MEETING SUMMARY
PRESIDENT'S CANCER PANEL
THE CONNECTED CANCER PATIENT: VISION FOR THE FUTURE AND RECOMMENDATIONS FOR ACTION

July 9, 2015
Chicago, Illinois

This workshop was the third in the President's Cancer Panel's (the Panel) 2014–2015 series on connected health and cancer. The workshop brought together leaders from academia, technology, government, advocacy, and healthcare. Participants discussed the desired future state for connected health in cancer prevention and care and identified steps that could be taken to achieve identified goals by 2020. Participants were encouraged to live-Tweet at #cHealth4Cancer during the workshop. This meeting summary was prepared to satisfy requirements established by the Federal Advisory Committee Act. The summary provides an overview of presentations and discussions occurring as part of the workshop and does not necessarily reflect the views of Panel members.

President's Cancer Panel

Barbara K. Rimer, DrPH, Chair

Owen Witte, MD

National Cancer Institute, National Institutes of Health

Abby Sandler, PhD, Executive Secretary, President's Cancer Panel

Meeting Co-Chairs

David K. Ahern, PhD, Special Advisor, Health Communications and Informatics Research Branch, Division of Cancer Control and Population Sciences, National Cancer Institute

Bradford W. Hesse, PhD, Chief, Health Communications and Informatics Research Branch, Division of Cancer Control and Population Sciences, National Cancer Institute

Participants

Neeraj K. Arora, PhD, Senior Program Officer, Science, Patient-Centered Outcomes Research Institute

Ethan Basch, MD, Director, Cancer Outcomes Research Program, Associate Professor, Medicine and Public Health, University of North Carolina, Chapel Hill

Donald M. Berwick, MD, MPP, President Emeritus, Senior Fellow, Institute for Healthcare Improvement[*]

Wen-Ying Sylvia Chou, PhD, Program Director, Health Communication and Informatics Research Branch, Division of Cancer Control and Population Sciences, National Cancer Institute

Robert T. Croyle, PhD, Director, Division of Cancer Control and Population Sciences, National Cancer Institute

Marcia R. Cruz-Correa, MD, PhD, Associate Professor of Medicine and Biochemistry, Director, Basic and Translational Science, University of Puerto Rico, Comprehensive Cancer Center

Karen Emmons, PhD, Vice President for Research, Director, Kaiser Foundation Research Institute

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[*] Dr. Berwick was not in attendance but participated via a prerecorded presentation.

Janet Freeman-Daily, MS, ENG, Lung Cancer Patient, Patient Advisory Board, Addario Lung Cancer Foundation

Gilles J. Frydman, Chairman, Smart Patients

M. Chris Gibbons, MD, MPH, Chief Health Innovation Officer, Federal Communications Commission; Chief Executive Officer, The Greystone Group, Inc.

Katherine Kim, PhD, Assistant Professor, Betty Irene Moore School of Nursing, University of California, Davis

Kenneth D. Mandl, MD, MPH, Professor, Harvard Medical School, Children's Hospital Informatics Program, Boston Children's Hospital

Thomas A. Mason, MD, Chief Medical Officer; Acting Director, Office of Programs and Engagement, Office of the National Coordinator for Health Information Technology, U.S. Department of Health and Human Services

Olufunmilayo Olopade, MD, FACP, Director, Center for Clinical Cancer Genetics, Professor of Medicine and Human Genetics, Associate Dean for Global Health, The University of Chicago

Aydogan Ozcan, PhD, Chancellor's Professor, Howard Hughes Medical Institute Professor, University of California, Los Angeles

Corrie Painter, PhD, Associate Director, Operations and Scientific Outreach, Broad Institute; Vice President, Angiosarcoma Awareness

Stacey Tinianov, Breast Cancer Patient, Advocate, and Blogger

John T. Wald, MD, Medical Director, Public Affairs and Marketing, Mayo Clinic

WELCOME AND INTRODUCTIONS

Dr. Rimer welcomed invited participants and other attendees to the meeting on behalf of the Panel. She introduced Panel members, provided a brief overview of the history and purpose of the Panel, and described the aims of the current series of meetings. Dr. Rimer thanked the two workshop co-chairs, Drs. David Ahern and Bradford Hesse. She also introduced workshop facilitator Robert Mittman and Panel staff members.

OPENING ROUNDTABLE

The goals of the workshop were to (1) review, discuss, and agree on a reasonably attainable future state with respect to connected health in cancer and (2) identify concrete recommendations for achieving a future state that benefits patients and the public. Participants introduced themselves and were asked to identify a single area related to cancer for which connectivity would make the most significant contribution. Participants emphasized the need for all stakeholders to work together as a team and be supported. Patients, families, and caregivers should be included as integral parts of this team and equal partners with providers. A deeper understanding of the benefits of patient engagement and the factors that support it are needed. It also is important to acknowledge that individuals are unique, with different health conditions and personal wants and needs. It is critical that information is available in useful and actionable forms when it is needed. Health literacy and English proficiency levels often must be taken into account when information is provided. Incompatibilities between current clinical workflow and delivering effective preventive care also were noted, as was the need for interoperable, standardized electronic health record (EHR) systems.

SCENARIO 2020: CONNECTED HEALTH AND CANCER OUTCOMES

Presenters expounded on the need for greater connectivity in healthcare and described a vision for the desired future state of connected health in cancer care that could be reasonably attainable within five

years. Participants discussed this vision—referred to as Scenario 2020—and its implications for people with or at risk for cancer.

DR. BRADFORD W. HESSE

CONNECTED HEALTH IN CANCER: IDENTIFYING THE OPPORTUNITY

Background

Dr. Hesse received his degree in social psychology from the University of Utah in 1988 with an accompanying internship in the nascent field of medical informatics. After completing his degree, he served as a postdoctoral fellow in the Department of Social and Decision Sciences at Carnegie Mellon University. For more than 20 years since, he has been conducting research in the interdisciplinary fields of social cognition, health communication, health informatics, and user-centered design. He was recruited to the National Cancer Institute (NCI) in 2003 and has focused his energies on bringing the power of evidence-based health communication to bear on the problem of eliminating death and suffering from cancer. He continues to direct the Health Information National Trends Survey, a biennial general population survey aimed at monitoring the public's use of health information during a period of enhanced capacity at the crest of the information revolution. He also serves as Program Director for the Centers of Excellence in Cancer Communication Research, a cutting-edge research initiative aimed at expanding the knowledge base underlying effective cancer communication strategies. Dr. Hesse has authored or coauthored over 160 publications, including peer-reviewed journal articles, technical reports, books, and book chapters. In 2009, his coauthored book entitled *Making Data Talk: Communicating Public Health Data to the Public, Policy Makers, and the Press* was named book of the year by the *American Journal of Nursing*.

