

# President's Cancer Panel Meeting

Meeting Minutes  
Closed Session

*Evaluating the National Cancer Program*

**November 19, 1999**

**Salt Lake City, Utah**

## Overview

The President's Cancer Panel was chartered to monitor and evaluate the development and execution of the National Cancer Program (NCP) and to report to the President on barriers to Program implementation. The second in a series of meetings to assess the progress of the National Cancer Program since its inception and identify steps to improve Program effectiveness, this meeting brought together seven experts in legislative history, ethics, health policy, health care finance, population health and health outcomes, and social and organizational policy to discuss the current program and key elements of change in social and political systems.

## Meeting Participants

### President's Cancer Panel

Harold P. Freeman, M.D., Chairman

Paul Calabresi, M.D.

Frances M. Visco, J.D.

### National Cancer Institute

Maureen O. Wilson, Ph.D., Assistant Director, NCI, and Executive Secretary, President's Cancer Panel

### Speakers

Robert Cook-Deegan, M.D., Director, National Cancer Policy Board, Institute of Medicine and Commission on Life Sciences, National Academy of Sciences

Randall Ellis, Ph.D., Boston University, CAS Economics

Marsha Gold, Sc.D., Mathematica Policy Research, Inc., Washington, D.C.

Robert Huefner, D.B.A., Gov. Scott M. Matheson Center for Health Care Studies, University of Utah

Thomas LaVeist, Ph.D., School of Public Health, Johns Hopkins University

Kathryn Mooney, R.N., Ph.D., Professor of Nursing, University of Utah

Jeffrey Prottas, Ph.D., Schneider Institute for Health Policy, Heller Graduate School, Brandeis University

## Welcome

Dr. Simone welcomed the Panel, and noted that the Huntsman Cancer Institute was initiated approximately five years ago. The Institute's recently completed main building houses three floors of laboratory space, a new clinic, a Cancer Learning Center for patients and families, an auditorium, a dining area, and other space.

## NCI Director's Report

Representing Dr. Richard Klausner, Director, NCI, Dr. Wilson indicated that:

- Dr. Simone has been of great assistance to the NCI in recent years as the Institute has made organizational and programmatic changes.
- NCI is awaiting final agreement on its budget for the coming year. Though an increase over last year's budget is expected, its exact amount has yet to be confirmed. Funding delays such as these are difficult administratively for NCI staff, but they have the most impact on researchers and administrators in the field. When funding is delayed, salaries are paid first, followed by ongoing commitments; new applications for funding are last to be paid. NCI is pleased that the expected budget increase will support ongoing activities and expand the scope of activities that can be funded, but some new initiatives (e.g., transition awards for new investigators) are likely to be affected in the short term by the funding delay.
- To improve communication with the community, NCI has registered a new Web domain: cancer.gov. This is expected to make it easier to find the NCI site and its wealth of cancer information. On November 17, 1999 the newly enhanced CancerNet Web site, [cancernet.nci.nih.gov](http://cancernet.nci.nih.gov) was released; for the first time, users will find frequently asked questions (FAQs) and other information that will help them learn and navigate the site. The site has redesigned graphics and layout, and contains an expanded dictionary of cancer terms, a publications locator, and prepackaged information on common cancers (including information on prevention, detection, diagnosis, therapy, statistics, coping, and clinical trials). Moreover, the site enables the user to conduct full-text searches of the Physician Data Query (PDQ) database and NCI fact sheets, and also permits both the public and health providers to search for clinical trials by disease stage, open/closed trial status, trial phases, modalities employed, and other parameters. PDQ information summaries, links to cancer literature, and the clinical trials Web site have been integrated. CancerNet now offers a national directory of cancer genetics professionals who provide risk assessment, counseling, and related services. Feedback on the redesigned site is encouraged.
- NCI's Board of Scientific Advisors has recently approved the concept to create a shared pathology informatics network. This resource is envisioned as a Web-based system that will allow both government and extramural researchers to request and receive data from existing medical data bases at multiple institutions. The system will help to identify and obtain data for cases meeting search criteria; patient confidentiality will be protected. Such access will enable researchers to review data on a large number of specimens to plan marker or other assay validation studies. The system will not, however, provide funds for accessing the tissue samples themselves. Initial awards under this new initiative will be to approximately ten institutions over a five-year period, with subsequent program expansion. It is hoped that this initial phase will enable NCI, in coordination with the institutions selected, to develop and test various communications protocols for

easy access, transmission, and sharing of data. Data requirements will include patient demographics, diagnostic information, vital statistics, clinical history, outcome data, and if available, information about recurrence and additional treatment.

- A Request for Applications (RFA) is being issued for an image data base for research analysis. The initial call is for applications to form a consortium on spiral computed tomography (CT) imaging for the purpose of achieving a consensus on standards for lung cancer imaging using this technology. This effort will help evaluate spiral CT as a method for lung cancer screening of patients at high risk.
- In addition, NCI is developing a trial of spiral CT as a diagnostic option. Demand for spiral CT, which is not yet validated for early lung cancer detection, points out an issue of ongoing importance: continuing technologic advancements are creating new services for which demand is generated simply due to their availability. It is essential to quality cancer care that new technologies are not used in routine practice until they have been validated through the clinical trials process. The Panel has commented on this issue in the past, and it is one with which NCI contends regularly in working with the community to develop practice guidelines and criteria for quality care.
- NCI is developing partnerships between minority-serving institutions and NCI cancer centers. This partnership initiative is aimed at expanding research and training capacities at minority institutions; it will begin with planning grants and progress to establishing specialized centers with full Cooperative Group funding. It is hoped that this initiative will build and stabilize independent competitive research and research training capabilities at minority-serving institutions and both create and enhance collaborative activity between those institutions and the NCI-designated centers. The partnership initiative also will support research, training, education, and outreach focused on the problems and issues relevant to the disproportionate cancer burden in ethnic minority populations. Moreover, the initiative will be linked to the Cancer Genetics Network, the Cooperative Groups, the Early Detection Research Network, and the Special Populations Network.

## **Overview: Evaluating the National Cancer Program**

### *Background*

#### **Dr. Harold Freeman**

On December 23, 1971, with the passage of the National Cancer Act (NCA), then-President Nixon declared a War on Cancer. The President's Cancer Panel was created under the NCA, with a stated mission to monitor the development and execution of the activities of the National Cancer Program, to report annually to the President of the United States, and to bring to the immediate attention of the President any delays or blockages in the rapid execution of the NCP.

As Chair of the Panel for nine years, Dr. Freeman has worked closely with current and past members of the Panel to frame the issues considered by the Panel, and to help guide

the Panel in its examination of the status of the NCP. In 1991, the Panel met to discuss the role of poverty as a determinant of disease, considered training opportunities and challenges in science, and reviewed in depth research and progress against breast cancer. In 1992, the interrelated issues of cancer research and technology transfer were explored, as were characteristics and needs of underserved populations that contribute to excess cancer mortality. In addition, the role of cancer-related voluntary organizations in reaching and serving the public was examined, and a special review focused on basic research, screening, detection, and treatment options for prostate cancer.

In 1993, the Panel reviewed the Specialized Program of Research Excellence (SPORE) as a model for more quickly transferring basic research findings into clinical application, and for relaying clinical science observations back to the laboratory. In conjunction with the American Cancer Society, the Panel examined the effects of cancer diagnosis on the patient and family. The same year, the Panel heard testimony on evaluating the NCP, and also discussed issues and obstacles to reaching affected populations in regions of the country where cancer mortality is particularly high.

