

# Improving Cancer-Related Outcomes with **CONNECTED HEALTH**



A Report to the President of the United States  
from the President's Cancer Panel



# THE PRESIDENT'S CANCER PANEL

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This report is submitted to the President of the United States in fulfillment of the obligations of the President's Cancer Panel to appraise the National Cancer Program as established in accordance with the National Cancer Act of 1971 (P.L. 92-218), the Health Research Extension Act of 1987 (P.L. 99-158), the National Institutes of Health Revitalization Act of 1993 (P.L. 103-43), and Title V, Part A, Public Health Service Act (42 U.S.C. 281 *et seq.*).

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## PRESIDENT'S CANCER PANEL

The President  
The White House  
Washington, DC 20500

Dear Mr. President,

Throughout your tenure, you have demonstrated to the people of the United States your deep commitment to advancing the nation's health—particularly with regard to cancer, which touches the life of nearly every American. You and your administration have overseen huge advances in the use of technology to improve health. We appreciate your leadership of this important area. We are excited to present you with our report that shows how connected health, a term that captures the ways technology is changing how we manage health, is essential to achieving your vision of a healthier America.

Your President's Cancer Panel defines connected health as “the use of technology to facilitate the efficient and effective collection, flow, and use of health information.” We live at a most exciting and critical time of technological advances with potential to help individuals manage and improve their own health and support high-quality, patient-centered cancer care. As you have noted, the future is likely to be even better and more conducive to efficiencies and effectiveness for health professionals and engagement for patients. But, today, many patients cannot access or share their own health information; care teams experience electronic health record fatigue and frustration due to lack of interoperability, among other challenges; and researchers do not have a central location to compile, analyze, or even access critical data. Although technologies have been widely adopted in healthcare settings as well as among the general population, health information often remains trapped in silos. Patients, caregivers, care teams, researchers, and health agencies often lack the tools they need to access and optimally use these data.

While the challenges to connected health are daunting, they can be overcome. Our report outlines specific recommendations and action steps to achieve the full vision of connected health in cancer. Connected health technologies have the potential to maximize the value of our nation's investments in cancer by supporting empowered individuals and patients. The report concludes that connected health is truly about *people* more than technologies, and that timely and equitable access to data is imperative to improve health outcomes. In addition, a culture of collaboration is essential to accelerate progress.

Mr. President, you are the most “connected” leader the United States has ever had, and we are especially grateful for your leadership in health information technology (IT). In your remaining time in office, we ask your help in urging all stakeholders—health IT developers, healthcare organizations and providers, researchers, government agencies, and patients and their families—to mobilize and collaborate so we may realize the full potential of connected health in reducing the burden of cancer (and so many other diseases) in the United States. That potential, as you suggested in your recent article in *Wired* magazine,\* lies on the other side of the barriers we haven't broken through yet. The time to act is now. Connected health can be the catalyst for making cancer prevention, care, and research advances that benefit every person in this country and beyond, helping to achieve the Cancer Moonshot goal of doubling the rate of progress against the disease over the next five years. We are grateful for the privilege of having been your President's Cancer Panel.

With deep appreciation,



Barbara K. Rimer, DrPH



Hill Harper, JD



Owen N. Witte, MD

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\* <https://www.wired.com/2016/10/president-obama-guest-edits-wired-essay>



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# TABLE OF CONTENTS

<b>EXECUTIVE SUMMARY</b> .....	<b>i</b>
<b>PREFACE</b> .....	<b>vii</b>
<b>PART 1: CONNECTED HEALTH AND CANCER: THE TIME IS NOW</b> .....	<b>1</b>
<b>Growing Role of Technology in Society and Health</b> .....	<b>2</b>
<b>President’s Cancer Panel Focus on Connected Health</b> .....	<b>4</b>
<b>PART 2: TAKING ACTION TO ENHANCE CANCER PREVENTION, CARE, AND RESEARCH WITH CONNECTED HEALTH</b> .....	<b>11</b>
<b>Objective 1: Enable interoperability among institutions and individuals that support care delivery across the cancer continuum, from prevention through treatment, survivorship, and end-of-life care.</b> .....	<b>13</b>
Action Item 1.1: Health IT stakeholder groups should continue to collaborate to overcome policy and technical barriers to a nationwide, interoperable health IT system. ....	15
Action Item 1.2: Technical standards for information related to cancer care across the continuum should be developed, tested, disseminated, and adopted.....	18
Action Item 1.3: Standard, open API platforms should be developed and used to facilitate development of cancer-related apps.....	19
<b>Objective 2: Enable individuals to manage their health information and participate in their care across the cancer continuum.</b> .....	<b>21</b>
Action Item 2.1: Develop and validate interfaces and tools that support individuals’ engagement in their care across the cancer continuum.....	22
Action Item 2.2: Organizations should develop processes that enable individuals to flag perceived errors in their medical records and ensure that responses are provided and appropriate changes are made in a timely manner.....	28
Action Item 2.3: Create tools and services that help individuals identify cancer-related clinical trials appropriate for their particular situations.....	29
<b>Objective 3: Ensure that federal programs and health IT tools support the oncology workforce as it delivers care.</b> .....	<b>31</b>
Action Item 3.1: Federal incentive programs should promote use of health IT to enhance provider delivery of high-quality, patient-centered care. ....	32
Action Item 3.2: EHR vendors and healthcare organizations should employ human-centered design principles to ensure that EHR interfaces are intuitive and aligned with providers’ workflows. ....	33
Action Item 3.3: Develop and test tools and interfaces, including apps, tailored to needs of the oncology workforce.....	34
<b>Objective 4: Facilitate health information access and sharing by ensuring adequate Internet access.</b> .....	<b>37</b>
Action Item 4.1: Support initiatives and programs to ensure that everyone in the United States has adequate Internet access if so desired. ....	37
Action Item 4.2: Support initiatives and programs to ensure adequate Internet access for all healthcare providers and organizations.....	42

<b>Objective 5: Facilitate data sharing and integration to improve care, enhance surveillance, and advance research.</b> .....	<b>42</b>
Action Item 5.1: Use learning healthcare systems to support continuous improvement in care across the cancer continuum.....	43
Action Item 5.2: Use health information technologies to enhance cancer surveillance.....	47
Action Item 5.3: Integrate data from various sources to create knowledge networks for cancer research.....	49
<b>PART 3: HIGH-PRIORITY RESEARCH TO ADVANCE CONNECTED HEALTH FOR CANCER</b> .....	<b>55</b>
1. Improve understanding of how connected health can enable effective teamwork in healthcare. ....	56
2. Identify strategies to enhance individuals' engagement in their healthcare.....	57
3. Develop approaches for using data from connected devices in meaningful ways to enhance clinical care.....	58
<b>CONCLUSIONS</b> .....	<b>61</b>
<b>REFERENCES</b> .....	<b>63</b>
<b>APPENDIX A: Workshop Dates and Roster of Participants</b> .....	<b>73</b>
<b>APPENDIX B: President's Cancer Panel Action Items and Responsible Stakeholders</b> .....	<b>75</b>
<b>APPENDIX C: Acronyms</b> .....	<b>77</b>





# EXECUTIVE SUMMARY

There are many exciting and inspiring examples of how technology can help some individuals manage and improve their own health and support delivery of high-quality, patient-centered cancer care. These success stories illustrate the potential of connected health.

The President's Cancer Panel (the Panel) held a series of workshops across the United States in 2014-2015

to explore the role and potential of connected health in cancer, with the goal of identifying ways to optimize the development and use of technologies to promote cancer prevention, enhance the experience of cancer care for patients and providers, and accelerate progress in cancer research. In this report, the Panel presents objectives and action items that should be pursued to advance the use of connected health for cancer.

## Part 1: Connected Health and Cancer: The Time Is Now

Widespread uptake of technology has significant implications for health and healthcare, creating new ways to collect and access information, communicate, and use data to support decision

**Connected health is the use of technology to facilitate the efficient and effective collection, flow, and use of health information.**

making. Connected health includes a variety of tools and technologies being used by and developed for healthcare stakeholders. Cancer—with its complex biology, multispecialty care teams, transitions between treatment phases, and profound impact on the lives of patients and families—is an area of healthcare likely to benefit especially from improved coordination,

communication, information access, and health behavior change facilitated by connected health. The capacity to share and integrate data also has potential to expedite scientific discovery, enabling identification and development of strategies to more effectively prevent and treat cancers. However, technical, financial, policy, and cultural barriers have precluded optimal development and use of connected health technologies for cancer and other diseases. These barriers to effective implementation

of technology in healthcare are significant threats to quality cancer care.

The Panel concluded that although connected health for cancer has not yet been achieved, technology has significant potential to help accomplish the following critical goals: improve the experience of care for cancer patients and their caregivers, improve the experience of the oncology workforce in providing care, and reduce the burden of cancer at the population level. To accomplish these goals, technologies must be developed and implemented thoughtfully and then continually improved based on users' experiences and evidence. Cross-sector collaborations among those in the healthcare, biomedical research, and technology fields will be essential.

The Panel urges all stakeholders to collaborate to ensure that technologies are developed and implemented to meet the needs of *people*—patients, families, and the many professionals working to support patients and reduce the burden of cancer on patients and their families and communities. The time is now. We will not achieve our highest potential to meet these needs unless we make the most of the opportunities afforded by connected health.

## Part 2: Taking Action to Enhance Cancer Prevention, Care, and Research with Connected Health

Connected health has potential to transform cancer prevention, care, survivorship, and research. However, effective application of technologies to achieve this goal is not inevitable. Although technologies have been widely adopted in healthcare settings and among the general population, health information often remains trapped in silos, and individuals and healthcare providers often lack the tools they need to access and optimally use these data. Thoughtful and steadfast actions are needed to eliminate barriers to connected health and design and implement tools that capitalize on the potential of existing and emerging technologies.

In this report, the Panel identifies critical objectives and associated action items that, if implemented, should enhance access to health information, support patient-centered cancer care and patient engagement, enhance the experience of providing care for physicians and other members of the oncology workforce, and accelerate progress in cancer research.

### **Objective 1: Enable interoperability among institutions and individuals that support care delivery across the cancer continuum, from prevention through treatment, survivorship, and end-of-life care.**

Connected health is defined by the efficient and effective flow of information among all stakeholders. To accomplish this, health information technology (IT) systems and software applications must be able to communicate with one another, exchange data, and use the information that has been exchanged. This high-level connectivity among systems is referred to as interoperability. The potential benefits of interoperable connected health tools and systems are particularly great for oncology because the delivery of care across

the cancer continuum depends on access to accurate and complete information, as well as extensive coordination among patients, caregivers, and diverse teams of providers.

Creation of a nationwide interoperable health IT infrastructure was a central goal when the Office of the National Coordinator for Health Information Technology (ONC) was formed in 2004. Some progress in health information exchange has occurred over the past decade, but widespread interoperability remains challenging in many contexts, hindering the ability of the healthcare workforce to deliver safe, effective, and timely patient- and family-centered care. Collaborative efforts should continue to address technical and policy barriers to nationwide interoperability while promoting the flow of information.

**Action Item 1.1:** Health IT stakeholder groups should continue to collaborate to overcome policy and technical barriers to a nationwide, interoperable health IT system.

**Action Item 1.2:** Technical standards for information related to cancer care across the continuum should be developed, tested, disseminated, and adopted.

**Action Item 1.3:** Standard, open API platforms should be developed and used to facilitate development of cancer-related apps.

### **Objective 2: Enable individuals to manage their health information and participate in their care across the cancer continuum.**

A core principle of connected health is that individuals are empowered to decide when, whether, and how

much to participate in their health and healthcare. Connected health tools are needed to ensure that people at risk for cancer, cancer patients, and cancer survivors have access to the information they need when they need it and in formats that meet their needs. When it is appropriate and patients agree to share, information also should be accessible by family members and caregivers, who often play critically important roles in supporting people with cancer. Tools should also enable individuals' active participation in their health and healthcare by supporting decision making, data sharing and integration, and clinical trial participation, among other activities aligned with individuals' needs and preferences.

**Action Item 2.1:** Develop and validate interfaces and tools that support individuals' engagement in their care across the cancer continuum.

**Action Item 2.2:** Organizations should develop processes that enable individuals to flag perceived errors in their medical records and ensure that responses are provided and appropriate changes are made in a timely manner.

**Action Item 2.3:** Create tools and services that help individuals identify cancer-related clinical trials appropriate for their particular situations.

**Objective 3:** Ensure that federal programs and health IT tools support the oncology workforce as it delivers care.

Effective delivery of care across the cancer continuum is dependent on an engaged, productive workforce. Those involved in cancer care, like all health professionals, have had to adapt to massive changes in healthcare over the last several years, some of

which have had a negative impact on the experience of providing care. The rollout of electronic health record (EHR) systems, in particular, has contributed to providers' frustration and burnout.

The transition to EHRs will not be reversed, and few physicians wish to return to paper-based medical records. However, the significant challenges that have arisen during the initial rollout of EHRs should be addressed, and more work is needed to ensure interfaces are intuitive and aligned with care teams' workflows. Recent survey results suggest that progress is being made, as satisfaction with EHR systems has increased in some settings over the past few years. Nevertheless, additional efforts are needed to ensure that federal programs and health IT tools support the oncology workforce as it strives to deliver the best possible care.

**Action Item 3.1:** Federal incentive programs should promote use of health IT to enhance provider delivery of high-quality, patient-centered care.

**Action Item 3.2:** EHR vendors and healthcare organizations should employ human-centered design principles to ensure that EHR interfaces are intuitive and aligned with providers' workflows.

**Action Item 3.3:** Develop and test tools and interfaces, including apps, tailored to needs of the oncology workforce.

**Objective 4:** Facilitate health information access and sharing by ensuring adequate Internet access.

The full benefits of connected health cannot be achieved unless everyone in the United States who wants to participate and the organizations that support health and deliver healthcare have adequate access to high-speed Internet service. Access

depends both on the availability of broadband service and the resources needed to obtain and maintain service. For individuals, access to online tools, such as patient portals, is necessary to receive information from and communicate with healthcare providers. Universal Internet access could help engage medically underserved populations and overcome disparities in health and other areas. For healthcare providers and systems, robust broadband access is needed to facilitate collection and sharing of increasing quantities of health-related data.

Public- and private-sector stakeholders should continue to facilitate access to broadband Internet services at speeds adequate to support participation of individuals and healthcare providers and organizations in connected health. Given the central role of the Internet in modern society, access to the Internet should be viewed as a right, not a privilege.

**Action Item 4.1:** Support initiatives and programs to ensure that everyone in the United States has adequate Internet access if so desired.

**Action Item 4.2:** Support initiatives and programs to ensure adequate Internet access for all healthcare providers and organizations.

**Objective 5:** Facilitate data sharing and integration to improve care, enhance surveillance, and advance research.

Recent decreases in the U.S. cancer mortality rate stem from investments in cancer surveillance and research that have led to development of new approaches and wider use of proven strategies to prevent, detect, diagnose, and treat cancers.

However, there is remarkable need—and tremendous opportunity—to further accelerate progress by developing better ways to prevent and treat the hundreds of diseases that make up cancer and ensuring that knowledge is effectively applied.

Unprecedented amounts of data about people at risk of cancer and cancer patients are being collected in medical records, as part of research studies, and by individuals themselves. In the past, health data remained wherever they were collected and generally were used in limited ways to serve the specific needs of whoever collected them. These silos represent a significant missed opportunity. Connected health technologies have an important role to play by facilitating linkages of systems and data sets and creating tools that enable researchers, clinicians, and patients to use data in meaningful ways. To achieve the development of a national infrastructure to support sharing and processing of cancer data, technical and logistical challenges to data integration must be overcome, and the cancer community must foster a culture of collaboration that encourages data sharing and free exchange of ideas. Care also must be taken to ensure that federal, state, and organizational policies appropriately balance data sharing for research with individuals' privacy and security.