Key Points

▪ Discontinuities in communication lead to fragmented care across the cancer continuum. About 70 percent of smokers interact with the healthcare system, but few receive adequate follow-up related to smoking cessation. One study found that more than half of patients being treated for late-stage cervical cancer in community hospital settings had not been screened. Among teen and young adult cancer patients, 63 percent do not adhere to their treatment regimens. In addition, communication problems have devastating consequences for cancer patients receiving end-of-life care and cancer survivors.

▪ The 2013 Institute of Medicine (IOM) report *Delivering High Quality Cancer Care: Charting a New Course for a System in Crisis* indicates there are several stresses that likely will exacerbate existing fractures in cancer care. These stresses include an aging U.S. population, increasing cancer incidence, complexity in oncology care, increasing numbers of cancer survivors (estimated 18 million by 2022), a shrinking oncology workforce, and the rising costs of cancer treatment.

▪ The consequences of poor communication are described in IOM reports *To Err is Human: Building a Safer Health System* (1999) and *Crossing the Quality Chasm: A New Health System for the 21st Century* (2001). For example, inefficient handoffs between providers can lead to errors. This is particularly relevant in oncology because patients receive care from several providers (e.g., radiologist, oncologist, primary care provider).

▪ The Joint Commission (formerly the Joint Commission on Accreditation of Healthcare Organizations) has recommended that effective communication should be an organizational priority to protect the safety of patients. The emergence of new communication technologies in healthcare could help address current problems (e.g., smart scheduling routines, effective reminders, telemedicine apps).

- In a 2008 full-page advertisement in *The Washington Post* entitled Unleashing the Power of Connectivity in Health Care, Kaiser Permanente stated that healthcare is suffering from a communication crisis.

- The Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 enabled the federal government to provide incentives for EHR adoption. EHR Meaningful Use criteria relate to safety and effectiveness; patient engagement; continuity of care; population health, including health disparities; and private and secure communications.

- The first workshop in the Panel series on connected health and cancer, entitled *Engaging Patients with Connected Health Technologies*, was held on December 11, 2014, in Cambridge, Massachusetts. At that workshop, presenters discussed the effectiveness of connected health interventions; the need for connected infrastructure; the importance of integrating research, clinical care, and data; and the need to improve access to technologies to address health disparities.

- The second Panel workshop in this series, entitled *The Personal Health Data Revolution: Connected Health and Cancer*, was on March 26, 2015, in San Francisco, California. At that workshop, participants discussed the value of patient involvement and patient-generated data in research. Presenters also talked about how integrated systems can support patient-centered care and improve quality of care.

DR. DAVID K. AHERN

CONNECTED HEALTH IN CANCER: VISION AND RECOMMENDATIONS FOR THE FUTURE

Background

Dr. Ahern is Director of the Program in Behavioral Informatics and eHealth within the Department of Psychiatry at the Brigham and Women's Hospital and Assistant Professor of Psychology (Psychiatry) at Harvard Medical School. His specialty is focused on the intersection of informatics and behavioral science to improve health and healthcare. He is also on special assignment to NCI whereby he serves as a special advisor on health information technology (IT) to the Health Communication and Informatics Research Branch within the NCI Behavioral Research Program.

Key Points

- Four primary dimensions were identified as being central to the vision of connected health for the future: personal health information and data sharing; person- and family-centered care; devices, sensors, and apps; and a national health information infrastructure. These dimensions are not mutually exclusive or exhaustive but represent important facets of connected health.

- Collection and sharing of personal health information have potential to fundamentally change medical care and research. Technologies can be catalysts for these activities. In the desired future state for connected health, personal access to physiologic and clinical data will contribute to a culture of health and better self-management. Personal health data will be massively generated and collected from devices attached to and within the body. Importantly, these devices will be controlled by the individuals to whom they are linked. Patient data also will be secure with informed consent processes that allow data to be shared with designated healthcare professionals and researchers. This vision relates to the Precision Medicine Initiative, which takes into account genomic information and other factors that influence individual disease risk and outcomes and aims to pioneer a new model for doing science that emphasizes engaged participants, responsible data sharing, and privacy protection.

- In the desired future state, healthcare will have been transformed to a fully patient- and family-centric system that includes patient and family values as core components of every cancer care plan. Patients will feel more connected to their cancer care providers, and providers will have access to information

in patients' records. To achieve this, strategies are needed to more effectively engage families and caregivers in patients' care.

- Devices, sensors, and apps have tremendous potential to facilitate information gathering and convert this information to knowledge. In the desired future state, 85 percent of the U.S. population will have access to mobile computing by 2020, with broad adoption across racial/ethnic groups, regions, and literacy levels. Just-in-time, adaptive interventions will become ubiquitous and accessible through a vibrant ecosystem of evidence-based, interoperable apps.

- A national health information infrastructure is needed to support connected health. In the desired future state for connected health, the Office of the National Coordinator for Health Information Technology (ONC) goal of an interoperable infrastructure for data flow controlled by individuals will be achieved. This infrastructure will integrate stakeholders in ways that were not possible in the past.

DR. DONALD M. BERWICK

COMMENTARY ON SCENARIO 2020 (PRE-RECORDED PRESENTATION)

Background

Dr. Berwick was President and Chief Executive Officer for the Institute for Healthcare Improvement (IHI) for nearly 20 years. In July 2010, President Obama appointed Dr. Berwick to the position of Administrator of the Centers for Medicare & Medicaid Services (CMS), a position he held until December 2011. He was formerly Clinical Professor of Pediatrics and Health Care Policy at Harvard Medical School, and Professor in the Department of Health Policy and Management at Harvard School of Public Health. Dr. Berwick has served as Vice Chair of the U.S. Preventive Services Task Force, the first "Independent Member" of the American Hospital Association Board of Trustees, and Chair of the National Advisory Council of the Agency for Healthcare Research and Quality (AHRQ). An elected member of the Institute of Medicine, Dr. Berwick served two terms on IOM's governing council and was a member of IOM's Global Health Board. He served on President Clinton's Advisory Commission on Consumer Protection and Quality in the Healthcare Industry. He is a recipient of several awards and author of numerous articles and books, including *Curing Health Care* and *Escape Fire*.

Key Points

- Dr. Berwick related his personal experiences with cancer and cancer care. When he was 15 years old, his mother died of cancer. More recently, a close friend was diagnosed with multiple myeloma. Having received excellent care, this friend has been cancer-free for nearly three years and may have been cured of his disease.

- Two IOM reports—*To Err is Human: Building a Safer Health System* (1999) and *Crossing the Quality Chasm: A New Health System for the 21st Century* (2001)—brought attention to the idea that better care is the best route to excellence in outcomes and sustainability in cost. The IOM reports were preceded by work of the President's Advisory Council on Consumer Protection and Quality in the Healthcare Industry and the National Cancer Policy Board report. These highly evidence-based reports documented high rates of defects in American healthcare, far beyond what the public and most professionals expected.