The Panel's meetings in 1994 began with a review of Federal cancer-related research activities, to assess the extent of coordination gaps and duplication of effort within the government. At another meeting, the Panel examined current understanding of avoidable causes of cancer and strategies for transferring this knowledge and information to the public. The Panel also reviewed clinical, societal, and governmental challenges related to lung cancer. Lastly in that year, the Panel considered how the varied cultures of America act as prisms through which cancer-related and other information is viewed, how culture influences care-seeking behaviors in interactions with the health care system, and the effect of culture itself on cancer.

In 1995, the Panel reviewed implications of the Human Genome Project for cancer patients and cancer research. At a separate meeting, malignancies prevalent (at that time) among HIV-infected individuals were discussed in depth. The remaining two Panel meetings in 1994 examined issues in leukemia and issues related to the growing information superhighway and how it might advance technologic aspects of cancer care and improve communication to the public.

The Panel's 1996 meeting series focused on the effect of health care system changes on the conduct and financial support of clinical cancer research, related training, and associated issues of access to cancer care. In 1997, the Panel examined the concerns of special populations (including minorities, the elderly, the poor, and the under served) in the National Cancer Program. This included a meeting on the meaning of race in science which concluded that racial classifications are socially and politically determined and have no basis in biological science. Speakers pointed out the need to define race as, at least, a social variable in scientific studies. That year, the Panel also heard from experts in both cancer and gerontology on critical issues shaping cancer research and policy for the growing elderly population, which experiences the highest incidence of cancer. Other meetings in 1997 considered (1) the significance of recent cancer statistics and whether mortality reductions apparent since 1990 have been achieved in all segments of the

population and (2) how the health care system can better meet the needs of special populations, including cancer survivors.

Cancer care quality was the focus of the Panel's meetings in 1998. Testimony centered on three major issues: defining quality in cancer care, developing and using cancer care guidelines, and the impact of cancer care on quality of life. The Panel's report describes a number of important steps needed to address key issues in these areas.

### **Key Points**

- The purpose of the current series of Panel meetings is to evaluate the status of the National Cancer Program and make recommendations for the future. The first meeting of the series, held in July, 1999 in Boston, Massachusetts focused on the genesis and evolution of the Program. Speakers provided historical perspectives and raised a number of issues concerning future goals. Questions discussed at that meeting included, but were not limited to:
  - What was the original concept of the NCP as envisioned by its creators?
  - Where are we now in implementing this original vision?
  - Have we varied from the original goals, and if so, why?
  - Have changes in the Program been beneficial?
- The Panel believes this is an appropriate time to retrace the history of the NCP, acknowledge the advances that have taken place since 1971, examine the current status of the NCP, and discuss its future. To encourage innovative thinking in the latter regard, the Panel elected to involve individuals from policy and related fields not typically involved directly with the Program. Key questions for the discussion are: How should we reframe the scope and purpose of the National Cancer Program for the coming century? How could we implement such a program, and who would be responsible to do so?
- These questions and other concerns have been incorporated into a concept paper received earlier by today's participants. It is intended to serve as a catalyst for the day's discussion but should in no way limit it. The paper is based on the proposition that the NCP has from its inception suffered from a lack of coordination and lack of clarity as to its definition and scope. As noted in the paper, the NCP also appears at this time to be weighted heavily in favor of research compared with its emphasis on the application and delivery of research results to reduce the cancer burden—we are not applying what we know nearly well enough, quickly enough, or widely enough. The paper also suggests that the problem is not a lack of knowledge about how to apply research findings, but a lack of willingness to pay the associated costs.
- The concept paper further notes that professional consensus is lacking as to what constitutes quality care, and cost considerations are in many cases being allowed to overshadow patient welfare. Many Americans with good health insurance are not receiving what is believed to be the best care available. Those with inadequate insurance are receiving less care, and an estimated 44.3 million have no insurance at all—no matter what we know as a result of research, these people will not

benefit. Economic barriers also reduce access to care and cause financial catastrophe for patients and their families.

- In addition, the current health care financing environment has reduced the flow of funds traditionally used by academic institutions to train new generations of researchers and care providers. Significant improvements in cancer prevention and control programs are needed to reduce the impact of lifestyle behaviors (e.g., smoking, sedentary lifestyle, poor diet). Without such new interventions, major reductions in cancer incidence and mortality are unlikely. Moreover, some sectors of society that contribute to the cancer problem (e.g., the media, the food industry) do not see themselves as participants in the National Cancer Program.
- The Panel has noted these and other problems in its reports and recommendations over the past decade.
- As a starting point for developing the concept paper, the Panel reviewed the 1994 report, *Cancer at a Crossroads: A Report to Congress for the Nation*. Developed by a subcommittee of the National Cancer Advisory Board in response to a Congressional request for a review of the NCP, the report characterizes the Program as (1) involving all individuals, and all public, private, and voluntary organizations and agencies whose actions affect the national cancer problem, and (2) spanning basic, translational, and applied research across the cancer continuum (from risk assessment through end of life care) that results in enhanced care for all.
- The concept paper also suggests that to wage a war on cancer we must increase our focus on outcomes relative to discovery. Though discovery is extraordinarily important and must continue, it is of limited benefit if it is not applied. The Panel believes that discovery and its application have become disconnected in the current approach to the cancer problem as a whole.
- Among other goals, the paper also indicates that we must increase public and professional awareness of the magnitude and complexity of the cancer problem. It concludes with three overarching questions:
  - What do we need to do differently?
  - What must be done to make it happen?
- The Panel's report on these issues will be delivered to the President of the United States, and the Panel is asking today's meeting participants to think innovatively to help in defining the specific questions that must be asked in connection with these overarching questions and identifying those who should provide the answers.

## PRESENTATION HIGHLIGHTS

### HISTORY, ETHICS, AND HEALTH POLICY

#### **Dr. Robert Cook-Deegan**

The name, "National Cancer Program," originated with passage of the National Cancer Act of 1971. The Act was passed during a critical period in cancer politics, a time of great optimism about both the future of cancer research and the ability to transform the American health care system. A loose consensus held that the main problem confronting the Nation concerning cancer was a lack of organization and commitment of national resources to the problem. Rhetorical icons used as policy-making models included the Manhattan (atomic bomb) project, the Apollo project, and the campaign to eradicate polio. Using this essentially industrial model to apply and refine existing knowledge through increasingly sophisticated protocols, successful chemotherapies (particularly for childhood leukemia and other childhood cancers) were developed in the 1960s and 1970s. These successes fueled the belief that a such an approach to a National Cancer Program could yield similar success against all types of cancer. Similarly, screening and early detection technologies (e.g., Pap smear and mammography) and declining smoking rates in the wake of the 1964 Surgeon General's report created optimism that all of the needed technologies and treatments to conquer cancer were just around the corner. It was perceived, however, that the National Cancer Program encompassed all research and related activities leading up to, but not including, the delivery of health care. The dominant paradigm was clinical research; molecular biology was still an infant science. The Medicare and Medicaid programs, created in 1965, were viewed as a prelude to universal health care coverage.

The seminal document of the period was the Yarborough Report, prepared by a distinguished panel (the Yarborough Commission) in response to a 1970 request from then-Senator Yarborough, Chair of the Senate committee on health. Simply stated, the report indicated that the principal missing ingredients in the national approach to cancer were: a coherent administrative framework, a plan, and sufficient (Federal) resources. The report's recommendations set the framework for what would become the National Cancer Act and its initial definition of the National Cancer Program. A key influence in the development of the National Cancer Act was an ongoing tension between Democrats and Republicans (specifically, Senator Edward Kennedy and President Richard Nixon), with both sides eager to claim credit for the assault on cancer.

