

# MEETING SUMMARY

## PRESIDENT'S CANCER PANEL

### ENGAGING PATIENTS WITH CONNECTED HEALTH TECHNOLOGIES

December 11, 2014  
Cambridge, Massachusetts

This workshop was the first in the President's Cancer Panel's (the Panel) 2014-2015 series on connected health and cancer. The workshop brought together leaders in academia, technology, government, advocacy, and healthcare to explore how use of new technologies by healthcare systems and patients/individuals could transform management of health and chronic diseases, including cancer. 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, Dr.P.H., Chair  
Hill Harper, J.D.  
Owen Witte, M.D.

#### ***National Cancer Institute, National Institutes of Health***

Abby Sandler, Ph.D., Executive Secretary, President's Cancer Panel

#### ***Meeting Co-Chair***

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

#### ***Participants***

Gabriel Eichler, Ph.D., General Manager, PatientsLikeMe  
Joshua Feast, M.B.A., CEO, Cogito Health  
Gilles J. Frydman, Chairman, Smart Patients  
M. Chris Gibbons, M.D., M.P.H., Associate Director, Urban Health Institute, Johns Hopkins University  
Thomas Goetz, M.P.H., Co-Founder, Iodine  
David H. Gustafson, Ph.D., Director, Center for Health Enhancement Systems Studies, University of Wisconsin-Madison  
Kamal Jethwani, Ph.D., M.P.H., Corporate Manager of Research & Innovation, Center for Connected Health, Partners HealthCare  
Warren A. Kibbe, Ph.D., Director, Center for Biomedical Informatics and Information Technology,  
National Cancer Institute  
Joseph C. Kvedar, M.D., Director, Center for Connected Health, Partners HealthCare, Massachusetts General Hospital, Harvard Medical School  
Kenneth D. Mandl, M.D., M.P.H., Professor, Harvard Medical School, Children's Hospital Informatics Program, Boston Children's Hospital  
Elizabeth D. Mynatt, Ph.D., Executive Director, Interactive Computing, Institute for People and Technology

Rosalind W. Picard, Sc.D., Professor, Media Arts and Sciences, Massachusetts Institute of Technology;  
Director, Affective Computing Research, MIT Media Lab

Ruth Rechis, Ph.D., Vice President, Programs & Strategy, LIVESTRONG Foundation

Erin Siminero, M.P.H., Consumer eHealth Portfolio Lead, Office of the National Coordinator for Health Information Technology, U.S. Department of Health and Human Services

Paul Tarini, Senior Program Officer, Robert Wood Johnson Foundation

Kasisomayajula “Vish” Viswanath, Ph.D., Professor of Health Communication, Harvard T. H. Chan School of Public Health, Dana-Farber Cancer Institute, Dana-Farber/Harvard Cancer Center

## **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. Dr. Hesse, who is Chief of the Health Communication and Informatics Research Branch in the National Cancer Institute Division of Cancer Control and Population Sciences, was unable to attend the workshop, but contributed significantly to its planning. Dr. Rimer also introduced workshop facilitator Robert Mittman and Panel staff members. Dr. Rimer emphasized that while the term “patients” is often used, individuals who use connected health tools for prevention are not necessarily patients. Perhaps the greatest potential of connected health lies in the power to prevent cancer and other diseases.

## **OPENING ROUNDTABLE**

The goals of the workshop were to explore the potential of connected health to revolutionize the way people manage their health and chronic diseases, including cancer, and to provide input on future workshops in the Panel’s 2014–2015 series *Connected Health: Improving Patients’ Engagement and Activation for Cancer-Related Health Outcomes*. Participants introduced themselves and were asked to describe a cancer-related problem for which engaging patients through connected health would provide the best solution. Participants emphasized the need for support across the cancer continuum, from prevention, screening, and diagnosis through treatment, survivorship and end of life. Connected health could reduce patients’ feelings of distress, empower patients to actively participate in decision making, and facilitate transitions in care. The need to reduce misinformation and help individuals engage with the healthcare system at the right times and in the right ways was discussed. The technology associated with connected health also could provide insights into and manage aspects of cancer care that are important to patients, such as pain, fatigue, other sequelae of the disease and/or treatment, and financial issues. Caregivers should be engaged and supported, and the informed consent process should be improved. Connected health may help researchers and providers gather information from medically underserved communities and use this information to reduce disparities experienced by these communities, both in the United States and around the world.

## **SETTING THE CONTEXT FOR CONNECTED HEALTH**

Select participants prepared short presentations to describe the current state of connected health technologies and patient engagement.

## **DR. JOSEPH C. KVEDAR**

### **CONNECTED HEALTH: TRANSFORMING CARE THROUGH TECHNOLOGY**

#### **Background**

Dr. Kvedar, founder and Director of the Center for Connected Health, Partners HealthCare, is creating a new model of healthcare delivery, developing innovative strategies to move care from the hospital or doctor's office into the day-to-day lives of patients. He is leveraging information technology—cell phones, computers, networked devices, and remote health monitoring tools—to improve care delivery. Based on the technology platform developed at the Center, a personalized health technology company was launched and later acquired by a leading insurance company to support its program encouraging healthy behavior and wellness education among employee populations. Dr. Kvedar also established the first physician-to-physician online consultation service in an academic setting, linking patients from around the world with specialists at Harvard-affiliated teaching hospitals. He is internationally recognized for his leadership and vision in the field of connected health and has authored over 90 publications on the subject. Dr. Kvedar serves as a strategic advisor at Qualcomm Life, West Health Institute, Puretech Ventures, and BD Technologies and is a mentor at Blueprint Health, providing guidance and insight to developing companies. He is also a judge for the President's Challenge for Entrepreneurship hosted by the Harvard Innovation Lab.