- Rising healthcare costs have become a significant burden on the U.S. economy and on individuals. U.S. healthcare costs are the highest, by far, in the world. Evidence indicates that these high costs are not necessary to produce value and could be reduced through improvements in care (not rationing or withholding care), which would free resources for other priorities.

- *Crossing the Quality Chasm* articulated six aims for improvements: safety, effectiveness, patient centeredness, timeliness, efficiency, and equity. In the mid-2000s, IHI articulated the Triple Aim,

which condensed these six aims into three larger aims: better care, improving the health of populations (prevention), and lower per capita costs for health care.

- The Triple Aim has been accepted globally as a vector of goals that any modern healthcare system could and should embrace. However, the U.S. healthcare delivery system is not structured in a way that supports the Triple Aim. Improving quality of care requires a different care system.

- Over the past few decades, there has been some progress in improving the U.S. healthcare delivery system. In efforts like these, there tend to be "leading arms," or areas that are particularly amenable to change because of leadership structures, public awareness, and/or science. These areas often become prototypes, defining the ways that systems are redesigned. Oncology could be a leading arm for healthcare delivery reform.

- In environmental science, the term "charismatic species" is used to describe animals which, if threatened, raise awareness and attract public attention. Cancer could be a charismatic species for healthcare. Cancer care is charismatic because most people have a personal connection to cancer, either through their own diagnosis or the diagnosis of a friend or family member. Cancer also could be a strong prototype because cancer care requires team-based care, patient centeredness, and proper use of modern technologies with appropriate attention to the risks involved. These characteristics make the cancer care delivery system vulnerable to rupture. Any frailty in a healthcare system will be revealed in the way that system delivers cancer care. Cancer care is not unique in its complicated nature and vulnerability, but successful redesign of cancer care delivery could inform changes in all areas of healthcare.

- Every production system, including healthcare, has fundamental underlying design principles that influence overall operations. One example of a change in these principles took place in the banking sector with the shift from bank tellers to automated teller machines (ATMs). *Crossing the Quality Chasm* includes ten principles of system design that will support achievement of the six aims for improvement. Though these ten principles are sound, they do not address the role of technology in communication because current opportunities for connectivity were not available at the time the report was written.

- Many other changes have occurred in the 14 years since *Crossing the Quality Chasm* was released. A deeper understanding of patient-centered and person-centered care has emerged as the result of the work of courageous leadership, vocal consumers, and an alert and interested workforce. A national strategy for information sharing also has been developed, and there have been tremendous breakthroughs in technology development.

- IHI has formed the IHI Leadership Alliance, a group of 40 organizations that are working to achieve new levels of performance across healthcare. The Alliance has articulated 11 principles of redesign. Included among these principles is the need to change the balance of power by moving decision making and control into the hands of the people who are being served by the system. Consideration must be given to how we can equip people to control the way they receive care. The principles of redesign also emphasize cooperation over super-specialization and individual excellence. Two of these redesign principles—the call to standardize some elements of care and the importance of customizing care to individual patients—may seem to contradict one another but do not. It is important to standardize things that make sense to standardize while still listening carefully to every individual and maintaining the capacity to respond to individual needs and capabilities.

- The redesign principle that is perhaps most relevant to the current Panel series is the call to move knowledge, not people. With current technologies, it should be possible to have the best knowledge reach everyone in the world at low cost and with no delay. Dr. Sanjeev Arora adopted this principle when he created Project ECHO, an effort that allows all hepatitis C patients in New Mexico to access the best-possible care for their disease in health care centers near their homes. Nurse practitioners and rural physicians across the state are supported remotely by experts and are able to deliver the best-

possible care in their local environments. The patients experience the same or better results as those patients who travel to large medical centers to receive care.

- The themes presented in the Panel's scenario revolve around the concept of system redesign. The modern use of systems of connection aids all of the redesign principles articulated by the IHI Leadership Alliance. Democratization of access to personal health information with appropriate attention to confidentiality and data sharing to promote rapid learning are linked fundamentally to the vision of a shift in the balance of power and the need to customize care to each individual. Collection and use of this information also are critical to wise standardization.

- Person- and family-centered care also are closely linked to the redesign principles. The need to reorient care to meet individual needs is central to the redesign envisioned by the Alliance. This concept is embraced by current IHI President and CEO Maureen Bisognano, who says the healthcare system needs to stop asking people what is the matter with them and start asking what matters to them.

- Devices, sensors, and apps provide opportunities to implement the principle of moving knowledge, not people. One example is an English ophthalmology project called Peek, which uses cell-phone-based technologies to perform retinal imaging of children all over the world.

- The national health information infrastructure is not yet sufficient. EHRs have become a burden as well as an asset because of the ways in which they have been designed and implemented. Though they have been adopted widely, they lack the necessary interconnectivity. Unfortunately, EHRs are being used to support the status quo of the healthcare system rather than change it. However, with the proper support, and perhaps the example of cancer care, the national health information infrastructure can achieve new levels of interconnectivity.

- Redesign of the healthcare system will require cultural and sociological changes. Implementation of truly person- and family-centered care will challenge current concepts of the proper roles and capabilities of patients, families, and providers. Widespread connectivity will threaten world boundaries and raise issues of licensure and accreditation. There will be resistance to these changes. Support for telemedicine and telehealth has been limited in some settings because of resistance from established guilds and those with economic interests in the status quo. This resistance, however, is transitional. Change is needed, and the oncology field should take the lead.

- The current healthcare delivery system should not be replicated in digital form. A new and improved system should be created through better use of information technologies and modern technologies.

- In addition to achieving better care and promoting prevention, the new healthcare system must reduce per capita healthcare costs. At current levels of spending, U.S. healthcare is confiscating resources from non-healthcare efforts like education, housing, infrastructure, and social justice. This level of spending is not needed to achieve high-quality care, and it cannot continue.

DISCUSSION

Participants were asked to comment on the proposed Scenario 2020 and consider the impact it would have across the cancer continuum for people with cancer and those at risk for cancer.

- There is tension associated with fundamental redesign of the healthcare system proposed by Dr. Berwick. It would be difficult to accomplish this by 2020 because there is not widespread acceptance at the national policy level that redesign is necessary. It also likely will take longer than this to achieve the types of cultural changes in patients, health-seekers, and providers that will be required to support this system.

- The connectivity of patients with each other is an important theme that was not emphasized in the scenario. Connection of patients to each other has transformative potential.

- Digitizing the current, ineffective healthcare system is not desirable. In the absence of system redesign, the healthcare system would benefit from increased integration and/or interaction with peer-to-peer groups and other groups, some of which provide exceedingly good support to patients. Some patients like the fact that their peer-to-peer networks are separate from their healthcare, but the healthcare system could learn from these groups.

- It is not useful to share data if those data are incorrect or incomplete. There must be a focus on data quality and completeness.