Much of the debate in connection with the National Cancer Act centered on the function and role of the National Cancer Institute (NCI), and whether the NCI should remain within the National Institutes of Health (NIH) or become an independent agency dedicated to cancer (much as the National Aeronautics and Space Administration had been created as an independent agency dedicated to the space program). It was eventually decided that NCI should remain within NIH, but with certain special characteristics. Specifically, responsibility for the National Cancer Program was vested in the NCI Director, with assistance from a National Cancer Advisory Board (NCAB). Both the NCI

Director and NCAB were Presidentially-appointed, a departure from customary procedure. In addition, NCI was given a unique ability to circumvent the usual budgeting process within NIH and the Department of Health and Human Services (then Health, Education, and Welfare) and make its budget request directly to the President. This "Bypass Budget" was a powerful tool in the first few years following passage of the National Cancer Act; in recent years it has begun to be used as a tool for budgetary priority setting at NCI.

The President's Cancer Panel was established by the National Cancer Act, and initially met monthly. Its first Chair, Dr. Benno Schmidt, had ready access to the White House, and was able to circumnavigate the bureaucracy to secure White House approval for resources the Panel and NCI deemed to be needed.

In addition, planning processes employed during the Apollo project and in planning for the Vietnam war created optimism about the power of planning within organizations. Upon passage of the National Cancer Act, a highly detailed planning process for the National Cancer Program was developed and initiated. This planning effort was important during the first several years of the Program, but became less so in subsequent years.

### **Key Points**

- The current environment with respect to cancer research and cancer care is far different from the environment that existed in the years surrounding passage of the National Cancer Act. Today, oncology is a big business, involving vast amounts of money, many institutions, and a huge infrastructure for surveillance and the delivery of care. This infrastructure includes cancer centers and a number of mechanisms within NCI for the translation of research findings into interventions for patients.
- In 1970, there was little private sector interest in cancer screening, diagnosis, and treatment research and development (R&D). The 1980s witnessed a huge escalation of private R&D across the pharmaceutical and biotechnology industries, in cancer and as a whole. As of approximately five years ago, annual private sector biomedical research has exceeded Federal investment.
- The health care system that was anticipated to become a universal, Federally-dominated system has instead become far more fragmented. Within science, the center of gravity has shifted significantly from clinical research toward molecular biology.
- In addition, tobacco use, after two decades of decline, leveled off in the last decade and in recent years has increased among youth and women. Thus, progress against the biggest cause of cancer mortality has slowed.
- Insufficient translation of research findings into cancer care for people is still a major problem. The National Cancer Policy Board (NCPB) has addressed this issue in two reports; one focuses on tobacco use, the other on quality of care. There is a major gap between what we know and the care that people receive. At the same time, we still have much to learn about even the most common cancers.

- Moreover, cancer is not a single problem, but a disparate collection of problems that will not be solved by an engineering approach.
- The notion of appointing a "cancer czar" persists; this is essentially the role of the NCI Director as envisioned in the National Cancer Act. In the current environment, however, in which the Federal Government is not the dominant player in either cancer research or care, such a czar would have no empire. At this point, it is not clear who controls any aspect of the system.
  - The current infrastructure for cancer research is unrivaled by that established for any other disease, however, these structures are highly inertial and resistant to change. It also is necessary to plan with humility, and to recognize that while research is necessary to improve our understanding of each type of cancer, most of the remaining issues related to cancer will not be solved by research. In the case of tobacco, for example, the crucial problems are getting people to change their behavior and addressing the social issue of an industry that sells products that kill; these problems can be addressed only in part by research.

## **Dr. Robert Huefner**

### **Key Points**

- The following three questions are of interest in the Panel's consideration of the current status of the National Cancer Program and discussion both of how the Program can or should change for the future and how the Panel should be involved:
  - What is the power of the Panel, and how might any such power be employed to enhance the national cancer effort?
  - What kinds of revolutions are taking place, and what is their likely result? What is the relationship of such revolutions to power?
  - What is the extent of fragmentation within the national cancer effort, and how does this fragmentation impact power relationships and the resolution of key issues?
- Underlying these questions is the necessity of living with uncertainty and learning how to use uncertainty to achieve desired goals. Many of the current issues concerning the conquest of cancer are political rather than scientific.
- The formal power of the President's Cancer Panel is limited; the Panel does, however, have some power as a "bully pulpit." Its challenge is to recognize and capitalize on opportunities to use this power effectively in an environment of highly powerful industries and agencies with objectives that do not support the reduction of cancer incidence and mortality in this country. For example, during the Kennedy Administration, the Surgeon General used an opportunity created by a question at one of the President's press conferences to persuade Kennedy to support producing the report that linked smoking and lung cancer and initiated a decades-long decline in smoking rates (mostly among men). Taking advantage of this opportunity required both luck and skill. Author Lee Fritchler has suggested that influencing public policy effectively requires luck, skill, and persistence.

- The U.S. has not had comprehensive health reform in the 20th century; the adoption of Medicare and Medicaid, though still incremental in both scope and result, were the most comprehensive health policy efforts to date. Favorable politics were also a key factor in the passage of these programs. In both programs, results have been quite different than expected, particularly with regard to program costs. Recently, an anti-HMO line in the script of the film, "As Good As It Gets" drew widespread cheers from audiences; this reaction resulted in Congressional attention, but it is yet unclear what, if any, change may result.
- Political scientists study revolution; they may be able to identify its genesis, but cannot predict its result, which typically is different from what the people who start it intended. In addition, those in power at the end of a revolution often are not those who begin it. Revolution, therefore, involves great uncertainty. Two major aspects of health care are in the midst of revolution. One of these is health care policy concerning the nature and structure of the health care market, which is facing enormous challenge from those who have great power, particularly financial power. This struggle is going to lead to incremental changes whose result will be hard to predict. The second area in revolution is technology, specifically information technologies that promise to change the delivery of care and the relationships between patients and physicians, and technologies that are expanding our understanding of genetic predisposition to cancer and other diseases.
- Growing genetic information fundamentally challenges our system of health insurance. Traditionally, insurance employed community rating, in which risk was spread across the community, thereby making insurance affordable for everyone. Knowledge of genetic risk for various diseases (making some individuals a potentially higher risk for health care costs) pushes the system increasingly toward experience rating, in which a community or insured population is segmented into risk categories with those at higher risk paying more. Politically, experience rating is not acceptable, yet it is the direction in which the market place is moving. As a result, insurance as we now know it may not be viable in the longer run.
- It is not clear where these revolutions will lead, but great change is likely. Another aspect of the Panel's power may be to monitor and raise awareness of the changes, as well as to identify opportunities to take advantage of them.
- Certain cancer-related or more broadly health-related indicators that are tracked by stakeholders (including the public) may offer opportunities for seeking change.
- Fragmentation is a continuing and debilitating problem in public health; it takes the form of disagreement over what is public good, what our purposes should be, who gets credit for what, and in the case of the cancer effort, whether or not there should be a czar. To make progress, it is essential to achieve the level of communication necessary to overcome some of this fragmentation; facilitating such communication may be an appropriate role for the Panel. By contrast, the tobacco companies, which are fiercely competitive with each other, are nonetheless able to join forces when faced with opposition from public health interests. This cooperation has enabled them in many cases to prevail in the face of significant opposition.

