Progress Review Group, publishing recommendations and strategic plans for the advancement of AYA Oncology. Dr. Hayes-Lattin also serves on an Expert Advisory Panel to the AYA Committee of the Children's Oncology Group and advises many advocacy groups on the medical needs of AYA cancer patients. At OHSU, Dr. Hayes-Lattin established a program in AYA Oncology that includes interdisciplinary clinical and supportive care services and functions as a platform for education, outreach, and research efforts.

Key Points

- The information revolution has generated a wealth of portable data. Moreover, these data are increasingly accessed and shared by cancer patients and patient-focused organizations (see HealthDataRights.org) to advance cancer research. Increasingly, individuals are empowered to gain ownership of their cancer data and to use tools that enable them to share these data.
- For example, through Patients Like Me (http://www.patientslikeme.com/), patients are gathering and reporting their own data, capturing what they feel are valuable results, and sharing this information both with other patients and potentially with health care professionals, industry organizations, and researchers to advance research.
- The Lance Armstrong Foundation manifesto states that unity is strength, knowledge is power, and attitude is everything. These beliefs relate to data and data sharing. "Unity is strength" speaks to the importance of sharing data. "Knowledge is power" relates to the fact that power lies with those who are able to access data. "Attitude is everything" reflects LAF's position that patients are empowered to own and share their data, not simply access it.
- Raw cancer data are "currency" for cancer research. These data include clinical measurements; the results of genomic, proteomic, or other molecular analyses; images (including the raw data used to generate images); and clinical outcomes of treatments. Biospecimens, which are a common source of raw data, are also valuable currency. To collect and share high-quality cancer data, one must follow universal standards in an environment of trust—whether the data are generated via private clinics, cancer centers, or industry trials.
- A patient sharing his or her "cancer story" may evolve to sharing his or her cancer data. However, most patients do not consider sharing their story the same as sharing their data or participating in clinical research. In fact, for most patients, the decision to participate in a clinical trial is motivated by the desire to access novel therapies rather than participate in research.
- Patients who are engaged in sharing their cancer data often want to be notified when an analysis is performed or published using their data. Keeping these patients engaged will necessitate the development of tools that present data in a uniform and simple form, such as the prognostic tool Adjuvant Online, where patients input their cancer experience and visually see expected benefit from the therapy. In addition, targeted social networks are needed not only so patients can find each other, but for reporting data in shared databases that can be used to identify biomarkers and aid in clinical trials matching.

DR. OTIS BRAWLEY:

AMERICAN CANCER SOCIETY

Background

Otis W. Brawley, M.D., is Chief Medical and Scientific Officer and Executive Vice President of the American Cancer Society. Dr. Brawley also currently serves as professor of hematology, oncology, medicine, and epidemiology at Emory University. In addition, he is a medical consultant to the Cable News Network (CNN). From April 2001 to November 2007, he was Medical Director of the Georgia Cancer Center for Excellence at Grady Memorial Hospital in Atlanta and Deputy Director for Cancer

Control at the Winship Cancer Institute at Emory University. He has also previously served as a member of the Society's Prostate Cancer Committee, co-chaired the U.S. Surgeon General's Task Force on Cancer Health Disparities, and filled a variety of positions at NCI, most recently serving as Assistant Director. Dr. Brawley is a member of the Centers for Disease Control and Prevention Breast and Cervical Cancer Early Detection and Control Advisory Committee. He previously served as a member of the FDA Oncologic Drug Advisory Committee and chaired the NIH Consensus Panel on the Treatment of Sickle Cell Disease. He is listed by Castle Connelly as one of America's Top Doctors for Cancer. Among numerous other awards, he was a Georgia Cancer Coalition Scholar and received the Key to St. Bernard Parish for his work in the U.S. Public Health Service in the aftermath of Hurricane Katrina. Dr. Brawley is a graduate of University of Chicago, Pritzker School of Medicine. He completed a residency in internal medicine at University Hospitals of Cleveland, Case Western Reserve University, and a fellowship in medical oncology at NCI.