**Action Item 5.1:** Use learning healthcare systems to support continuous improvement in care across the cancer continuum.

**Action Item 5.2:** Use health information technologies to enhance cancer surveillance.

**Action Item 5.3:** Integrate data from various sources to create knowledge networks for cancer research.

## Part 3: High-Priority Research to Advance Connected Health for Cancer

Additional research in several areas could increase the benefits of connected health for cancer. Better tools and interfaces could be developed if more were known about how healthcare providers work collaboratively and the factors that enhance

people's engagement with their health and healthcare. Research also is needed to ensure that the vast quantities of data being generated can be used in meaningful ways to support patient-centered care.

### High-Priority Research Areas

- Improve understanding of how connected health can enable effective teamwork in healthcare.
- Identify strategies to enhance individuals' engagement in their healthcare.
- Develop approaches for using data from connected devices in meaningful ways to enhance clinical care.

## Conclusions

Connected health is creating significant new opportunities to improve the quality and experience of health and healthcare in the United States and around the world. While technologies play a fundamental role in connected health, the actions recommended by the President's Cancer Panel in this report reflect the Panel's view that a clear and unwavering focus on the following guiding principles is even more important.

- People, not technologies, must be at the center of connected health for cancer.
- Timely access to data is imperative.
- A culture of collaboration will accelerate progress.

The challenges facing connected health cannot be addressed by any single organization or agency.

**The Panel urges all stakeholders—health IT developers, healthcare organizations, healthcare providers, researchers, government agencies, and individuals—to collaborate in using connected health to reduce the burden of cancer through prevention and improve the experience of cancer care for patients and providers.** In the end, the purpose of connected health is to improve knowledge, engagement, processes, and quality of cancer care, and, thereby, to save lives and improve quality of life for millions of people living with cancer.



# PREFACE

The President’s Cancer Panel was established in 1971 by the National Cancer Act (P.L. 92-218) and is charged with monitoring the progress of the National Cancer Program—which includes all public and private activities focused on preventing, detecting, and treating cancers and on cancer survivorship—and identifying barriers to effective implementation. The Panel investigates topics of high importance to the National Cancer Program for which actionable recommendations can be made. Information is collected through focused workshops and additional research, and findings and recommendations are compiled in reports to the President of the United States.

For its 2014-2015 series of workshops, the Panel focused on connected health for cancer, with the goal of identifying ways to optimize the development and use of technologies, broadly defined, to promote cancer prevention, enhance the experience of cancer care for patients and providers, and accelerate progress in cancer research. The Panel convened three workshops to gather information from many stakeholders in this area, including patients and patient advocates as well as leaders from academia, technology, government, and healthcare.

There are many exciting and inspiring examples of how technologies can help some individuals manage and improve their own health and support delivery of high-quality, patient-centered care. These success stories illustrate the potential of connected health. However, technical, financial, policy, and cultural barriers have precluded optimal development and use of connected health technologies for cancer and other diseases. The President’s Cancer Panel concurs with the President’s Council of Advisors on Science and Technology that overcoming these barriers through improvements in health IT and investments in health data infrastructure is critical to meeting the objectives of ongoing healthcare reform in the United States.<sup>1,2</sup> Connected health also can help achieve the goal set by the Vice President’s Cancer Moonshot of doubling the rate of progress in cancer research and treatment over the next five years.<sup>3</sup>

In this report, the Panel presents objectives and action items that should be pursued to advance the use of connected health for cancer. These recommendations are consistent with calls by the Institute of Medicine (IOM)<sup>4</sup> and the American Society of Clinical Oncology (ASCO)<sup>5</sup> to use health IT to improve the experience of cancer care for patients and providers. Several of the Panel’s recommendations align with those recently issued by the Cancer Moonshot Blue Ribbon Panel,<sup>6</sup> on which Panel Chair Barbara Rimer served. The Panel commends the work of the Blue Ribbon Panel—particularly in the areas of the data ecosystem, implementation science, and symptom management—and endorses its recommendations. The Panel also supports the implementation plans outlined in the recently released Cancer Moonshot Task Force report<sup>7</sup> and notes that there are many opportunities for connected health to help achieve the strategic goals of the Cancer Moonshot. The Panel also supports the goals set forth by ONC in the *Federal Health IT Strategic Plan*<sup>8</sup> and *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap*.<sup>9</sup> Although not cancer-specific, the robust health information networks and processes envisioned in these reports will form a strong and essential foundation for efforts to use connected health to enhance prevention and treatment of cancers if they are thoughtfully implemented and iteratively improved. Cross-sector collaborations with those outside of healthcare—including computer and data scientists—also are essential.

The Panel urges all stakeholders—individuals, healthcare providers, researchers, patient advocacy organizations, healthcare systems, government agencies, technology developers, and others—to collaborate to ensure that technologies are developed and implemented to meet the needs of *people*—patients, families, and the many professionals working to support patients and reduce the burden of cancer on patients, families, and communities. The time is now. We will not achieve our highest potential to meet these needs unless we make the most of the opportunities afforded by connected health today and push the boundaries of what is possible in the future.





**PART 1**

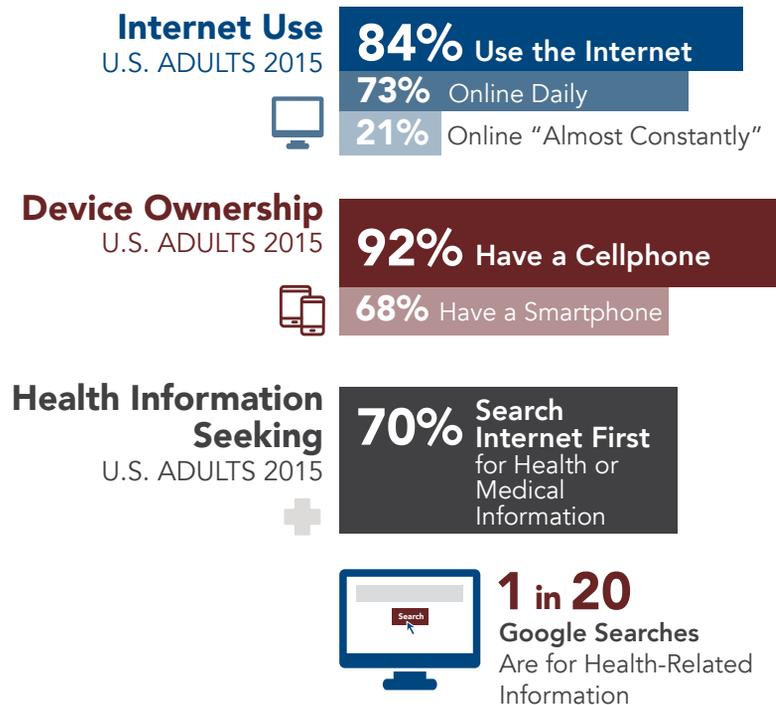
Connected Health and Cancer:  
The Time Is Now

## Growing Role of Technology in Society and Health

Technology has become nearly ubiquitous in modern society and has transformed the ways in which people shop, bank, travel, and manage their daily lives (Figure 1). Widespread uptake of technology

has significant implications for health and healthcare, creating new ways to collect and access information, communicate, and use data to support decision making. **The use of technology to facilitate the efficient and effective collection, flow, and use of health information is referred to as connected health.**

**Figure 1. Consumer Use of Technology**



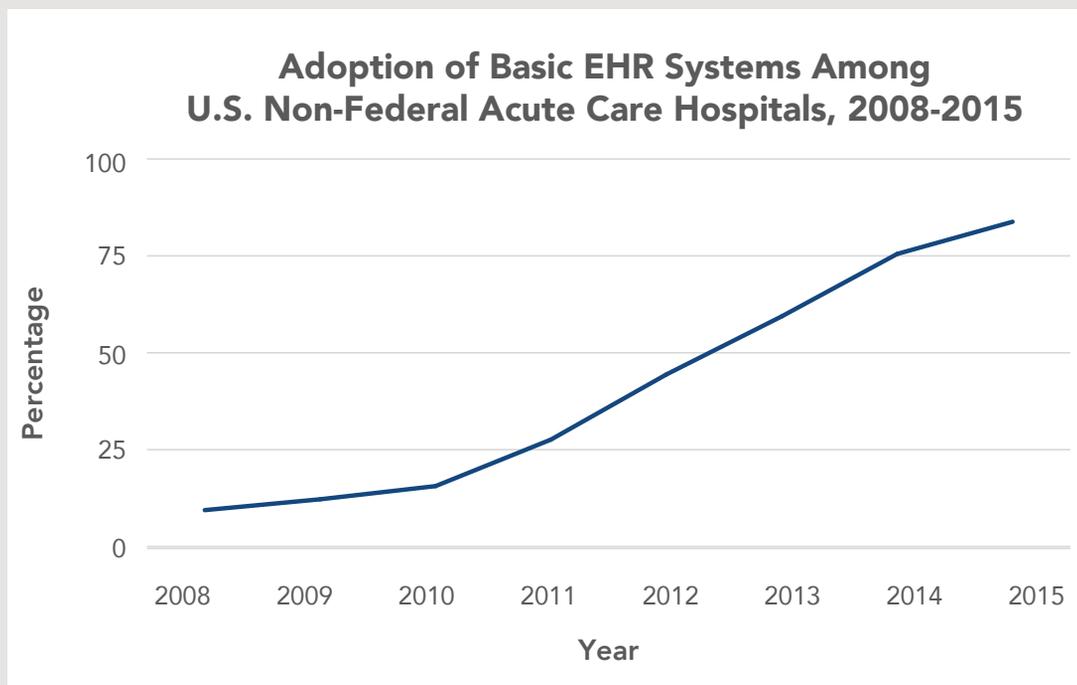
**Sources:** Perrin A, Duggan M. Americans' Internet access: 2000-2015. Washington (DC): Pew Research Center; 2015 Jun 26. Available from: <http://www.pewinternet.org/2015/06/26/americans-internet-access-2000-2015>; Perrin A. One-fifth of Americans report going online 'almost constantly' [Internet]. Washington (DC): Pew Research Center; 2015 Dec 8 [cited 2016 Feb 24]. Available from: <http://www.pewresearch.org/fact-tank/2015/12/08/one-fifth-of-americans-report-going-online-almost-constantly>; Anderson M. Technology device ownership: 2015. Washington (DC): Pew Research Center; 2015 Oct 29. Available from: <http://www.pewinternet.org/2015/10/29/technology-device-ownership-2015>; National Cancer Institute. Health information seeking on behalf of others: characteristics of "surrogate seekers." HINTS Briefs No. 29 [Internet]. 2015 Sep [cited 2016 Mar 2]. Available from: [http://hints.cancer.gov/docs/Briefs/HINTS\\_Brief\\_29.pdf](http://hints.cancer.gov/docs/Briefs/HINTS_Brief_29.pdf); Ramaswami P. A remedy for your health-related questions: health info in the Knowledge Graph [Internet]. Mountain View (CA): Google; 2015 Feb 10 [cited 2016 Mar 2]. Available from: <https://googleblog.blogspot.co.uk/2015/02/health-info-knowledge-graph.html>

Connected health encompasses a variety of technologies—such as devices, tools, and software—being used by and developed for healthcare stakeholders, including healthy individuals, patients, family members and caregivers, healthcare providers, healthcare systems, public health programs, and researchers. Consumers frequently turn to technology to help them manage their health and healthcare. The Internet is a commonly used source for health and medical

information.<sup>10,11</sup> In addition, an increasing number of patients are accessing their medical records online and exchanging emails and text messages with their healthcare providers,<sup>12</sup> enabled by the rapid proliferation since 2009 of electronic medical records (see *Electronic Health Records* below).<sup>13-16</sup> Wellness- and health-related devices and apps increasingly are being developed for consumers and healthcare providers, and many are in use today; their number is expected to increase many times over.

### Electronic Health Records

EHR adoption has increased dramatically in recent years, spurred largely by financial incentives established in the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009.



Source: Henry J, Pylypchuk Y, Searcy T, Patel V. Adoption of electronic health record systems among U.S. non-federal acute care hospitals: 2008-2015. *ONC Data Brief No. 35* [Internet]. 2016 May [cited 2016 Aug 3]. Available from: <http://dashboard.healthit.gov/evaluations/data-briefs/non-federal-acute-care-hospital-ehr-adoption-2008-2015.php>

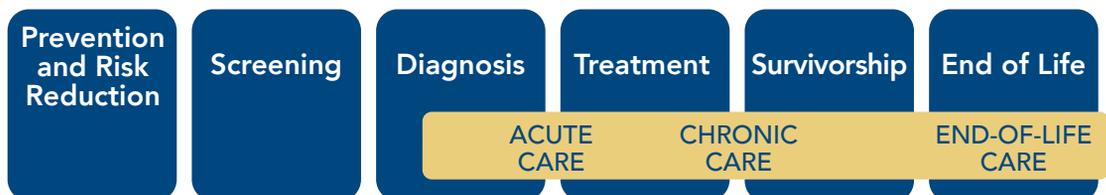
## President's Cancer Panel Focus on Connected Health

The President's Cancer Panel held a series of workshops across the United States in 2014-2015 to explore the role and potential of connected health in cancer prevention, care, and research in the United States. Cancer is the second most common cause of death in the United States, exceeded only by heart disease. More than 1.6 million people in the United States are diagnosed with cancer each year. As of 2014, nearly 14.5 million people in the United States were living with a personal history of cancer.<sup>17</sup> Although cancer prevention, early detection, and treatment have improved over the past several decades,<sup>18,19</sup> cancer care delivery will face significant challenges in coming years as the U.S. population ages, the oncology workforce shrinks, the costs of cancer care continue to grow, and medical advances expand treatment options.<sup>4,20</sup> Technology-based solutions have been proposed to address challenges in cancer and many other areas of healthcare. The potential benefits of connected health are particularly pronounced for cancer for several reasons.

- **Cancer has lifelong implications.** Cancer diagnoses are life-changing for patients and often impose significant burdens on families and caregivers. Patients may struggle to understand

their diagnoses and test results, including genomic testing results. They likely will interact with numerous providers and often must manage vast quantities of personal health information. They make decisions about treatment options and, in many cases, lack full access to the information needed to make informed choices. They also may have questions about participating in clinical trials. Challenges persist when patients transition out of active treatment. Some are faced with decisions about end-of-life care, while others cope with increased monitoring and may deal with long-term and late effects of their diseases and treatments for the rest of their lives. All of this may be compounded by financial strains due, in part, to the burden of cancer treatment. Cancer patients and their families and caregivers need varying types and levels of support throughout the different phases of treatment, from the time of diagnosis through survivorship and/or end of life. Healthy individuals also would benefit from information and resources that could help them reduce their cancer risk and increase the likelihood of early diagnosis through screening. Connected health could help individuals across the cancer continuum access and use information and resources, as well as better manage their health and cancer care (Figure 2).

**Figure 2. Cancer Control Continuum**



■ **Quality cancer care requires extensive coordination.** Cancer care frequently involves multiple interventions delivered by a variety of healthcare professionals who often are located in distinct clinical settings (see *Cancer Care Coordination* on page 6). There also are numerous transitions in care as patients move between active treatment, survivorship care, and/or end-of-life care. Patients and their family members and caregivers are critical components of the care team and play important roles in care coordination. Frequent and extensive communication among patients, their family members and caregivers, and providers is essential to ensure patients receive evidence-based care consistent with their preferences and values. This is particularly challenging within the U.S. healthcare system, which often is fragmented and difficult to navigate. Connected health could help all stakeholders communicate and access information in timely and efficient ways, enabling delivery of higher-quality care.

