the middle school years.

Dissemination research still is in its infancy, but its utility for reaching public and health provider audiences with new cancer knowledge and interventions appears to be gaining recognition. For example, the National Cancer Institute's Comprehensive Cancer Centers may now apply for support of a dissemination research program as a supplement to the center's core grant; one such program has been funded. Dissemination activities, however, remain almost entirely unfunded at the cancer centers and in large measure continue to be conducted in a fragmented fashion by foundations and underfunded Federal, state, and community-based agencies. To leverage resources and expertise and reduce public confusion about health-related information, meeting participants suggested that information and advocacy organizations focused on chronic diseases with similar risk factors (e.g., cancer, heart disease, diabetes) join forces to meld similar disease prevention, management, and wellness messages into a broader approach that crosses disease boundaries. At a higher level, however, the continuing lack of leadership and support for both dissemination research and dissemination activities must be addressed.



## Overarching Issues

Several themes suffused the discussions at the Panel's meetings, regardless of the specific topic at hand. None are new; the Panel has addressed each in numerous previous reports. Yet these pervasive issues are more pressing with each passing year as the American population ages, the total number of cancer cases increases as a function of age-related risk, and health care costs, including for both the most basic and the most advanced life-saving cancer interventions, continue their upward spiral as insurance benefits shrink.

### Fiscal Constraints

For the first time in more than 70 years, the U.S. cancer death rate declined slightly, even though the number of new cancer cases continued to increase.<sup>1</sup> Albeit small, this success in reducing cancer mortality reflects the impact of research advances, including earlier cancer detection methods, better diagnostic tools, and better treatments. This momentum must not be lost. Current fiscal constraints affecting cancer research and cancer care derive from three detrimental trends: declining Federal research budgets, the potential for escalating mandatory contributions from the NCI budget to broad NIH initiatives, and increasingly meager insurance reimbursements by public and private health care payors. This situation cannot help but have a negative impact on the twin goals of making cancer a disease people can live with, rather than die from, and rendering cancer a largely preventable disease.

The debilitating impact of scarce funding could be traced throughout the Panel's meetings. For example, oncology professionals noted that reimbursement seldom is available for the considerable time and costs associated with developing and discussing the detailed treatment summaries and follow-up care guidance needed by newly discharged cancer patients. Creative ideas for improving cancer information and care services were immediately met with questions about where the necessary funding would come from.

In addition, the Panel's 2004–2005 report on research translation highlighted the escalating threat to continued progress against cancer due to fiscal realities related to the drug patent, development, approval, and marketing processes. The cost of bringing a drug to the marketplace currently exceeds \$800 million,<sup>2</sup> and the number of new cancer drug approvals is low.<sup>3</sup> Even if used to treat common cancers, the potential market for any new cancer drug is small compared with medications for hypertension, diabetes, or heart disease management. Moreover, our success in identifying subgroups of common cancers that require different treatments actually is further shrinking the markets for individual anticancer drugs and industry's interest in developing them.

Of equal concern, as older cancer drugs (e.g., cisplatin) that are the mainstay of many current treatments lose patent protection and their profitability, some pharmaceutical companies are electing to cease production of these essential agents, potentially leading to short supplies of life-saving medications. The Panel reiterates its contention that to encourage new cancer drug development and ensure adequate supplies of mainstay treatments, cancer should be designated an orphan disease,<sup>4</sup> thereby enabling drug developers and manufacturers to obtain support to offset specific elements of cost and extend patent protection for approved agents.

**...we face a continued decline in reimbursement....we are constantly fighting that battle so that clinical research programs can stay alive, because the patients are...staying in the community.**

– Community oncologist

The myriad ramifications of scarce funding for critical cancer research and cancer care activities are cause for urgent concern. Even if these problems are addressed, all stakeholders involved in cancer research and cancer care must seek out and seize every opportunity to work collaboratively and efficiently to make the most of available resources.

### Health Care Coverage

People who have had cancer need lifelong care to monitor for and treat late effects of cancer therapies, recurrences, and second cancers, and to address psychosocial, nutritional, rehabilitation, and other needs that may arise years after treatment ends. More than 10 million people in this country are living with a history of cancer; in 2006, nearly 1.4 million new cases of cancer will be diagnosed.<sup>5</sup> According to the most recent available estimate, 45.8 million people in the United States lack health insurance of any kind,<sup>6</sup> and many millions more are underinsured for the costs of initial and ongoing cancer care. Employer-sponsored employee and retiree health benefits are declining in terms of the numbers of people covered, the scope of benefits, and increased premium, deductible, and copayment cost-shifting onto insureds.<sup>7</sup> Medicaid budget cuts scheduled over the next five years are very likely to put targeted, individualized cancer care – or even standard care – further out of the reach of the nation’s poor and widen disparities in cancer care and outcomes already experienced by poor and underserved individuals. In addition, the existing health care system continues to focus on acute care rather than disease prevention and the benefit to national productivity that accrues from maintaining individual wellness.