Key Points

- Cancer prevention and treatment are issues that need to be approached ethically, logically, and rationally. The public needs to be told what is known scientifically, what is not known scientifically, and what is believed, and these things need to be labeled accordingly.
- In the United States, some people consume too much medicine, meaning unnecessary care is given. Others consume too little, meaning necessary care is not given. There is thus an opportunity to decrease wasteful health care expenditures while improving overall health.
- True health care reform is not only reforming how health care is paid for, but rather, how it is provided and consumed. That calls for the rational use of medicine, not the rationing of medicine as many people believe.
- In the 1970s and 1980s, the number of cancer deaths was on the rise. Due primarily to smoking cessation, cancer deaths stopped rising by 1992. If the trend that began in the early 1990s continues, this will translate into 2.5 million fewer men and more than 1.25 million fewer women dying from cancer between 1991 and 2020 than would have been expected based on the higher rates of cancer death observed in earlier decades. If what is known about preventing and treating cancer is applied even more broadly from this point forward, nearly 3.0 million men and 1.6 million women will be saved from cancer death. If we stop applying our knowledge, cancer deaths will begin to rise again.
- In 2007, 23 percent of white high school students smoked—an improvement from 40 percent in the late 1990s, but anything more than zero is too high. If tobacco use were prevented before it even began, tremendous numbers of lives could be saved. If it could be decreased by even another 25 to 30 percent, large numbers of lives would be saved.
- In the United States, black and white women had the same death rate for breast cancer until 1981. The disparity started as an improved understanding of how to treat the disease was developed and differences in how the disease was treated by race began to occur.
- From 1991 to 2006, 766,000 Americans did not die of cancer because of the implementation of cancer control technologies in the prior 30 years; it is estimated that 57,000 of these were women who did not die from breast cancer due to good screening, early detection, and aggressive treatment. It is estimated that only 45-50 percent of women were screened for breast cancer during that time. If 100 percent of women had been screened for breast cancer, another 57,000 lives would have been saved in the same 15-year period.
- Despite the lives it has saved, however, mammography is not an ideal screening test. Among women screened for breast cancer by mammography, 65,000 deaths will be prevented over 10 years but 450,000 women will die from the disease over the same time period. Women in their 40s who choose mammography decrease their risk of death from breast cancer by only 0.05 percent over 10 years,

while women in their 50s decrease their risk by only 0.07 percent. New screening tests for breast cancer are needed.

- Between 1991 and 2006, 765,870 cancer deaths were prevented—77,000 would have been due to colorectal cancer. These deaths were prevented by screening, early detection, and aggressive treatment. It is estimated that screening prevalence was 30 to 35 percent during the period.
- Thirty-five percent of American adults can currently be categorized as obese. An additional 25 percent or so are overweight. Obesity, high caloric intake, and lack of physical activity have the potential to cause more cases of cancer in the United States by 2030 than does tobacco use. These factors are already causing a rise in cancer incidence.
- Among children 6 to 11 years old, 4 percent were obese in 1971 to 1974. This figure increased to 20 percent in the same age group in 2007 to 2008. It is critical to address childhood obesity and lack of physical activity today to prevent cancer 50 to 70 years from now.
- Sun avoidance can potentially decrease melanoma death rates by half—saving as many as 60,000 lives every 10 years. Sun avoidance actually can be as powerful a cancer prevention tool as annual mammography for all women over the age of 40.

MS. GWEN DARIEN:

ADVOCATES IN CANCER RESEARCH: BUILDING SUCCESSFUL COLLABORATIONS

Background

Gwen Darien is Executive Director of the Samuel Waxman Cancer Research Foundation (SWCRF). She is also a 17-year cancer survivor. Prior to joining SWCRF, Ms. Darien was Editor-in-Chief of *CR Magazine* and Director of the American Association for Cancer Research (AACR) Survivor and Patient Advocacy Program. Ms. Darien is also chair of the NCI Director's Consumer Liaison Group and a member of the Secretary's Advisory Committee on Health, Genetics, and Society. She has served on the faculties of the AACR/American Society of Clinical Oncology's Methods in Clinical Cancer Research Workshop, the American Society of Breast Disease Annual Symposium, and the Accelerating Anti-Cancer Agent Development Workshop. Ms. Darien is on the advisory board of the Health Advocacy Program at Sarah Lawrence College and an external advisor to the Breast Cancer Specialized Program of Research Excellence (SPORE) at the Duke Comprehensive Cancer Center. She was an adjunct faculty member of the MFA Photography and Related Media Program at School of the Visual Arts (1997-2003). From 1991 to 1995, she was Executive Director of Los Angeles Contemporary Exhibitions (LACE). Ms. Darien was also Deputy Director of P.S. 1 Contemporary Art Center in Long Island City, New York, from 1984 to 1990. Ms. Darien is a graduate of Sarah Lawrence College.