- It is important to consider the desired outcomes for various elements of redesign so that value can be measured and results can be optimized. Some changes may not increase survival but may improve patient satisfaction. Some changes may increase cost but provide other valuable benefits, such as improving communication or information flow.

- Changes and interventions to achieve the proposed scenario will be effective only if they take into account the context in which they are being implemented. It is important to ensure that systems are effectively implemented before drawing conclusions about their impact on outcomes.

- It is important to better integrate patients in the healthcare system, even if it does not improve outcomes.

- There was a recent proposal to expand the Triple Aim to the Quadruple Aim to address the provider burnout that is being caused by health information technology initiatives and other demands. The provider point of view needs to be considered as part of any healthcare system redesign.

- As connectivity expands, it is important to consider the capacity of patients and individuals. Patients become involved in activities such as social networks and research projects by choice. However, if opportunities and requests for connectivity increase, patients may become overwhelmed. An effective system should be optimized to each patient's needs and capacity.

- Patients need to be involved in research throughout the process, starting in the design phase.

- While democratization of data is potentially powerful, providing information to patients also may cause stress and confusion if it is not provided in a meaningful way.

- The ability of safety-net health centers to achieve connectivity must be considered since the populations served in these settings have relatively high cancer burdens. These centers may have a difficult time managing many aspects of the proposed scenario.

CALIBRATION OF ASSESSMENT AND RECOMMENDATIONS

Dr. Witte informed participants that, at the conclusion of the series, Panel members and staff will review workshop outcomes and additional relevant information to inform development of recommendations to be included in the report to the President. The Panel aims to identify recommendations that are specific, linked to a responsible stakeholder(s), and reasonably attainable. While the President and his scientific advisors are the primary audience of Panel reports, these reports are also for the larger group of National Cancer Program stakeholders—including public and private members—that can accelerate progress against cancer. Participants were asked to discuss the four elements of Scenario 2020 and propose recommendations for achieving this desired future state in these areas.

PERSONAL HEALTH INFORMATION AND DATA SHARING—ASSESSMENT AND RECOMMENDATIONS

Technology has created opportunities for generating and sharing enormous amounts of health information. Participants were asked to consider how these opportunities could be harnessed to improve cancer care across the continuum. These comments reflect views of meeting participants from one to

many. There was a lot of discussion about what kinds of structures might be needed to facilitate connected health in general and for cancer care more specifically.

- Data fluidity is an issue that relates to all four components of the scenario. Patients should maintain access to and control of data that are collected from them for clinical or research purposes.

- The Department of Health and Human Services (DHHS) should create an Office of the Engaged Patient. Unlike efforts that work to engage or activate patients, this Office would be a venue for engaged patients to play an active role in policy making, research, and other decision making across DHHS. This Office also could examine how patients are engaged across different agencies and programs. Currently, patients must go to several sources and websites to find ways to get involved. It would be helpful if there were a single, coordinated program that could help patients identify and access opportunities. The Office of the Engaged Patient also could promote research on the science of patient engagement, which would provide insight into the value of patient engagement and ways to enhance it. One risk of creating an Office of the Engaged Patient is that other parts of the federal government might feel it is no longer their responsibility to work directly with patients. Susannah Fox, the new DHHS Chief Technology Officer, is an expert in peer-to-peer communication and would be a good person to drive this idea forward.

- An alternative to the Office of the Engaged Patient would be to create a steering committee within DHHS or AHRQ that would interact with and learn from independent patient groups. This would allow federal agencies to benefit from the knowledge and activities of these groups without imposing an additional burden on patients.

- It is important to consider the perspectives of healthy individuals, providers, and others in addition to patients. This could be done through a DHHS Office of Connected Health, which would be broader than the proposed Office of the Engaged Patient. The Office of Connected Health would differ from ONC because it would focus on patient care as opposed to IT solutions. The patient care focus would include IT but would also incorporate consideration of provider care plans, patient engagement, and other factors that facilitate effective care.

- It is critical to have all stakeholders at the table so that they can learn from one another. Providers can learn from patients, and patients can learn how to better interact with the healthcare system.

- All health system general counsel, privacy officers, compliance officers, and medical records staff should receive training that makes it clear that the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule is not intended to prevent patients from accessing their medical records.

- Providers often do not have access to their patients' EHRs from other institutions or providers. Patients often need to provide paper copies of their records to providers. There should be a service, similar to the credit bureau, that maintains a minimal set of information about patients' cancer diagnosis and treatment. Patients could provide access to their providers as needed. It may be possible to populate this database using national cancer registries (e.g., NCI Surveillance, Epidemiology and End Results [SEER]) rather than building a new system.

- EHR data often contain inaccurate and/or incomplete information. Patients should have the ability to flag or change incorrect data. Health records should represent the whole patient, not only the most immediate illness.

- EHRs currently include notes from providers, but are not designed to capture notes from patients. It would be beneficial if patients could comment on provider notes or provide notes of their own.

- There should be a uniform, public, open-programming interface that enables patients, providers, and apps to have uniform access to EHR data. This would enable patients to gain access to their data and integrate data from different sources. It also would allow healthcare apps—either clinician-, researcher-, or patient-facing—that are written once to run in all healthcare settings. These application programming interfaces (APIs) are not dependent on standards for every data element but provide a

way for users to request certain types of information. EHR vendors are in the process of adopting APIs, but optimizing their functionality will require guidance from the provider and patient communities. The most effective way to drive progress toward this aim is for healthcare systems to demand API integration into EHR systems. One reason that Meaningful Use was not as effective as desired is that EHR vendors were told what features to include in their systems and healthcare systems were told what systems they had to buy. Consumers were not directly applying market pressure to EHR vendors.

- API adoption also may benefit from minimal regulatory oversight from ONC, CMS, or another agency to define system requirements; however, care must be taken that the regulations do not impede innovation. Regulatory oversight is particularly challenging in this area because of the fast pace of technology development.

- Standardization and quality control are critical to any data system. Quality control measures are particularly important when data are being generated by a significantly distributed and complex network of individuals and devices. It is also important to keep in mind that general trends revealed by analyses of big data may or may not be relevant to individual patients.

- Health Level Seven International (HL7) is an industry association that develops IT standards. HL7 may have a role to play in development of APIs for healthcare. HL7 is overseeing vendor adoption of an API for the SMART HealthIT initiative. The National Institute of Standards and Technology (NIST) also could convene stakeholders to discuss standards. AHRQ also may be able to participate in guideline development.

- The 21st Century Cures Act currently includes language indicating that the Health IT Policy Committee should incorporate policies to update interoperability standards for EHRs.

- CMS may have a role in developing and implementing standards. CMS has an interest in incentivizing better connectivity and coordination of care. The Center for Medicare and Medicaid Innovation (CMMI) Oncology Care Model Demonstration Project (OCM), which is being rolled out in 200 academic and community oncology practices across the country, requires patient navigation, EHR use, incorporation of patient-reported outcomes into EHRs, and 24-hour patient access to a knowledgeable provider for questions. These practices are struggling to define the best ways to accomplish these goals.

