President's Cancer Panel

The National Cancer Program: Assessing the Past, Charting the Future
1999 Annual Report

June 11, 2000

The President
The White House
Washington, D.C.

Dear Mr. President:

Our Nation has made real and substantial progress against cancer, particularly in recent years. Yet each day, more than 1,500 Americans still lose their lives to cancer. That this death toll is not being reduced more quickly is not a failure of our research effort. It is instead our failure to apply fully throughout the population the cancer prevention and cancer care interventions research has shown to be effective.

In accordance with its charge, in 1999 the President's Cancer Panel reviewed the history and evolution of the National Cancer Program and considered how the national effort against cancer should now move forward to more rapidly reduce the burden of this disease. The Panel concluded that *the equal importance of the research and delivery components of the national effort against cancer must be recognized*, and that the current barriers keeping quality cancer prevention and care from reaching people in all of the neighborhoods of the Nation must be overcome. Moreover, the unequal burden of cancer carried by the poor, ethnic minorities, and the underserved must be relieved.

Although we can be rightfully proud of our research discoveries and of the current downturn in cancer mortality, if we do not bridge the persistent disconnect between the research and delivery enterprises, our progress against suffering and mortality from cancer will continue to be slow, uneven, and incremental. The cancer problem in America is not just a scientific and medical issue, but a moral and ethical challenge that must be met.

To meet this challenge, the Panel believes that:

- **Actions must be taken to remove barriers that prevent the benefits of research and quality cancer care from reaching all populations. Specifically:**
    - **It is the responsibility of legislators and policymakers to enact laws and policies needed to ensure access to quality cancer care for all**, including evidence-based interventions across the spectrum of cancer prevention and care, and participation in quality clinical trials.

    - **Mechanisms are needed to ensure that public and private health care payers have access to, understand, and accept sound scientific evidence concerning the benefit of cancer care interventions of all types, such that these services are incorporated into the standard of care for all.**
    - **Both the public and health professionals must become more aware of the cancer problem and what we currently know about prevention and all aspects of care.** This should be accomplished through culturally appropriate public education targeting children and adults, enhanced medical school curricula, and continuing medical education.
- **Public pressure must be brought to bear in recruiting to the national cancer effort sectors that traditionally have not perceived themselves to have a role in the cancer problem; these sectors include agriculture, the media, the food industry, other industry, and trade.** To this end, the public must be made aware of actions of these sectors that perpetuate and exacerbate the national cancer burden.
- **The current and future cancer workforce-researchers and care givers of all types-requires greater training and expertise in prevention, rehabilitation, cancer control, communications, the use of new technologies, end of life care, and other areas.** As the number of survivors and our understanding of cancer grow, we must maintain sufficient human and institutional capacity to provide this training. In addition, the cancer workforce must become more representative of our diverse population and more sensitive to cultural issues relevant to specific communities.

To further explore these issues and develop a list of more detailed recommendations, the Panel will next conduct a series of regional meetings to explore the cancer care delivery challenges faced by communities and how they are being addressed. These meetings will be based on our understanding that cancer care delivery problems are local and varied, and their solutions must likewise be tailored to local environments, enabled by appropriate national and local policy. This second phase in the Panel's examination of issues facing the national effort against cancer will culminate in a report to your office in 2001.

Mr. President, the public is rightfully dissatisfied with the continuing high toll of death and suffering from cancer. The Panel recognizes that these recommendations call for a new approach to the cancer problem that will require concerted, unprecedented, and collaborative actions that transcend barriers separating the diverse public and private sector stakeholders involved. I would welcome an opportunity to speak with you personally regarding this critical issue for the American public.

Sincerely,

Harold P. Freeman, Chairman

Preface

The President's Cancer Panel, created by the National Cancer Act of 1971, is charged to monitor the development and execution of the National Cancer Program and to promptly advise the President of any delays or blockages in the rapid execution of the Program.

In 1999, the Panel undertook, through a series of meetings, an overall evaluation of the National Cancer Program. In doing so, the Panel invited testimony from a diverse group of experts, both within and outside of the cancer research and cancer care communities, concerning the Program's history, its evolution since 1971, its current status, and the issues and concerns that require action for the Program to function most effectively to reduce the burden of cancer in America. The Panel recognizes that invited testimony does not carry the weight of empirical study. However, this testimony, provided to the Panel by respected leaders in cancer research, medicine, health care policy and economics, legislative history and analysis, health communications and education, sociology, anthropology, ethnography, medical ethics, and the consumer community, reflects recurrent and emerging issues relevant to the Program.

This report, ***The National Cancer Program: Assessing the Past, Charting the Future***, is the Panel's analysis and commentary, based on the testimony received during the past year, on issues now facing the National Cancer Program and its recommendations for legislative, policy, and programmatic directions to address them. This is the first of two reports to the President on the future of the National Cancer Program; the second report, to be completed in 2001, will follow a series of meetings to explore and document successes and barriers experienced by communities in bringing cancer prevention and cancer care to all of the people of the Nation.