#### **Key Points**

- William Gibson's quote, "The future is already here. It's just not evenly distributed," is applicable to connected health in cancer. Exciting work is being done in this area, but it is being done most comprehensively in only a few places in the United States.
- Partners HealthCare is committed to improving population health and has outlined a three-phase model to support this effort. Improving population health starts with primary care. All Partners HealthCare primary care practices are now patient-centered medical homes (PCMH), which focus on team-based care and create opportunities for virtual care. The second phase of work for improving population health includes secondary care (i.e., relationships between primary care providers and specialists) and patient engagement. Finally, improvements in population health depend on wellness promotion.
- Partners HealthCare utilizes a value-based reimbursement model, which focuses on keeping patients healthy. Connected health can help optimize the value of physician-patient interactions by providing physicians with both population and individual perspectives. The population view helps identify patients who need the most attention, while the individual view allows providers to interact effectively with individual patients.
- The goal of the Partners HealthCare Center for Connected Health is to integrate care into the day-to-day lives of patients. Benefits of this approach include improved self-care by patients and the potential to provide just-in-time care to patients. Feedback loops are critical to accomplishing this. Providers have access to patient data and can reach out to patients if data suggest there is a problem (e.g., high blood sugar at a certain time three days in a row). Provider involvement encourages patient engagement and often improves patient outcomes.
- The Center for Connected Health technology platform collects patient data via devices and self-reports. These data are integrated into a remote-monitoring data repository and displayed in both the electronic medical record and patient portal.
- The Center for Connected Health approach was evaluated to determine whether it could decrease rates of hospitalization for heart failure. Patients monitored their vital signs and uploaded their data to the system daily. Nurses monitored the data and interacted with patients if there was a problem or if

data were missing. Hospitalization rates for heart failure and overall hospitalization rates decreased by about 50 percent.

- The Diabetes and Blood Pressure Connect program monitored blood glucose and blood pressure. Data were uploaded, and nurses contacted patients whose values were worrisome. Patients wanted to avoid being contacted by nurses, which motivated them to take better care of themselves. Participants in this program achieved beneficial reductions in hemoglobin A1c levels and blood pressure.
- The Center for Connected Health is pilot-testing a program for depressed college students that facilitates virtual communication for follow-up visits.
- The Center for Connected Health created a mobile app to help cancer patients self-manage their pain because patients often are unsure about how to manage their pain and worry about becoming addicted to pain medications. When patients enter their pain levels, the app advises how to manage their pain and then follows up a few hours later. Patients can use the app to connect via phone to the oncology service, if needed; however, patients rarely use this option because they feel empowered to manage pain on their own.
- The Center for Connected Health also is developing an app to improve patient adherence with oral chemotherapy regimens.
- There are many commercially available tools that allow patients to manage their own health. For example, Bluetooth-powered scales and blood pressure cuffs can send data directly to a tablet computer. The Wellocracy website helps consumers engage with self-tracking devices. The Text 2 Move app utilizes an automated messaging system to support type 2 diabetes patients, and its use has been shown to lower hemoglobin A1c levels.

## **DR. DAVID AHERN**

### **CONNECTED HEALTH AND CANCER**

#### **Background**

Dr. Ahern is Director of the Program in Behavioral Informatics and eHealth within the Department of Psychiatry at the Brigham & 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. Recently, he began a special assignment to the National Cancer Institute (NCI) where he serves as a special advisor on health information technology to the Health Communications and Informatics Research Branch within the NCI Behavioral Research Program.

#### **Key Points**

- Some research has been done on the impact technology-enabled approaches can have on health outcomes. Many participants in the current workshop have been involved with this research. For example, Dr. Dave Gustafson has done extensive work on the Comprehensive Health Enhancement Support System.
- The Robert Wood Johnson Foundation (RWJF) Healthy Technologies Initiative supported 26 investigators who did pioneering work related to technology-mediated approaches for disease management and health behavior change. With support from Healthy Technologies, Dr. Barbara Rimer and Gilles Frydman analyzed discourse within the Association of Cancer Online Resources (ACOR) community, which was the first investigation of its type. This analysis revealed the information sharing, emotional support, and decision-making support that was taking place among ACOR members. This work also showed the need for relevant methodologies for this type of research. NCI has been working on mixed-methods approaches that include both qualitative and quantitative components.

- Traditional research methods focus on the average response of a group of people. This type of approach is not adequate in the age of individualized interventions. The RWJF Agile Science project is focused on deconstructing interventions to identify which components are likely to work for which people. This is the future of research in connected health.
- Over the last 30 years, behavioral researchers have generated a robust evidence base demonstrating how behavior can be changed. Coupling behavior-change science with technology could yield substantial improvements in health and healthcare in the United States and the world. There have been efforts to bring together the biomedical informatics and behavioral science communities, including a presentation at a recent American Medical Informatics Association meeting. Fostering connections among researchers from these fields could create enormous opportunities for improving outcomes.
- Research is needed to identify factors that influence patient engagement.
- There is a crisis in cancer care in the United States. In coming years, there will not be enough oncology specialists to care for the aging U.S. population. Cancer has shifted from an acute to a chronic disease, which creates challenges for disease management. Major oncology societies are citing the need to reconsider how cancer care is delivered. Connected health may be able to help address some of the challenges in oncology care.

## MR. THOMAS GOETZ

### INCORPORATING PATIENT PERSPECTIVES

#### Background

Mr. Goetz is co-founder and CEO of Iodine, a digital health company that is pioneering the use of data and design to improve people's healthcare decisions. His new book, *The Remedy: Robert Koch, Arthur Conan Doyle, and the Quest to Cure Tuberculosis*, was selected by Amazon and iTunes as a Best New Release. His previous book, *The Decision Tree*, was chosen by *The Wall Street Journal* as a Best Health Book of 2010 and widely hailed as offering a new vision for healthcare in the United States. He also writes the LaunchPad column for *Inc.* magazine. Mr. Goetz recently served as Entrepreneur-in-Residence for the Robert Wood Johnson Foundation, the leading force for better health and healthcare in the United States. While there, he created Flip the Clinic, an RWJ Signature Program that aims to transform the practitioner-patient encounter. He also developed Visualizing Health, a joint project with the University of Michigan School of Public Health to develop new ways to communicate health risk information to individuals. He was previously executive editor at *WIRED*, where he led the magazine to a dozen National Magazine Awards from 2001 through 2012. His writing there was repeatedly selected for the Best American Science Writing and Best Technology Writing anthologies. Mr. Goetz holds a Master of Public Health from the University of California, Berkeley, and a master's in American literature from the University of Virginia. He graduated from Bates College and plays the cello.

#### Key Points

- *How to Stay Alive in the Woods*, a book by Bradford Angier, provides instructions for surviving in the wilderness. Patients often feel like they are in survival mode. They need to navigate the system and make decisions but do not have the benefit of a manual to guide them. Medical care generally is delivered in a highly structured environment, but this does not reflect or take into account the daily lives of patients, which more closely resemble a wilderness.
- Iodine seeks to measure the "messiness" of daily life because it has an impact on health outcomes. This messiness is complicated and subjective, which is one reason the medical field has been resistant to considering it. It includes things like what people can tolerate and the demands and stresses of

people's daily lives. These things influence whether a patient will adhere to a protocol or attend his/her next medical appointment. Information about patients' lives cannot and should not replace highly precise clinical data, but the former can complement the latter.