## Discussion

### Key Points

- The opposite of fragmentation in the context of power is full collaboration; this term is used frequently in discussions of how to remedy problems in the cancer community. The danger in full collaboration, however, may be that it eliminates outliers (i.e., the perspectives that differ from the popular or dominating view). If full collaboration results in maintenance of the status quo, no progress will occur. Addressing this issue is important to ensure the flow of new ideas into research and in discussions of cancer care and cancer policy issues. A key question, therefore, is how to balance the need for collaboration with the need to make certain that outliers' viewpoints are included.
- The tobacco industry has the advantage of having a single common goal: profit. Public health proponents, by contrast, are hurt by varied perspectives on what constitutes the public interest. Being committed to the public good, they find it very hard to compromise, and compromise is essential in a democracy. But compromise does not necessarily mean that principles are abandoned.
- The public health community is likewise challenged to agree on any set of indicators, because the same fragmentation and power issues come into play. In the realm of monetary policy, indicators have been developed through a combination of public and private sector effort; the involvement of academia has served not only to ensure a scientific approach to the process, but also has provided some necessary political insulation. Developing a set of meaningful indicators for cancer would be difficult, but it can and should be done. However, indicators developed unilaterally and issued by a cancer czar would almost certainly not be accepted. The Healthy People projects have been a step in the direction of developing indicators of population health, and suggest that such measures could be developed for cancer.
- It is not particularly useful to spend a great deal of time debating the scope of the National Cancer Program. It is more important to attempt to agree on the goal(s) of a national cancer effort. While a first response may be "to eradicate cancer," some do not believe total eradication of the disease is possible and would not agree to that as a goal. Progress is stymied when people expect to reach agreement on fundamental goals and are unable to move ahead without doing so.
- The idea of central coordination of the cancer effort through a cancer czar has not been acceptable to the cancer community. It is likely, however, that discrete public health problems (e.g., colon cancer mortality) for which we have a substantial body of knowledge and effective interventions can benefit from directed, cooperative efforts (e.g., to increase use of screening) and targeted funding. In areas that still require significant basic research and for which no, or few, effective interventions exist (e.g., pancreatic cancer, brain tumors), widespread exploration and limited control are important.
- At the same time, we also have technologies such as mammography that are used most by the population at relatively low risk and for whom it is less clearly

effective (women aged 40-49 years) and used least by those at higher risk, for whom benefit has most clearly been demonstrated benefit (women aged 50-69). The principal problem is implementation in older women, but a research problem (efficacy in younger women) also persists that cannot be resolved by available data and has fueled highly polarized and unproductive debate in the scientific, medical, and consumer communities. Concerning mammography, it also is unclear how much money should continue to be devoted to collecting efficacy data on a technology or approach (screening) that is an incomplete answer to the problem of breast cancer.

- Approximately 93 percent of cancer patients are covered by government (principally Medicare) or other insurance; exploiting this reality may offer opportunities to have a major positive impact on this large group of patients.
- Despite problems experienced with some managed care systems (e.g., excessive utilization and cost control), managed care has emphasized evidence-based medicine, preventive services, and screening to a greater extent than fee-for-service systems. There is some concern that the pendulum is swinging back in the direction of fee-for-service, with decreasing emphasis on evidence-based, quality care. Though the American public appears to be more satisfied with this shift, it may not serve patients well. Not all participants agreed with this assessment; it was suggested that the real difficulty is that while we have an extraordinary engine for creating new knowledge and new technologies up to the point of demonstrating efficacy of a drug or technology, we lack a locus of responsibility for creating evidence about effectiveness and cost effectiveness in populations. Neither the Health Care Financing Administration (HCFA) nor the Agency for Health Care Policy and Research (AHCPR) have been charged with, or are able to take on this responsibility. The result is a huge gap in our ability to create the evidence that would allow us to make rational health care decisions.
- Perhaps the two most important policy problems facing cancer today are: (1) For many cancers, we lack effective prevention and therefore must attempt to understand the cancer in order to develop better treatments. This dilemma drives the research focus of the NCP. As noted earlier, however, the health care delivery system is not structured to create the evidence as to what works and what does not. When we discover what works, it is paid for, but this should not be the primary responsibility of the research agency. (2) In cancer, the issue of care for the uninsured (seven percent of cancer patients) may be less critical than the issues of underinsurance for cancer care costs, lack of coverage of services, and lack of evidence as to what should or should not be paid for. It was suggested that the key issue for the next five years is the gap between what we know and what is delivered in the world, and how to close that gap.
- Understanding the history of the NCA and NCP is important because although we now understand that cancer is far more complex than was thought in 1971, we are still approaching the problem in essentially the same manner (i.e., like an Apollo project, which could succeed because the requisite knowledge existed and it remained only to properly organize and fund the effort).
- Another difficulty is that those giving the charge to solve the cancer problem (i.e., legislators) share responsibility for some of the issues, such as ensuring access to

care, but inappropriately are placing all of the responsibility on the research community. It is unclear how these questions can or should be resolved in a democracy, and how the Panel can be instrumental in challenging the community to address all of the attendant issues honestly.

- We still need to train more translational researchers to help move basic (particularly molecular biological) science discoveries toward application, but serious problems also exist at the application end of the spectrum. State and local departments of health, for example, are focused on vaccination, infectious diseases, prevention, and other areas, not on chronic diseases such as cancer. Many local communities are not prepared to move the results of clinical trials into practice, and the eventual reclassification of tumors at a molecular rather than histologic level will pose a substantial burden in terms of retraining pathologists and other health professionals.
- Rather than expecting total victory against cancer, as the "war" metaphor implies, we should more realistically expect a succession of steps against the disease, and be alert to opportunities that will help in realizing those steps.
- There is no economic model for allocating resources among basic, translational, or applications research. These decisions are being made politically, and it is essential that this political process is led by people who understand the relevant data and issues and yet are not locked into a particular model of what right or effective. This situation also underscores the need for indicators or other data to guide decision making. The Panel may be well positioned to work within this political process.
- It is useful to compare cancer policy questions with larger health policy questions to determine what is common to both areas and what is unique about cancer. Where questions are the same, there already may be efforts underway to resolve them, and the cancer community need not expend its resources or political capital in addressing them except to encourage those already taking up those questions. Instead, it could focus on the areas unique to cancer and work to address those issues. If it is perceived that taking up general health policy questions will have salutary effects for cancer, then it may be a good decision to do so. Such analyses also will help the cancer community identify natural and possible allies. The cancer community must weigh when it is to its advantage to use the privileged position conferred by the National Cancer Act and when it is better to address the larger health policy questions.
- It was observed that fragmentation is not a misfortune, it is a condition of life. The challenge is to choose the fragments on which to focus where the likelihood of having influence and positive results is greatest. In the area of health insurance, for example, universal coverage may not be the most important issue for cancer; rather, the scope of coverage for cancer care appears to be the area in which improvement is needed. However, this issue is complicated by other factors: insurance does not guarantee access, the treating physician may not always know the best treatment for an individual's disease, and cultural influences may interfere with care-seeking or receipt of care even if an individual is insured.
- Even if the cancer community could agree on a set of goals, there will be disagreements as to the most important problems and on how best to pursue those

goals. This is likely to occur in part because various groups have their own specific areas of focus (e.g., breast cancer, public health, the environment) that may not align neatly with discrete cancer-related goals.