The National Cancer Program:
Assessing the Past, Charting the Future
Introduction

Despite real and substantial improvements in our understanding of cancer and in our ability to detect and treat it, cancer remains a scourge that takes more than a half million lives each year in this country. Although the National Cancer Institute (NCI) Act of 1937 marked the first passage of anti-cancer legislation, the National Cancer Act of 1971 (P.L. 92-218) in certain respects formalized our fight against cancer by establishing an expanded and intensified National Cancer Program (NCP). The National Cancer Act also established the President's Cancer Panel, [1] which is charged to monitor the development and execution of the NCP, prepare an annual report on the status of the Program, and bring to the immediate attention of the President any delays or blockages in its rapid execution.

The Panel believes the national cancer effort is hampered by serious problems-particularly by current limitations in our ability to bring the benefits of research to all people-that must be addressed fully and rapidly. Therefore, it is appropriate at this time-29 years after passage of the National Cancer Act and on the threshold of a new century-to consider the lessons of the past, assess the status of the national cancer effort, and offer recommendations for strengthening our Nation's campaign to reduce suffering and death from this most feared of diseases.

History of the National Cancer Program [2]

From the 1940s through the 1960s, American history was marked by several landmark scientific achievements that seemed to prove that with enough knowledge, resources, and persistence, any goal was achievable. In this period we developed effective polio vaccines, built the atomic bomb, and sent men to the moon. Moreover, public sentiment was growing that something could and should be done to eradicate cancer.[3] This optimism stemmed in large part from recent successes in treating childhood cancers and in chemotherapy development,[4] together with a greater openness about cancer, which previously was not discussed publicly and was kept secret in families stricken by the disease.

These successes and attitudinal changes gave rise in the late 1960s to a belief among a number of prominent individuals that sufficient knowledge existed to mount a national campaign to conquer cancer. Mary Lasker, a philanthropist and influential medical research lobbyist, was the chief proponent of a crusade against cancer. She and her allies believed that cancer research advances had produced the requisite knowledge, but that this knowledge was not being translated quickly enough into better cancer prevention and care. They persuaded Senator Ralph Yarborough, then Chair of the Senate Labor and Public Welfare Committee, to establish a panel of consultants to recommend how to conquer cancer at the earliest possible time. This blue-ribbon panel, known as the Yarborough Commission, reported in 1970 that a national program against cancer was needed to exploit the opportunities presented by research advances of the previous decade. The report asserted that such a program required three key ingredients: a new, independent National Cancer Authority, a comprehensive national plan, and expanded financial resources.

The Yarborough Commission report also called for increased support of existing cancer centers and for establishing new centers across the country as an organizational approach to facilitate multidisciplinary (clinical and nonclinical research) interaction, teaching, diagnosis, preventive programs, and the development and demonstration of better patient care delivery methods. It also was envisioned in the report that the centers could work with local medical centers and clinics to ensure dissemination of the best available detection and treatment methods and conduct data collection and dissemination to professionals and the public. Thus, the Commission sought to increase emphasis on application and delivery relative to research.

It is noteworthy that within the Yarborough Commission, there were strongly held differences of opinion on issues that remain contentious in the current national cancer effort. These issues include: how much to invest in basic research compared with applied research and development; the relative merit of centralized planning and direction versus an investigator-initiated approach to the research program; how far a Federal agency can and should go in coordinating cancer-related activities in other Federal and/or state agencies or the private sector; and how much effort a research agency should devote to technology development and transfer.

These issues were debated strenuously in the year leading to passage of the National Cancer Act, but the dominating issue was the advisability of creating an independent National Cancer Authority that would encompass the National Cancer Institute and report directly to the President. It reflected the deeply divided views of the Lasker group, the scientific community, and other public and private sector stakeholders on the appropriate scope of the Federal effort against cancer and the level of autonomy participants should retain.

Definition and Vision of the National Cancer Program

The National Cancer Act was passed on December 23, 1971. Instead of providing for a new, independent agency, NCI was elevated to a bureau, and the NCI director was made a Presidential appointee; moreover, NCI was given expanded funding and authority to submit an annual budget request directly to the President. A National Cancer Program was established, for which the NCI director was given planning and coordination authority beyond NCI. Specifically, Section 407 gave the NCI director authority to coordinate all cancer-related activities of the National Institutes of Health (NIH) and of all other governmental and non-governmental organizations. The NCI director also was given several other research-related responsibilities, including encouraging and coordinating cancer research by industrial concerns and collecting, analyzing, and disseminating all data useful in cancer prevention, diagnosis, and treatment. It is important to note, however, that no discrete definition of the NCP was included in the National Cancer Act, nor was it defined in subsequent amendments. The National Cancer

Act also included sections creating new programs intended to extend research into practice, such as national cancer research and demonstration centers for clinical research, training, and demonstration of advanced diagnostic and treatment methods. The cancer control program was re-established with a separate appropriation. Elaborate planning, including a strategic plan sent to Congress in 1973 and annually updated five-year plans, was a key feature of the NCP's early years. In later years, however, the planning effort became a cursory exercise conducted principally by staff, without the scientific community input included in the earlier plans. Reaction to the early plans was primarily concern about overplanning NCI's own research program, particularly in research on the majority of cancers, about which the knowledge base was still seriously lacking.