- The mantra of personalized medicine has been: right patient, right drug, and right dose. A better approach might be responsive medicine, with a mantra of: real person, real world, and real time.
- Drugs have benefits and drawbacks. Though the risks of drugs are considered through the regulatory process, people's subjective experiences with drugs are not taken into account. Iodine is trying to do a quantitative assessment of these subjective experiences. Rather than focusing on the comparative effectiveness of therapies, Iodine is thinking about "comparative satisfaction" from the patient perspective. Do patients like the therapy? Can they tolerate it? The answers to these questions offer clues to whether patients will adhere to a therapy.
- Iodine has surveyed 150,000 Americans about their experiences with a range of medications. In addition to asking about whether a medication works, the survey asks about the hassle of taking the medication and whether it was worth taking given the benefits and hassles. These data can be analyzed by age, gender, and other demographic characteristics and can help individuals think about what drug might be better for them based on other people's experiences.
- Iodine has created a tool to help people choose cold therapies. Although there are more than 400 products available to treat colds, they are based on about 40 formulations and only 4 active ingredients (decongestant, pain reliever/fever reducer, cough suppressant, and antihistamine). Iodine's tool collects information about a patient's symptoms and recommends a medicine that will treat those symptoms without unneeded active ingredients. It also takes into account whether other people with similar symptoms have found certain drugs to be more or less effective. A similar model could be developed for cancers.
- The only way to get information about people's experiences is to ask them—in plain language and in a way that encourages responses. Many people do not feel comfortable with clinical language. Nonclinical assessments can have incredible clinical implications.

## **LANDSCAPE OF CONNECTED HEALTH AND PATIENT ENGAGEMENT**

Participants were asked to describe the current state of connected health, including the extent of connected health implementation and relevant trends in healthcare systems and technologies.

- The burden of cancer in the United States will increase as the population ages, and many people with cancer will have comorbid conditions. So far, connected health has been underutilized in oncology, but there is a need for tools that will help people manage their diseases. There is opportunity to couple what has been learned in behavioral science with what is known about connected health and apply these lessons in oncology. This could change the course of cancer care over the next decade.
- Electronic interfaces are often fragmented. For example, at one academic medical center, there are four patient portals, each of which provides access to a different type of information (e.g., billing, laboratory test results). This is in part because of meaningful use regulations, which required each practice to create a patient portal. This illustrates the need for systems thinking during regulation development. Meaningful use regulations strongly influenced the ways in which hospitals invested in their infrastructure. The focus on meaningful use pulled resources away from other efforts that might have been more beneficial.
- Perspectives of providers and patients were not taken into account during development of the meaningful use criteria. These criteria were established by government committees. Vendors developed tools based primarily on these criteria and did not necessarily consider the needs of the healthcare system. In addition, in large organizations, Chief Financial Officers often are charged with

selecting which products to purchase; they are more likely to select tools that handle finances and less likely to select tools that do a good job supporting clinical care.

- There has been a lot of emphasis on and investment in electronic health records (EHRs), but EHRs do not seem to be useful or important to patients. They are not discussed within online patient networks, including Smart Patients and Facebook groups.
- There is extensive inefficiency in the healthcare system. Patients are asked to provide the same information numerous times. They also are asked to undergo testing that will not influence their care. In addition, money is spent on treatments that will not benefit patients, particularly at the end of life. Technology might be able to help address these inefficiencies, but it is not yet doing so.
- The current approach to patient-centered care involves putting patients at the center of the existing healthcare system. A better approach would be building healthcare systems around patients.
- It is often difficult to integrate new types of information into existing systems. For example, one research group collected information from breast cancer patients on symptoms, but the information could not be integrated into the EHR because of technical and legal barriers. Clinical workflows often are dictated by fragmented systems, and it is often difficult to introduce new information into workflows, even if the information is important.
- Patients are asked to change behaviors that are very difficult to change. Feedback loops may be useful for promoting behavior change. It will be important to determine the appropriate amplitude and periodicity of feedback for various behaviors and issues. Both could have significant impact on effectiveness. Feedback loops need to be tailored for specific behaviors; the feedback for pain control might be very different than the feedback to promote physical activity.
- Research has suggested that feedback loops can increase desired behaviors by about 10 percent. Feedback loops work well for some people, but not as well for others. Multiple approaches will be needed to effectively reach all people.
- From a behavioral science perspective, the best type of feedback loop would be one that causes sustained change. In some cases, when feedback is removed, the original behavior returns. In other cases, the behavior change is sustained. For example, text messaging to reduce asthma symptoms seems to cause sustainable changes in practices; even if the text messages stop, asthma outcomes remain good.
- It is important to be aware of the full impact of feedback loops. One intervention for diabetic patients involved multiple blood sugar measurements each day. The patients were able to better control their blood sugar, but they were doing it through overuse of insulin, which can cause long-term damage.
- Social networks seem to create a powerful feedback loop for some people. Many patients are engaged in social networks. It is unlikely that isolated interfaces will have the same impact as technologies with a social component.
- Individuals are parts of both formal and informal networks. They may connect with others through electronic networks (e.g., Facebook), but they also have connections through community-based organizations, churches, and other organizations.
- Many people are concerned about the spread of misinformation via social networks. However, there is very little evidence of damage done through the spread of misinformation through these channels. One finding from the ACOR study was that misinformation often was corrected by others in the network; it was a sort of built-in system of checks and balances.
- There are many Facebook groups that provide excellent support systems for people with rare conditions. Members of these groups are able to get support and advice that they could not get anywhere else.