- The Panel could use its "bully pulpit" to promote a set of achievable, near-term goals and a set of more far-reaching goals to be addressed as we advance. It is important, however, to clearly identify the audience for these messages (e.g., cancer researchers, the cancer control community, legislators, patients/survivors, the public, some or all of these). It may be necessary to tailor the messages for various audiences; for example, a participant suggested that legislators do not just want the issue explained to them, they want to know what specific action is being requested of them.
- It also was observed that health policy changes where the political will exists to effect that change. It is necessary to be vigilant, however, of the wider ramifications of changes intended to address specific, narrow issues. For example, a particular group advocated the removal of chlorine from drinking water because it may increase breast cancer risk; this position ignored the much larger public health benefit of chlorinating water supplies.
- Another approach for moving forward is a policy framework that uses cancer as a model to address larger health system problems. This is already happening with respect to quality monitoring measures now being developed for breast and prostate cancer; these efforts are becoming a model for solving quality monitoring issues more generally. In addition, cancer in many respects is already a model—no other disease has a Presidentially-appointed panel overseeing efforts against the disease, nor equivalents to the surveillance system, cancer centers, or discovery engine that exist in cancer. In solving cancer-specific problems (e.g., access to clinical trials, protection against genetic discrimination by insurers and employers) it is important that the solution not preclude other diseases from getting access to the same services or employing the same solution.
- The Panel's role is to raise issues to the President and to transmit information to the public, which broadly includes insurers, health professionals, and the lay public. The Panel also has a role to address the deep confusion in the minds of many, including legislators, that the NCI comprises the entire National Cancer Program. This confusion has stymied progress in many areas, including national cancer policy. The Congress continues to ask the NCI to address access issues with research solutions, and it is assumed by many that disseminating findings to the cancer centers is the same as dissemination to the community. In fact, in some areas, populations in neighborhoods immediately surrounding cancer centers have little or no access to care at the center or elsewhere.
- It might be productive to divide the National Cancer Program into two major components: a research program and a cancer care delivery program. The research program would encompass all research efforts of the government and private sectors; while NCI is no longer the major funder of cancer research, it logically could play a leadership role in the research realm. The delivery program might be the province of the Centers for Disease Control and Prevention (CDC), another agency, or some group of agencies, rather than the NCI.

- Much of the dialogue and policy in cancer is centered on drug development, while the recent reductions in cancer mortality are due principally to lifestyle changes rather than improved treatments. There is relatively little support for behavioral and lifestyle research, seemingly because it has little or no identified profit potential. This problem may well grow worse as the private pharmaceutical and biotechnology industries fund an ever-greater percentage of cancer-related research.
- While it is somewhat encouraging that seven percent of cancer patients lack health insurance coverage compared with 16 percent of the general population, the statistic obscures the fact that lack of insurance prevents people from getting cervical, colorectal, and other cancer screenings that could catch precursor lesions before they become invasive cancer.
- The public has relatively little understanding of the complexity of cancer, cancer care, and the critical importance of coordinating the care of individual patients. The model for coordinating care is found in pediatric oncology, in which the efforts of a treatment team including the radiologist, surgeon, medical oncologist, and others are coordinated by a lead physician who follows the patient through all aspects of care. This can be accomplished well in pediatric oncology, in which there are approximately 90,000 new cases per year. It is more difficult in adult oncology, in which there are 1.2 million new cases annually and a much broader range of practitioners, greater geographic dispersal of cases and treatment resources, and diverse standards and quality of care. A patient's outcome depends greatly on the best efforts of a series of physicians and other experts, which must be administered at the right time and in the right order based on accurate pathologic (increasingly, cytobiochemical) and other information. In addition, coordinating care is complicated by the fact that the medical personnel involved in an individual case will vary depending on the cancer site.
- A participant from the audience noted that (1) there are far more drug target candidates (i.e., genes or proteins) than can be tested with current capacities and the true biological function of many of these potential targets remains unknown; (2) no agency is currently charged to pursue behavioral research in a comprehensive manner; (3) FDA efficacy trials are contrived, based on an erroneous definition of efficacy, and tend not to represent the experience in general usage of the agent tested. The construct of how devices and drugs are approved should be revisited; FDA should be charged to raise the standard for safety prior to drug approval and another agency should assess efficacy in the real world. Currently, efficacy trials are extremely expensive and do not provide the information practicing physicians need. Other participants noted for the record that the speaker's remarks were not reflective of either the Panel's view or that of much of the cancer community.
- To date, we have had little real success in changing lifestyle behaviors; the success in reducing cardiovascular mortality is due largely to the introduction of cholesterol-controlling and anticoagulant agents, not changes in dietary and exercise patterns. We encourage the drug companies to focus on finding pharmaceuticals to solve problems associated with lifestyle behaviors, because it is easier than trying to get people to avoid risky behaviors.

## **FINANCIAL INCENTIVES, POPULATION HEALTH, AND HEALTH OUTCOMES**

**Dr. Randall Ellis**

### **Key Points**

- The Panel is to be applauded for considering the perspectives of some of the social sciences about the challenges of a National Cancer Program. In the early period of the Program, the problems were viewed as largely technological and scientific; more recently we are realizing that many social challenges exist.
- Dramatic changes in five areas over the past five years have significant implications for discussions of cancer policy and the National Cancer Program. These are: the rise of managed care, the Balanced Budget Act of 1997, capitation and risk adjustment, accelerating technological change, and the growth of the uninsured population. An effective cancer program should take into account the policy environment in which the Program is being implemented.
- One of the main activities of managed care organizations (MCOs) is choosing providers. This selective contracting with providers represents a major change from traditional indemnity care, in which patients could go to any physician they chose. An effect of provider contracting is increased cost consciousness. The desirability of MCOs' mechanisms for containing costs is a contentious issue. MCOs also are perceived as being unwilling to subsidize clinical research; this reluctance affects the National Cancer Program. A policy issue centers around whether to change the way clinical research is conducted or mandate that MCOs contribute their fair share.
- Competition in the health market place seems to have shifted from the provider level to the plan level. As little as four years ago, doctors and hospitals competed for patients, and patients looked at the quality of the providers in deciding where to go for care. Now the real emphasis is on choosing a plan, which involves selecting a network of providers.
- In addition, health plans do not necessarily compete to excel in every area. This is a controversial area being studied by economists; some providers are aware of the issue, and policy makers are just becoming aware of it. In the Boston area, for example, some of the centers of excellence hospitals have been unable to contract with all of the health plans, because the plans are not willing to pay the higher cost of having the most expensive kinds of treatment. As a result, some enrollees may choose not to join these managed care plans, choosing indemnity coverage instead. This self-selection of more serious cases into indemnity plans has important consequences for quality of care and the types of insurance available.
- People are only beginning to appreciate the enormous impact of the Balanced Budget Act of 1997 on providers and plans. Medicare program changes have drastically cut funding of teaching hospitals, effectively removing the teaching

adjustment from the Medicare Diagnosis Related Group (DRG) payments. This action has forced the hospitals to find other ways of raising these funds. Payments to urban high cost HMOs have been slashed, while payments to low cost rural HMOs have been increased. Overall, Medicare has decreased its funding by four percent in fiscal year 1999.

- The Balanced Budget Act also encouraged report cards on plans and hospitals; this has affected the way that plans compete. For instance, the report cards typically report complication or mortality rates for selected procedures; unless the report cards are fully adjusted for severity of cases in different patient populations (severity adjustment), plans and providers are encouraged to avoid the more severe and complex cases because it makes their future report cards look worse. This situation has implications for cancer treatment.
- Health plan funding has moved away from both community and experience rating to a greater reliance on capitation, in which the plan gets a fixed amount for the total care of an individual. Capitation affects the incentives of the plans as to the type of person they want to enroll. When risk adjustment is imperfect, plans will compete to attract healthy, profitable enrollees ("creaming"), minimize services to chronically ill enrollees ("skimping"), and avoid high cost enrollees ("dumping"). There are attempts underway to develop better risk adjustment models to reflect the healthiness of the enrollees in a given plan. This will level the playing field by providing formulas for compensating plans more when they enroll sicker people, and paying them less for the healthiest enrollees. Potentially, capitation can encourage preventive care, which is central to a cancer program. If the plan avoids high future costs, they will benefit financially and will attract enrollees because they are known to provide high quality preventive and other care.
- Spending on health is growing much faster than the Gross National Product (GNP). Most new medical technologies are cost increasing, and a key question for the future will be how (and which of) the new technologies will be financed. These may be difficult choices.
- The growth of the uninsured and underinsured populations are partly a result of the trends described above. Lack of insurance is particularly serious for children. Most of those affected are working non-poor families; they are likely to have no access to or avoid preventive and prenatal care. If they do receive screening services, may not follow up on a negative test result.
- New components of national cancer policy might include: (1) acknowledging the key role now played by managed care plans, and establishing regulatory mechanisms to offset plans' undesirable selection activities and their incentive to compete by not providing certain services. Such activities could include mandating coverage for cancer treatment or cancer prevention services, and arranging risk pools for certain types of services. (2) influencing provider behavior and plan competition through report cards, improved consumer information, and financial incentives, (3) working with HCFA (or other payer agencies) to further reform Medicare payment policy, increase emphasis on cancer care, mandate coverage of preventive services, and add pharmacy coverage to Medicare.