- The National Quality Forum has convened panels on patient- and family-centered care and on patient engagement and standards. There has been progress in developing standards for patient-centered coordination of care, and there is ongoing discussion about how to integrate these into pay-for-performance systems.

- Policies and standards should be developed to guide collection and use of patient-generated data, including data from consumer health tools.

PUBLIC COMMENT

- There was no comment from the public.

PERSON- AND FAMILY-CENTERED CARE—ASSESSMENT AND RECOMMENDATIONS

Participants were asked to discuss ways in which connected health could support person- and family-centered care for cancer.

- When considering healthcare system redesign and implementation of connected health, it is critical that the perspectives and needs of all stakeholders are taken into account. The patient perspective is extremely important and often has been ignored within the traditional healthcare delivery system. However, an effective system also needs to acknowledge and address provider needs. Many of the

mandates that have been implemented or are being discussed create a burden for providers. Providers will not support a system that does not alleviate this burden, and a system that does not have provider support will fail. The perspectives of healthcare systems and payors also need to be considered. The proposed Office of Connected Health would consider the perspectives of all stakeholders, not only those of patients.

- An Office of Connected Health could potentially identify weaknesses in the healthcare system and identify strategies for addressing these weaknesses using technology or other means.

- Licensure of healthcare professionals in the United States is done on a state-by-state basis, which prevents coordinated care. This issue could be addressed by the Office of Connected Health. One potential solution would be to create a way for patients to consent to receiving care from providers licensed in any state.

- The Office of Connected Health could help define and support telemedicine.

- Current reimbursement practices are a barrier to implementation of connected health.

- Passage of legislation necessary to create a new federal office would take at least three years. For this and other reasons, it may not be preferable to create a new office like the proposed Office of Connected Health to drive connected health.

- The Panel should look at ongoing work of ONC and other offices and organizations before proposing creation of a new office. Some of the proposed functions could be carried out within existing organizations. In its early years, ONC administered large amounts of grant funding, but it now is focused on promotion of interoperability and creating linkages across the healthcare continuum.

- Rather than recommending creation of a new office, the Panel should focus on how to achieve a broader level of engagement among all stakeholders and to foster communication and cross-pollination. It may be possible to accomplish this by increasing meaningful interactions among existing groups rather than creating a new organization. One way to do this might be to support travel for stakeholders to attend one another's conferences (e.g., patients attend provider-focused conferences) and/or sponsor side sessions at conferences to promote formal cross-stakeholder discussions. Funding organizations also could promote interactions by issuing Funding Opportunity Announcements that require grantees to collaborate across sectors. The Patient-Centered Outcomes Research Institute (PCORI) has adopted this approach; each proposal submitted to PCORI is required to include an engagement plan in addition to a research plan.

- It would be useful to identify the types of data needed to illustrate the value and effectiveness of connected health. Research funding organizations like NCI and the Robert Wood Johnson Foundation could be asked to support research to address information and evidence gaps.

- Many providers do not understand the meaning of the term "connected health" or the value of this approach to healthcare. There should be a broad awareness campaign to educate providers and others about this topic. The Federal Communications Commission (FCC) Connect2Health Task Force has been charged with raising awareness of the value of connectivity in health.

- Communication between patients and providers and among providers is a critical part of an integrated health system, but it is also important to have resources to support patients and providers. Kaiser utilizes certified diabetes educators to work with newly diagnosed diabetes patients. This infrastructure goes beyond communication and helps relieve the burden on providers.

- Misinterpretation of HIPAA at the provider and institutional levels is impeding data portability and information sharing. Institutions need guidance on appropriate implementation of HIPAA. HIPAA makes it difficult for researchers to share medical information. Researchers are unsure whether information should be shared with patients and/or their healthcare providers. There also are issues related to communicating genetic risk to family members of patients and research participants.

Researchers cannot currently inform people that one of their family members has tested positive for a genetic mutation and advise them to get tested.

- Quality metrics are needed to measure whether providers and health systems are delivering patient- and family-centered care. Quality assessment organizations, payors, EHR vendors, providers, and patients should be convened to discuss and develop appropriate metrics. Once these are developed, it will be possible to create incentive payments to promote this care paradigm.

- It will be important for the Panel to highlight barriers to connected health that are specifically relevant to cancer. A potential recommendation would be to build an evidence base for connected health in cancer. For example, the need for coordinated care is particularly pronounced in cancer, as is the need to address rising costs of care. Research could be done to characterize the costs and consequences associated with fragmented cancer care and identify connected health solutions to overcome this fragmentation. If the interventions require additional resources without reducing costs or increase the burden on providers, they will not be adopted. Once evidence and metrics of effectiveness are established, it will be possible to link payment to connected health activities.

- Care coordination efforts should include coordination of all services patients receive, including services received outside the traditional healthcare setting.

- Many cancer patients receive care that is not in alignment with their values, and clinicians miss about half of symptoms experienced by patients during cancer treatment. Many clinicians are concerned about these and other issues in cancer care, but they are unsure how to address them within their practices. Research should be done to identify problems in cancer care and develop interventions that address these problems at the systems level. Implementation research also is needed to determine the best ways to promote widespread adoption of effective interventions.

- When patients and providers engage in shared decision making, providers learn more about their patients' values and understanding of disease and treatment. The American Society of Clinical Oncology published a conceptual framework for shared decision making in June 2015 and has asked for public opinion.

- Funding agencies need to think more broadly about how to conduct research on connected health. Nontraditional information sources may be useful (e.g., social networking sites), and capacity and infrastructure will be needed to extract valuable information from these sources.

- A study of the types of information being discussed by patients in peer-to-peer groups would be informative. The results could point to gaps in other areas that could be addressed. For example, patient networks can provide insight into patient perspectives on patient-provider conversations, such as the types of information that patients miss or misunderstand when they are talking with their providers. Patients end up talking to one another about these issues. Providers could use this information to guide conversations with future patients.

- Connected health strategies need to take into account that many patients have low health literacy and lack resources. A successful system must meet the needs of these patients as well as those who are savvy and highly connected.

DEVICES, SENSORS, AND APPS—ASSESSMENT AND RECOMMENDATIONS

Dr. Ozcan presented examples of technologies poised to transform healthcare delivery and health management. Participants were asked to discuss opportunities to use devices, sensors, and apps to support connected health and propose recommendations for consideration by the Panel.