■ **Cancer biology is complex.** Cancer is not a single disease but, rather, a set of diseases driven by myriad molecular aberrations and influenced by numerous environmental and lifestyle factors. Past research has led to development of targeted therapies for some cancer subtypes in recent years, improving outcomes for many patients. Knowledge of factors underlying development of various cancer subtypes and their responses to treatment is expected to increase even more in coming years through efforts such as the Precision Medicine Initiative (PMI)<sup>21</sup> (see *Precision Medicine Initiative* below) and the Cancer Moonshot<sup>3</sup> (see *Cancer Moonshot* on page 43), opening the door to exciting advances in cancer prevention and treatment. Individuals and physicians will need tools to help them effectively manage and use the unprecedented volumes of data that will be available to inform personal and clinical decision making.

### Precision Medicine Initiative

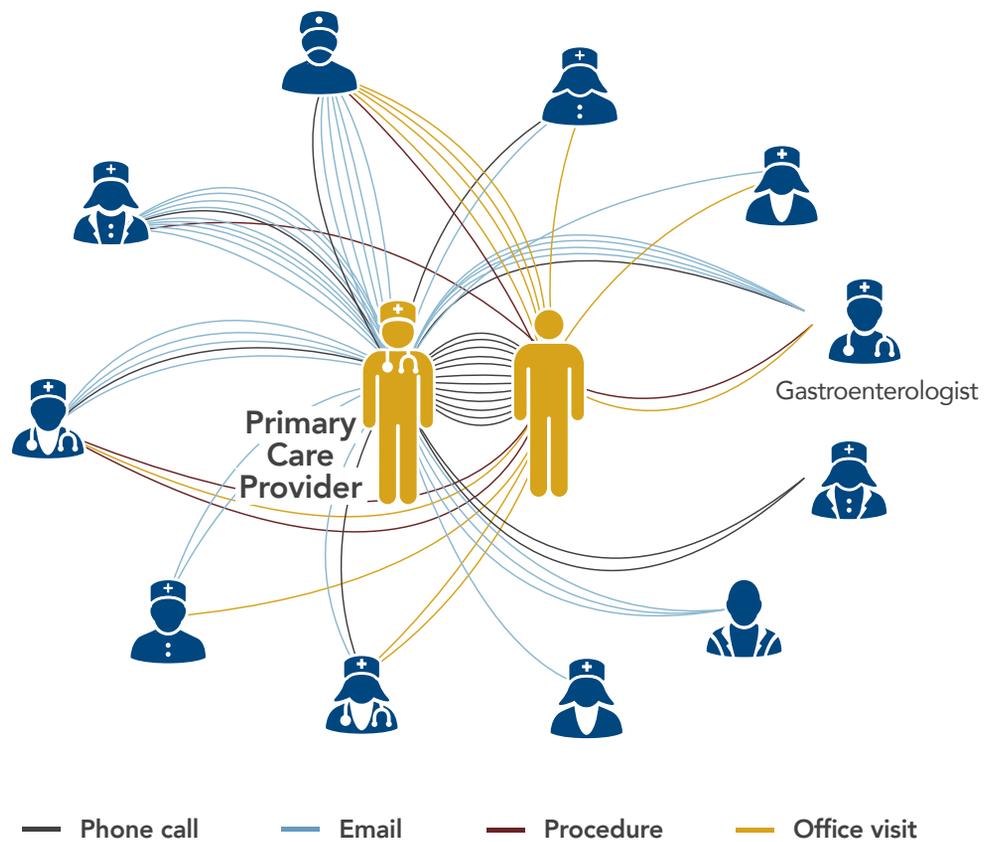
The PMI was launched by President Obama in 2015 to enable a new era of medicine through research, technology, and policies that empower patients, researchers, and providers to work together toward development of individualized care. The goal of precision medicine is to better prevent and treat diseases by taking into account individual differences in people's genes, environments, and lifestyles. As part of PMI, the National Institutes of Health (NIH) is creating a voluntary national research cohort of at least 1 million people from diverse backgrounds. Although PMI will yield insights in a number of areas, cancer is a high priority. As part of PMI, the National Cancer Institute (NCI) is expanding its investment in precision oncology with the goal of using genomics to identify and target molecular vulnerabilities of individual cancers.

**Sources:** The White House Office of the Press Secretary. President Obama's Precision Medicine Initiative [Fact Sheet]. Washington (DC): the White House; 2015 Jan 30. Available from: <https://www.whitehouse.gov/the-press-office/2015/01/30/fact-sheet-president-obama-s-precision-medicine-initiative>; National Institutes of Health. About the Precision Medicine Initiative Cohort Program [Internet]. Bethesda (MD): NIH; [cited 2016 Mar 23]. Available from: <https://www.nih.gov/precision-medicine-initiative-cohort-program>; National Cancer Institute. NCI and the Precision Medicine Initiative [Internet]. Bethesda (MD): NCI; [updated 2016 Mar 10; cited 2016 Mar 23]. Available from: <http://www.cancer.gov/research/key-initiatives/precision-medicine>

## Cancer Care Coordination

A study in the United Kingdom found that cancer patients met with at least 13 different doctors during the course of their cancer care. More than half of patients met with 30 or more doctors. One primary care physician recently recounted his experience when one of his patients was diagnosed with bile duct cancer. In the 80 days between the day the tumor was detected via computed tomography scan and its removal, the physician had 40 communications with 11 other providers and communicated with the patient or the patient's wife 12 times.

### Ambulatory Care Coordination for One Patient over 80-Day Period



Sources: Press MJ. Instant replay—a quarterback's view of care coordination. *N Engl J Med.* 2014;371(6):489-91. Copyright © 2014 Massachusetts Medical Society. Reprinted with permission from Massachusetts Medical Society; Smith SD, Nicol KM, Devereux J, Cornbleet MA. Encounters with doctors: quantity and quality. *Palliat Med.* 1999;13(3):217-23.

The Panel learned about many exciting and promising applications of technology in health and healthcare, and examples are described throughout this report.\* However, patients and providers who use these technologies often report significant challenges and frustrations. Patients say they frequently identify errors in their medical records and have difficulties getting these errors corrected. Physicians report that EHRs disrupt their workflows and that they spend hours each week, often outside the office, entering data. Many patients and physicians feel that technology interferes with the personal interactions that are so critical to patient-centered care. Current technologies do not yet support free exchange of health information—EHR systems at different organizations, even those created by the same vendor, often are not interoperable.<sup>1,2,22,23</sup> Thus, healthcare information often still is shared via fax or in paper form by patients themselves, even when the data are in digital form. Furthermore, technical barriers and inadequate models for patient consent have precluded large data sets stored in EHRs from being used for surveillance or large-scale research activities. These barriers to

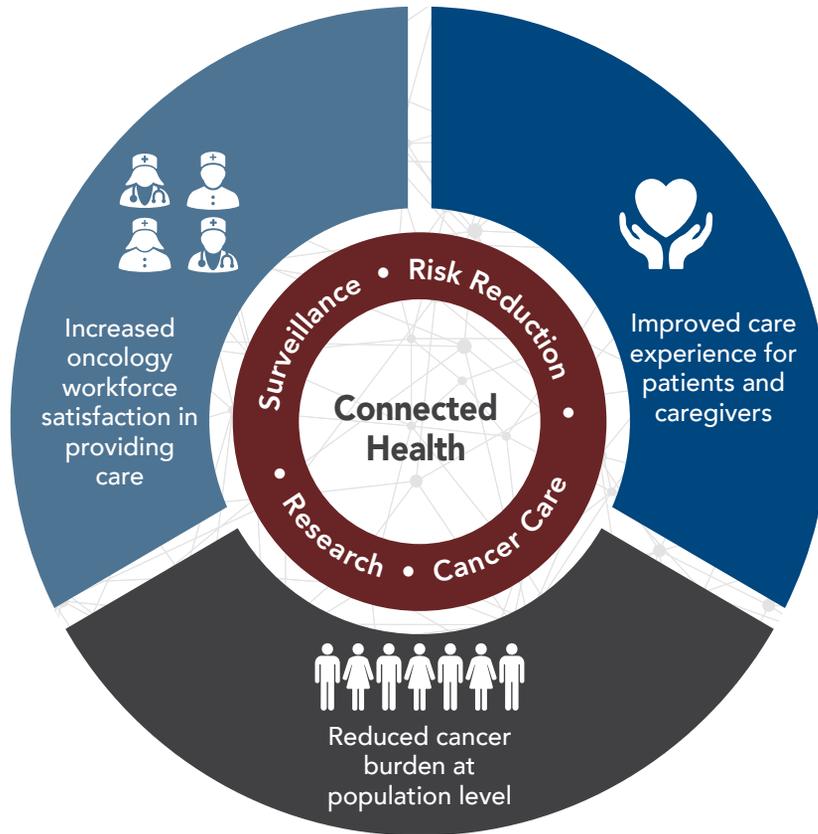
effective implementation of technology in healthcare are significant threats to quality cancer care.

**The Panel concluded that although connected health for cancer has not yet been achieved, technology has significant potential to help accomplish the following critical goals: improve the experience of care for cancer patients and their caregivers, improve the experience of the oncology workforce in providing care, and reduce the burden of cancer at the population level (Figure 3).** To accomplish these goals, technologies must be developed and implemented thoughtfully and then continually improved based on users' experiences and evidence. Cross-sector collaborations among those in the healthcare, biomedical research, and technology fields will be essential. The Panel has identified several principles that should guide efforts to expand and improve applications of technology in cancer to advance connected health in ways that truly support efficient and effective collection, flow, and use of information (see *Principles of Connected Health* on page 9).

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\* Inclusion of examples in this report does not represent endorsement by the President's Cancer Panel of any organization, company, or product.

**Figure 3.** Connected Health Can Help Achieve Critical Cancer Care and Research Goals

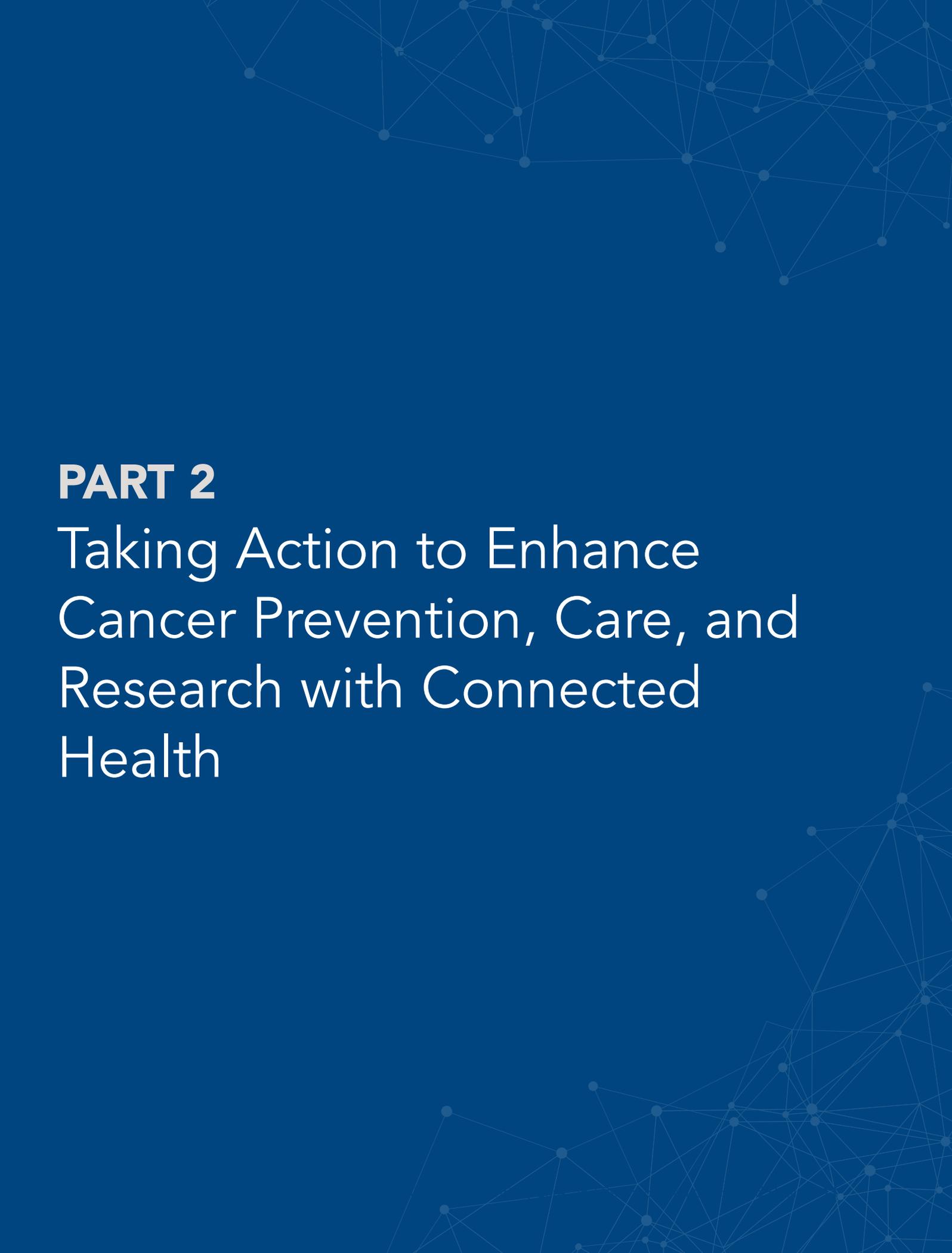


**Note:** These goals were informed by the Triple Aim, which was developed by the Institute for Healthcare Improvement, and recent proposals to expand the Triple Aim to the Quadruple Aim with the addition of a goal focused on improving the experience of the healthcare workforce in providing care. Sources: Institute for Healthcare Improvement. The IHI Triple Aim [Internet]. Cambridge (MA): IHI; [cited 2016 Aug 25]. Available from: <http://www.ihl.org/engage/initiatives/tripleaim/pages/default.aspx>; Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. *Health Aff (Millwood)*. 2008;27(3):759-69; Sikka R, Morath JM, Leape L. The Quadruple Aim: care, health, cost and meaning in work. *BMJ Qual Saf*. 2015;24(10):608-10; Bodenheimer T, Sinsky C. From triple to quadruple aim: care of the patient requires care of the provider. *Ann Fam Med*. 2014;12(6):573-6.

## Principles of Connected Health

- Systems and interfaces for data collection and use are designed and implemented to meet the needs of people using them.
- Individuals are empowered to decide when, whether, and how much to participate in their health and healthcare and whether and how to involve their family members and caregivers. Decisions about participation may change over time.
- A culture of collaboration ensures that data are shared in a timely manner and appropriate formats to enable patient engagement, decision making, patient-centered clinical care, and research.
- Information is accurate and complete. Potential errors are addressed when identified.
- Privacy/confidentiality of individuals and their data are protected.
- Technology and computational power are harnessed to simplify tasks and make large and complicated data sets more usable.
- All populations benefit from connected health, regardless of income, education, race/ethnicity, age, disability, or geography.