- Sustainability of social networks needs to be considered. Many social networks are very active, but people drop out of them frequently, even if they report finding them useful. About 60 percent of members of an addiction-focused social network dropped out after 8 months, despite claiming that the network was important to their lives.
- Poor populations, which bear a disproportionate burden of disease, are less likely to be part of connected systems but could benefit greatly from them. In the past, lack of connectivity was the major concern for underserved populations, but discontinuity in connectivity is now a bigger problem.
- The metaphor of the elephant curve was discussed. The body of the elephant is large and unable to move quickly. However, the trunk of the elephant can rapidly move and adapt. The small portion of the population with privilege and access to information is akin to the trunk of the elephant. Efforts must be made to move other segments of the population out of the body of the elephant and into the more agile trunk.
- Current healthcare payment structures preclude innovation. Providers are hesitant to try new things because they will not get paid to do them. Incentive structures need to be changed to promote innovation within medicine. Incentives are needed for both individual providers and larger organizations (e.g., hospitals). Hospitals were able to dramatically cut rates of hospital-acquired infections after the Centers for Medicare & Medicaid Services (CMS) decided it would not pay for treatment of these infections.
- Patients are more likely to look for health information on line than talk to their doctors. The healthcare system needs to recognize that patients are moving away from the system and try to address the reasons for this.
- The medical system has traditionally been paternalistic, which has created an expectation among patients that they will be treated in a paternalistic way. Systems need to be created that support a more collaborative healthcare system.
- The concept of portals is outdated in the technology field.
- The medical system generally fails to recognize patients' families as a resource.
- Many patients feel isolated.
- Patients do not want to be defined by their disease. They want to be acknowledged as whole persons.
- Cancers historically have been defined by their organ site, but this paradigm is changing as many cancers now are being defined by their driver mutations. Online communities already have started reformulating to adjust to this paradigm shift.
- Many people doubt the effectiveness of interventions for psychological distress. As new tools are developed to address psychological components of chronic diseases, efforts will need to be made to convince people that these interventions are effective.

## **CONNECTED HEALTH FOR INDIVIDUALS AND PATIENTS: DESIRED FUTURE STATE**

Select participants were asked to prepare short presentations to describe the desired future state of connected health and how it would affect cancer control and treatment, from prevention through end-of-life care.

## DR. ROSALIND W. PICARD

### WEARABLES FOR WELLNESS

#### Background

Dr. Picard is founder and director of the Affective Computing Research Group at the Massachusetts Institute of Technology (MIT) Media Lab and co-director of the Things That Think Consortium, the largest industrial sponsorship organization at the lab. She has co-founded two businesses, Empatica, Inc., creating wearable sensors and analytics to improve health, and Affectiva, Inc., delivering technology to help measure and communicate emotion. Dr. Picard holds a bachelor's degree in electrical engineering with highest honors from the Georgia Institute of Technology, and master's and doctorate degrees, both in electrical engineering and computer science, from MIT. Dr. Picard was instrumental in starting the field of affective computing and was a founding member of the IEEE Technical Committee on Wearable Information Systems, which helped launch the field of wearable computing. Dr. Picard has authored or co-authored over 200 scientific articles and chapters spanning computer vision, pattern recognition, machine learning, human-computer interaction, wearable sensors, and affective computing. She is an active inventor with multiple patents, including wearable and noncontact sensors, algorithms, and systems for sensing, recognizing, and responding respectfully to human affective information. Her inventions have applications in autism, epilepsy, sleep, stress, autonomic nervous system disorders, human and machine learning, health behavior change, market research, customer service, and human-computer interaction. Dr. Picard has been honored with dozens of distinguished and named lectureships and other international awards. She is a popular speaker and has given over 100 keynote talks.

#### Key Points

- The Picard laboratory built wearable sensors designed to measure stress levels from the surface of the skin. Dr. Picard wore four of these sensors to Six Flags, one on each wrist and ankle. The sensors showed high levels of electrodermal activity during roller coaster rides, but the highest peaks of the day occurred in the morning while she was preparing to leave the house with her young son. Another interesting observation was that the amplitudes of the peaks were different depending on the side of the body on which the sensors were worn: the peaks from the right-side sensors were much higher than those from the left-side sensors. Initially, Dr. Picard thought this was an artifact, but subsequent work showed that these differences were authentic.
- One of Dr. Picard's students borrowed two sensors to monitor the stress levels of his autistic, nonverbal younger brother. The data revealed a spike in electrodermal activity on one side of the body shortly before a grand mal seizure. Based on this observation, Dr. Picard began collaborating with Dr. Joe Madsen at Boston Children's Hospital on an observational study of children who had repeated seizures and were undergoing surveillance to determine whether brain surgery was warranted. Dr. Picard's sensors were used to capture electrodermal activity; electroencephalography (EEG) and electrocardiogram (ECG) data also were collected. Among the children in the study, 100 percent of myoclonic seizures reported by participants and 86 percent of complex partial seizures identified via EEG data were associated with a large surge in sympathetic nervous system activity.
- Studies using the electrodermal sensors have revealed new insights into how the brain works. This information was discovered because the technology was built and researchers were willing to be surprised and learn from what they observed. Early discoveries using these sensors have led to research in other disease areas.
- Many people are interested in wearable electrodermal sensors because they may provide warning for a seizure or emotional event. For example, people on the autism spectrum are interested in using these sensors so they can identify rising stress levels before they reach a critical point. Detecting a seizure even a few minutes before it occurs also may make a difference in outcomes.

- The wearable electrodermal sensors developed by the Picard laboratory are now available for purchase on Empatica's Web site. They measure activity and sleep and can provide stress alerts. They are waterproof and can be cleaned with alcohol. For a limited time, for every sensor purchased, a sensor will be donated to the Epilepsy Foundation for a family in need.

## **DR. WARREN KIBBE**

### **CANCER INFORMATICS AND ENGAGING PATIENTS**

#### **Background**

Dr. Kibbe is Director of the Center for Biomedical Informatics and Information Technology (CBIIT) at NCI. Under his leadership, CBIIT engages the cancer informatics and overall cancer communities to accelerate the application of innovative solutions in cancer treatment, prevention, research, and informatics to improve human health and reduce the risk of cancer. Prior to joining NCI, Dr. Kibbe was at Northwestern University for more than 20 years and was most recently Professor of Health and Biomedical Informatics in the Feinberg School of Medicine and Director of Cancer Informatics and Chief Information Officer for the Robert H. Lurie Comprehensive Cancer Center. He received his Ph.D. in chemistry from Caltech, and was a visiting scientist at the Max Plank Institute for Biophysical Chemistry in Göttingen, Germany, before joining the faculty at Northwestern. Dr. Kibbe is an active member of the open biomedical ontologies community; is part of the Gene Ontology Consortium; was a member of the Clinical and Translational Science Awards Ontology Working Group; and was a founder of the open-source, open-access Human Disease Ontology.