DR. AYDOGAN OZCAN

DEMOCRATIZATION OF NEXT-GENERATION IMAGING, SENSING, AND DIAGNOSTICS TOWARD CONNECTED HEALTH

Background

Dr. Ozcan is the Chancellor's Professor at the University of California, Los Angeles (UCLA) and a Howard Hughes Medical Institute (HHMI) Professor leading the Bio- and Nano-Photonics Laboratory at UCLA School of Engineering. He is also Associate Director of the California NanoSystems Institute. Dr. Ozcan holds 30 issued patents (all licensed) and more than 20 pending patent applications and is also the author of one book and coauthor of more than 400 peer-reviewed research articles in major scientific journals and at conferences. Dr. Ozcan is a Fellow of the International Society for Optics and Photonics (SPIE) and The Optical Society, and has received major awards, including the Presidential Early Career Award for Scientists and Engineers, the SPIE Biophotonics Technology Innovator Award, the SPIE Early Career Achievement Award, the Army Research Young Investogator Award, the National Science Foundation (NSF) CAREER Award, the National Institutes of Health (NIH) Director's New Innovator Award, the Office of Naval Research Young Investogator Award, the Institute of Electrical and Electronics Engineers Photonics Society Young Investigator Award, and Massachusettes Institue of Technology's TR35 Award for his seminal contributions to near-field and on-chip imaging and telemedicine-based diagnostics. Dr. Ozcan is also the recipient of the National Geographic Emerging Explorer Award, the National Academy of Engineering Grainger Foundation Frontiers of Engineering Award, the Popular Scientist Brilliant 10 Award, the Gates Foundation Grand Challenges Award, the Popular Mechanics Breakthrough Award, the Netexplorateur Award, the Microscopy Today Innovation Award, and the Wireless Innovation Award organized by the Vodafone Americas Foundation, as well as the Okawa Foundation Award.

Key Points

- Conflict of interest disclosure: Dr. Ozcan is co-founder of Holomic LLC, a startup company in Los Angeles that is commercializing some of the devices presented.

- Technology, broadly defined, will be part of the solution for cancer. It may not be the most significant element for better patient care and outcomes, but transformative technologies might open up new avenues and opportunities that previously could not be imagined.

- Questions to be addressed through the presentation include: Can we convert patients' homes into advanced laboratories for medical diagnosis, monitoring, and preventive and personalized medicine? Can we manage costs through early diagnosis, better treatment, and better adherence? Can innovative and cost-effective technologies be used on massive scales to improve cancer diagnosis and care in resource-limited settings? Can big and small data be harnessed to achieve better patient outcomes?

- Consumer devices benefit from economies of scale. These devices are affordable because so many people purchase and use them. For example, there are 7 billion cell phones in use worldwide.

- Many of the technologies embedded in consumer devices (e.g., mobile phones, tablets, personal computers) can be reengineered for new purposes. Leveraging these platforms could allow many of the medical tests traditionally performed in medical or laboratory settings to be cost-effectively carried out in other settings. Many technologies are combining mobile phones and three-dimensional printing to make advanced biomedical measurements.

- Slide scanners used by histopathologists can cost between $50,000 and $100,000. It is possible to use mobile phone technology to create a high-end microscope that recreates images using shadows instead of using lenses like a traditional microscope. The lens-free device is similar in weight and height to an iPhone and is capable of capturing images at gigapixel resolution. Data can be captured

in the field and transmitted across long distances to wherever pathologists are located. Lens-free imaging can be used to analyze histopathology slides of breast tissue or Pap smears.

- Mobile phone attachments can be used to view viruses and single DNA molecules. This technology could be used to analyze copy number variation, distribution of genes, and single-nucleotide polymorphisms, as well as to carry out other types of genetic testing. These types of portable devices also can be used to carry out diagnostic tests and measure biomarkers.

- Data gathered using mobile devices can be shared, creating new opportunities in the areas of micro- and nano-analysis, medical diagnostics, and epidemiology.

- Mobile devices could facilitate collection of data from patients while they are in their homes. These devices also could be used to allow limited-resource settings, such as small nurse offices in low-income countries, to function like advanced hospitals through the use of telemedicine.

- The potential of mobile medical devices will be realized only if the technologies are cost-effective. Using technology already being manufactured for consumer devices helps achieve this; however, the market lifetime of consumer technologies is short, which creates some challenges.

- Standards and quality control are critical for generating useful data.

- Portable medical devices must be designed so that they can be used effectively by the average patient.

- There are challenges related to deployment and adoption of new technologies in medicine.

DISCUSSION

- Devices, sensors, and apps have potential to enhance cancer therapy and cancer research.

- Creation of the previously discussed uniform, public, open-programming interface will support development of apps that facilitate connected health.

- Low-income populations often experience discontinuity in access to technology. For example, individuals may frequently transition between cell phone plans and have periods during which they have no service. FCC should be charged with ensuring that all people in the United States have consistent access to broadband service. For example, subsidies should be provided to low-income families to maintain broadband access.

- FCC currently has a $400 million program to promote connectivity of rural healthcare programs, but the program is undersubscribed. Only about $200 million is distributed each year. FCC is looking into the reasons for this. There also are non-rural areas of the country that face connectivity challenges, so there is opportunity for further support.

- Tools should be developed to address the social issues facing cancer patients. Many patients undergoing treatment do not have family members or caregivers nearby and may suffer from social isolation.

- Technologies must be relevant to target users or they will not be widely adopted. Developers must take into account health literacy and technology literacy levels of target users. Most technology developers are focused on profit and may not invest in tools specifically for underserved populations.

- Devices and technologies can provide data without necessarily being patient centered or providing actionable information. The focus should be on the types of devices and information that enhance patient experiences and connectivity in a way that leads to improved outcomes. In oncology, devices that measure activity may help providers understand how patients are doing following treatment. Technologies that allow collection of patient-reported outcomes between visits also may be helpful.

- The HIV/AIDS community has developed strategies and point-of-care technologies that have allowed them to deliver interventions to villages in Africa. The oncology field should learn from this approach and find ways to deliver care, treatment, and health management to individuals in their communities.

- Careful consideration must be given to the quality of data collected from devices and apps. Poor-quality data can lead to false impressions. Standards also are important when data are aggregated. In addition, decisions will need to be made about what types of patient-generated data should be integrated into EHRs.

- Standards for metrics of patient-reported outcomes in cancer care are needed, as are standards for how that information is represented in EHRs. The Food and Drug Administration (FDA) should be engaged to help develop these standards since there already are ongoing discussions within FDA about how to utilize patient-reported outcomes in drug approval deliberations in cases in which survival or tumor shrinkage are not appropriate endpoints.

- The NIH and NSF Small Business Innovation Research (SBIR) programs could be charged with supporting development of technologies to address gaps in connected health. For example, consumer-facing apps could be developed to provide patients with high-quality data.

- Data can be collected and reported more frequently when collected via device rather than by a clinician or researcher. This could have significant implications for clinical trials by allowing more frequent measurement of pharmacokinetic data and/or indicators of adverse events (e.g., hematocrit measurement). This could facilitate faster development of effective drugs and earlier elimination of ineffective or potentially dangerous drugs. Research should be done to validate sensors and devices for use in clinical trials so that FDA will accept data from these devices in decisions about drug authorization.