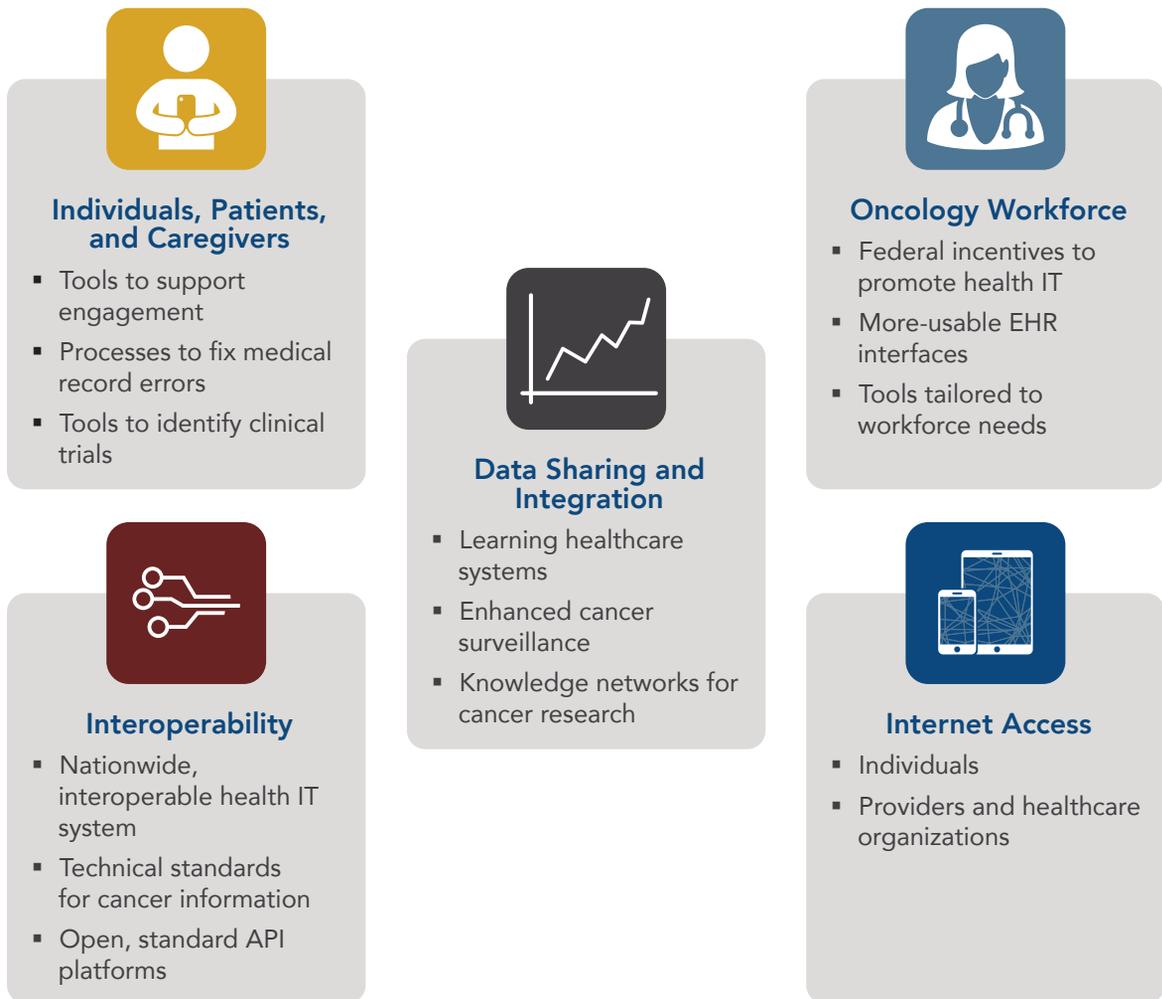
## **PART 2**

# Taking Action to Enhance Cancer Prevention, Care, and Research with Connected Health

Connected health has potential to transform cancer prevention, care, survivorship, and research. However, effective application of technologies to achieve this goal is not inevitable. Although technologies have been widely adopted in healthcare settings and among the general population, health information often remains trapped in silos, and individuals and healthcare providers often lack the tools they need to access and optimally use these data. Thoughtful and steadfast actions are needed to eliminate barriers

to connected health and design and implement tools that capitalize on the potential of existing and emerging technologies. In this report, the Panel identifies critical objectives and associated action items that, if implemented, should enhance access to health information, support patient-centered care and patient engagement, enhance the experience of providing care for physicians and other members of the oncology workforce, and accelerate progress in cancer research (Figure 4).

**Figure 4. Action Items to Advance Connected Health for Cancer**



## Privacy and Security

Breaches of health information can harm individuals, large groups of people, and organizations, damaging stakeholder trust. Without this trust, stakeholders will be less willing to share their data, undermining the goals of connected health. Although none of the recommendations in this report directly address privacy and security, the Panel encourages all stakeholders to take steps to appropriately protect privacy and ensure security while also sharing health data for learning to the extent possible. Additional information can be found on the Office of the National Coordinator for Health Information Technology website or in *ONC's Guide to Privacy and Security of Electronic Health Information*. Information on how the Health Insurance Portability and Accountability Act (HIPAA) protects privacy and security of health information can be found on the U.S. Department of Health and Human Services website.

**Sources:** Office of the National Coordinator for Health Information Technology. Health IT privacy and security resources [Internet]. Washington (DC): ONC; [updated 2016 Feb 12; cited 2016 Oct 3]. Available from: <https://www.healthit.gov/providers-professionals/ehr-privacy-security/resources>; Office of the National Coordinator for Health Information Technology. Guide to privacy and security of electronic health information. Washington (DC): ONC; 2015 Apr. Available from: <https://www.healthit.gov/sites/default/files/pdf/privacy/privacy-and-security-guide.pdf>; U.S. Department of Health and Human Services. Health information privacy [Internet]. Washington (DC): DHHS; [cited 2016 Oct 3]. Available from: <http://www.hhs.gov/hipaa>



## OBJECTIVE 1

**Enable interoperability among institutions and individuals that support care delivery across the cancer continuum, from prevention through treatment, survivorship, and end-of-life care.**

Connected health is defined by the efficient and effective flow of information among all stakeholders. To accomplish this, health IT systems and software applications must be able to communicate with one another, exchange data, and use the information that has been exchanged. This high-level connectivity among systems is referred to as interoperability (see *What Is Interoperability?* on page 14).<sup>24</sup> The potential benefits of interoperable connected health tools and systems are particularly great for oncology because the delivery of care across the cancer continuum depends on access to accurate and complete information, as well as extensive coordination among patients, caregivers, and diverse teams of providers.

## What Is Interoperability?

Interoperability is the capacity of health IT systems and software applications to communicate, exchange data, and use the information that has been exchanged without special effort on the part of the user.



Source: Office of the National Coordinator for Health Information Technology. Connecting health and care for the nation: a shared nationwide interoperability roadmap. Washington (DC): ONC; 2015 Oct. Available from: <https://www.healthit.gov/sites/default/files/hie-interoperability/nationwide-interoperability-roadmap-final-version-1.0.pdf>

Creation of a nationwide interoperable health IT infrastructure was a central goal when the ONC was formed in 2004. Some progress in health information exchange has occurred over the past decade, in part spurred by the HITECH Act, the State Health Information Exchange Cooperative Agreement Program, and other

initiatives and programs of ONC and the Centers for Medicare & Medicaid Services (CMS).<sup>25-30</sup> Despite this progress, widespread interoperability remains challenging in many contexts, hindering the ability of the healthcare workforce to deliver safe, effective, and timely patient- and family-centered care.

## Action Item 1.1

### Health IT stakeholder groups should continue to collaborate to overcome policy and technical barriers to a nationwide, interoperable health IT system.

Over the past few years, the urgency surrounding interoperability has grown, in part, because widespread adoption of EHRs and other health IT has increased the potential benefits of a fully connected system. In October 2015, the ONC released *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap*, which describes public- and private-sector actions that must be undertaken to realize the vision for a seamless health data system.<sup>9</sup> The Roadmap emphasizes the need for a healthcare payment and regulatory environment that incentivizes interoperability—namely, a shift from volume-driven to value-based payment for healthcare services. It also outlines several policy and technical components that must be in place to enable interoperability.

The federal government is addressing interoperability on multiple fronts. In April 2015, Congress declared it

a national objective to achieve widespread exchange of health information through interoperable certified EHR technology nationwide by the end of 2018 (P.L. 114-10). Furthermore, CMS and ONC have emphasized that interoperability will be a high priority of a new incentive system that rewards Medicare providers for using technology to support improvements in clinical outcomes. ONC also has a number of initiatives and activities that address the various technical components of interoperability, including standards development and testing,<sup>28,31-33</sup> health IT certification,<sup>29</sup> and issues related to privacy and security.<sup>34</sup> The Department of Health and Human Services Office for Civil Rights recently published documents that clarify individuals' rights to their health information under the HIPAA Privacy Rule and provide guidance to organizations on how to adhere to privacy and security standards when exchanging data.<sup>35</sup>

Several private-sector and collaborative efforts focused on health information exchange and interoperability also are under way (see *Private-Sector and Collaborative Interoperability Efforts* on page 16). Numerous organizations have signaled their intent to promote interoperability by signing the ONC Interoperability Pledge (see *ONC Interoperability Pledge* on page 17).

### Private-Sector and Collaborative Interoperability Efforts

- The **Care Connectivity Consortium** began in 2011 as an effort to facilitate health information exchange among the six founding healthcare systems and recently began making interoperability solutions available to the broader community.
- The **Center for Medical Interoperability**, formed in 2013 and led by healthcare systems, has created a technical lab to develop solutions to interoperability challenges. It plans to use the collective purchasing power of its members to drive development of health IT products that enable seamless information exchange.
- Several competing health IT vendors came together in 2013 to form the **CommonWell Health Alliance**, a trade association focused on developing interoperability solutions that can be embedded natively within health IT products.
- In August 2016, the interoperability framework developed by the public-private **Carequality** initiative went live. The framework—which provides the necessary legal terms, policy requirements, technical specifications, and governance processes to enable interoperability—has been adopted by 13 health organizations to date, and several others are in various stages of adoption and implementation planning.

Sources: Care Connectivity Consortium. Home page [Internet]. CCC; [cited 2016 Apr 4]. Available from: <http://www.careconnectivity.org>; Center for Medical Interoperability. Home page [Internet]. Nashville (TN): the Center; [cited 2016 Apr 5]. Available from: <http://medicalinteroperability.org>; CommonWell Health Alliance. Home page [Internet]. CommonWell Health Alliance; [cited 2016 Apr 4]. Available from: <http://www.commonwellalliance.org>; Van Dyke D. Patient record sharing increases using Carequality interoperability framework [Press Release]. McLean (VA): The Sequoia Project; 2016 Aug 16. Available from: <http://sequoiaproject.org/carequality-news/patient-record-sharing-increases-using-carequality-interoperability-framework>

## ONC Interoperability Pledge

ONC has urged stakeholders to agree to three core commitments to improve the flow of health information to consumers and healthcare providers:

- **Consumer Access:** To help consumers easily and securely access their electronic health information, direct it to any desired location, learn how their information can be shared and used, and be assured that this information will be effectively and safely used to benefit their health and that of their community.
- **No Blocking/Transparency:** To help providers share individuals' health information for care with other providers and their patients whenever permitted by law, and not block electronic health information (defined as knowingly and unreasonably interfering with information sharing).
- **Standards:** Implement federally recognized, national interoperability standards, policies, guidance, and practices for electronic health information, and adopt best practices, including those related to privacy and security.

As of September 2016, the pledge had been signed by EHR vendors that collectively provide 90 percent of hospital EHRs nationwide; numerous healthcare systems, including the five largest in the country with facilities in 47 states; and over a dozen health information exchanges, professional organizations, and advocacy groups.

**Sources:** Office of the National Coordinator for Health Information Technology. Interoperability pledge: what you can do [Internet]. Washington (DC): ONC; [cited 2016 Apr 6]. Available from: <https://www.healthit.gov/commitment>; U.S. Department of Health and Human Services. HHS announces major commitments from healthcare industry to make electronic health records work better for patients and providers [Press Release]. Washington (DC): DHHS; 2016 Feb 29 [cited 2016 Mar 22]. Available from: <http://www.hhs.gov/about/news/2016/02/29/hhs-announces-major-commitments-healthcare-industry-make-electronic-health-records-work-better.html>

The Panel is encouraged by widespread support for and attention to health IT interoperability, an indispensable component of connected health for cancer. **All public- and private-sector health IT stakeholder groups, including government agencies, healthcare systems, providers, laboratories, standards development organizations, and health IT developers, should work cooperatively to achieve interoperability as quickly**

**as possible, with the ultimate goal of optimizing the flow of information to serve the needs of patients, caregivers, and providers.** In addition to addressing technical aspects of interoperability, stakeholders should enact policies and foster cultures that promote collaboration and do not allow information blocking, which interferes with the effective and efficient flow of information (see *Information Blocking* on page 18).

## Information Blocking

There have been assertions that some healthcare systems, hospitals, and health IT vendors knowingly and unreasonably interfere with the exchange or use of electronic health information. This conduct is referred to as information blocking. Examples of information blocking include developing or implementing technology in non-standard ways likely to substantially increase the costs, complexity, or burden of sharing health information; refusing to share information or establish connections with competitors; charging prohibitive fees for data exchange that have no relation to costs; using contract terms or policies to limit data sharing; or refusing to transmit data where an individual directs it, as is required by law. These behaviors are inconsistent with the principles of connected health and undermine delivery of high-quality, patient-centered care.

**Sources:** Black P, Kendrick DC, Kibbe DC, Mirro MJ. Testimony. Presented at: Achieving the promise of health information technology: information blocking and potential solutions (full committee hearing of the U.S. Senate committee on Health, Education, Labor, and Pensions); 2015 Jul 23; Washington, DC. Available from: <http://www.help.senate.gov/hearings/achieving-the-promise-of-health-information-technology-information-blocking-and-potential-solutions>; Allen A. Connecticut law bans EHR-linked information blocking. Politico.com [Internet]. 2015 Oct 30 [cited 2016 Apr 9]. Available from: <http://www.politico.com/story/2015/10/connecticut-law-bans-ehr-linked-information-blocking-215400>; HIMSS Electronic Health Record Association. Letter to: Office of the National Coordinator for Health Information Technology. 2015 Sep 25. Available from: <http://www.himssehra.org/docs/EHRA%20Information%20Blocking%20Response%20Letter.pdf>; American Society of Clinical Oncology. Barriers to interoperability and information blocking. Alexandria (VA): ASCO; 2015. Available from: [http://www.asco.org/sites/www.asco.org/files/position\\_paper\\_for\\_clq\\_briefing\\_09142015.pdf](http://www.asco.org/sites/www.asco.org/files/position_paper_for_clq_briefing_09142015.pdf); Office of the National Coordinator for Health Information Technology. Report on health information blocking [Report to Congress]. Washington (DC): ONC; 2015 Apr. Available from: [http://www.healthit.gov/sites/default/files/reports/info\\_blocking\\_040915.pdf](http://www.healthit.gov/sites/default/files/reports/info_blocking_040915.pdf)

## Action Item 1.2

### Technical standards for information related to cancer care across the continuum should be developed, tested, disseminated, and adopted.

Health IT systems across the country currently use a variety of technical procedures, formats, and vocabularies, so healthcare organizations often cannot use automated processes to recognize, process, and interpret data from external sources. A set of common technical standards for health IT systems would facilitate more efficient and effective data sharing and

integration. The President's Cancer Panel supports ONC's assertion in the 2015 Roadmap that common technical standards must be developed, widely deployed, and iteratively improved.<sup>9</sup> Development could be carried out through standards development organizations or open-source processes. In particular, standards for cancer-related information are needed to fully realize the benefits of health IT interoperability for cancer care across the continuum.

Until recently, no such standards existed. The American Society of Clinical Oncology—in collaboration with interoperability experts and the healthcare-focused standards development organization HL7—has begun developing an

oncology-specific EHR standard designed to improve coordination and quality of care for cancer patients. Initial work on the standard, called Clinical Oncology Treatment Plan and Summary (COTPS), focused on data elements needed for preparation of treatment planning and summary documents to support communication and coordination of care during and after treatment for early-stage breast cancer and colon cancer.<sup>36</sup> COTPS is listed in the ONC Interoperability Standards Advisory,<sup>28</sup> and ASCO currently is integrating its survivorship care plan into COTPS.<sup>37</sup> In addition to supporting cancer care, cancer-related standards will help improve surveillance and research. Oncology-specific standards will support creation of learning healthcare systems for cancer (see *Action Item 5.1*). The Centers for Disease Control and Prevention (CDC) and its partners made use of COTPS when they developed guidance for reporting by ambulatory healthcare providers to cancer registries (see *Action Item 5.2*).<sup>38</sup>

The Panel lauds the work of ASCO as a critical first step in developing oncology-specific standards. **However, more must be done to develop and disseminate technical standards for information related to cancer prevention and care.** COTPS should be expanded to include disease-specific information for additional cancer types. Furthermore, standards for cancer screening and factors that influence cancer risk and outcomes—including genomic, environmental, and lifestyle factors—must be developed and used. Patient care also would benefit if patient-reported outcomes were validated and then collected in standardized ways. **Health IT vendors and healthcare organizations should adopt and use standards for cancer-related information.** Current and emerging oncology standards should be evaluated in real-world practice and refined to optimize their value for providers and patients.