#### **Key Points**

- National challenges related to cancer data include determining how to engage: (1) the public to increase understanding of risk and modify behavior and (2) patients to increase understanding of disease and optimize therapies, outcomes, and the survivorship experience. It is important to engage all populations so data are representative.
- National challenges in the area of cancer informatics include reducing barriers to data access and integrating different types of data to enable prediction and improved outcomes. In order to address these challenges, the cancer research community needs to practice open science (e.g., open access, open data, open source) and focus on the creation of interoperable and sustainable models for informatics infrastructure, services, and data.
- High-throughput technologies—including gene sequencing, genomics, proteomics, and metabolomics—have fundamentally changed the field of biology by facilitating an integrated systems view of biological systems.
- There is opportunity to build a patient-centered national learning health system for cancer that comprises institutions and patients across the country. This would involve sharing and integrating data, including clinical genomics data, to help identify factors driving patient outcomes.
- The era of precision medicine and precision oncology is predicated on the integration of research, care, and molecular medicine, and the availability of data for modeling, risk analysis, and optimal care. Translational research policies should be re-engineered to put patients at the center of health care and enable creation of a learning healthcare system.
- Mobile devices are having an impact on individuals and society. Recent data indicated that there were 6.6 billion active mobile phone contracts, including 1.9 billion smartphone contracts. The number of mobile phone contracts is nearly as high as the world population of 7.1 billion, although mobile phone access is not distributed equally. In the United States, there are 287 million smartphone contracts for a population of 313 million.

- Individuals are no longer only data consumers but are also data producers.
- Social media may be one avenue for modifying behaviors that result in cancer. Properly orchestrated social media can have a dramatic impact on quality of life for cancer patients and survivors. Social media also can reach all segments of the population, including underserved populations.
- Modifiable factors—including smoking, infectious disease, poor nutrition, and lack of exercise—contribute to at least half of the current cancer burden in the United States. The benefits of positively changing these behaviors would be tremendous.
- To achieve the promise of connected health, strategies are needed to capture, store, analyze, mine, visualize, predict, and learn from the data collected by sensors embedded in patients' devices. It is also important to use ontologies in order to deliver meaningful data and create communities for cancer patients using devices. Information should be provided to patients so they will be motivated and empowered to participate in cancer research.
- Elastic computing “clouds,” social networks, and big data analytics will be important parts of the future of connected health.

## DISCUSSION

Participants were charged with discussing the desired future state of connected health in five to ten years from three perspectives: (1) individuals, including the general public, people at risk of cancer, and patients; (2) the clinical enterprise; and (3) the social enterprise.

### Individuals

- Connected health can help people and their families stay “one step ahead” (e.g., able to anticipate and understand next steps in cancer screening or treatment planning), which should reduce stress.
- Connected health can help people feel empowered to reduce their risk of cancer by changing their behaviors. It also should empower and assist them in making decisions about their healthcare and treatment, recognizing that decision making is a dynamic process. Patients who are actively involved in making decisions about their own treatments are more likely to adhere to those treatments.
- Connected health tools should help patients without stigmatizing them.
- Connected health could seamlessly connect individuals to other people, organizations, and institutions that play roles in their lives. To accomplish this, technologies need to be integrated into daily life and easy to use, even for those with limited technological knowledge and skills.
- Connected health can promote healthy behaviors and disease prevention in people outside the context of the healthcare system. Self-organizing groups of people are using technology to share their data and get input from others about ways to meet their health goals. This provides a way for people to take care of their own health and rely on the formal healthcare system only when they need it.
- Many people are consumed by the day-to-day challenges of life, like paying household bills and providing food for their families, and do not have the time or energy to think about how their choices are influencing their health. One of the challenges of connected health is to figure out how to reach and support these populations.
- It would be optimal if the envisioned learning health system knew the types of information that patients wanted and needed and delivered this information with minimal effort from patients. It is often difficult for patients to access information that can help them make personal decisions. Information should not be limited to clinical information but should also include information about social and economic barriers to care (e.g., child care, transportation).
- Technological tools should be compatible with people’s social and cultural experiences and provide patients with support, not just data.

- Connected health should help patients become more involved with the research enterprise. Patient involvement from the beginning of the research process might lead to more engagement and potentially solve some of the problems with cancer clinical trial accrual.
- Technologies should be developed with consideration for the social and emotional dynamics of collecting data from patients. Patients should feel that their feelings and experiences are respected. For example, it is helpful to empathize with patients if they are providing information about a difficult situation.

## **Clinical Enterprise**

- The clinical enterprise should utilize information from nonclinical sources, including peer networks and individuals. Communication should include learning from patients and other sources rather than focusing solely on educating patients.
- Connected health might help pediatric cancer patients transition into survivorship care as they reach adulthood. Ideally, posttreatment cancer survivorship should be considered as beginning at the time of diagnosis.
- The envisioned learning health system will allow physicians to make recommendations to their patients based on data from other people with similar characteristics (e.g., genomic profile, family history, disease subtype). Currently, physicians have information generated only by traditional clinical trials, which may not have been done with populations similar to their patients.
- Connected health systems could increase the efficiency of team-based care by providing all team members access to accurate and comprehensive patient information. This should help team members avoid replicating each other's work.
- Many providers do not like to spend time using EHRs because this time is not reimbursable. In the future, technology could add value by helping providers identify patients who need care.
- Connected health can complement changes in reimbursement policies, although it is unclear how widespread these changes will be within the next five to ten years.
- To be sustainable, the healthcare system should be structured in a way that meets the needs of both patients and providers. Connected health can play a role in making sure this happens. Patients and providers are both dissatisfied with the current healthcare system.
- Assumptions about the best ways to deliver healthcare should be reconsidered. For example, walk-in physician visits might be more efficient than appointment-based visits. This would help avoid the inefficiencies created by appointment cancellations.
- The healthcare system could be radically different in a few years if the definition of care is expanded to include care from family members and peer groups rather than only care from healthcare providers.
- Informed consent processes and terms of service agreements should be revisited and revised to reduce barriers to data access.
- Research institutions should have policies allowing patients to recover the data that have been collected from them.
- Ideally, data would be freely shared among patients, the clinical enterprise, and the public sector. This will not be accomplished within the next five years, but it would be helpful to establish principles for the establishment of a trusted environment for data sharing. These principles could include value, trust, control, and inclusion.
- The amount of available clinical data and knowledge will be exponentially higher in five years, which will make clinicians' jobs even more difficult. Informed patients can help address this problem. Patients can learn from their peer networks and other sources and take this information to their clinicians. This may be particularly relevant for cancer patients treated in community cancer centers.