Key Points

- Collaboration between investigators and advocates is critical to achieving the goal of preventing and curing cancer. Since the early 1990s, it has been increasingly common, and understood to be very valuable, to incorporate advocates into the process of cancer research.
- There are many types of cancer advocates, many of whom have experiences themselves as cancer survivors. Among advocacy roles are personal and one-to-one advocacy (e.g., patient navigation), policy advocacy, media and public advocacy, and, increasingly, research advocacy.
- The field of health care advocacy may be traced to the founding of organizations focused on raising awareness of specific diseases, such as the American Society for the Control of Cancer (the predecessor of the American Cancer Society) and the March of Dimes. Beginning in the 1980s, health care advocacy began to take a more activist approach, with the founding of groups like the National Coalition of Cancer Survivorship and the National Breast Cancer Coalition.

- Some of the earliest involvement of research advocates was in the Department of Defense Congressionally Directed Medical Research Programs. NCI has also worked with advocates in many different ways, such as the Director's Consumer Liaison Group, which is now under the Office of Advocacy Relations.
- Reasons for including advocates in the research process are many. Advocates add a human face and sense of urgency to cancer research, ensure patient focus, provide a diverse perspective, stimulate discussion by asking questions, and, expand public understanding of science.
- Sound practices for engaging advocates begin with creating formal opportunities to engage them in a way that is meaningful to both sides, not just to advocates and not just to researchers. There have to be parameters for effective collaborations. For example, there must be appropriate training of advocates and matching of the right advocate to the right activity. In addition, clarity of roles (e.g., length of time commitment, compensation, and expectations), ethical standards, and success factors and benchmarks are critical.

DR. BRUCE CHABNER:

THE NATIONAL CANCER ADVISORY BOARD'S AD HOC WORKING GROUP TO CREATE A STRATEGIC SCIENTIFIC VISION FOR THE NATIONAL CANCER PROGRAM AND REVIEW OF THE NATIONAL CANCER INSTITUTE

Background

Bruce Chabner, M.D., serves as Director of Clinical Research for the Massachusetts General Hospital Cancer Center and Professor of Medicine at Harvard Medical School. He serves as Associate Director of Clinical Science at Dana-Farber/Harvard Cancer Center and has held additional academic appointments, including the position of Director of the Division of Cancer Treatment of the National Cancer Institute from 1982 to 1995. Dr. Chabner's research focuses on the biochemistry and pharmacology of folate antagonists, experimental therapeutics, and clinical trial design. He is a senior editor for *The Oncologist* and serves on the executive advisory boards for some of the industry's leading innovators in drug development. In 2006, Dr. Chabner received a presidential appointment to the National Cancer Advisory Board at the National Cancer Institute. Over the years, Dr. Chabner has received awards including Phi Beta Kappa, Alpha Omega Alpha, the Public Health Service's Distinguished Service Medal, the Karnofsky Award of the American Society for Clinical Oncology, and the Bruce F. Cain Award for Drug Development of the American Association for Cancer Research. In 2006, he was the first recipient of the Bob Pinedo Award for Contributions to Improvement in the Care of Cancer Patients.

Key Points

- The National Cancer Advisory Board was established by the National Cancer Act in 1971 and serves as an advisory and oversight group for NCI. NCAB was also charged with conducting a yearly review of the National Cancer Program and reporting findings to NCI and the Executive Branch; however, NCAB had not been carrying out this function.
- In February 2010, NCAB established a Working Group to review progress in NCI-sponsored cancer research over the past 10 years and to identify gaps and suggest areas for enhancement and restructuring in major NCI programs.
- This review is taking place at a time of transformative change in American science and medical care. Funding for biomedical research has not grown in recent years, while opportunities for research have exploded. In addition, there has been a growth of industry involvement in the development of cancer therapeutics and diagnostics, in part through partnerships with academic centers.
- The co-chairs of the Working Group include Philip Sharp from Massachusetts Institute of Technology; Robert Ingram, former CEO of GlaxoSmithKline; William Goodwin, former CEO of

Wachovia and a major philanthropic supporter of several cancer centers; and Dr. Chabner. The remaining membership of the 25-person committee draws from NCAB, industry, and academia. Dr. Kripke also serves as a member. The Working Group held three 1.5-day meetings, one each in May, July, and August 2010.