- In addition, we are only beginning to understand the impact of report cards and other (particularly Web-based) consumer information on the services that consumers demand and the plans in which they choose to enroll. These patterns may have implications for cancer policy.
- The colorectal cancer screening literature suggests that far more research emphasis has been placed on screening healthy populations than on the highly challenging issues concerning the desirable intensity of surveillance of people known to be at high risk or cancer survivors. These issues have enormous cost implications because the cost of surveillance may eventually dominate the cost of screening.
- An important goal for cancer policy research may be further exploration of the impact of guidelines on practice. Health plans and providers need guidelines to know what standards they are expected to achieve. Coordination with HCFA and AHCPR may be the best avenue for conducting this research.

## **Dr. Marsha Gold**

### **Key Points**

- There is a disconnect between science/medicine and how the delivery system works; the people involved in each arena seldom communicate or recognize the connection between the two.
- Certain aspects of the managed care concept offer potentially attractive opportunities for cancer. For example, the infrastructure of managed care offers an opportunity to resolve some of the fragmentation of care that currently exists.
- Purchasers (employers) and payers are unlikely to pay more for care; this reality is one to which people and the health care system will have to adapt. In addition, the managed care system focuses heavily on accountability and performance results. The provider community (particularly the academic medical community) perceives the situation as a threat and is reacting in a self-protective manner. How the system will reshape itself in response to these forces is the topic of considerable debate.
- Research funding is an issue in a market driven system, and health plans do not want to subsidize research through higher provider fees. At the same time, physicians and institutions should streamline research costs (i.e., eliminate waste in the system) if they wish to make a better case for health plan participation in research funding. The cancer community also can strengthen its case with payers through education, communication, and showing proof that specific preventive and therapeutic practices improve patient outcomes.
- Most people on Medicare still are not in managed care plans; the nationwide average is approximately 17 percent, though enrollment in some areas is much higher. In these higher enrollment areas, the opportunity to influence cancer care to beneficiaries by taking advantage of positive aspects of the managed care infrastructure is greater. The Medicaid program in many states is grossly underfunded and not well organized; as a result, it is more difficult to have a well-

reasoned delivery structure for Medicaid recipients. This suggests that efforts to decrease fragmentation of cancer care by using managed care's infrastructure should first focus on Medicare managed care, then on the urban commercial market, and lastly, on the Medicaid population.

- Though there is argument about the specific measures used, managed care plans are being measured on delivery of Pap smears, mammograms, and other screening and preventive services. These indicators of performance are becoming more developed and offer an entree to making such services part of standard care. Managed care plans also have greater outreach capacities than most traditional payers.
- It must be recognized that delivery of care is local and varies considerably by market; cancer community leaders who do not simply view managed care as the enemy will find opportunities for collaborative efforts. To influence practice, it is necessary to go to the local level and deal with the providers at that level.
- Dr. Freeman indicated that the report deserves more attention; the Panel will use the report as a point of departure for discussions in its meetings this year.

### **Dr. Kathy Mooney**

#### **Key Points**

- The National Cancer Program has been too narrowly focused; choosing several narrow goals (an approach suggested by other speakers) at this point would serve to make even more invisible some of the areas that require greater attention. The Program also lacks coordination to reduce some of the fragmentation that hampers Program effectiveness.
- The existing infrastructure has not included all of the stakeholders needed to make progress against cancer. Cancer advocates and survivors have had to be assertive and persistent to interject themselves into the policy process; similarly, the voices of the underserved and ethnically diverse communities are seldom heard. Many cancer care providers, including nurses, have not been included equally at the table of cancer policy making. This situation shortchanges our ability to have a united effort that works on multiple fronts to discover, translate, and bring the benefits of our advances to the public.
- Scarce resources are the likely reason that the National Cancer Program has been so narrowly focused. These resource constraints necessitated devoting the most resources to research on what has been viewed as the priority-eradicating cancer. Yet our greatest weakness has been the actual delivery of care, and delivery is where the population of nurses is massed; these professionals could help with solutions to the cancer care delivery problem if they were part of the discussion.
- Focusing on delivery does not mean that funds for basic research should be diminished; in fact, they should be increased. Funding is not limitless, of course, but focusing on delivery should not be at the expense of other areas.
- The 1971 National Cancer Act was envisioned as a war on cancer, yet the total budget to wage this war has been less than the cost of a few pieces of real military

equipment. The toll on American lives from cancer far outpaces the ravages of war; over a half million people die from cancer yearly. This is far more than the number of Americans who have died in all U.S. wars in this century. These statistics bear repeating to remind us of the magnitude of the cancer problem.

- What we have accomplished in the past 28 years has been incremental; it has not been a war. A key policy question is whether we want a war or if we are satisfied with incremental gains. If we continue as in the past, we will continue to see incremental change. The notion of having a greater impact, of being more revolutionary, however, contrasts with suggestions that taking incremental steps is more practical. We have to make a decision as to our vision for moving forward.
- The National Cancer Program has focused too heavily on basic research; areas needing additional research attention include prevention-the ultimate eradicator of cancer-and behavioral research to help people decrease avoidable risk and seek early detection. Behavioral research should not focus only on the individual. It also should focus on our culture and how different cultures within our Nation influence or create barriers to behavioral changes. This is important but difficult research, though not more difficult than drug discovery. We also need to continue our translational and clinical research efforts.
- Research should not just focus on whether people with cancer die or are cured. People suffer from cancer and its treatment, and we must legitimize and mainstream research to prevent and ameliorate suffering through research discoveries that improve quality of life, symptom management, supportive care, and end of life care. We need to recognize that eradication of cancer is not our sole goal and bring a stronger focus to the issues of suffering and quality of life. The lives we save must be worth living.
- Currently, research on symptom management and quality of life is virtually invisible at NCI and most cancer centers. Most of the needed research is at the level of mechanisms, patterns, and how to assess them. Pain has been studied most, but our understanding of how to treat cancer pain has not become part of routine cancer care; most cancer patients continue to suffer needless pain. Other symptoms, such as peripheral neuropathy, which affects individuals' ability to work and enjoy life, have received little research attention. In addition, symptoms (including pain) are not included in routine data collection efforts and thus are not included in databases. As we rely increasingly on databases to conduct outcomes research, this gap poses a major barrier to progress.
- Good symptom management requires a team approach; the team should include physicians, nurses, exercise physiologists, and others. Though many models for such team approaches exist, these have been insufficiently tested to determine what works best. In addition, reimbursement for symptom control remains a difficult issue.
- Nurses, who have the most contact with patients, have a great role to play in improving symptom management care. Yet health system changes have eliminated many oncology nursing positions, particularly for Masters-prepared clinical oncology nurse specialists. Though some of these positions have been reinstated recently, there are no longer candidates for them, because most of these nurses returned to school to become nurse practitioners. According to one survey,

approximately one-third of oncology nursing Masters programs in nursing colleges have closed in the past five years. Soon we will not have people specialized in providing oncology nursing training. At the Bachelor level in nursing, training is general; it is acknowledged that curricula include little cancer-specific preparation. The result is that cancer care will increasingly be delivered by nurses who learn on-the-job. Nurses now are encouraged to be generalists rather than specialists. Recognizing these problems, the Oncology Nursing Society (ONS) is conducting an 18-site national study of symptom outcomes of cancer patients to compare the extent of specialized oncology nursing care with specific symptom outcomes. A 1995 study (Grant, Farrell) found that a nursing intervention at a California cancer facility saved \$3 million in unscheduled admissions for cancer pain in one year (expenditures the previous year had been \$5 million).