- Other industries have developed ways to glean useful information from large, complex data streams. This will be a challenge for the healthcare field, but it is a solvable problem.
- There are some concerns that connected health and new technologies will create issues related to liability for providers. This should be addressed through clear communication between providers and patients. Patients should understand that there are benefits to connected health systems, but that they are not a replacement for emergency care or communication with providers about acute problems.
- Different types of people and organizations can play important roles in cancer research. Research on Gleevec was driven by the patient organization ACOR and individual patients who shared information about their experiences with the drug and fundamentally changed the research process and influenced the timing of the Food and Drug Administration's decision regarding the drug.
- There will be dramatic advancements in sensors over the next five years. It likely will be possible to measure variables that currently can be measured only in sophisticated laboratories (e.g., post-treatment monitoring for biomarkers).
- Diabetes patients, who often are socioeconomically disadvantaged, are currently closely monitored. However, these patients are generally not happy with the tools used to monitor them or with the resources available to support them. Lessons learned from the experiences of patients with diabetes should be applied to ensure that connected health is better implemented in the future.
- Electronic health systems should reflect workflows and normal processes of clinicians and patients.

## **Social Enterprise**

- The cancer community should be more active in combating childhood obesity. This is a major problem that should be addressed as part of cancer prevention. Fast food and beverage companies and other organizations that promote unhealthy behaviors have a strong social media presence.
- Efforts should be made to eliminate waste and rework, in part by improving understanding of the processes associated with planned interventions and services. The cancer field needs to consider the efficiency and effectiveness of its activities.
- Sickness is a natural part of life, and there are some benefits to getting sick if the illness is treatable. It can be a reminder to slow down. Some people with serious illnesses find that the experience changes their perspective in a positive way.
- There should be enhanced communication among all stakeholders in patients' healthcare, including primary care providers, specialists, and family members. Information needs to be shared with everyone who is helping to support the patient. For example, it may be appropriate to share information with the adult children of cancer patients, with the approval of patients, but this is not always done.
- The cost burden of cancer in the United States will increase in the future. A more efficient system of care is needed. This includes aspects of care provided outside the clinical enterprise. Cancer is now often a chronic disease and should be managed differently than in the past.
- End-of-life care and support are very important for patients and families, and learning networks could play a role in this. People currently do not have access to tools to help them make decisions during this time, and it can be very isolating. There are many cultural and religious issues that need to be considered.
- The goal should be to help people transition back into their lives, not necessarily into survivorship. Some people do not want to be defined by their cancer experience.

## PUBLIC COMMENT

- Connected health could help keep oncologists informed about how their patients are doing outside of appointments. For example, a patient may be more tired than usual or be struggling with anxiety.

## BARRIERS TO THE DESIRED FUTURE STATE FOR CONNECTED HEALTH

Select participants were asked to prepare short presentations to characterize barriers to achieving more widespread use of connected health.

### DR. KENNETH D. MANDL

#### CONNECTED HEALTH AND CANCER

##### Background

Dr. Mandl is Professor at Harvard Medical School in the Center for Biomedical Informatics and Chair in Biomedical Informatics and Population Health in the Boston Children's Hospital Informatics Program. Through scholarship intersecting epidemiology and informatics, he pioneered use of information technology and big data for population health, discovery, patient engagement, and care redesign. He leads the transformative SMART Platforms initiative to design the "app store for health" and is Principal Investigator of the Scalable Collaborative Infrastructure for a Learning Health System across Boston hospitals and nationally. Recognized for research and teaching, Dr. Mandl received the Presidential Early Career Award for Scientists and Engineers and the Clifford A. Barger Award for top mentors at Harvard Medical School. He was advisor to two Directors of the Centers for Disease Control and Prevention (CDC) and chairs the Board of Scientific Counselors of the National Institutes of Health's National Library of Medicine.

Dr. Mandl's clinical training and experience is in pediatrics and pediatric emergency medicine. He has been elected to multiple honor societies, including the American Society for Clinical Investigation, the Society for Pediatric Research, the American College of Medical Informatics, and the American Pediatric Society. He is the 2014 recipient of the Donald A.B. Lindberg Award for Innovation in Informatics.

##### Key Points

- Dr. Mandl and Dr. Isaac Kohane co-authored an article in the *New England Journal of Medicine* urging the health system to make EHR data available to app developers to encourage healthcare innovation. Currently, if a startup company wants to access health system data, it must contract with individual hospitals.
- The open system proposed by Drs. Mandl and Kohane is similar to the model used by Apple for the iPhone. Apple has an application program interface (API) that enables any developer to create an app that will work on all iPhones. A similar system allows developers to create an app that will work on all Android devices.
- Dr. Mandl and his colleagues received a grant from the Office of the National Coordinator for Health Information Technology for the SMART Platforms initiative, with the goal of developing an API for health information technology. The API can work with any of the major EHR systems, including Cerner and Epic. This allows innovators to develop tools that will connect patients with healthcare data.
- One app has been developed that integrates EHR data with data from a consumer genomics company to generate risk maps for individual patients based on their genomic profiles. Another app that calculates risk of a cardiac event was developed in only eight days using the API.

- EHR vendors are interested in the API functionality. Epic participates in weekly technical meetings with Dr. Mandl's group. Epic and Cerner have committed to ensuring that products released in 2015 will be compatible with the API.
- Analysis of claims data from a major health plan has provided insights into the current status of team-based care. The data revealed that about 2.6 million unique provider pairs shared at least one patient. Of these pairs, 54 percent shared only one patient, and 19 percent shared two patients. The data also revealed about 15.4 million unique collaborative triads of providers. Of these, 92 percent shared only one patient, and only 0.2 percent shared ten or more patients. These data suggest that providers rarely form stable teams but, rather, come together to care for single patients.
- Dr. Mandl and Clayton Christensen formed a company that supports teamwork in healthcare. The model focuses on providing patients and caregivers with the “state of play” of their medical teams rather than just detailed medical data.
- Ideally, providers would use technologies to engage patients in an integrated way within the context of healthcare system processes. This is fundamentally different from providing information to patients through fragmented portals or EHRs.