- The Working Group examined numerous programs, including both intramural and extramural science, and considered factors such as productivity, budgets, and leadership. Several accomplishments and areas of concern were identified. The group found that the cancer centers have made substantial contributions to the cancer program over the past decade, as has the NCI intramural research program.
- Participation on and support of the Working Group has been a valuable experience for the Working Group members, NCAB members, and NCI staff. The resulting report, which is due to be presented to NCAB in December, will be timely in light of the recent change in NCI leadership and also in the context of the burgeoning fields of molecular science and targeted therapies as well as the fiscal constraints facing the NCP. Once the report is approved by NCAB, it will be sent to Dr. Varmus and HHS leadership.

DISCUSSION AND CONCLUDING COMMENTS:

PANEL II

Key Points

- Most people think primarily of research and research infrastructure when they think about the NCP; however, it is also important that the NCP encompass delivery of care. In particular, steps must be taken to ensure that the standard of care is delivered to all populations.
- The NCP should focus on integration of ongoing activities and the convergence of resources to reduce cancer incidence and improve outcomes for patients with cancer.
- There is some question as to whether it would be beneficial to have a national cancer plan with common goals and objectives for all stakeholders. If a national cancer plan were to be developed, it would be important that it be adaptable so that it could respond to the changing state of the science and challenges facing the NCP.
- Instead of identifying concrete actions, the national cancer plan should be built on universal principles. For example, a focus on cancer prevention could be a principle of the national cancer plan. Prevention is acknowledged as important, but this has not led to a meaningful investment in disease prevention. Another guiding principle should be research.
- Incentives are critical for changing behavior. For example, collaboration is essential for translating discoveries into practical applications but current systems are not designed to encourage or reward people to build or be part of multidisciplinary teams. Rather, systems tend to reward individual accomplishments. To address this issue, the metrics used in promotion and tenure consideration must be changed. Physicians should be recognized for enrolling patients on large, network-based clinical trials rather than only being rewarded for the revenue they generate.
- Some programs—such as the SPOREs—have successfully used incentives to bring researchers together.
- Historically, clinical research—particularly government-funded research—has been subsidized by the profits of clinical services. However, as the revenue from clinical care has been declining, it has become more difficult to justify subsidizing clinical trials. As a result, some institutions are hesitant about conducting government-funded trials. The clinical trials system must fairly compensate the organizations and people involved in the research in order to be sustainable.

- Representatives from various agencies should be brought together not to have open-ended discussions, but to develop solutions to well-defined problems.
- Public-private partnerships can be very effective for the development and delivery of treatment and prevention interventions.
- It is important to bring together researchers from diverse disciplines to address a common problem. The example was provided of a University of Chicago research team that was trying to determine why women of color with breast cancer have worse outcomes than their white counterparts. A sociologist on the team noted that research in rats has shown that if normally social female rats are isolated in a cage by themselves, they will display signs of stress and hypervigilance and will develop mammary cancer. This led the team to do a study to determine whether women who lived on lower floors of housing projects—who would be expected to display higher levels of hypervigilance—have higher rates of breast cancer than those living higher up in the building.
- It is becoming increasingly clear that team science with representation from different disciplines is necessary for making high-impact discoveries. However, it is also important to support individual researchers and basic science research. The cancer program should attempt to balance its portfolio among these different types of approaches to research.
- It is difficult to determine how the cancer research portfolio should be balanced. Epidemiological research that incorporates consideration of environmental factors may be helpful for uncovering some of the causes of cancer. Large-scale clinical research will likely provide insights for prevention of cancer. Basic science and genomic research are needed to identify biomarkers that will help distinguish aggressive cancers that require interventions from lesions that do not pose a threat to the health of the patient and will also contribute to an understanding of the progression from normal tissue to malignant cancer. However, advances that will transform cancer care could come from unexpected areas of research. As such, it is important to invest broadly. In addition, overall funding for cancer research should be increased.
- Genomic research is very important but it is also critical to develop a systems biology approach to research in order to gain insight into how the components of an organism come together to generate an effect. This is the type of thinking and work traditionally done by pharmacologists and physiologists.
- Investments in genetic research will make it possible to identify polymorphisms that result in increased disease susceptibility, but it is important that research also be conducted so that there are ways to manage genetic risk through education, behavior modification, or other interventions.
- In addition to direct funding for research, the NCP must address infrastructure needs such as the need for specimen banks and standards. It is important to ensure that standards and regulations support research and do not become cumbersome to the point that they hinder progress.
- Part of the reason the regulatory structure is so cumbersome is because there are many different government bodies, including several within HHS, that have overlapping oversight. If this oversight could be streamlined, it would be very helpful.
- Medicine tends to be conservative and to continue to use certain interventions rather than consider that there may be more appropriate approaches. In addition, the medical field has adopted some interventions that have not been adequately evaluated. For example, hormone replacement therapy had been widely used for decades and the first studies linking these drugs to breast cancer were published only in the past six or seven years. Also, chest x-rays were once promoted to screen for lung cancer before they were shown by a Mayo Clinic trial to have no benefit.
- Efforts should be made to learn more from medicine being practiced outside the context of controlled clinical trials. Although this type of research may be less rigorous than clinical trials, it could generate a wealth of information.