- The Balanced Budget Act has put significant pressure on HCFA in its attempts to decrease Medicare costs. It took enormous effort by ONS to persuade HCFA that bundling the costs of supportive care drugs into certain supportive care services (with the result that the drug costs would not be reimbursed) was not in the interest of cancer patients. When an area such as symptom management is relatively invisible, it appears to be an easy place to cut costs. A particular concern is that actions by or priorities established by HCFA often are taken up by commercial markets.
- Physician-assisted suicide has become an issue because of inattention to patient suffering and symptom management. Legislation to control physician prescribing patterns proposed following passage of the Oregon physician-assisted suicide law is likely to limit physicians' willingness to prescribe adequate narcotics to patients with cancer pain. This is an example of lack of coordination between a social issue and a political issue that results in a barrier to quality cancer care.
- Outcomes research in cancer has been very limited. This research is necessary to examine the ultimate benefit of discoveries when they are implemented in day-to-day clinical care, and to determine how care is best delivered. Having this data will strengthen our bully pulpit concerning outcomes and the difficult decisions that must be made as to what treatment is provided, particularly in the context of managed care. Outcomes research also is necessary to raise awareness of the public, employers, policy makers about what constitutes quality care and to support informed decision making.
- As stated in the concept paper prepared for this meeting, research alone will not solve the cancer crisis, and we must examine all of the barriers that prevent us from moving forward and translating the benefits of research to the public. A comprehensive National Cancer Program must not only engage the cancer community, but must capture the will of policy makers, legislators, regulators, cancer care payers, health plans, the media, and the public. To accomplish this, we need to better explain what we are doing, and need to do, to address cancer.

## Discussion

### Key Points

- At least 42 percent of cancer patients use complementary and alternative medicines (CAM) or therapies. In some cases, these medicines or therapies are used in place of mainstream medicine, sometimes depriving patients of lifesaving standard treatments. Used in conjunction with standard treatment, some alternative medicines interfere with the action of chemotherapeutic agents, either potentiating or counteracting effects of the chemotherapy drugs. A billion dollars a year is spent on CAM; these dollars might be better used to provide better supportive care. The limited time physicians now have to provide supportive care and counseling, managed care, the technological specialization of medicine, and the overall unresponsiveness of the health care system to patients' needs all foster patients' interest in CAM. In addition, patients more than ever before want to consider all sources of information and all possible treatment options, not just those offered by doctors. It also was suggested that many patients do not view herbal medicines and clinical trials as being much different (i.e., both are unproven therapies), and patients do not necessarily recognize the value in systematic evaluation of an intervention as is done in a trial. Further, the effectiveness of some chemotherapy protocols is so low that patients may feel they have just as good a chance for cure with an alternative method. It was further noted that a majority of cancer patients are treated with off-label drugs (an FDA-approved drug being used for a condition not specified in the approval); in effect, they are being treated on protocols for which there is no evidence of effectiveness; to many patients this may seem little different from alternative methods.
- Clearly, patients are finding value in CAMs, but these remedies have received little research attention or drug company interest because there is no patentable idea and relatively little profit potential. CAM may deserve more research attention than it has been getting, but efficacy studies of these medicines and other interventions are difficult to do.
- Resource allocation is an underlying issue in many of the problems being discussed. Pharmaceutical firms, for example, are hesitant to invest in developing oral chemotherapy drugs (which would be desirable to many patients) because Medicare may not pay for them. Rather than villainizing each other, stakeholders need to engage in discussions to learn where there are shared values that can inform resource allocation decisions.
- Though we are unlikely to enact a major change in our health care system, it may be useful to study other countries as models for systems, or parts of systems, that are more effective than our own. Currently, we have higher health care spending and more uninsured people than other industrialized countries; our cancer care is considered the best, but our patient outcomes are not dramatically better than those in other countries.

- To a greater extent than in the U.S., other countries use cost effectiveness analysis to try to prioritize various types of treatments. The U.S. historically has not handled these types of decisions well, tending to decentralize them or approach them with no formula for how prioritization should be done. It is particularly difficult to establish a formula for resource allocation for research in which there are generational differences, i.e., allocations for new discovery versus allocation for applying what we already know.
- These discussions of resource allocation presume that monies can be easily shifted from one area to another; this is not necessarily the case under the current institutional framework. Such shifting might be from one area of health research or health care to another, or from other areas (e.g., military) to health. Having two distinct cancer enterprises - research and delivery - as was suggested, might only complicate attempts to shift funds from one area of emphasis to another. Optimally, it will be possible to add funds to areas of need without taking funds from other pursuits.
- Oregon may offer a model for a collaborative approach to resource allocation. Though the Oregon system did not really work as a rationing tool, it proved to be a way of gaining consensus to move toward providing health care coverage for more people in the state.
- Health delivery systems in many other countries are constrained by the need to budget a fixed sum for health care, and there is less private control of the number of hospitals, doctors, magnetic resonance imaging (MRI) equipment, and other resources. The U.S. has much more of a mixed private-public system that relies on market forces rather than budgeting.
- Those who envisioned and launched the managed care movement were well-intentioned, but managed care has turned out to be far different from its original concept. When its control shifted to the corporate world, it began to be run according to business models. The result has been managed cost rather than managed care. A participant suggested that employers put substantial pressure on the managed care plans to control costs; further, when enrollment in MCOs jumped from 29 percent of workers in 1988 to 88 percent currently, the delivery infrastructure was unable to adapt quickly enough, and plans resorted to primarily managing costs in order to keep premiums down. Providers and patients need to be brought back into the discussions about how care should be delivered and financed to obtain the best results for patients at an affordable cost.
- Managed care works better for some diseases than others; cancer may be one of the diseases in which it works less well. For example, colon cancer screening (colonoscopy) could save health plans substantial long-term colon cancer treatment costs, but plans are more interested in the bottom line for the current year, and are unwilling to pay the short-term additional costs of the screening. Similarly, primary care physicians who must see a patient every 12 minutes to meet health plan productivity demands cannot take the time to counsel patients about exercise, diet, and smoking prevention, even though the potential long-term cost savings are great.

