Statements from the President's Cancer Panel

Meeting

Evaluating the National Cancer Program
November 19, 1999

Evaluating the National Cancer Program" was the focus of the President's Cancer Panel meeting on November 19 in Salt Lake City, hosted by the Huntsman Cancer Institute at the University of Utah. This was the second public meeting held this year to explore the current state of the Program and discuss future directions. To obtain fresh insights into this subject, the Panel adopted a new format by inviting experts in a variety of related fields-ranging from political science to economics to public health policy-that are not usually represented at PCP meetings. Dr. Harold, Freeman, the Panel Chair, urged participants to "think out of the box," going beyond scientific questions to provide a broader perspective on the issues related to the goals of the National Cancer Program.

Dr. Robert Cook-Deegan, of the National Academy of Sciences, compared expectations surrounding the establishment of the NCP in 1971 with the realities of 1999. The eradication of cancer through basic research is now seen as an unrealistic goal. Cancer is a large set of difficult and disparate problems, many of which are behavioral and economic. While enormous progress has been made in scientific knowledge and a formidable infrastructure has been created for cancer research, surveillance, and treatment, the fundamental barrier to delivering the benefits of new knowledge to the American people is our fragmented health care system. The NCP may need to be realigned as two complementary structures: a research program and a health care delivery program.

Dr. Robert Huefner, of the Governor Scott M. Matheson Center for Health Care Studies at the University of Utah, suggested that the Panel lacks formal power to shape the future of the NCP, but should make use of its "bully pulpit" power in drawing attention to these its problems and influencing public policy to address them. Current revolutions in technology (such as the Internet) and basic science (such as understanding the role of genetics in cancer) are having unpredictable effects on the evolution of the health care system; the Panel must remain alert to the impact of new developments to be able to make appropriate recommendations. One model is the Federal Reserve Board, which develops and monitors indicators that the Nation watches and responds to.

Dr. Jeffrey Prottas, of the Schnider Institute for Health Policy at Brandeis University, stressed the need to define the differences and overlap between health policy and cancer policy. Some issues that have been identified as problems within the NCP, such as lack of insurance, are actually broader health policy issues. The PCP can be more persuasive in dealing with decision makers if the specific goals of the NCP are more clearly stated and prioritized. Coordination of the NCP is a political process that requires change, and change cannot be implemented unless all of the institutions

involved understand what changes are required and who is responsible for carrying them out.

Randall P. Ellis, a health economist from Boston University, argued that an effective NCP must reflect the current policy environment. Recent developments include the rise of managed care; the Balanced Budget Act of 1997; the use of capitation and risk adjustment in health care financing; the acceleration of technological change; and the growth of the uninsured. Dr. Ellis suggested several new directions for the NCP: work with State and Federal agencies to regulate managed care plans; develop strategies to influence provider behavior (such as report cards and consumer information); work with HCFA to reform Medicare; and explore the impact of guidelines on practices.

Dr. Marsha Gold, of Mathematica Policy Research, Inc., said that in theory, managed care provides opportunities to work around fragmentation issues and the disconnect between science and health care delivery. Potentially, managed care reaches all of the fragmented pieces of the cancer community. The "bully pulpit" of the PCP should be used to encourage providers to be more open to change. Researchers should attempt to work out arrangements with providers to implement protocols and to use the managed care infrastructure to help measure outcomes. Areas of mutual interest between the NCP and managed care should be explored. Because managed care emphasizes accountability, it is more likely to provide coverage for new treatments if claims for improved outcomes are supported by well-presented evidence. Resource allocation is a "hard reality" issue. The cost-effectiveness models used by other countries are not likely to be adopted in the United States, where the market drives resource allocation.

Dr. Kathy Mooney, Professor of Nursing at the University of Utah, stressed that some stakeholders in the NCP, including oncology nurses, have been excluded from discussions concerning the status and future of the Program. Symptom management has been left out of the NCP infrastructure; models of multidisciplinary teamwork to manage pain and other symptoms are not being tested. Increased research on outcomes following clinical trials could provide valuable evidence for the PCP's "bully pulpit" efforts to improve access to care. Nurses can play an important role in shaping policy regarding behavioral research, cultural factors that affect risk, quality of life issues, and delivery of health care, but their opportunity to do so is hindered by the tendency of managed care to reduce their numbers.

Dr. Thomas Laveist, of the Johns Hopkins University School of Public Health, stressed the need for the NCP to place more emphasis on psychosocial, behavioral, and cultural factors related to treatment outcomes, medical effectiveness, survival, and quality of life, particularly those factors that lie outside the medical setting. The role of social and behavioral research is missing from the NCP model. In discussing the example of the relationship between tobacco use and cancer, Dr. Laveist argued that there are several levels of tobacco addiction. The obvious level is the individual's dependence on tobacco; however, a wide variety of institutions and organizations are

dependent on income generated by tobacco, such as sales taxes, political contributions, and advertising. Some of the institutions that have the greatest potential as advocates for reducing the use of tobacco are the most dependent on tobacco-related money.

In his closing remarks, Dr. Freeman noted that cancer is much more complex that it was believed to be in 1971. In designing a program to fight the war on cancer, the authors of the National Cancer Act did not understand importance of health care delivery and access. To make real progress against cancer, we have to do better that today's incremental changes in incidence and mortality. Revolutionary change is needed in our understanding of the issues involved in cancer research and health care delivery, and in a democracy revolutionary change is not a small endeavor. Several key questions remain: Is there a political will to change? If fragmentation is a basic condition of life, is coordination of the NCP possible? If access to cancer care is expanded, where will the resources come from? How does cancer fit into the larger arena of health care policy? How broad or narrow should the agenda of the NCP and the PCP be? The next steps will include deciding what questions to ask the PCP's various audiences-the public, the Congress, and the Executive Branch-and identifying what we are asking each audience to do.