- It is very difficult for patients who are not being treated in large centers to participate in research. Large academic centers often try to build networks with smaller private practices and hospitals but it is very difficult for these small organizations to support the costs of conducting research. This precludes patients being treated at these organizations from participating in research.
- The United States once attracted the best and brightest young people from around the world to come and study in its universities. Some of these international students eventually returned to their home countries but some stayed in the United States and became an important part of the U.S. research workforce. However, it is unclear whether this country is still viewed as a desirable place to study and work. Part of this issue may be that other countries are investing in their own science programs. It is also possible that immigration laws have made the United States a less welcoming place for international students.
- It is unclear whether young people view careers in cancer research as exciting and rewarding options. The perception of research careers could be improved through public education and exposure of young people to cancer researchers. However, it is not enough to get young people excited about science. The research career path needs to be a viable and attractive option. Currently, young people see that it is very difficult and time consuming to be a successful researcher. Young people may also be unwilling to take on debt to pursue careers in science and medicine; loan repayment programs may help in this regard.
- Graduate students and postdoctoral fellows are not prepared for the realities of the modern research enterprise. They are not taught to work in teams. In addition, the current funding environment is increasing competition among scientists rather than promoting collaboration.
- ACS often provides young investigators with their first independent grants, and the research supported through these grants can build the foundation for these investigators' first successful R01 applications. However, ACS provides new investigator funding for a maximum of six years. With the current funding environment, many promising investigators are losing their ACS support and are unable to transition to receiving NCI or NIH funding. Many of these investigators are going into other fields or getting jobs in the private sector.
- It is a challenge to communicate effectively with the U.S. population in order to help people understand what cancer is and what is being done to address it. The public does not have a strong foundation of scientific knowledge. This makes it difficult to educate people about advances in the area of genetics and inform them about their risks. It is also important to increase competence regarding cancer among patients and caregivers, including professionals in the health delivery field (e.g., physicians, nurses, social workers).
- It is very challenging to change people's behavior, particularly within the general population (i.e., those who have not been diagnosed with cancer). Structural approaches to changing behavior may be more effective; these include strategies like increasing access to healthy foods and developing built environments that promote physical activity. Policy approaches have also contributed to declines in tobacco use.

PUBLIC COMMENT

Key Points

- There is often a tendency among scientists to reinforce existing paradigms of thought, but there is likely a tremendous amount that could be learned by looking carefully at the "exceptions" —the results of well-designed experiments that do not conform to the currently accepted paradigm. For several years, many researchers have advanced the notion that cancer research should focus only on the cellular or genomic level. However, there is increasing evidence that external factors, such as

stromal cells and other components of the microenvironment, can have significant influence on cancer incidence and progression.

- There should be increased focus on preventive medicine. Although it is important to improve treatments for cancer, it would be better to prevent the disease.
- It is clear that host factors play a significant role in cancer development. One area of research should be on the types of alterations in host physiology that allow cancer to develop and progress.

CLOSING REMARKS—DR. LEFFALL

- Dr. Leffall thanked the speakers for their excellent presentations and contributions to the discussions and stated that the Panel would carefully consider what it had heard at the meeting.

CERTIFICATION OF MEETING SUMMARY

I certify that this summary of the President's Cancer Panel meeting, *The Future of Cancer Research: Accelerating Scientific Innovation*, held September 22, 2010, is accurate and complete.

Certified by: _____ Date: December 2, 2010

LaSalle D. Leffall, Jr., M.D.
Chair
President's Cancer Panel