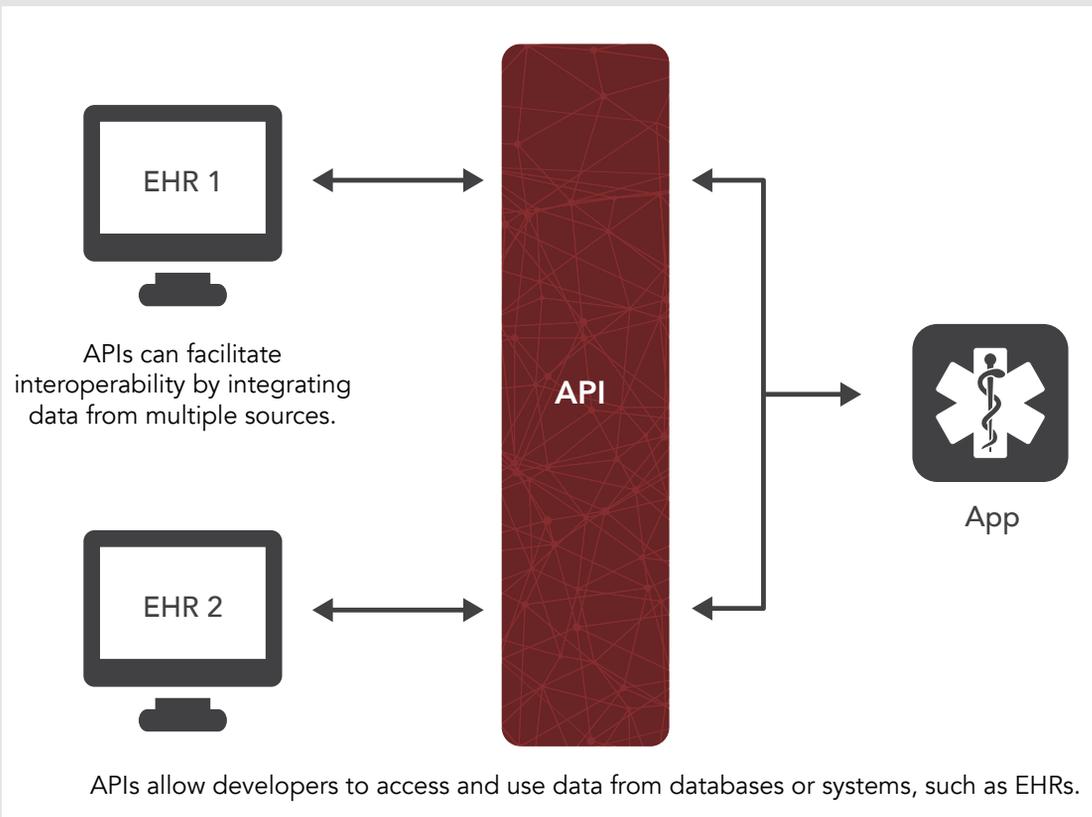
## Action Item 1.3

### Standard, open API platforms should be developed and used to facilitate development of cancer-related apps.

One approach to health IT interoperability that has garnered enthusiasm is the use of application programming interfaces, or APIs, to provide access to data and facilitate development of apps and other interfaces (see *What Is an API?* on page 20). APIs underlie the success of the app market for mobile devices, enabling development of novel, diverse, high-quality apps by an almost unlimited number of third parties. Implementation of APIs by EHRs and other health IT products would open up a health app marketplace capable of catering to the specialized needs of a variety of users and adapting quickly to changes to the healthcare system. Within the context of connected health for cancer, APIs would enable development of customized, cancer-specific tools and interfaces with potential to support patients' access to and control of their health information (see *Objective 2*) and enhance providers' workflow (see *Objective 3*).

## What Is an API?

APIs, or application programming interfaces, let health IT developers know what information they can request from a database or system (such as an EHR), as well as how to ask for and receive that information. Using APIs, health IT developers can develop apps and other software products that display and/or use health data in ways that meet users' needs. Once developed, an API-based app can be used interchangeably with any system that uses the same API. API-based apps also could integrate information from multiple sources, including multiple EHRs and other types of sources.



Source: Patterson M. What is an API, and why does it matter? [Internet]. Chicago (IL): Sprout Social; 2015 Apr 3 [cited 2016 Sep 8]. Available from: <http://sproutsocial.com/insights/what-is-an-api>

A pair of reports from JASON, an independent group of scientists that advises the U.S. government on matters of science and technology, identified standard, open APIs as a critical need in health IT.<sup>22,23</sup> The ONC Roadmap also calls for development and use of a limited number of APIs,<sup>9</sup> and the 2015 Edition Health IT Certification Criteria includes a requirement that health IT developers use and publish APIs that permit third parties to request and receive certain types of data.<sup>29</sup>

The Joint ONC Federal Advisory Committee recently examined privacy and security concerns related to APIs and concluded that, when appropriately managed, the potential benefits of APIs outweigh the risks.<sup>39</sup> EHR vendors are warming to the idea of APIs. Several companies and healthcare organizations support the Argonaut Project, a collaborative effort to implement the API specification based on the Fast Healthcare Interoperability Resources (FHIR) and Substitutable

Medical Applications and Reusable Technology (SMART) on FHIR standard to expand access to EHR data via API.<sup>40,41</sup>

The Panel supports the API requirement in ONC health IT certification criteria and is encouraged by progress in API development and support for API use. **To further**

**expedite API-driven health IT interoperability, the Panel urges continued development and testing of APIs and eventual adoption of standard, open API platforms for health IT.** As stated in the ONC Roadmap, simply publishing APIs is not enough; there must also be a limited number of standard APIs to reduce complexity.<sup>9</sup>



## OBJECTIVE 2

### Enable individuals to manage their health information and participate in their care across the cancer continuum.

A core principle of connected health is that individuals are empowered to decide when, whether,

and how much to participate in their health and healthcare (see *Principles of Connected Health* on page 9). Decisions about participation may change over time. Connected health tools are needed to ensure that people at risk for cancer, cancer patients, and cancer survivors have access to the information they need when they need it and in formats that meet their needs. The latter includes cultural and linguistic sensitivity. When it is appropriate and patients agree to share, information also should be accessible by family members and caregivers, who often play critically important roles in supporting people with cancer.

### The Right to Obtain Health Information

The Health Insurance Portability and Accountability Act establishes the rights of individuals and their personal representatives to receive copies of their health information from their doctors and other providers. They also have the right to have their data directly transmitted to a third party, such as a researcher. Any or all types of medical information that are used to make decisions about the individual can be requested, including summaries of office visits, diagnoses, doctors' notes, laboratory results, medication information, images (X-rays, MRIs, etc.), and account and billing information.

**Sources:** Office of the National Coordinator for Health Information Technology. Accessing your health information [Internet]. Washington (DC): ONC; [updated 2013 Jun 26; cited 2015 Nov 10]. Available from: <https://www.healthit.gov/patients-families/accessing-your-health-information>; U.S. Department of Health and Human Services. Individuals' right under HIPAA to access their health information 45 CFR § 164.524 [Internet]. Washington (DC): DHHS; [cited 2016 Sep 5]. Available from: <http://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access>

## Action Item 2.1

### Develop and validate interfaces and tools that support individuals' engagement in their care across the cancer continuum.

People who are actively involved in their health and healthcare tend to have better outcomes and care experiences, improved quality of life, and, in some cases, lower costs.<sup>42-45</sup> For example, an analysis of patients in a large health system found that higher Patient Activation Measure scores (see *Patient Activation Measure* below) were associated with better health outcomes for 9 of 13 indicators, including smoking status and screening for cancer. Furthermore, increases in activation scores over time were linked to improvements in health outcomes.<sup>43</sup>

Patient engagement is a central pillar of health policy and healthcare reform efforts in recent years, including the Affordable Care Act. This has been accompanied by a growing emphasis on self-management, shared decision making, and patient-centered care that is respectful of and responsive to individuals' preferences, needs, and values.<sup>46</sup> Health information technologies and digital communication tools provide opportunities

to enhance individuals' active participation in their health and healthcare by linking them to information, resources, and people who can support and guide them. These tools could be particularly useful for people managing their health and navigating complex healthcare systems after a cancer diagnosis, as well as those seeking to reduce their risks for cancer.

Numerous consumer-facing, health-related tools and apps have emerged in recent years, including some related to cancer.<sup>47-49</sup> Many healthcare organizations have developed patient portals (see *Patient Portals* on page 23), and the Apple iOS and Android app stores include hundreds of health-related apps.<sup>50,51</sup> Such tools and apps are only the tip of the iceberg. The connected health and wellness market is projected to top \$117 billion by 2020, and consumer-facing products and services—including those developed using tools such as ResearchKit and CareKit (see *Apple ResearchKit and CareKit* on page 26)—are expected to play a significant role in this growth.<sup>52</sup> While exciting, current activity is not sufficient to fully harness the potential of connected health for cancer. It is not enough to create *more* tools; the focus must be creating *better* tools that effectively support individuals' active participation in their health and healthcare and help overcome barriers that still exist based on culture, literacy, education, comprehension, and broadband access.

### Patient Activation Measure

The Patient Activation Measure is a metric used to quantify engagement, activation, or self-management capabilities. It assesses patients' knowledge, skill, and confidence to manage their health and healthcare. A growing body of literature indicates that patients who are more activated as measured by the Patient Activation Measure make more effective use of healthcare resources and engage in more positive health behaviors compared with other patients.

Sources: Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res.* 2004;39(4 Pt 1):1005-26; Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood).* 2013;32(2):207-14.

## Patient Portals

Many healthcare organizations have developed patient portals that enable patients' access to some information in their health records. Some portals also permit patients to exchange secure messages with providers, schedule non-urgent appointments, request prescription refills, update contact information, make payments, download and complete forms, and/or view educational materials. Although study results have varied and opportunities for improved usability and functionality have been identified, use of patient portals has been linked to improvements in medication adherence, patient-provider communication, patient satisfaction, self-management of chronic disease, and uptake of some preventive screenings and services.

**Sources:** Office of the National Coordinator for Health Information Technology. What is a patient portal? [Internet]. Washington (DC): ONC; [updated 2015 Nov 2; cited 2016 Feb 11]. Available from: <https://www.healthit.gov/providers-professionals/faqs/what-patient-portal>; Kruse CS, Bolton K, Freriks G. The effect of patient portals on quality outcomes and its implications to meaningful use: a systematic review. *J Med Internet Res.* 2015;17(2):e44; Kruse CS, Argueta DA, Lopez L, Nair A. Patient and provider attitudes toward the use of patient portals for the management of chronic disease: a systematic review. *J Med Internet Res.* 2015;17(2):e40; Irizarry T, DeVito Dabbs A, Curran CR. Patient portals and patient engagement: a state of the science review. *J Med Internet Res.* 2015;17(6):e148.

**The President's Cancer Panel urges healthcare organizations and health IT developers to develop tools and incorporate features that support high levels of user engagement. Research funding organizations should create initiatives to spur development of consumer-facing apps and tools.** Such tools should reflect the wide variations among people in their preferences and needs for information and tools. The ONC Patient Engagement Playbook provides guidance for enhancing patient participation using patient portals and other health IT (see *Patient Engagement Playbook* on page 24). Examples of strategies to support varying levels of user engagement are shown in Figure 5. While many existing tools and apps engage users in their health and healthcare in very limited ways (e.g., providing general information about a topic or displaying raw data),<sup>50,51</sup> technology has created opportunities to do much more. Tools should help individuals **interpret** their data, displaying information in plain language and using visual aids when appropriate based on patients' preferences. Connected health tools should incorporate **decision support** to help users weigh their

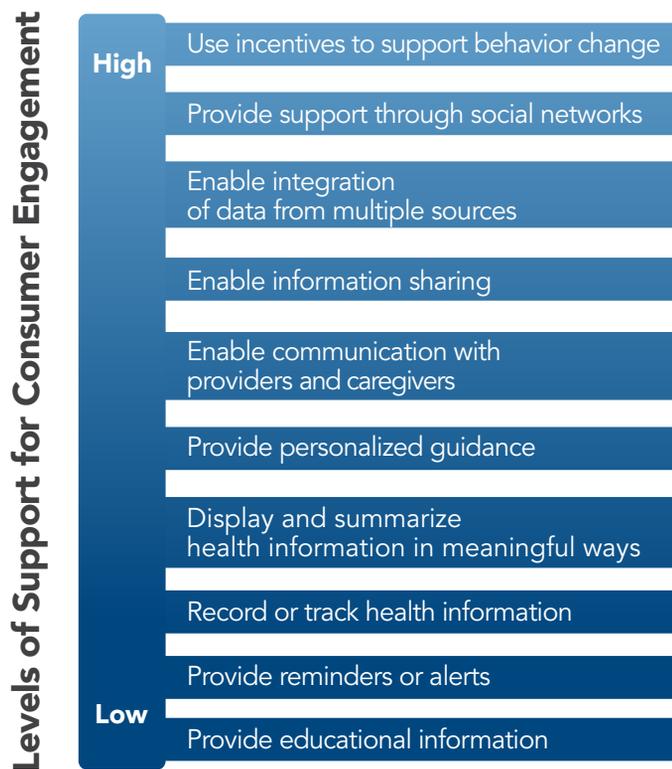
options when faced with choices about their health and healthcare, including decisions about treatment. Tools also are needed to support patients' **communication** with providers and peers and enable **sharing** of data with whomever they choose—other providers, caregivers, researchers, or others. Connected health tools have great potential to **support behavior change** and progress toward health goals (e.g., smoking cessation, physical activity), which may help reduce cancer risk or improve cancer-related outcomes. Only a small proportion of existing consumer-facing health- and cancer-related apps focus on behavior change, and very few of these have been tested for efficacy.<sup>51,53</sup> While there is much reason for optimism about the potential of connected health tools, there also is reason for caution about drawing conclusions before more data are available.<sup>54</sup> Developers, information scientists, and behavioral scientists should partner to ensure that robust evaluations are conducted. There also are opportunities to use artificial intelligence to enhance consumer-facing apps and tools.<sup>55</sup> Some examples of tools that support individual engagement are shown in *Tools Supporting Consumer Engagement* on page 25.

### Patient Engagement Playbook

The Patient Engagement Playbook is an evolving resource for providers, practice staff, hospital staff, and other innovators seeking to use health information technology to engage patients. The Playbook is a compilation of tips and best practices related to patient enrollment, features desired by patients, patient rights to access or request transmission of their health data, sharing of data among providers, caregiver proxy access, and integration of patient-generated health data.