As originally envisioned, the National Cancer Program concept called for greater effort to identify research areas in which sufficient knowledge existed such that a focused effort could yield substantial progress in cancer control. It was not envisioned that NCI would become the national cancer care system, but it was anticipated that the Institute would become involved both in developing research results into applications and in working with cancer care delivery institutions to bring these applications to communities as part of the national attack on cancer.

Between 1971 and 1993, provisions of the National Cancer Act were amended five times.[5] Though some of these amendments expanded the information collection and dissemination authority of the NCI and mandated a stronger emphasis on cancer control (specifically, education and demonstration programs in local communities and hospitals and cancer control research funding set-asides), the amendments primarily strengthened the research emphasis of the NCP. In addition, the language of the 1971 Act specifying that the NCP include cancer-related research activities of other Federal and non-Federal programs was dropped. These changes appear to reflect the political and scientific will during those years that has strongly influenced Program direction and continues to influence the national cancer effort in the present. Clearly, the Program has become something other than it might have been under the original statutory language and the vision of its creators. Further, the current research emphasis has evolved without taking into account the delivery system that would be needed to take advantage of research advances.

In 1994, responding to a Congressional request, a subcommittee of the National Cancer Advisory Board published a review of the NCP, *Cancer at a Crossroads: A Report to Congress for the Nation*.[6] Two members of the President's Cancer Panel participated in this effort. In addition to specific recommendations for improving the NCP's design and implementation, the report defined the NCP as a program that should:

- Involve all individuals and public, private, and voluntary organizations and agencies whose actions affect the cancer problem (see Appendix 1), and
- Include basic, translational, and applied research spanning the cancer care continuum, from risk assessment through end of life care (see Appendix 2), that results in enhanced cancer care for all.

This vision of the stakeholders and components involved in the cancer problem goes well beyond the concept of the National Cancer Program as interpreted in the National Cancer Act and its amendments, which focus on the government's role in combating cancer.

The Cancer Problem in America

Unquestionably, we have made major strides against cancer since passage of the National Cancer Act, yet more than 1,500 people in the United States still die *each day* from the diseases we collectively call cancer. The annual national death toll from cancer exceeds fatalities from all wars fought by the United States in the last century. This year, as in recent years past, more than a million new cancer cases will be diagnosed, despite estimates that approximately two-thirds of all cancers are preventable through dietary and other lifestyle modifications.[7] [8] [9]

Rapidly changing demographics portend an even greater national cancer burden in the coming years. The most important factor contributing to this alarming prospect is the aging of our population. Cancer is predominantly a disease of older age; 80 percent of cancers are diagnosed in people 55 years of age and older.[10] Our middle-aged and older populations also are paying the cost, in terms of cancer, of damaging lifestyle behaviors-lung cancer due to smoking, melanoma caused by excessive sun exposure, and other cancers related to obesity, poor diet, and inactivity. In addition, home country cancer patterns of our growing immigrant populations (e.g., stomach and esophageal cancers among some Asian populations; cervical cancer among some Hispanic populations) must be better understood and addressed. It also has been demonstrated that immigrant populations rapidly acquire U.S. majority population cancer rates with increasing length of residence and acculturation. Recent data suggest that the modest overall decline in cancer mortality observed since 1990 is continuing despite the growing and aging population (see Appendix 3), but it is questionable whether this trend can be maintained or accelerated unless we develop and implement significant improvements in cancer prevention and control. In addition, while overall mortality from cancer appears to be falling, certain vulnerable populations still bear a disproportionate burden of cancer.[11]

Continuing changes in our health care financing and delivery systems have had a vast impact on the national effort against cancer, and can be expected to do so in the future. The shift from fee-for-service (FFS) to managed care systems has had some beneficial effects (for example, some studies indicate that managed care enrollees may receive mammography and certain other recommended cancer screening services more than those in FFS systems). However, in the evolving health care system, emphasis on cost control also has fragmented care and erected barriers to some care. Enrollees under both managed care and FFS systems continue to have difficulty accessing treatment under clinical trials and other state-of-the-art cancer care. Insured populations under any system, including Medicare, have limited access to cancer prevention services. As a result, even people with good coverage may not be receiving the best possible cancer care. In addition to clinical trials, excluded or severely limited services frequently include psychosocial services, outpatient pain management, rehabilitative care, and adequate end of life care. Moreover, there is a widespread perception that cost considerations are being allowed to overshadow patient welfare.