- Clinical trialists also should be urged to utilize mobile-based surveys to collect patient-reported outcomes.

- Mobile technologies may help address health disparities by providing point-of-care services to populations that may not otherwise access the care they should receive, including follow-up care. Mobile technologies also could help researchers learn about underserved populations that often are underrepresented in clinical trials.

- Data from technologies and devices used by patients should be integrated with clinical data and be part of the clinical workflow so that patients and providers can use them to inform decision making.

- Apps could be created to support patients being treated with specific drugs. The apps could provide information on potential side effects, allow patients to report side effects, facilitate prescriptions to treat side effects, and connect patients with other patients taking the same drugs. This would enable creation of a database of side effects, which would be particularly useful for new drugs. This type of app could be useful for informing providers about side effects, but anonymous collection of symptoms and side effects also may be useful because patients often are reluctant to report these types of things to their oncologists. A group at the Center for Connected Health in Boston is working on a similar app development project However, there may be challenges associated with developing an app that provides medical advice (i.e., how to deal with side effects).

- Apps and devices also could be used to enhance clinical trial recruitment or support new types of clinical trials.

- Patients should have access to all data generated about them for clinical or research purposes.

- There have been enormous investments of capital in technology and app development in healthcare, but little of this has been focused on cancer. The Panel should recommend that various mechanisms—such as challenges, competitions, and prizes—be used to promote development of apps and devices specifically for cancer. There are many developers who would be thrilled to work in this area if given an incentive. Patient advocates have many ideas about what types of apps and technologies would be useful. Funding agencies could sponsor a workshop with a variety of patient advocates and innovators to solicit these ideas.

- Some apps and other technologies have been integrated into clinical workflows. Brigham and Women's Hospital recently authorized development of an app for pain management that will be available to all patients treated at the institution. Chronic and mismanaged pain is a huge cost driver across a range of conditions, and this app has potential to address that problem.

- Small technology development companies often do not communicate with larger companies until their projects are in a late stage of development. The federal government may be able to facilitate relationships between small and large companies earlier in the development process by funding consortia or through other strategies.

- Oncologists understand the benefit of EHRs, but they create workflow challenges and consume a lot of time. EHRs should be integrated with other technologies so clinical data can be used for other purposes.

NATIONAL HEALTH INFORMATION INFRASTRUCTURE—ASSESSMENT AND RECOMMENDATIONS

Dr. Mason provided an update on ONC activities with respect to EHRs and connected health. Participants were asked to discuss infrastructure-related barriers to connected health and propose recommendations for overcoming these barriers.

DR. THOMAS A. MASON

IMPROVING THE QUALITY OF HEALTH AND CARE THROUGH INFORMATION AND TECHNOLOGY

Background

Dr. Mason is Chief Medical Officer in the Office of the National Coordinator for Health Information Technology, which is at the forefront of the nation's health information technology efforts to adopt and meaningfully use health IT and collectively achieve health IT interoperability as a foundational element of better health for everyone in America. Dr. Mason leads and champions clinical oversight of ONC programs and clinical coordination within ONC. Dr. Mason is a board-certified internist with an emphasis on primary care and preventive medicine with 14 years of clinical experience. Throughout his career, he has led implementation of multiple EHR systems and has more than ten years of additional experience and training in the principles of public health and population medicine. Prior to his role at ONC, Dr. Mason was Chief Medical Informatics Officer of the Ambulatory and Community Health Network of The Cook County Health and Hospitals System (CCHHS) in Chicago, the third largest public hospital system in the country. In this role, he led implementation of an outpatient EHR system consisting of 16 primary care health centers and 110 specialty care clinics staffed by more than 600 physicians and serving more than 200,000 patients per year. He also played a vital role in the implementation of the Patient-Centered Medical Home wellness management and disease prevention model at CCHHS and led both CCHHS hospitals to the successful attestation of Stage II Meaningful Use. In addition to his duties as Chief Medical Informatics Officer, Dr. Mason was also Medical Director of a CCHHS community health center in Chicago's Southside, where he actively cared for patients. Dr. Mason earned his MD from the University of Illinois College of Medicine and completed his residency in internal medicine at Rush University Medical Center and Cook County Hospital.

Key Points

- ONC was created in 2004 by Executive Order and was legislatively mandated by the HITECH Act in 2009. The HITECH Act created four grant programs to be administered by ONC, one of which is the Regional Extension Center (REC) Program. The goal of the REC Program is to support adoption and use of health IT by 100,000 of the nation's 302,000 primary care providers. There are 62 RECs across the United States. Each REC has a defined service area and specific number of providers and provides

- unbiased, practical support for health IT issues. Services include practice-level health IT education, EHR vendor selection support, EHR implementation support, practice workflow redesign, Meaningful Use optimization, and other types of support.

- Three milestones are defined within the REC Program: provider enrollment in the program, going live with an EHR, and achieving Meaningful Use. RECs currently are working with more than 150,000 primary care providers in the United States. Over 144,000 of these have active EHR systems, and 112,000 have demonstrated Meaningful Use.

- The percentage of physicians who e-prescribe has increased dramatically in every state as EHR adoption has increased. In 2008, fewer than one in five physicians e-prescribed, while in 2014 rates of e-prescribing were between 80 and 100 percent in some states and were not lower than 40 percent in any state. E-prescribing eliminates the risk of illegible prescriptions and improves efficiency. In addition, patients no longer have to make a separate trip to the pharmacy to drop off a prescription.

- Over 75 percent of U.S. hospitals have basic EHR systems, and a similar percentage of physician practices have adopted EHR systems. The increase in EHR adoption over the past several years has been driven in part by American Recovery and Reinvestment Act funding.

- ONC is shifting from focusing on EHR implementation to optimization. Health IT is not a solution; it is a tool. Consideration is being given to ways to redesign workflow and increase interoperability to optimize performance.

- DHHS is working to create an interoperable learning health system that achieves better care, smarter spending, and healthier communities. Areas of focus in this effort include improving the way providers are paid, improving and innovating care delivery models, and broadly sharing information with providers and consumers to support informed decisions.

- The ONC interoperability roadmap—which is a collaborative effort of federal, state, community, and private partners—describes a health IT ecosystem where health IT is readily available to empower consumers, support clinical decision making, inform population and public health, inform value-based payment, and advance science. The roadmap is currently in draft form and will be finalized later in 2015. It is built on five pillars, each of which is associated with specific critical actions. These pillars include core technical standards and functions; certification to support adoption and optimization of health IT products and services; privacy and security protections for health information; supportive business, clinical, cultural, and regulatory environments; and rules of engagement and governance.

- The roadmap has near-term, intermediate, and long-term goals. Within two years, the goal is to achieve the ability to send, receive, find, and use a common clinical data set. The common clinical data set includes a standardized way to capture patient goals, which should facilitate creation of longitudinal care plans. By 2020, the goal is expansion of interoperable data, users, sophistication, and scale. By 2024, it is hoped that a large-scale learning health system will be in place.