The Panel has strongly recommended a renewed effort to craft national comprehensive health care reforms, and reiterates this recommendation here. In the Panel’s view, incremental remedies, including those currently proposed (e.g., Health Savings Accounts/high-deductible consumer-directed health plans), are not and will not be adequate to address fundamental health system problems and may even have the effect of reducing coverage by increasing out-of-pocket costs, particularly for those least able to afford them.

**...once you’re diagnosed with a life-threatening illness, it is there for life. I don’t care whether you had cancer when you were a child, that’s going to follow you for the rest of your life as far as insurance is concerned.**

– Patient advocate

### Education and Communication

Education and communication needs permeate nearly every cancer research and care issue. Though critical for success across the research and care continuum, education and communication activities often get short shrift and small budgets.



The need to improve public understanding about cancer and the importance of cancer research is virtually undisputed. For example, cancer myths and misconceptions (e.g., that exposing cancer to air can cause it to spread, that research participants are “guinea pigs”) continue to flourish. Nearly half of U.S. adults who participated in a recent national survey believe they have little or no control in reducing their risk of cancer.<sup>8</sup> To counter discrimination still experienced by some cancer survivors, employers, lenders, and insurers (including health, life, and disability coverage providers) must be informed of the longevity and renewed productivity most survivors can now expect due to research advances. People diagnosed with cancer and their caregivers need immediate access to accurate information about treatment options and available resources. Likewise, survivors need reliable, up-to-date information sources to stay abreast of research and care advances relevant to their individual situations.

For the public to benefit from research advances, new knowledge, technologies, and resources must be disseminated rapidly to the provider community, with follow-up information and communication to encourage new intervention adoption. In addition,

**It's wonderful to develop all of these things and provide the evidence that there are interventions that work. It's another thing to get them outside of the cancer centers and into the community.**

– Cancer center executive

health and ancillary care providers of all types need ongoing education about cancer as a disease, and about the importance of early detection, the value of clinical trials, and survivorship issues. This information is critical if providers are to make appropriate treatment recommendations and referrals (including to clinical trials); explain treatment options, informed consent, and other issues to patients; and coordinate patient care effectively.

Information and communication needs in the research community also are diverse. For example, researchers involved in drug or medical device development must understand regulatory requirements and communicate effectively with regulators, funders, and insurers. Effective communication with patients and family members about specific clinical trials and informed consent for treatment or use of tissue or other biologic samples is crucial. In addition, researchers from different disciplines and institutions must be able to communicate and share data as needed to best design and carry out research projects.

The unanticipated consequences of privacy provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) remain a significant continuing impediment to data sharing, cancer care provision, research, and other communications. Electronic health records development and use, health provider-patient/caregiver communication, restrictions on researchers' ability to use stored tissue samples or to contact survivors to inform them about new findings or treatments – all are affected adversely by HIPAA. The Panel has called for an evaluation of HIPAA-related barriers to guide whatever legislative or regulatory changes may be needed to alleviate them, and urges that this evaluation be undertaken and completed with all possible speed.

## **Coordination**

The Panel has commented frequently on the need for coordination of National Cancer Program activities. The need for coordination emerged again strongly at the Panel's meetings, however, the form such coordination should take was repeatedly at issue. Many meeting participants maintained that any centralized coordinating function would create an additional layer of bureaucracy comprised principally of individuals whose scope

of knowledge could not possibly encompass all of the relevant research- and care-related issues. Targeted, subject-specific partnerships and collaborations were viewed as the preferable approach.

It continues to be the Panel's observation, however, that this piecemeal approach often produces uneven results, and further, that collaborative efforts often are preceded by redundant and/or incompatible activities that can waste limited resources and create proprietary stances that later may be difficult to relax. In the Panel's view, the diverse stakeholders within the cancer community have the responsibility, if they do not want centralized coordination, to find more effective and efficient ways to communicate about ongoing and planned activities, and to work together earlier and more cohesively to address issues across the cancer research and cancer care enterprises.

In summary, the Panel believes progress has been made toward resolving some of the issues described in its recent reports, but a great deal remains to be accomplished. Importantly, many of these findings apply not only to cancer research and cancer care, but to biomedical research in general and the entire health care system. Therefore, to maintain progress and advance the pace of change in the current challenging health care and economic environments, all of us who strive to improve the lives of people with cancer, their families, and others at risk for cancer must bring to bear the maximum measure of our creativity, skills, resources, and dedication for their benefit.