At the opposite end of the insurance spectrum, the population of uninsured-currently estimated at 44.3 million-continues to grow. The uninsured include the non-working poor; workers (including former welfare recipients) in low-income jobs or jobs at small companies that do not offer benefits and who also are not eligible for Medicaid; and unemployed persons from higher socioeconomic groups. Hispanics (particularly Hispanic males) and African Americans are the most likely to be uninsured.[12] The uninsured have little or no access to cancer care of any type. They are perhaps the most likely to avoid seeking care for suspicious symptoms and as a result, are often diagnosed at late stages of disease. Even when diagnosed with cancer, they may be unable to afford needed treatment.

Between these ends of the insurance spectrum is a vast, but underappreciated population of people who are underinsured for the catastrophic costs of cancer. For many people, a cancer diagnosis proves to be a financial disaster as well as a life-threatening health crisis. Certain aspects of care may not be covered or covered in full. Cancer survivors who change jobs may find that coverage for follow-up care and/or treatment of a recurrence is excluded for up to a year under a pre-existing condition clause of the new employer's health insurance plan. Those who lose their jobs and their group health coverage may find premiums for an individual plan unaffordable.[13] Mounting expenses from deductibles, copayments, and the costs of unreimbursed supportive and other care, especially if combined with reduced income (often of both the patient and caregiver) cause some patients to make care decisions based on cost rather than benefit and to work more than may be advisable. It is not unusual for the family's savings and security to be sacrificed to finance the cost of cancer care.

Moreover, regardless of the configuration of the health care system or insurance status, some populations in this country continue to have unequal access to care and less favorable cancer outcomes. These disparities include differences in geographic and financial access to cancer care services of all types and important differences in referral for cancer screening, treatment, and other types of care. Those most affected are special populations, including racial/ethnic and cultural minorities, the elderly, the poor, women, and urban and rural underserved populations. For example, recent studies have found that African American cancer patients are less likely to be referred for surgery to treat early-stage lung cancer,[14] and that African American women are less likely than white women to receive the minimum expected treatment for newly diagnosed breast cancer.[15] Similar disparities between African American and white populations have been found in patient access to care for non-cancer conditions.[16] [17] [18] [19] Disparities between Hispanic and white patient populations have been reported relative to physician prescribing patterns for hormone replacement therapy[20] and pain control for long bone fractures.[21] Compared with data on disparities affecting African Americans, however, there is an unfortunate lack of evidence concerning health disparities in other ethnic and minority populations.[22]

Gender issues in women's health care are relatively well documented.[23] [24] As the paragraphs above illustrate, the cancer problem in America is multi-faceted and complex. We still have much to learn about cancer and how to prevent, detect, and treat it, but the most important deficiencies in our approach to cancer lie in the slowness with which new discoveries are translated into interventions, and the limited extent to which proven interventions are incorporated into routine practice and applied in all of the neighborhoods of the Nation.

I. Status of the National Cancer Program

Major Successes of the National Cancer Program

When the War on Cancer was declared in 1971, cancer was believed to be one disease-a formidable but singular foe. Research since then has shown us that in fact, cancer is more than 100 diseases, many of which also have subtypes that require differing treatment regimens. The growth in knowledge about cancer biology and genetics that has accompanied this evolution-and the insights and interventions that have derived from it-are perhaps the greatest success of the national cancer effort since passage of the National Cancer Act.

The quest for knowledge about cancer has spawned a cancer research enterprise that has expanded exponentially in terms of its scope, capacity, funding, and effectiveness. In 1971, there was relatively little interest or participation of the private and voluntary sectors in cancer research, or in biomedical research more generally. In recent years, however, private and voluntary sector funding of cancer research has exceeded the Federal investment and resulted in a cancer research enterprise that is far more robust and market-driven than was ever envisioned by framers of the National Cancer Act.[25] This development has had unquestionable benefits, particularly in the level of intellectual and fiscal capital that have been brought to bear on understanding the genetic and molecular mechanisms of cancer.

Similarly, cancer care technologies, drugs, and devices for detection, diagnosis, and treatment have become more diverse and more available to a greater percentage of the population. Imaging devices such as magnetic resonance imaging (MRI) and positron emission tomography (PET), drugs such as the taxane and platinum-based agents, fine-needle biopsy techniques, and patient-controlled pumps that dispense pain medication are just a few examples.

The 1971 National Cancer Act envisioned that NCI Cancer Centers would serve as hubs from which cancer care advances could be disseminated to the public. The Cancer Centers Program at NCI has expanded substantially since then. However, an overarching recommendation of Cancer at a Crossroads was that the network of NCI Cancer Centers should be expanded still further, both geographically and demographically, to improve distribution of state-of-the-art, multidisciplinary cancer care and strengthen the centers' connection to community-based clinical trials groups and community oncology practice. Since 1994, several Cancer Centers have been added to the network with some improvement in geographic coverage of the Nation, and designation of additional centers is planned. Crossroads also recommended that NCI should establish in high-incidence and high-mortality cancer areas Cancer Centers with a principal focus on cancer control activities and the application of research findings. This recommendation for increased focus on application has begun to be implemented.