- The roadmap's guiding principles include leveraging the market and empowering individuals, among other things. Consumers should drive the need for interoperability. Incentives and policies that favor data flow are critical.

- The success of interoperability depends on standardization of technical standards, patient engagement and empowerment (including understanding that health takes place outside the healthcare setting), a person-centered approach to coordinated care across the continuum, and education of providers on current privacy and security rules.

- It is important to motivate use of standards and information exchange through appropriate incentives. It also is critical that EHRs be practical and useful to providers and consumers at the point of care.

- An interoperable system is needed that will go beyond the healthcare system to promote population health management. Health IT should be advanced beyond EHRs.

- ONC recognized the need to provide incentives to increase the flow of information. ONC has released a Funding Opportunity Announcement that will award cooperative agreements to states interested in increasing data movement and interoperability.

- It is important to have frontline providers engaged in decision making during technology design.

DISCUSSION

- There are some concerns that local customization of EHR systems impedes data flow between organizations. This is one reason why "standardization of standards" is important. Congress is interested in this issue and has asked ONC to provide documentation on business practices or models that impede the flow of data. If appropriate standards are in place, customization should not prevent data sharing.

- ONC is focused on reducing the administrative and documentation burden on providers while streamlining certification criteria. This should be reflected in the 2015 edition of the ONC standards for certified EHR technology, which currently are under development.

- ONC is focused on the healthcare system as a whole. Many of the principles in the roadmap are highly relevant to cancer, but one of the areas that has particular potential to improve cancer care is creation of EHR systems that capture meaningful family history data in a way that is standardized and helps providers counsel patients regarding prevention and treatment.

- It is important that ONC receives input from other stakeholders on various issues. However, patients and providers often are unaware of ongoing efforts by ONC and other federal agencies. There should be a structured way of informing stakeholders about comment periods and other ongoing policy work.

- Regulations and policies often have unintended consequences. In an effort to avoid fines and/or legal liability, legal counsel often advise their organizations to implement restrictive policies that may not be consistent with appropriate data sharing or delivery of patient-centered care. There should be increased communication with organizations to clarify regulatory intent. There is information on HIPAA privacy protections on the website of the Office for Civil Rights that may be useful for these purposes.

- Studies conducted using linkages between the NCI SEER database and Medicare databases and other data sources have provided substantial insights into quality of care. However, one limitation of SEER is that it is not linked to EHR systems. Also, SEER-Medicare studies are limited to populations covered by Medicare, which are not representative of the U.S. population as a whole. It would be beneficial if SEER could be linked to EHR systems and private payor data. NCI is conducting pilot studies to explore linkages of SEER with other databases.

- In North Carolina, state cancer registry data have been linked to data from public and private payors. This has yielded useful information, but it has not yet been possible to link these data to EHR data.

- Linkages with EHR systems have been accomplished on a local scale in some settings, but there are challenges associated with doing this on a larger scale, particularly on a national scale. One complicating factor is that patients move and change insurance providers, which makes linkage difficult. There also are policy barriers. States have different laws and regulations about registry data and linkages. State legislation generally allows registries to collect data without consent because they are used for public health purposes. In many cases, this prevents access to data for research or other purposes. The Panel could recommend that states make the legislative changes necessary to allow registry data to be used for other purposes.

- SEER data are not always accurate. For example, in California, a cancer recurrence often is recorded as a primary cancer. In other instances, cancer stage information may be incorrect because only the stage at diagnosis is recorded. There also are limitations with payor data; for example, these data indicate that radiation was administered but do not specify whether it was for treatment or palliative

purposes. Before data are shared and used for research and other purposes, data quality issues must be considered and addressed.

- Patients should have access to their data in accessible formats so they can share them with whomever they choose and use them for whatever purpose they choose. Patients also should have the ability to correct mistakes in their records. Most patients report at least some problems with their medical record data, and current mechanisms for making corrections often do not work. This should be considered an urgent priority. Delays in implementation of Meaningful Use criteria related to patient access to data are discouraging.

- Provider workflows often are not conducive to capturing comprehensive and accurate information. There is not sufficient time during appointments to collect and document information. One potential way to address some of these challenges would be to ask patients to compile information before an appointment and then review it with the provider.

- Shortcomings in EHR data are problematic for providers as well as for patients. Providers often cannot get a good sense of a patient's history and problems from the EHR because these systems are optimized to facilitate reimbursement, not patient care. Strategies are needed to improve the quality of medical record data. The Federal Aviation Administration has employed systems engineering techniques to address its data issues. A similar approach may be effective to improve quality of medical records. The Panel could recommend that NCI or AHRQ or another funding agency work with ONC to provide support for a pilot study to explore this idea.

- The ONC Office of Consumer e-Health is working on a Consumer e-Health Action Plan. One of the cornerstones of this effort is the Blue Button Initiative, which aims to ensure that consumers have electronic access to their health information. A secondary goal of the Initiative is to ensure that patients are able to correct inaccuracies in their data. Over 600 organizations have pledged to liberate their data and are in various stages of releasing data to consumers. It may be possible to leverage this effort to increase data quality in EHRs.

CONCLUSIONS AND CROSS-CUTTING RECOMMENDATIONS

- Clinicaltrials.gov does not meet the needs of providers and patients. There should be resources that help patients and providers identify appropriate clinical trials based on a number of factors (e.g., genetic mutation, geography, insurance). This is particularly relevant as genetic testing for specific mutations becomes more common and the number of precision medicine trials and treatments increases. Providers in community settings likely will need support in understanding the options for patients with less-common mutations. Patients currently often need to help each other identify clinical trial options.

- Public and private funders should come together to develop a consolidated strategy to fund technology development projects from beginning to end. Several steps and phases are required for successful development, and it can be difficult to secure funding from separate sources for various phases. There are some examples of collaborations among funders—the John Hartford Foundation is funding development of an initial blueprint on alignment of care delivery with patient preferences for patients with multiple chronic conditions. Once this pilot is completed, PCORI is going to fund the next phase.

- The Panel should reach out to the Robert Wood Johnson Foundation to discuss how connected health could be incorporated into the Culture of Health initiative.

- It would be helpful to have a system to facilitate rating of connected health tools and apps by consumers and/or a dedicated third party.

PUBLIC COMMENT

- There was no comment from the public.

CLOSING REMARKS

Panel members thanked participants for their contributions. They expressed hope that participants will be willing to provide additional input throughout the remainder of the series and report development process.

CERTIFICATION OF MEETING SUMMARY

I certify that this summary of the President's Cancer Panel meeting, *The Connected Cancer Patient: Vision for the Future and Recommendations for Action*, held July 9, 2015, is accurate and complete.

Certified by: _____   Date: September 14, 2015
                                                            _____

       Barbara K. Rimer, DrPH
       Chair
       President's Cancer Panel