## **DR. M. CHRIS GIBBONS**

### **ENGAGING PATIENTS WITH CONNECTED HEALTH TECHNOLOGIES: BARRIERS TO A CONNECTED HEALTH FUTURE**

#### **Background**

Dr. Gibbons is an Associate Director of the Johns Hopkins Urban Health Institute and an Assistant Professor of Medicine, Public Health, and Health Informatics at Johns Hopkins University. He is a healthcare disparities and urban health expert, physician informatician, and behavioral interventionist. Dr. Gibbons has been named a Health Disparities Scholar by the National Center for Minority Health and Health Disparities at the National Institutes of Health. He has authored/edited six books, including *eHealth Solutions for Healthcare Disparities*, and his work is leading the emergence of the field of populomics. Dr. Gibbons is an advisor and expert consultant to several state and federal agencies and policymakers in the areas of urban health, eHealth, minority health, and healthcare disparities. He is also the Distinguished Scholar-in-Residence at the Federal Communications Commission's (FCC) Connect2Health Task Force. The Connect2Health FCC Task Force is a senior-level, multidisciplinary group created by FCC Chairman Tom Wheeler and is charged with exploring the intersection of broadband, advanced technology, and health. The Task Force is focused on further charting the broadband future of health and care in order to ensure that the FCC stays ahead of the health technology curve.

Dr. Gibbons obtained his medical degree from the University of Alabama. He then completed residency training in preventive medicine, fellowship training in general surgery and molecular oncology basic research, and a Master of Public Health focusing on health promotion among urban and disadvantaged populations, all from Johns Hopkins University.

#### **Key Points**

- There is no single app or technology that will be effective for all people or patients. A “technology cabinet” of options is needed to meet the needs of diverse populations.
- To improve the functionality of a technology, modifications can be made to the technology, the user, or the user context. In healthcare, the usual approach is to focus on the technology and largely ignore the user and user context. The user context includes the many factors in people's environments that influence whether a technology is used and/or if it is useful.

- Technology-related contributors to health disparities include lack of broadband connectivity, lack of access to hardware/software, low levels of digital literacy/trust, low levels of health literacy, technologies with poor usability, social determinants of health, unrecognized/underappreciated cultural norms, and fragmented clinical services. Strategies for addressing these issues include improving broadband connectivity, enhancing digital literacy, and improving technology designs.
- Increased understanding of the unique behavioral challenges associated with various users and user contexts would improve technology designs. Developers should employ user-centered design processes with representative sets of users from different populations. It also is important to integrate sociocultural norms and realities into designs.
- Many technologies are designed to deliver information rather than promote information sharing. Many cultures value sharing personal experiences, and the opportunity to do this can make patients feel like they are participating in decision making.
- Many people prefer technologies with video, voice, and/or social components over text-based technologies. Real-time behavioral feedback also can be a powerful tool for influencing behavior change.
- The historic mission of the FCC was to ensure 100 percent telephone penetration at reasonable cost and regulate the spectrum of wireless devices. The emerging FCC focus is not just about connectivity but about ensuring that every American can experience the benefits broadband has to offer.
- The FCC Connect2Health Task Force vision is, “Everyone connected to the people, information, and supports they need to get healthy and stay well.”
- The hypothetical scenario of a 76-year-old congestive heart failure patient named Ruby was presented. Ruby lives alone and has struggled with multiple hospitalizations a year. The new availability of broadband infrastructure has improved Ruby’s care. A connected scale can transmit Ruby’s weight to her community health worker and physician. The community health worker contacts Ruby if she gains 3 pounds or more. Ruby also is supported by IRLA (Interactive Voice Response Lifestyle Assistant), which can analyze Ruby’s diet and physical activity and make suggestions for improvements. IRLA can contact Ruby’s children or doctor and schedule appointments and arrange for transportation. IRLA also can explain medical information in the language with which Ruby is most comfortable.

## DISCUSSION

Participants were asked to discuss barriers to the desired future state of connected health.

- Current research methodologies are inadequate for evaluating personalized health technologies.
- The costs of research are high, and human subjects research regulations (e.g., informed consent requirements) create many hurdles to obtaining and using data. Even patient-powered research networks have difficulty accessing data. The Health Insurance Portability and Accountability Act, and misconceptions about this law, also can prevent data sharing.
- The evidence base for most connected health technologies is lacking.
- Connected health technologies often are developed without consideration for the context in which they will be used. In addition, the processes and procedures needed to effectively implement technologies often are not considered.
- Policies often are developed in a fragmented way. Specifically, social and telecommunications policies are developed separate from health policies and often do not take health issues into account. For example, increasing broadband access in urban public housing is a social issue, but it has an impact on health.

- Access to health data, including patient data and institutional data, is fragmented. Providers are often unable or unwilling to share information with one another. Patients often bear the burden of compiling and sharing their medical information, despite the fact that they are unable to curate their own medical data.
- The low quality of healthcare technologies disseminated to date has led to public disillusionment and lack of confidence that future tools will be helpful.
- Clinical institutions are experiencing “new-technology fatigue,” in large part because of ongoing implementation of EHRs. They often do not have the capacity to try new things.
- The public experiences scientific information overload because of the rapid pace of scientific discovery. In addition, poor scientific reporting in mainstream media makes it difficult for people to discern what information is accurate and important.
- Innovations designed to reduce costs often do not accomplish this goal because the expenses they were designed to replace are not eliminated. Ineffective and inefficient approaches should be removed to make room for more effective approaches.
- Current incentive structures for providers do not support adoption of innovations. Change is difficult, because the existing system is profitable for many providers and institutions.
- Innovations are developed to support populations who can pay for them. This approach neglects the needs of populations perceived to be unable to pay for technologies or resources. Innovations should focus on public health, not revenue, as the primary goal.
- There is a paucity of qualified people to work at the user-technology interface, and the trained workforce is concentrated at a small number of institutions.
- Minority and underserved populations are often unrepresented or underrepresented in technology development.
- Academic incentives and traditions favor investments in drug development over connected health. This results in less funding for technology and connected health, as well as less focus on workforce development in these areas.
- Traditional conceptions of care and providers are narrow; they generally focus on care by medical professionals provided in medical settings. There also is a general lack of respect for families and their role in providing care.
- Approaches to address low health literacy are inadequate.

## **RECOMMENDATIONS FOR ACTION FOR THE PRESIDENT'S CANCER PANEL**

Participants were asked to identify barriers that, if addressed, would have the most significant impact on progress toward the future desired state of connected health in cancer. Three priority areas were identified: research methods and regulations, framework of patient-centered care, and technology development. Participants discussed the potential benefits of addressing the barriers and provided input on potential future Panel workshops focused on these areas.