Though cancer control and communications research-and the application of that research-has to date not been developed as fully as envisioned by the framers of the National

Cancer Act, emphasis on these areas has been growing in recent years, along with a greater understanding of their importance to quality of care. The maturation of epidemiology as a science and the growth of the advocacy community have been important influences in this trend. The NCI recently has reorganized and created organizational units to focus its research in cancer communications, behavioral research, patient outcome studies, and other cancer control research. The Centers for Disease Prevention and Control (CDC) has increased its focus on chronic diseases, including cancer. Private sector resources for these areas of research have been limited to funding from foundations and other voluntary agencies; cancer control and communications research has not experienced the huge infusion of private resources that has fueled progress in the basic sciences and in drug and technology development.

Recently, in response to reports by the Institute of Medicine,[26] [27] the NCI has intensified its attention to the issues of quality of care and health disparities; a number of initiatives have been implemented or are planned to address the many issues in these areas. Most of these are research efforts aimed at gaining a better understanding of key factors in cancer care quality and disparities and how they should be communicated, monitored, and measured. However, the newly formed Quality of Cancer Care Committee, in addition to research efforts, may also undertake to work with components of the delivery enterprise to accelerate the application of research findings.

Recognition of the role of tobacco in cancer initiation and promotion, and subsequent reduced smoking rates among some populations, also should be counted among the successes of the National Cancer Program. Though not due exclusively to the Program per se, Federally funded tobacco-related research (supported by NCI, CDC, and other agencies) has been a crucial underpinning of awareness and intervention efforts.

Continuing Issues

The Nation has reason to be proud of the progress made to date against cancer, but we still have far to go to lift the burden of this disease from our population. A number of exceedingly important issues must be resolved if we are to succeed.

Application of Research Results

Most importantly, the benefits of research-successful disease interventions-are not being incorporated sufficiently into routine cancer care. This situation reflects a serious disconnection between the research and delivery enterprises in this country. Simply put, we are not applying what we know-interventions demonstrated to be efficacious and validated through the clinical trials process-nearly well enough, quickly enough, or widely enough. This crucial divide between the research and delivery enterprises is depicted in Figure A (page 10), which expands upon the model offered in *Cancer at a Crossroads* to more clearly differentiate between applied research and the actual dissemination and routine delivery of quality cancer care practices to all populations. As the figure indicates, the key activities and those responsible for implementing them are substantially different between the research and delivery spheres.

Though more than half of all cancer patients now survive at least five years after diagnosis,[28] it is estimated that half of those who do not survive could do so if all of the American public received the benefit of current knowledge about cancer detection, diagnosis, treatment, and other care. It should be noted, however, that the five-year survival benchmark may not be an appropriate measure of survival from some cancers, particularly since it refers to overall rather than disease-free survival.

Yet even where proven preventive or early detection services are available and geographically accessible, coverage for such care may be denied or unattainable. For example, many insured people under age 65 are not covered adequately for preventive or screening services. Among Medicare beneficiaries, the largest insured population, preventive and screening services are not covered under Part A, for which there is no cost; to obtain these services, beneficiaries must pay a monthly premium for Part B coverage, plus 20 percent of the cost of some services.[29] These limitations on access to service are important because risk for most cancers rises with age.

Quality of Cancer Care and Cancer Disparities

Little professional consensus exists as to what constitutes quality cancer care. Many guidelines exist for the treatment of specific cancers, but these are unknown to or disputed by parts of the medical community. Furthermore, the existence of guidelines, even when there is consensus on their validity, does not guarantee that the recommended care will be accessible or delivered.[30] [31]

A continuing and critical barrier to improved quality of care is the slow and uneven manner in which advances across the continuum of cancer care are deemed eligible for reimbursement by public and private payers. This problem frequently blocks the integration of new interventions into the standard of care, since individual and institutional providers are less likely to offer services for which there is no reimbursement. Insufficient mechanisms exist to help ensure that both payers and providers have access to, understand, and accept scientific evidence of the benefit of new interventions.

The Surveillance, Epidemiology, and End Results (SEER) program and other cancer registries continue to document significant population disparities in cancer incidence and mortality. In addition, disparities in access to and receipt of appropriate cancer care, as well as in patient outcomes, continue to be reported in various populations.[32] [33] [34] [35] Vulnerable populations typically have been described in terms of their socioeconomic status, culture, race, geographic locale, gender, and age; they also may be described in terms of their insurance status. To understand and address cancer care disparities, it will be necessary to elucidate the biases that create them at the national, institutional, local, and individual levels. One step toward this goal will be to augment existing surveillance systems to gather information on socioeconomic status and eliminate imprecise and questionable categories such as race and ethnicity.

Scope of the National Effort Against Cancer

The current National Cancer Program, as it is understood by most, is overwhelmingly a research program that places relatively little emphasis on cancer prevention, cancer control, and patient outcomes (i.e., what happens to people with cancer) compared with its emphasis on basic (i.e., laboratory and preclinical) science discoveries.[36] To support the application of new discoveries to all aspects of cancer care, greater research emphasis is needed in:

- Behavioral research
- Rehabilitation
- Cancer communications and education
- Symptom control
- Diffusion strategies
- Survivor issues
- Health services research
- End of life care

As much as in cancer biology or genetics, research discoveries in these areas require routine application in the population.