## ORGANIZATION/ SOCIETY/ CHANGE

**Dr. Thomas Laveist**

### **Key Points**

- There is a need for more research into the role of psychosocial and behavioral factors in medical treatment effectiveness; such research must focus on the role that cultural factors play in the treatment of cancer and outcomes for cancer patients. In research to date, culture has been largely operationalized as race, ethnicity, gender, and social class. Research on psychosocial and behavioral issues is surprisingly lacking in cancer compared with cardiovascular disease and other chronic conditions.
- Though the study of race, gender, and social class differences should continue, we must begin to ask different questions about social and behavioral factors. For example, are there such things as behavioral cancer clusters-social and behavioral factors exclusive of exposure to known carcinogens (i.e., besides smoking)-that could identify patients at increased risk? Do cultural differences between patient and provider affect treatment decisions? New evidence indicates that as in cardiac care, patients' social characteristics are affecting provider behavior in cancer treatment.
- Patient behavior is perhaps more important than provider factors; much of what is done to prevent cancer is not done during the medical encounter. Instead, it takes place as people live their lives. How can we intervene to modify patient preventive behavior? Are there ways to do it outside the medical setting?
- Social and behavioral factors need to be considered at all stages of the cancer continuum; patient behavior in the treatment phase can impact outcome, patient quality of life can affect compliance. We do not know how patients' individual characteristics and social context affect functional life span.
- In addition, societal-level phenomena need to be addressed more forcefully. As states recover funds from the tobacco settlement, how will this influence tobacco exports to the Third World (both abroad and to domestic poor and underdeveloped areas)?
- Typically, we define tobacco addiction as the addiction of the individual smoker to the nicotine in cigarettes. However, tobacco addiction in this country occurs at least five levels: first, the addiction of the individual smoker to nicotine; second, the addiction of nonprofit social advocacy organizations for African-Americans and Latinos to donations from the tobacco (and alcohol) industries; third, the addiction of the black and Latino media to tobacco product advertising revenue; fourth, the addiction of black and Latino politicians to campaign contributions from the tobacco industry; and fifth, the addiction of state treasuries to tax revenue from the sale of tobacco.
- The summary of the July 1999 meeting of the Panel includes two figures from the 1994 report, *Cancer at a Crossroads: A Report to Congress for the Nation*. Figure

- 1 illustrates components of the National Cancer Program; it shows the individual at the center, circled by the resources of the government, private and voluntary organizations, and health care providers. How many of these entities can be identified as themselves having a tobacco addiction? The figure rightly shows the individual at the center; much of what we do know about cancer prevention is within the purview of the individual. However, the research model displayed in Figure 2 does not adequately reflect the central role of the individual, and the role of social and behavioral research is missing in several places. Basic social and behavioral research is needed to understand how individuals respond to prevention messages. Translational research is needed to determine how social and behavioral research can be brought to bear in changing individual and community behavior, understanding the social and behavioral factors that impact medical effectiveness, and defining the role of patient attitudes, values, and behaviors in quality care. In application, research is needed to determine what programs, community-based interventions, or modifications in medical practice can be instituted to improve patient quality of life after diagnosis.
- There have been major scientific advances in cancer detection and treatment in the 28 years since passage of the National Cancer Act, but much remains to be accomplished. Cancer research is an ideal venue for the collaborative efforts of social, behavioral, biogenetic, and clinical scientists. The President's Cancer Panel is well positioned to serve as a catalyst to move such multidisciplinary efforts forward.

## **Dr. Jeffrey Prottas**

### **Key Points**

- The agenda described in the concept paper appears quite broad; it might be more persuasive to decision makers if there was greater focus and a hierarchy of the ideas and goals presented. In addition, many of the suggestions (e.g., medical education, public education, unhealthy behaviors) seem not to be unique to cancer, though all are important issues with relevance to cancer. Tying these issues more explicitly to a clearly stated focus would be useful.
- Coordination is not a neutral goal, nor is it a question of deficiency. Coordination is a political goal involving an exercise of power. This usually involves asking people to do what they do differently. As a result, it is necessary to be very specific; people will not agree to coordinate their efforts with those of another group until they know what they have to do differently. Coordination necessitates change; if nothing will change, there is no point in asking for coordination. If people will be asked to change, they need to understand the nature of the changes, how they will benefit, why they should change, and what the group requesting coordination will invest in the process.
- It should also be remembered that one person's coordination is another person's fragmentation. The Panel does not want to take responsibility for coordinating

everything, but it is unclear from the concept paper who should take responsibility for what aspects of coordination and what institutional unit is to be targeted.

## Discussion

### Key Points

- Dr. LaVeist's observations on the extent of tobacco addiction in our society illustrate how hard it will be to generate the societal or public will to agree on common goals and truly address the cancer problem. Unfortunately, some of the people who are potentially the most powerful advocates for cancer, and some of the potentially most powerful anti-tobacco advocates are also some of the people most dependent on resources from the tobacco industry. This is clearly the case among some individuals and advocacy groups that represent minority populations. Though widely known, this issue is seldom discussed publicly, but it is an issue that needs to be discussed openly and addressed. Coordination of effort in this area appears needed; the Panel should consider making a statement to the President in this regard.
- Coordination is often viewed as a mechanism for reducing costs and duplication or standardizing approaches; this is too narrow a view. In research, coordination can take the form of a body or group of bodies that act to highlight underfunded areas of research, encouraging the diversity of ideas that research progress requires.
- The National Cancer Policy Board will soon publish a review of all public and private cancer research currently being conducted in this country, with the purpose of identifying areas of emphasis and areas requiring attention. We already know that in the private sector, and at NCI, relatively little money is devoted to psychosocial research, supportive care research, and health services research (this also is true in areas other than cancer). NCI has instituted a series of Progress Review Groups, organized by cancer site, to review the distribution and balance of research in each disease by research area. These activities are in accord with one of the major recommendations made in Cancer at a Crossroads. The reports of these groups are intended to guide decision making, with input from those with expertise in each field, concerning what areas should be emphasized relative to current resource allocations. It should be acknowledged that this becomes a political process in many respects, since resources are not infinite. The Panel can make a contribution to the decision making process by helping to establish criteria as to what questions are important and advocating for attention to understudied areas.
- Society (including the scientific community) tends to ask its questions within certain confines. In cancer research, the questions being asked and answered do not reflect the reality that despite our excellent scientific community and high technology, certain groups of people are receiving lower quality or less care than others and experiencing poorer outcomes. This gap should lead us to a set of questions that still need to be asked and answered: Why is there a gap? What can

- be done to narrow or eliminate this gap? It is true that people with access to the best cancer detection and care still die of their disease, but answering questions as to how to lower mortality and increase survival in populations with the highest mortality could serve the whole population. Once we have answers to some of these questions, we have to decide the next steps. Applying what we know to the whole population is logical, though potentially impractical.
- There also remains a huge set of purely research issues concerning cancers for which we have to effective treatment or prevention. We do not know how to treat pancreatic or esophageal cancer for anyone, rich or poor.
  - Though the need to address prevention and behavioral issues has been discussed for a long time, we have yet to set up any new mechanisms for doing so. We cannot expect to achieve substantially more within the current conventional system. Without adopting a new paradigm, we will keep making small incremental advances.
  - Discussion of whether to update or revise the National Cancer Act offers an opportunity for major public discussion of the National Cancer Program. It is unclear at this point, however, if a new Act is needed or, if it should be rewritten, what should be different. The issues of Program emphasis (i.e., basic research versus translation and/or application) may not be legislative, in which case spending a great deal of time and resources on rewriting the Act would be both incremental and wasteful. It was noted that rewriting the Act might encourage other disease-specific interests to advocate for the special status and advantages (e.g., bypass budget ) that cancer now enjoys.

### **Closing Remarks**

In his closing remarks, Dr. Freeman highlighted aspects of the day's presentations and indicated that the Panel will use the testimony provided at the meeting to inform the planning process for the next several meetings as well as in its report to the President.

I certify that this summary of the President's Cancer Panel meeting on the Genesis and Evolution of the National Cancer Program, held on November 19, 1999, is accurate and complete.

Certified by:           Date: 5/1/00

Harold P. Freeman, M.D.  
Chairperson  
President's Cancer Panel