Source: Office of the National Coordinator for Health Information Technology. Patient Engagement Playbook [Internet]. Washington (DC): ONC; [cited 2016 Jun 16]. Available from: <https://www.healthit.gov/playbook/pe>

**Figure 5. Levels of Support for Consumer Engagement Provided by Connected Health Tools**



Adapted from Singh K, Drouin K, Newmark LP, et al. Developing a framework for evaluating the patient engagement, quality, and safety of mobile health applications. New York (NY): The Commonwealth Fund; 2016 Feb. Available from: <http://www.commonwealthfund.org/publications/issue-briefs/2016/feb/evaluating-mobile-health-apps>

## Tools Supporting Consumer Engagement

- The Smart and Connected Health Program, a cross-agency initiative of the National Institutes of Health and the National Science Foundation, provided funding to researchers at Georgia Institute of Technology to develop tools to support the changing needs and goals of cancer patients as they undergo treatment and transition into survivorship. As part of a pilot test of the **My Journey Compass** program, breast cancer patients were provided with tablet computers that included a suite of tools integrated into patients' existing healthcare systems, as well as a broad range of clinical and nonclinical applications. Patients could customize tablets for their own personal use by downloading additional apps. The majority of patients used the tablets throughout treatment and into survivorship. Many patients reported that non-health resources—such as online games, social media applications, and YouTube—helped them cope with their cancer diagnoses and treatments. Researchers speculated that integration of health and non-health resources contributed to continued user engagement with the tablets, making it easier for patients to access health resources when necessary. The research team currently is developing a next-generation tool, MyPath, that integrates with patients' medical records and provides customized, dynamic content based on the patient's phase of cancer care and continuous user input.
- **MeTree** is a web-based family and personal health history collection and clinical decision support tool. Users provide information on medical conditions, diet, exercise, smoking, vital signs, and laboratory data, in addition to family health history. These data are used to create a 3-generation pedigree, calculate various health-risk scores, and assess risk for 20 cancers, 14 hereditary cancer and cardiovascular syndromes, and 21 other conditions. Reports are generated for both individuals and providers. Implementation of MeTree currently is being studied in an ongoing NIH-funded trial to understand how to best implement IT tools like MeTree in various settings and with diverse populations.
- **PatientsLikeMe** is a web-based community of over 400,000 patients, including many who have been diagnosed with cancer. The website enables patients to connect with other people dealing with the same health issue, providing a forum for information exchange and social support. PatientsLikeMe also provides tools for tracking and sharing symptoms, treatment information, and health outcomes. Patients can use these tools to help them manage their health, and PatientsLikeMe also aggregates and organizes the data to reveal new insights. The PatientsLikeMe Research Forum allows patients to submit ideas for research, and patients may be invited to participate in internal research projects or in projects being conducted in collaboration with outside partners.

**Sources:** National Science Foundation. Smart and Connected Health (SCH) [Internet]. Arlington (VA): NSF; 2016 Sep 12 [cited 2016 Sep 14]. Available from: <https://www.nsf.gov/pubs/2016/nsf16601/nsf16601.htm>; Jacobs M, Clawson J, Mynatt E. Lessons learned from a yearlong deployment of customizable breast cancer tablet computers. Wireless Health 2015 Conference; 2015 Oct 14-16; Bethesda, MD. New York: ACM; Everyday Computing Lab. Creating interactive models of healthcare journeys to improve patient-centered care and patient engagement [Internet]. Atlanta (GA): Georgia Institute of Technology; [cited 2016 Aug 30]. Available from: <https://research.cc.gatech.edu/ecl/projects/creating-interactive-models-healthcare-journeys-improve-patient-centered-care-and-patient-e>; Time to focus on your family health history. Duke Today [Internet]. 2015 Dec 15 [cited 2016 Sep 8]. Available from: <https://today.duke.edu/2015/12/metree>; PatientsLikeMe. Home page [Internet]. Cambridge (MA): PatientsLikeMe; [cited 2016 Feb 29]. Available from: <https://www.patientslikeme.com>

## Apple ResearchKit and CareKit

Apple, Inc., has created two open-source frameworks—ResearchKit and CareKit—that enable creation of apps that connect patients to healthcare providers and researchers.

**ResearchKit** allows researchers to work with developers to build apps for research. This framework contains three customizable modules:

- Informed Consent enables researchers to specify study requirements and participation risks, as well as collect participants' signatures using touch-screen technology.
- Surveys contains pre-built question and answer templates for qualitative and quantitative data.
- Active Task allows participants to collect data under partially controlled conditions using iPhone sensors such as accelerometer, gyroscope, microphone, and others.

Researchers can add custom modules, remind participants to complete surveys/tasks, and display individual participants' data, providing an immediate benefit to study participation. In addition, participants could be recruited world-wide rather than from the immediate vicinity of a hospital or clinic. The ResearchKit app Share the Journey is highlighted in the *Using Person-Generated Data in Cancer Research* sidebar on page 52.

**CareKit** enables healthcare providers to create apps to help patients manage their medical conditions. CareKit includes four customizable modules:

- Care Card displays a customized care plan and tasks necessary to perform during treatment such as taking medications, changing wound dressings, or exercising.
- Symptom and Measurement Tracker monitors subjective symptoms such as pain as well as objective measurements such as temperature and blood pressure.
- Insights displays individual results to visualize trends in treatment and symptoms and make personal health inferences.
- Connect engages healthcare teams and family members as partners in the personal health journey.

Data can be stored locally in the Care Plan Store or exported using Document Exporter to be shared with anyone on the care team.

These tools can be used separately or in combination. In addition, any Bluetooth sensors could be leveraged to seamlessly collect data with participants' permission to create powerful data collection and treatment follow-up tools.

Sources: Apple, Inc. ResearchKit and CareKit [Internet]. Cupertino (CA): Apple; [cited 2016 Aug 3]. Available from: <http://www.apple.com/researchkit>; ResearchKit. Home page [Internet]. Cupertino (CA): Apple; [cited 2016 Aug 3]. Available from: <http://researchkit.org>; CareKit. Home page [Internet]. Cupertino (CA): Apple; [cited 2016 Aug 3]. Available from: <http://carekit.org>

Connected health tools also should enable individuals to **integrate** information in their health records with information from other sources. Unfortunately, the vast majority of currently available health apps are disconnected from the healthcare delivery system.<sup>56</sup> Adoption by health IT vendors of a limited number of standard, open APIs would permit third-party app developers to request and use data from EHRs with patients' permission (see *Action Item 1.3*). This would facilitate creation of a virtually limitless collection of apps tailored to the diverse needs of individuals across the cancer continuum. Among other things, API-based apps could integrate personal health data from multiple EHR systems, enabling patients to store and view all of their health information in one place. Consumer-controlled aggregation of health data is the focus of the recent ONC Consumer Health Data Aggregator Challenge.<sup>57</sup> APIs also create opportunities to develop consumer apps capable of sending patient-generated data to EHRs (see *Part 3*).

Developers should take note of the extensive knowledge base on patient engagement and use validated instruments to evaluate the effects of their tools on patient activation<sup>58,59</sup> as well as on health outcomes. Every person is unique, and a diverse suite of tools is needed to support patients' needs and preferences. Differences in literacy and health literacy, as well as language and cultural preferences, also must be considered.<sup>60</sup> Regardless of the features or target population, all connected health tools—including patient portals, apps, and other types of tools—should be developed with meaningful input from intended users and have usable interfaces developed through early and iterative testing.<sup>61</sup>

Whenever possible, interfaces should be configured for mobile devices to reflect the growing adoption of mobile devices among Americans (see Figure 1 in *Part 1*) and the fact that nearly one in five adults in the United States largely rely on mobile phones to access the Internet.<sup>62</sup> Tools also should be tested using a variety of Internet browsers. For apps and tools that collect data for research, user-friendly informed consent processes should be incorporated as appropriate.<sup>63,64</sup> Any tool or app that collects or stores personal health data, including EHRs, must conform to any applicable federal, state, and organizational requirements regarding privacy and security. As was discussed in a recent report from ONC, health data collected by many personal devices and web-based resources are not covered by HIPAA.<sup>65</sup> Nonetheless, developers should take steps to ensure that users' health data are safe and secure. Users also must be informed of policies related to information access and sharing. This should be done in ways that are user-sensitive, not in multi-page disclosure statements that are read by few people. The Panel also is concerned about the trend toward privatization and monetization of personal health data.<sup>66</sup>

Individuals can, and should, choose apps that are right for them. Consumers may benefit from guidance in selecting from among the numerous connected health apps and tools that are and will become available.<sup>56</sup> Developers should cite credible information sources or sources of substantiating evidence for the efficacy of their products when available. Professional societies, provider organizations, and other trusted organizations may consider identifying high-quality tools relevant to their areas of focus.<sup>39</sup>

## Action Item 2.2

### Organizations should develop processes that enable individuals to flag perceived errors in their medical records and ensure that responses are provided and appropriate changes are made in a timely manner.

The President's Cancer Panel heard from cancer patients and advocates who are frustrated about what they regard as mistakes in their health records.<sup>67</sup> Analyses of medical records, including EHRs, have confirmed that deficiencies in data completeness and accuracy are far too common.<sup>68,69</sup> Studies at two cancer centers found that the medication lists

Studies at two cancer centers found that the medication lists in the EHRs of more than 80 percent of patients had at least one error or omission.

in the EHRs of more than 80 percent of patients had at least one error or omission.<sup>70,71</sup> Whether in paper or electronic form, medical record errors undermine patient safety and high-quality care, creating potential for dangerous drug interactions, inaccurate or missed diagnoses, and inappropriate or inadequate treatments. They also undermine healthcare professionals' credibility,

impair patient-physician relationships, and diminish the utility of health data for quality measurement, surveillance, and research.

The Health Insurance Portability and Accountability Act provides individuals with the right to request an amendment to information in their health records and requires healthcare organizations to respond to these requests within 60 days (45 CFR 164.526).<sup>72</sup> As

connected health tools increase individuals' access to their health information, questions about the accuracy of that information likely will become more common. However, processes for receiving and responding to change requests have not yet been incorporated into healthcare to the extent that they have been in some other industries (e.g., credit bureaus, online commerce).<sup>73</sup> An ONC-funded environmental scan of patient portals found that only a few encouraged or facilitated patient requests for corrections. In most cases, feedback was limited to certain types of data (e.g., allergies), and processes for addressing patient requests varied greatly.<sup>74</sup> Reports from patients in the literature<sup>75</sup> and provided directly to the Panel<sup>67</sup> suggest that these processes often are inefficient and ineffective.

The President's Cancer Panel recognizes that individuals can play a key role in ensuring the accuracy of their health information. Survey results indicate that patients are eager to fill this role,<sup>75</sup> and involving patients in this way also may help build trust. **The Panel strongly urges healthcare organizations and health IT developers to develop processes that enable patients and their caregivers to flag and request amendments to perceived errors in their medical records, preferably using connected health tools (e.g., patient portals).** Providers should encourage patients to review and provide feedback on their data. Organizations should establish processes for triaging and reviewing patient concerns and ensuring that appropriate changes are made in a timely manner. Patients should receive clear messages about expected response times and be informed of the results of the review process. The Panel also notes that improvements in EHR usability and data entry practices would help reduce the number of errors in medical records and should be pursued (see *Objective 3*). There also should be clear processes for flagging and correction of errors by healthcare delivery team members.

## Action Item 2.3

### Create tools and services that help individuals identify cancer-related clinical trials appropriate for their particular situations.

Clinical trials are essential for advancing knowledge about cancer and its risk factors and for developing better treatments for cancer. However, low patient participation remains one of the biggest obstacles to their success. Although recent data are lacking, it is roughly estimated that less than 5 percent of adult cancer patients in the United States currently participate in clinical trials.<sup>76,77</sup> People not participating in clinical trials say the main reasons for nonparticipation are that they are unaware that participation is an option and they have difficulty determining whether they are eligible to participate. Moreover, one of the main factors associated with clinical trial participation is a provider's referral, which all too often is not provided.<sup>78,79</sup> When surveyed, many patients say they would be willing to participate in a clinical trial if presented the option.<sup>80</sup> A clear role has emerged for online tools in helping to increase awareness about cancer clinical trials, particularly in the realm of social media, which has potential to spread information quickly and widely and mobilize entire communities into action. Indeed, many nonprofit and patient advocacy organizations and biopharmaceutical companies already have mobilized their constituents to participate in clinical trials via online social networks such as Twitter and Facebook.<sup>81,82</sup> Strategies to help participants identify clinical trials include enhancing the usability and effectiveness of current clinical trial search tools and developing new easy-to-use tools.

Various clinical trial search tools exist that are intended to help patients and physicians connect with appropriate trials. The National Institutes of Health maintains a large database of publicly and privately supported clinical trials, including cancer trials ([www.clinicaltrials.gov](http://www.clinicaltrials.gov)). The National Cancer

Institute also hosts a searchable database of cancer clinical trials it sponsors (<https://trials.cancer.gov>). However, the task of identifying appropriate clinical trials using these online tools is daunting for both providers and patients due to the large amount of data on thousands of clinical trials housed on these sites, often including closed trials or other outdated information, and search interfaces that are difficult to use. As a result, finding suitable clinical trials requires a large amount of motivation on the part of patients and physicians, and must often be undertaken at a time when patients have competing concerns. Further, matching an eligible patient to specified clinical trial criteria often requires access to the patient's disease profile (such as diagnosis, type and stage of tumor, or type of treatment). Obtaining this level of disease-related information creates additional burdens for patients.

Next-generation resources that provide individuals with useful clinical trials information and facilitate the clinical trial matching process could have a transformational role in connecting patients to clinical trials (see *Next-Generation Online Resources for Clinical Trial Matching* on page 30). In coordination with the Cancer Moonshot and the Precision Medicine Initiative, NCI is partnering with the White House Presidential Innovation Fellows to create more accessible and usable formats for clinical trial data from cancer.gov. Notably, as of September 2016, these data have been made available through an API (<https://clinicaltrialsapi.cancer.gov>) (see *Action Item 1.3*), which provides opportunities for developing new third-party applications customized to the needs and preferences of various patient groups, advocacy organizations, and healthcare systems. One future goal of these tools could be to facilitate automated clinical trial matching wherein patient-created profiles or existing medical records (also made available through an API) are used to match individuals to clinical trials based on their specific disease profiles and preferences. These tools could be used by motivated patients, but also in clinical settings as a way to facilitate the provider's role in the patient referral and enrollment process. For example, providers could receive alerts through their EHRs when

their patients are potentially eligible for one or more trials (see *Syapse Oncology* on page 36). While the full implementation of this vision may take time to achieve, the Panel believes it is worthy of pursuit.

**The President's Cancer Panel has identified the tremendous potential of connected health to expand individuals' access to clinical trials.**

Cancer-focused organizations, research institutions, and government agencies could play a pivotal role in increasing clinical trial awareness through social media platforms and other online community resources. The Panel applauds and supports efforts to enhance access to information on NCI-sponsored trials. NIH should explore options for making clinicaltrials.gov information more accessible. In

addition, efforts should be made to ensure that clinical trial information available through these databases is accurate and current. In particular, having well-structured eligibility and biomarker data would simplify matching of patients to appropriate clinical trials. The Panel also encourages third-party innovators to develop digital platforms such as apps that help individuals more efficiently access information in clinical trial databases. When possible, health IT developers and healthcare organizations should create automated matching tools that allow potential trials to be identified without special effort by patients or providers. The Panel recognizes that these goals are not easily attainable; however, these are areas in which innovation and entrepreneurship should be encouraged and incentivized.

### Next-Generation Online Resources for Clinical Trial Matching

Many organizations already host clinical trial search tools that allow information about the patient's specific disease profile (such as diagnosis, type and stage of tumor, or type of treatment) to be used to better match a patient to an appropriate trial.

The **Cure Forward Clinical Trial Exchange** is a matching service that connects patients with trial recruiters based on information the patient provides. Rather than searching for trials themselves, patients create personal profiles. Trial recruiters then can review patients' molecular testing, clinical criteria, and location preferences and contact those who may be eligible for a given trial.

**Smart Patients** recently launched a new resource for colorectal cancer patients where patients can specify a few key characteristics about their situations, including the molecular profile of their tumors, to identify clinical trial participation opportunities through data that have been made available on cancer.gov. A similar tool for kidney cancer patients currently is being developed.