However, the national effort against cancer encompasses far more than research. The delivery of care is at least as important as research, for without effective delivery, research discoveries are ultimately of little value. In addition to the provision of screening, diagnostic, and treatment services, delivery comprises prevention, supportive care, cancer communications, public education, and case management.

Coordination of the National Effort Against Cancer

Coordination continues to be an issue in the national cancer effort. Many in the research and clinical communities believe that coordination cannot be achieved without undue structure, control, or an undesirable vesting of power in a single agency or group. The central issues concern autonomy and ensuring that views and ideas outside the mainstream or status quo will be heard, but the issues differ somewhat between the research and delivery spheres. The Panel believes that strong centralized control of the research enterprise would stifle innovation and progress and would be untenable given the large private sector component of cancer research today. However, voluntary collaboration that identifies and addresses research gaps, minimizes unnecessary duplicative effort, and communicates information to all stakeholders is of value.

Coordination of the delivery effort is not necessarily synonymous with rationing or the undesirable restrictions on services imposed by some health plans. Like the research effort, strong central coordination of the delivery enterprise, which involves myriad private sector providers and payers, would likely be unrealistic. But a better distribution of medical resources and reduced fragmentation of care could greatly improve access and help ensure that all populations receive cancer preventive, therapeutic, and supportive services known to be of benefit.

At this time, however, there is no consensus in either the research or health care delivery communities as to whether, or in what manner, coordination of a total national cancer effort is possible or desirable. Since publication of Cancer at a Crossroads, a number of groups comprised of diverse stakeholders have been formed to consider cancer-related policy, research, and delivery issues, but it is not clear that any of these bodies is at this point positioned to provide coordination and leadership of the national cancer effort in any form that stakeholders might eventually accept.

Research and Delivery Environments

Unlike the research and health care environments that existed at passage of the National Cancer Act, the current environments are by far more market-driven, specialized, and competitive. For example, deep concerns exist that the profit motive of the private sector may cause research questions with the greatest potential public health benefit to go unexplored; cancer prevention strategies (with the exception of chemoprevention approaches) provide a key example in this regard. Thus, it may increasingly fall to publicly-funded research to ask the less market-driven and more public health-oriented questions relative to cancer (e.g., high risk research, research with low profit potential, questions related to low incidence cancers).

As with the research enterprise, there are concerns that the delivery of care-the clinical care enterprise-has become one driven more by market forces than public health needs. In addition, as cancer care becomes increasingly dependent on the use of costly technologies, the disparities in care between the well-insured with relatively full access to care and populations with less access appear to be growing.[37]

Countervailing Forces

Powerful forces continue to perpetuate and exacerbate the cancer problem. Some of these forces are recognized for their impact on cancer, while others largely are not. For example:

- Tobacco use is responsible for approximately one-third of cancer deaths. Even as governments sue the tobacco companies to recover Medicaid and other health care costs attributable to the tobacco use of public program beneficiaries, government support of the tobacco industry continues. Tobacco company settlement funds won in these suits are being diverted to highway and other projects unrelated to the tobacco problem; of the total dollars that will be paid to the states by the tobacco industry this year, less than ten percent have been allocated for state tobacco prevention programs.[38] Moreover, taxes on tobacco products are a significant source of state revenue; a variety of voluntary organizations that might normally be expected to oppose tobacco use rely on tobacco company contributions; and trade policies continue to permit tobacco exports. Annual expenditures for tobacco advertising vastly outstrip those for tobacco control.[39] [40]

- It is believed that approximately one-third of cancers are linked to diet. Some food industry actions (e.g., accelerating production and advertising of unhealthful products, increasing portion sizes) continue unchecked despite the known link of diet to certain cancers.[41] [42] The percentage of obese adults and children is rising,[43] [44] particularly in many minority populations.[45] Evidence is mounting that obesity, independent of diet, may be a risk factor for several cancers,[46] including colorectal,[472] esophageal,[48] endometrial,[49] and pancreatic cancer.[50]
- Emphasis on exercise in public schools is decreaing,[51] while sedentary lifestyle among children and adults is increasing. Growing evidence indicates the importance of exercise in cancer prevention overall and in prevention of specific cancers, such as breast and colorectal cancers.[52] [53]
- The media have an important role in communicating health information. They also have an underappreciated influence on individual values, desires, and actions.[54] For example, advertising for tobacco products and the glamorization of tobacco use in film and television programming are known to influence smoking initiation, smoking behavior, and tobacco product choice, particularly among youth.[55]
- The use and inappropriate disposal of known or suspected carcinogens continues in myriad industrial and workplace environments and in agriculture.

These aspects of the cancer problem could be reduced if more sectors or groups (e.g., agriculture, media, food processing and service, industry, trade officials) recognized and acknowledged their contribution to the cancer burden. The private components of these sectors are profit-oriented; this focus may not always coincide with the public good. Similarly, the public components of these sectors may be expected to protect or increase tax or trade revenues.