### **Research Methods and Regulations**

- There is a need for updated methods and research design strategies to address questions related to connected health in cancer. Specifically, strategies are needed to evaluate studies in which participants receive personalized interventions (i.e., “n of one” studies).
- Connected health can facilitate consumer participation in research (e.g., citizen science, participatory research). Consumers are beginning to have more influence on research questions and design. For example, a group of patients who suspected a certain drug was causing osteonecrosis of the jaw

organized a large survey and confirmed this problem, forcing the pharmaceutical company that manufactured the drug to issue an apology. PatientsLikeMe is initiating an observational study of a nutritional supplement that some amyotrophic lateral sclerosis patients believe is helping them.

- Connected health can integrate nonmedical information about patients' lives into research.
- Informed consent procedures and standards should be reconsidered. One option would be to allow patients to give general consent for their data or tissue to be used in research. However, it is important to be sensitive to past mistakes in using patient tissues for research without consent (e.g., HeLa cells).
- The technology sector utilizes OAuth, which is a standard protocol through which people can allow access to their data. Users are able to view a dashboard that provides details about permissions they have given for use of their data. Open mHealth is considering a similar model. This model of open and dynamic authorization may be best tested in a field like oncology.
- If patients provide their data for research, they should be provided with research results. Adoption of this policy would increase the likelihood of patient participation in research.
- It would be beneficial if systems were created that allowed experimental innovations to fail quickly before large investments of time and resources are made in comprehensive testing. This is the principle behind the RWJF Agile Science project.
- There is a difference between patient-reported outcomes and patient-desired outcomes. The former represents information researchers want to get from patients while the latter represents information important to patients. It is important to take patient-desired outcomes into account. Work through Project HealthDesign, which was supported by RWJF, revealed that patient-desired outcomes are often clinically relevant and valuable.
- Patients think research on long-term effects of cancer treatment should be a high priority. One participant shared the following quote from a patient living with throat cancer: "Research and patient care needs not only to be around the disease, but on the after-effects and lessening of them. Treatment ends and you really are on your own to figure out what to do with the damaged pieces you have left. This needs to change."
- Commercial companies that are involved in healthcare (e.g., Walmart, CVS, Rite Aid) may provide useful insights at a future Panel workshop. These companies currently are not engaged with research, but they could become important players in the future.
- Representatives from computer sciences should be engaged to discuss strategies for dealing with the "super data" that will result when various types of big data (e.g., genomic, behavioral, toxicological) are integrated.

## **Framework of Patient-Centered Care**

- The current conception of patient-centered care puts patients at the center of existing healthcare systems. An updated framework of patient-centered care is needed that starts with the patient and builds the necessary supports around the patient in the patient's environment. The health care system should be viewed as a visitor in patients' lives.
- Patient-centered healthcare needs to take into account the values and priorities of patients.
- The "Flip the Clinic" project funded by RWJF is focused on reimaging patient-doctor encounters. The project includes a series of workshops around the United States to encourage brainstorming about ways to improve the way patients and doctors interact. The "Flip the Clinic" idea is based on the Kahn Academy "flipped classroom" model that involves students viewing lectures at home and completing "homework" in the classroom with the teacher available to provide help.

- Most of patients' life experiences are invisible to their healthcare providers. Healthcare will not achieve patient centeredness unless the health system acknowledges the importance of these experiences and seeks to understand them.
- Empowering patients and families may allow them to catalyze changes in healthcare.
- Fundamental changes must be made if caregivers are to be integrated into the healthcare system. Moreover, caregivers are a diverse group—some have access to extensive resources while others struggle to help their loved ones while balancing many other daily challenges. Perspectives of all types of caregivers should be taken into account.
- The Panel would benefit from hearing about exemplars at future workshops. A Native American community in North Slope Borough, Alaska, has developed a community-based system of care that involves all members of the community from a young age. One adolescent boy developed an antismoking campaign that encouraged his peers to "smoke fish, not tobacco." This model was developed because the community is geographically remote and there are too few doctors to serve the community's needs.
- There may be merit in holding a meeting at which most of the participants are from outside the oncology field. These could include employers, representatives of faith-based organizations, and patients.
- Patient navigators, community health workers, community oncologists, representatives from companies like Facebook and Google, and representatives from fast food and beverage companies could contribute to future discussions related to the framework of patient-centered care. Social workers and representatives from other human service fields also may have insights into this issue because they frequently deal with daily challenges facing underserved populations and have developed strategies to address these challenges.
- Participants at a recent LIVESTRONG Foundation workshop identified 23 elements of patient-centered care. The report from this workshop may be useful to the Panel. C-Change also may be a useful resource. That organization has held workshops in the past focused on nontraditional caregivers such as navigators and members of faith communities. The American Society of Clinical Oncology also is doing work in this area.

## Technology Development

- The people in charge of product design at Facebook think it is important to get input from a broad spectrum of people because this results in better products.
- The technology field has done extensive work related to user engagement because user engagement is important for the success of technology products. Google has a principle called HEART, which stands for happiness, engagement, adoption, retention, and task success. These factors give an overall view of how happy end users are with a product. Medicine would benefit from developing a similar model for considering consumer satisfaction.
- A Panel workshop on this topic should include discussion of exemplars of technology design efforts that have been inclusive. There are some examples of inclusive development in low- and middle-income countries. For example, the Ushahidi platform was used to create a surveillance program to protect people in Kenya from being assaulted by the governing party. WhatsApp is popular in India because it can function even with limited bandwidth. Consideration also must be given to how to scale up successful efforts so they can be used to reach more people.
- Research in the field of cultural ergonomics might be useful. This field, which focuses on increasing understanding of culture to help build better systems, stemmed from globalization efforts. There is literature in this area, although it is outside the field of healthcare. Genevieve Bell, a cultural anthropologist at Intel, also has done similar work.

- People from diverse communities should participate if a future Panel workshop focuses on technology development. CDC fostered community-based interventions and may have useful insights.

## **PUBLIC COMMENT**

- The two models of patient centeredness could be described as “moving the patient to the center” and “starting with the patient.”
- Members of the public should be encouraged to attend and participate in meetings like this one.

## **CLOSING REMARKS**

Panel members thanked participants for their contributions. They also expressed their hope that participants would be willing to provide additional advice on future workshops and input on the topic of connected health.

## **CERTIFICATION OF MEETING SUMMARY**

I certify that this summary of the President’s Cancer Panel meeting, *Engaging Patients with Connected Health Technologies*, held December 11, 2014, is accurate and complete.

Certified by:

Date: March 5, 2015

---

Barbara K. Rimer, Dr.P.H.  
Chair  
President’s Cancer Panel