**Sources:** Cure Forward. Home page [Internet]. Boston (MA): Cure Forward; [cited 2016 Jul 11]. Available from: <https://www.cureforward.com>; Smart Patients. Home page [Internet]. Smart Patients; [cited 2016 Feb 29]. Available from: <https://www.smartpatients.com>



## OBJECTIVE 3

### Ensure that federal programs and health IT tools support the oncology workforce as it delivers care.

Effective delivery of care across the cancer continuum is dependent on an engaged, productive workforce. Those involved in cancer care, like all health professionals, have had to adapt to massive changes in healthcare over the last several years, some of which have had a negative impact on the experience of providing care.<sup>83</sup> The rollout of EHR systems, in particular, has contributed to providers' frustration and burnout.<sup>84,85</sup> Physician surveys have identified a number of ways in which EHRs significantly worsen professional satisfaction (see *Sources of Providers' Dissatisfaction with EHRs* below).<sup>86-88</sup> Among respondents to a 2015 ASCO survey of oncology practices, implementation and use of EHRs was the most commonly cited practice pressure, outranking payer pressures, staffing issues, and drug pricing.<sup>5</sup>

The transition to EHRs will not be reversed, and few physicians wish to return to paper-based medical records.<sup>86</sup> However, the significant challenges that have arisen during the initial rollout of EHRs should be addressed, and more work is needed to ensure interfaces are intuitive and aligned with care teams' workflows.<sup>85</sup> Recent survey results suggest that progress is being made, as satisfaction with EHR systems has increased over the past few years among physicians in larger practices.<sup>89</sup> Many members of the healthcare delivery team already enjoy some advantages of EHRs—such as remote access to patient data, electronic prescribing, integrated graphing tools that display changes in disease markers over time, and improved communication with patients and other team members.<sup>86,88,90,91</sup> Additionally, most providers believe EHRs have potential to support improvements in both patient care and physician professional satisfaction.<sup>86</sup> Improvements in interoperability, as discussed in Objective 1, will further increase the utility of EHRs for providers by automating data flows between laboratories and offices/hospitals. Nevertheless, additional efforts are needed to ensure that federal programs and health IT tools support the oncology workforce as it strives to deliver the best possible care.

#### Sources of Providers' Dissatisfaction with EHRs

- Time-consuming data entry
- Interfaces that do not match clinical workflow
- Difficulty finding important information
- Too many clicks required to complete common tasks
- Interference with face-to-face patient care
- Degradation of clinical documentation due to template-generated notes
- Inability to exchange information with other systems
- Too many automatic alerts and messages
- Costs of maintaining or changing systems

## Action Item 3.1

### Federal incentive programs should promote use of health IT to enhance provider delivery of high-quality, patient-centered care.

Widespread adoption of EHRs since the HITECH Act was passed in 2009 largely has been spurred by the Medicare and Medicaid EHR Incentive Programs, sometimes referred to as the “Meaningful Use” programs.<sup>92</sup> While the first stage of Meaningful Use, which focused on health IT adoption, generally is viewed as a success, providers increasingly have expressed concern about the second and third stages of the programs, citing inflexible assessment criteria, excessive documentation requirements, and

focus on process-based tasks that are not directly related to—and sometimes interfere with—high-quality patient care.<sup>93-95</sup>

In January 2016, the ONC and the CMS publicly agreed that federal EHR incentive programs should be modified to allow providers flexibility in their use of health IT and measure success based on the quality of patient care and outcomes. Efforts currently are under way to modify the incentive program for those who give care to Medicare beneficiaries to reflect this focus (see *Medicare Access and CHIP Reauthorization Act of 2015* below).<sup>96</sup> **The President’s Cancer Panel supports efforts to reform federal incentive programs for EHR adoption and use. Regulations should not distract providers from patient care. Inherent in this, reporting requirements should be minimized.**

### Medicare Access and CHIP Reauthorization Act of 2015

A new Medicare EHR incentive program for clinicians currently is being developed under the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA). MACRA calls for a Merit-Based Incentive Payment System to measure eligible professionals based on quality, cost, technology use, and practice improvement rather than on the volume of services provided. Although the details of the program are still under development, the proposed rule calls for clinicians to report customizable measures that reflect how they use technology in their day-to-day practice, with a particular emphasis on interoperability and information exchange.

**Sources:** Centers for Medicare & Medicaid Services. The Merit-Based Incentive Payment System (MIPS) & Alternative Payment Models (APMs) [Internet]. Baltimore (MD): CMS; [cited 2016 Apr 25]. Available from: <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/MACRA-MIPS-and-APMs/MACRA-MIPS-and-APMs.html>; U.S. Department of Health and Human Services. Administration takes first step to implement legislation modernizing how Medicare pays physicians for quality [News Release]. Washington (DC): DHHS; 2016 Apr 27. Available from: <http://www.hhs.gov/about/news/2016/04/27/administration-takes-first-step-implement-legislation-modernizing-how-medicare-pays-physicians.html>

## Action Item 3.2

### **EHR vendors and healthcare organizations should employ human-centered design principles to ensure that EHR interfaces are intuitive and aligned with providers' workflows.**

Many provider complaints about EHRs relate to poor usability and misalignment of interfaces with clinical workflows (see *Sources of Providers' Dissatisfaction with EHRs* on page 31). This may be, in part, because systems were designed to optimize billing rather than clinical care.<sup>97</sup> Physicians report spending more time on clinical documentation following EHR adoption, which often results in less time for direct patient care, less patient engagement during visits, and more time spent on data entry outside of normal office hours.<sup>85,86</sup> Poor health IT usability also can undermine data quality and contribute to medical errors, a significant problem in the U.S. healthcare system.<sup>98-100</sup> In a review of extant EHR systems by the National Research Council, informatics experts reported that many of these systems failed to improve patient outcomes precisely because they failed to provide value-added

support to healthcare delivery team members, patients, and their caregivers.<sup>101</sup>

Poor EHR usability is a significant barrier to deriving value from the sizable U.S. investment in health IT<sup>99</sup> and advancing connected health for cancer. **EHR vendors and healthcare organizations should employ human-centered design processes during EHR development, as well as during deployment and testing phases, to ensure EHR interfaces are intuitive and aligned with providers' workflows** (see *Human-Centered Design* below). Well-designed systems should reduce providers' cognitive burden by automating routine tasks, minimizing the number of clicks it takes to complete an order, and adding point-of-need information for crucial decision making.<sup>101</sup>

**Better medical record systems are needed that are dissociated from billing, intuitive and helpful, and allow physicians to be fully present with their patients.**

Source: Zulman DM, Shah NH, Verghese A. Evolutionary pressures on the electronic health record: caring for complexity. *JAMA*. 2016;316(9):923-4.

### Human-Centered Design

Human-centered design is a systematic approach to problem solving that is well suited for addressing complex issues at the intersection of people and technology. It encourages developers to repeatedly consider the context, emotions, needs, and desires of the intended users of a product and engages end users in the design process.

Source: Matheson GO, Pacione C, Shultz RK, Klugl M. Leveraging human-centered design in chronic disease prevention. *Am J Prev Med*. 2015;48(4):472-9.

### Action Item 3.3

#### Develop and test tools and interfaces, including apps, tailored to needs of the oncology workforce.

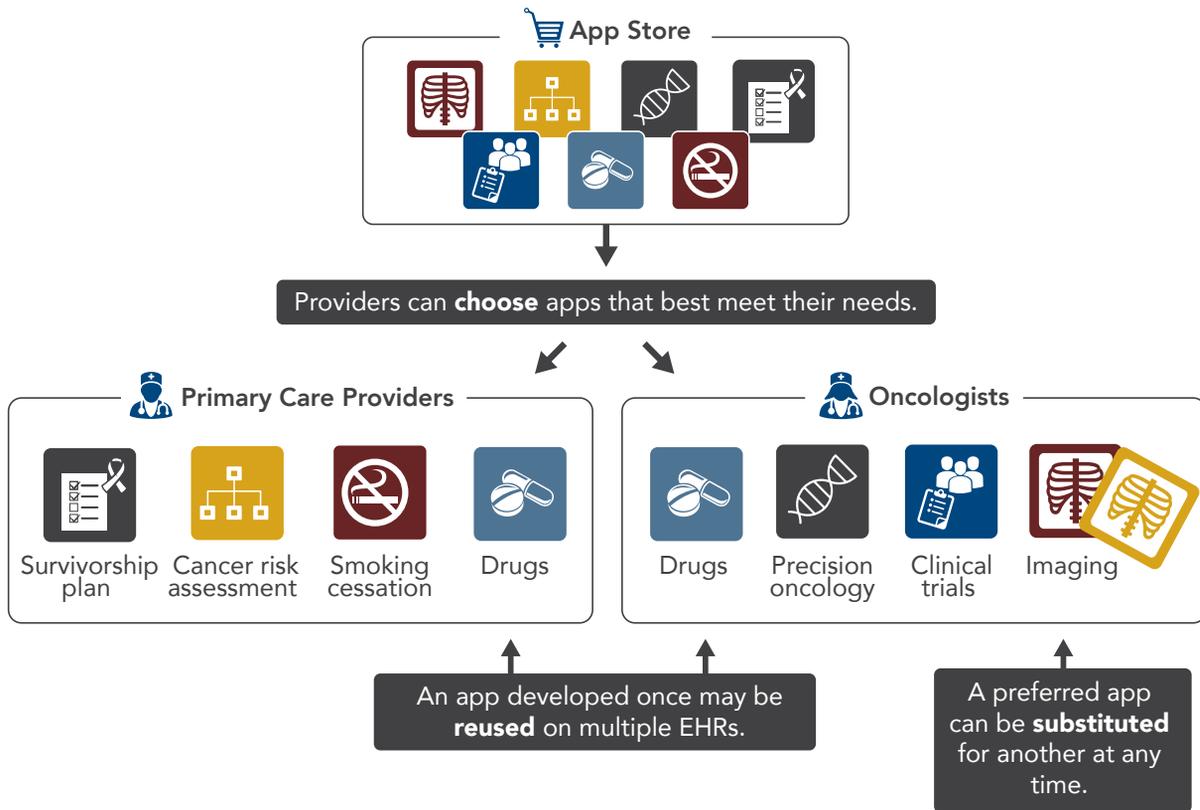
Innovative health IT tools and interfaces, including apps, could supplement traditional EHR interfaces in a number of ways, such as integrating and displaying data in meaningful ways, providing links to outside resources and knowledge bases, guiding delivery of evidence-based care, providing decision support, and facilitating communication among healthcare delivery team members. Tools that analyze large data sets and provide actionable recommendations based on the results—perhaps using artificial intelligence or machine learning<sup>102</sup>—will become more valuable, even essential, with the emergence of data-driven precision medicine (see *Precision Medicine Initiative* on page 5 and *Cancer Moonshot* on page 43). These types of tools have potential to meet the specialized and diverse needs of the oncology workforce across the cancer continuum (Figure 2). To date, most tools developed have been for physicians, but other healthcare professionals who care for cancer patients—nurses, advanced practice providers, pharmacists, and others—also would benefit from customized tools.

Effective health IT tools can be developed by healthcare organizations and EHR vendors,<sup>103</sup> but the needs of the oncology workforce will be met most effectively if the full innovative capacity of the health IT community is harnessed. To enable this, EHR vendors and

healthcare organizations must permit third-party health IT developers to safely and securely access their EHR data through APIs (see *Objective 1*). Developers then will be able to develop a diverse suite of apps from which providers can choose based on their needs and preferences (Figure 6). Apps can be developed and modified more quickly than traditional EHR interfaces, allowing the marketplace to keep pace with advances in medical science and be responsive to providers' feedback. Online resources—such as the app discovery site being developed by Boston Children's Hospital with support from ONC<sup>104</sup>—can help providers find the apps and tools that best meet their needs.

Within the past few years, some EHR vendors have begun working collaboratively to expand API-mediated access to their systems.<sup>40</sup> ONC's recent decision requiring health IT developers to include API functionality in their products and openly share API specifications in order to be certified will further increase third-party access to EHR systems.<sup>29</sup> API-based apps for providers are being developed and tested (see *Precision Cancer Medicine App Helps Oncologists Use Genomic Information* and *Syapse Oncology* on page 36), but more investment is needed in this area. **The President's Cancer Panel urges research funding organizations, such as the National Cancer Institute, to create initiatives to spur development by the health IT community of cancer-specific apps and tools for providers delivering cancer care across the continuum.** The efficacy of tools and apps, particularly those designed to influence provider behavior, should be evaluated in order to identify the approaches that are most effective in a variety of settings and populations.

**Figure 6. API-Enabled Tools for Providers**



Adapted from Mandl K, Mandel J, Kohane I. Driving innovation in health systems through an apps-based information economy. *Cell Systems*. 2015;1(1):8-13.

### Precision Cancer Medicine App Helps Oncologists Use Genomic Information

Genomic data increasingly are informing treatment decisions for cancer patients and those at risk for cancer, but commercially available EHRs generally cannot display clinical genomic data in meaningful ways. The Precision Cancer Medicine (PCM) app was designed to present patients' genomic test results to oncologists in real time as a component of clinical practice, as well as provide links to external knowledge bases that otherwise would be unavailable through the native EHR system. PCM was piloted at Vanderbilt University and integrated into that institution's EHR system. However, because the app was developed based on an open-access API (Substitutable Medical Applications and Reusable Technology, or SMART) and uses the emerging HL7 Fast Healthcare Interoperability Resources standard, it could easily be deployed for other compatible EHR systems.

**Sources:** Mandel JC, Kreda DA, Mandl KD, Kohane IS, Ramoni RB. SMART on FHIR: a standards-based, interoperable apps platform for electronic health records. *J Am Med Inform Assoc.* 2016;23(5):899-908; Warner JL, Rieth MJ, Mandl KD, Mandel JC, Kreda DA, Kohane IS, et al. SMART precision cancer medicine: a FHIR-based app to provide genomic information at the point of care. *J Am Med Inform Assoc.* 2016;23(4):701-10.

### Syapse Oncology

Syapse, a bioinformatics company founded in 2008, has developed a software platform that helps healthcare organizations systematize precision oncology. The software integrates with organizations' EHRs and creates a unified, longitudinal view of each patient's clinical, pathology, radiology, treatment, and molecular data. It also provides clinical decision support, suggesting targeted therapies based on patients' genomic data, and permits providers to compare their patients with others within their organization based on tumor type, stage, genomic variants, and other factors. The Syapse platform also includes an automated clinical trial matching tool that identifies candidate patient-trial matches based on somatic mutation profile, clinical data, demographic information, or other criteria. In response to Vice President Biden's Cancer Moonshot, Syapse also is working with multiple partners to make aggregate clinical data available for research through the Oncology Precision Network (OPeN).

**Sources:** Syapse. Home page [Internet]. Palo Alto (CA): Syapse; [cited 2016 Sep 9]. Available from: <http://www.syapse.com>; Bin Han Ong M. Stanford, Intermountain, and Providence use Syapse platform to integrate their data. *The Cancer Letter.* 2016 Jun 24;42(25):1-6.



## OBJECTIVE 4

### Facilitate health information access and sharing by ensuring adequate Internet access.

The full benefits of connected health cannot be achieved unless everyone in the United States who wants to participate and the organizations that support health and deliver healthcare have adequate access to high-speed Internet service. Access depends both on the availability of broadband service and the resources needed to obtain and maintain service.

#### Action Item 4.1

### Support initiatives and programs to ensure that everyone in the United States has adequate Internet access if so desired.