Public and Professional Education

Cancer-related education for the public (both youth and adults) is inadequate to ensure that individuals are able to make informed lifestyle and cancer care decisions. Cancer prevention is a lifetime commitment that begins with the development of healthy behaviors in early life and is reinforced through education, communication, and informed medical practices throughout life.[56] As noted above, cancer communication and behavioral research are key areas in which research is needed to learn how best to reach people of diverse cultures and various educational and socioeconomic levels with cancer-related messages that will stimulate lasting behavior change.[57] The public also requires education on how to access and evaluate cancer information to support decisionmaking concerning all aspects of cancer care. Educational strategies and programs are needed to take best advantage of the new media, particularly the Internet, but must not ignore the information needs of those without access to these technologies.

Health professionals of all types need training to help ensure that they make appropriate recommendations for cancer prevention, screening, and care. In addition, health professionals need effective tools and skills training to help them become better communicators of cancer-related information (e.g., addressing psychosocial needs; explaining clinical trials; understanding, using, and protecting genetic information). This training should begin in medical school and should be available to practicing professionals throughout their careers. As for the public, education for health professionals is needed for those with access to and familiarity with information technologies, as well as for those without access or who choose not to use these media.

Funding of the National Cancer Effort

In recent years, changes in the health care financing and delivery system-most notably the rise of managed care, increasingly "managed" indemnity insurance, and decreased reimbursements under Medicare and Medicaid-have seriously decreased revenues that academic institutions, cancer centers, hospitals, and clinics have relied upon to subsidize research, train the next generation of cancer researchers and caregivers, provide care for the uninsured, and fund supportive and outreach activities.[58] No mechanism has been established to replace these funds lost in the current health financing environment. Recent research funding increases at NCI and NIH may have relieved some pressure on academic institutions' research budgets (though distribution of funding across the research spectrum may not be markedly changed), but they do not respond to the resource needs in training, indigent care, or other delivery areas. There is continuing concern as to how these important needs will be met in an increasingly market-driven health care delivery system.

II. Conclusions

- **The cancer problem in America is not just a scientific and medical issue, but a moral and ethical issue.** We cannot yet eradicate cancer, but we do have the knowledge, the technologies, and the resources to substantially reduce the national cancer burden. As a Nation, we have a moral and ethical imperative to use this capacity to minimize suffering and death from cancer in all segments of the population.
- **To date, we have not as a Nation addressed the cancer problem with an approach that acknowledges all of the relevant issues and players**. In particular, we have not acknowledged the equal importance of the delivery effort relative to research in addressing cancer, nor have we acknowledged the impact on the cancer problem of both public and private sector actions that perpetuate and exacerbate cancer incidence and mortality.
    - **We must mobilize the public and political will to launch and sustain a full national effort against cancer**. The public is rightfully dissatisfied with the continuing high toll of death and suffering from cancer. Yet there is no consensus on what a full national effort should comprise, and this impedes progress against the disease.
    - **In the War on Cancer, access and delivery issues are not being addressed adequately**. The cancer problem is more than a research problem, yet we continue trying to address delivery problems with research solutions. The research effort is making good progress and should continue to be supported fully. However, the NCI is being asked to answer for the consequences of insufficient application of discoveries about cancer and inadequate access to appropriate cancer care; as a research agency, it cannot solve these aspects of the cancer problem.
    - **Legislators and policymakers have a responsibility to use their power to address the cancer problem**. The Congress must be better informed about the cancer problem at the community level and must understand that research alone will not solve the cancer problem. Research being funded and conducted today will not see application for years, and no matter how much research is conducted, the cancer problem will never be substantially reduced unless all people have timely geographic, cultural, and financial access to appropriate cancer prevention and cancer care services. Public officials and legislators are central to solving these access issues.

      Federal payers and providers (e.g., Health Care Financing Administration, Health Resources and Services Administration, Department of Defense, Veterans Administration), and state/local public providers enact policies and procedures in accordance with legislation that governs their actions. Many of these entities would like to do more for their beneficiary populations, but depend on the legislatures to provide funds and appropriate authority for their programs. Private providers and payers also act in accordance with regulations to which they are bound, but may be motivated by their profit orientation to provide only those services required by regulation or demanded by purchasers of care. Moreover, legislation, and the programs, regulations, and policies that flow from it, must be based on concepts that promote better cancer care.

    - To remove economic barriers to quality care, **it will be necessary for public and private agencies and private insurers to accept the evidence generated by the research and clinical trials processes and based on that evidence, provide coverage for preventive, therapeutic, supportive, rehabilitative, and end of life care that has been shown to be of benefit**. These services must also be available to the uninsured, the underinsured, and others without the means to pay. Further, the biases that underlie some disparities in access to and quality of care must be addressed. Even though statistics suggest a slight downward trend in cancer mortality overall, certain vulnerable populations still bear a disproportionate burden of cancer.[59]
    - **The national effort against cancer really consists of two interrelated, but separate components.**

- **One component encompasses the research effort**, in which translational and applied research should be expanded to speed the development of basic science discoveries into interventions that will benefit people with cancer and those at risk for the disease. Cancer-related research spans the continuum from risk assessment and prevention through end of life care or survivorship. It includes investigation of human behaviors and how they impact the burden of disease, as well as applied research to determine what works and how best to employ new interventions. It also encompasses how we collect information and communicate conclusions drawn from that information to influence human behaviors. In particular, it must emphasize patient outcomes-considering survival, morbidity, economic impact, quality of life, and mortality-to evaluate the true benefit of preventive and therapeutic interventions. In the research effort, NCI is a major player, but other Federal agencies (e.g., DoD, CDC, Agency for Healthcare Research and Quality) also have large research programs. Similarly, private industry (e.g., pharmaceutical, biotechnology) and some voluntary agencies (e.g., American Cancer Society, Komen Foundation, CaP CURE) are major supporters of cancer research.
- In tandem with the research enterprise, **the second component of the national cancer effort focuses on delivery**, including primary and secondary prevention, cancer control, education, and access to high quality, evidence-based care. As in the realm of research, agencies involved in application and delivery are highly diverse. A vast array of public sector providers and payers (e.g., CDC, HCFA, other Department of Health and Human Services programs, Veterans Administration, DoD, State and local health departments) and private agencies (e.g., service providers, advocacy organizations) are currently involved in various aspects of cancer control, prevention, treatment, and education/communication.

- **Stakeholders in each of these two components will need to collaborate to ensure that we apply what we know and deliver quality cancer prevention and care to all people**. Failure to fully bring the benefits of research to the population has been a major weakness of the National Cancer Program. Even if this equal but dual emphasis in the national cancer effort is accepted and adopted, acceptable forms of communication and collaboration are necessary to bridge the current divide between the research and delivery efforts. Lacking some form of collaboration or coordination, the current divide between the two is likely to persist, and we will not consistently or sufficiently integrate new knowledge and new interventions into the standard of care for all populations, or ensure that outmoded interventions are replaced.
  - **Any attempt to resolve the gap between what we know about cancer and what care is delivered in the community will have to address the continuing tension between public health-oriented approaches and individual-centered approaches to cancer care.** This issue goes to the heart of what we define as quality cancer care.
  - **Mustering the national will to combat cancer at all levels will require comprehensive public education**. Education is needed to overcome the public's lack of awareness of or complacency about the magnitude of the cancer problem and our ability to reduce it. In addition, education to modify lifestyle behaviors known to increase cancer risk (e.g., smoking, sedentary lifestyle, unhealthful diet) must begin in childhood and extend to all age groups. Targeted education also is needed to overcome fatalistic attitudes about cancer held by some cultural groups. Public preferences and choices will drive the offerings of industry and the media. Public demand for change will affect the actions of legislators and policy makers.

III. Recommendations

The equal importance of the research and delivery components of the national effort against cancer must be recognized. The Panel understands that overcoming the current divide between these two components will be difficult, and will require concerted action by all stakeholders in the national cancer effort. Regardless of the volume or scope of our research discoveries, if we do not better connect the research and delivery enterprises to improve cancer prevention and care for all people, our progress against suffering and mortality from cancer will continue to be slow, uneven, and incremental. This is a moral and ethical challenge for our Nation.

The Panel recommends that:

1. Barriers that currently prevent the benefits of research and quality cancer care from reaching all populations must be removed. Applied research to develop tools to be used in the process of application is not sufficient. Actions must be taken to make community application a reality. To accomplish this:
    - It is the responsibility of legislators and policymakers to enact laws and policies needed to ensure access to quality cancer care for all, including interventions validated by evidence-based research processes and participation in quality prevention and treatment clinical trials.
    - Mechanisms should be established to ensure that public and private health care payers have access to, understand, and accept sound scientific evidence concerning the efficacy of preventive, screening, diagnostic, therapeutic, rehabilitative, and palliative cancer interventions such that these services are incorporated into the standard of care for all.
    - Public and health professional awareness of the cancer problem and what we currently know about prevention and all aspects of care must be increased through culturally appropriate public education campaigns targeting children and adults, enhancements to medical school curricula, and continuing medical education.
2. Public pressure must be brought to bear in recruiting to the national cancer effort sectors that traditionally have not perceived themselves to have a role in the cancer problem (e.g., agriculture, media, food industry, other industry, trade). A first step in this process will be promoting public awareness of the actions of these sectors that perpetuate and exacerbate the national cancer burden.
3. The current and future cancer workforce-researchers and caregivers of all types-requires greater training and expertise in prevention, rehabilitation, cancer control, communications, the use of new technologies, end of life care, and other areas. As the number of survivors and our understanding of cancer increase, sufficient human and institutional capacity must be maintained to provide this essential training. In addition, the cancer workforce must become more representative of our diverse population and sensitive to cultural issues relevant to specific communities.

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