Internet use in the United States is at a record high and continues to increase. In 2015, 84 percent of U.S. adults reported using the Internet, up from 52 percent in 2000.<sup>105</sup> Internet use has increased among virtually all segments of the population, although rates continue to lag among some groups, including older adults, racial/ethnic minorities, individuals with lower incomes and lower levels of education, and those living in rural settings (Figure 7).<sup>105</sup> Unfortunately, the disadvantages of lack of Internet access disproportionately affect populations that commonly experience worse health

outcomes, including higher mortality rates for many cancers and/or less consistent access to high-quality cancer care.<sup>106-109</sup> Connected health tools could help these at-risk populations by linking them with the people, information, and support they need to get healthy and stay well.

A 2015 Pew Research Center survey found that cost was the major reason cited by most people who did not have broadband connections. About two-thirds of those who did not have a home broadband subscription indicated either the monthly service fee or the cost of a computer as a barrier to adoption.<sup>110</sup> Even if they could afford it, high-speed broadband service is not available to millions of Americans in their communities.

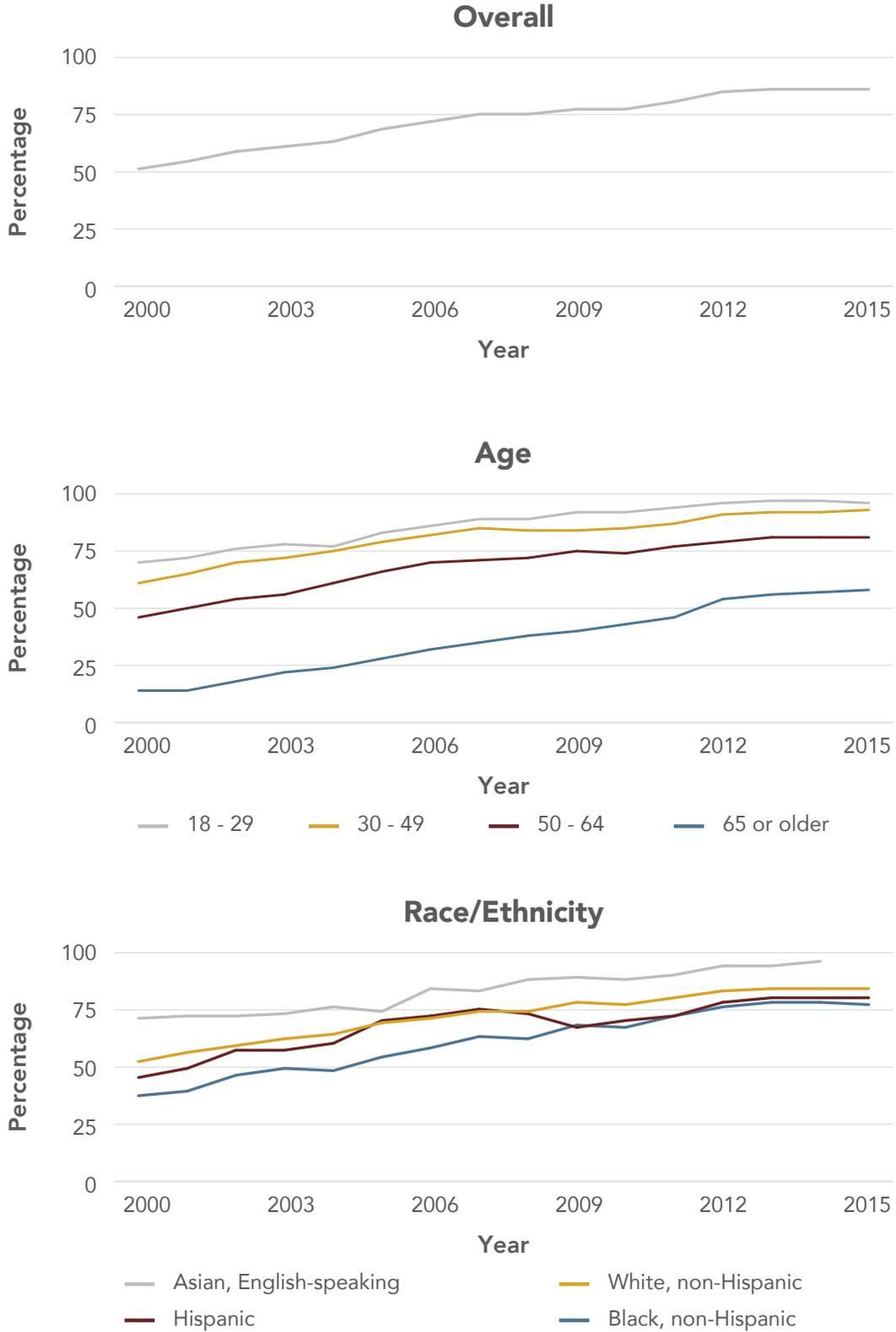
The Federal Communications Commission (FCC) estimated that, as of December 2014, 10 percent of the U.S. population—approximately 34 million people—lived in places in which high-speed broadband Internet service was not available.<sup>111\*</sup> Although Internet service is unavailable in some urban areas, rural populations are far more likely to lack adequate Internet access. More than 39 percent of Americans living in rural areas lack access to high-speed Internet compared with 4 percent of those living in urban areas. Survey data indicate that even with regular Internet access, rural residents are less likely than their urban counterparts to manage their personal health information online or email their doctors.<sup>112</sup>

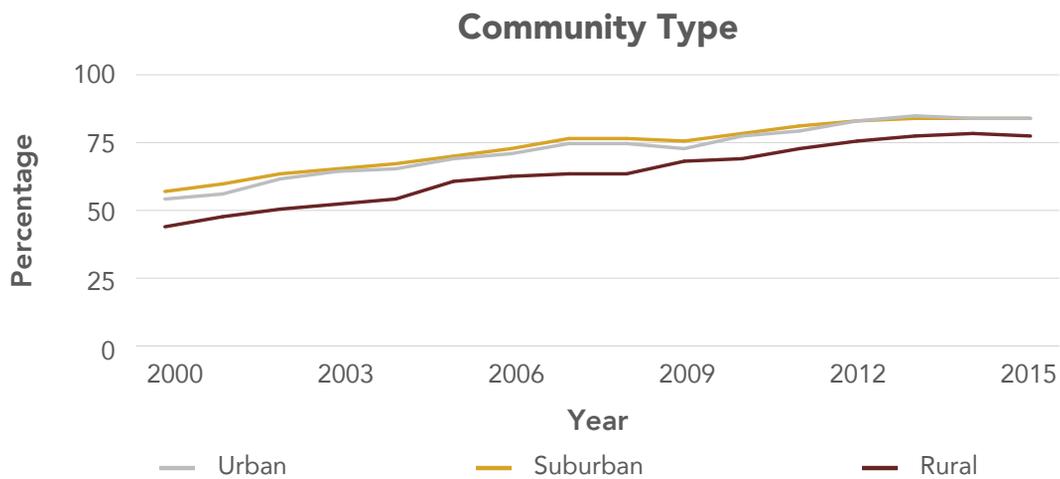
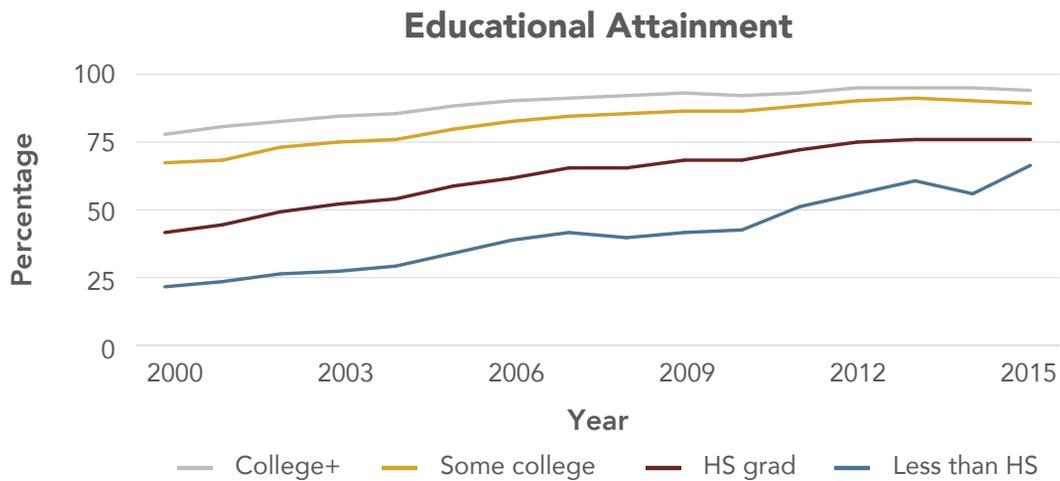
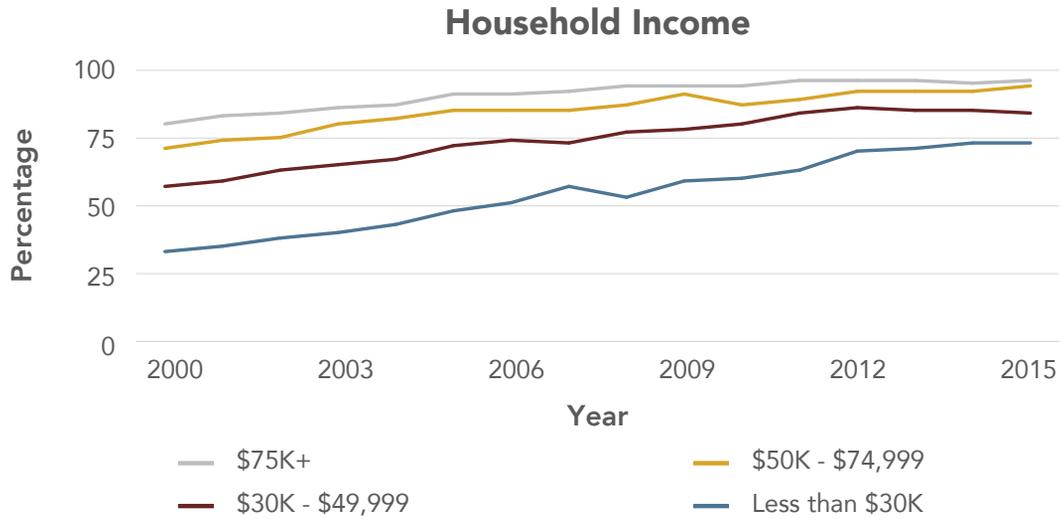
**“Access to high-speed broadband is no longer a luxury; it is a necessity for American families, businesses, and consumers.”**

— President Barack Obama, Memorandum

\* Based on the definition of broadband as 25 Mbps download speeds and 3 Mbps upload speeds adopted by the Federal Communications Commission in its 2015 broadband progress report.

**Figure 7. Percentage of U.S. Adults Who Use the Internet, 2000-2015**





Source: Perrin A, Duggan M. Americans' Internet access: 2000-2015. Washington (DC): Pew Research Center; 2015 Jun 26. Available from: <http://www.pewinternet.org/2015/06/26/americans-internet-access-2000-2015>

**The President's Cancer Panel unequivocally supports the long-term goal of President Obama set forth in FCC's 2010 National Broadband Plan that everyone in the United States should have affordable access to robust broadband service and the means and skills necessary to subscribe if they so choose.**<sup>113</sup> Given the central role of the Internet in modern society, access to the Internet should be viewed as a right, not a privilege.<sup>114</sup> The Internet should be regarded as a utility. With the mandate for EHRs, access to online tools, such as patient portals, is necessary for patients to receive information from and communicate with healthcare providers. Universal Internet access could help engage medically underserved populations and overcome disparities in health and other areas.

There has been encouraging progress in expanding Internet access in recent years. Since 2009, investments from the federal government have led to the deployment or upgrading of well over 100,000 miles of network infrastructure, and 45 million additional

Americans have adopted broadband.<sup>115</sup> Several federal agencies and public-private initiatives continue to expand broadband access by providing support for broadband planning, public access, adoption, deployment, and digital literacy (see *Programs and Initiatives Focused on Increasing Internet Access* on page 41). However, more work is needed to overcome the barriers to broadband access that persist for many. Federal agencies, Internet service providers, other private-sector entrepreneurs, and nonprofit organizations should continue to facilitate access to broadband Internet services at speeds adequate to support individuals' participation in connected health. Sponsored data can make it easier for individuals with limited data plans—including many from medically underserved populations—to access high-quality health information and personal health data online (see *Sponsored Data* below). However, even if the barriers of access and availability are overcome, it is critical that navigation and content are provided in a manner consistent with the culture, language, and communication skills of potential users.

### Sponsored Data

Companies and organizations can partner with mobile phone carriers to make their content available free of charge to customers. When customers access the sponsored data, also called zero-rated data, it does not count toward their monthly data allotments.

## Programs and Initiatives Focused on Increasing Internet Access

- The **Connect2HealthFCC Task Force** was created by FCC Chairman Tom Wheeler to explore ways to accelerate the adoption of healthcare technologies by leveraging broadband and other next-generation communications services. The long-term goal is to help make broadband networks work for everyone, from those living in rural and remote areas to those in underserved inner cities. The Task Force will work to expedite this vital shift by identifying regulatory barriers and incentives and building stronger partnerships with stakeholders in the areas of telehealth, mobile applications, and telemedicine.
- **BroadbandUSA**, an initiative of the National Telecommunications and Information Administration, provides assistance to communities that want to expand their broadband capacity and promote broadband adoption. Resources include: *BroadbandUSA: Guide to Federal Funding of Broadband Projects*, which lists and summarizes key federal programs that offer funding for broadband-related projects, and *Introduction to Effective Public-Private Resources*, which is an overview of common broadband partnerships and factors communities should consider when developing partnerships.
- **ConnectHome** is a public-private initiative focused on increasing home Internet access for over 275,000 low-income households. Launched in 2015, ConnectHome brings together the Department of Housing and Urban Development, nonprofit organizations EveryoneOn and US Ignite, and several for-profit Internet service providers to provide free or low-cost broadband, technical assistance, devices, and/or digital literacy training to families living in public and assisted housing across America.
- The FCC telephone subsidy program **Lifeline** was expanded in March 2016 to support Internet access for low-income Americans. Eligible households soon will be able to apply their monthly Lifeline subsidy to broadband service or bundled voice and data service packages.

**Sources:** Federal Communications Commission. Connect2HealthFCC [Internet]. Washington (DC): FCC; [updated 2015 Oct 26; cited 2016 Jan 26]. Available from: <https://www.fcc.gov/about-fcc/fcc-initiatives/connect2healthfcc>; National Telecommunications and Information Administration. BroadbandUSA: connecting America's communities [Internet]. Washington (DC): NTIA; [cited 2016 Oct 3]. Available from: <http://www2.ntia.doc.gov>; National Telecommunications and Information Administration. BroadbandUSA: guide to federal funding of broadband projects. Washington (DC): U.S. Department of Commerce; 2015 Sep. Available from: [https://www.ntia.doc.gov/files/ntia/publications/broadband\\_fed\\_funding\\_guide.pdf](https://www.ntia.doc.gov/files/ntia/publications/broadband_fed_funding_guide.pdf); National Telecommunications and Information Administration. BroadbandUSA: an introduction to effective public-private partnerships for broadband investments. Washington (DC): NTIA; 2015 Jan. Available from: [http://www2.ntia.doc.gov/files/ntia\\_ppp\\_010515.pdf](http://www2.ntia.doc.gov/files/ntia_ppp_010515.pdf); The White House Office of the Press Secretary. ConnectHome: coming together to ensure digital opportunity for all Americans [Fact Sheet] [Internet]. Washington (DC): the White House; 2015 Jul 15 [cited 2016 Jan 25]. Available from: <https://www.whitehouse.gov/the-press-office/2015/07/15/fact-sheet-connecthome-coming-together-ensure-digital-opportunity-all>; Federal Communications Commission. Lifeline support for affordable communications [Internet]. Washington (DC): FCC; 2016 Aug 17 [cited 2016 Sep 8]. Available from: <https://www.fcc.gov/consumers/guides/lifeline-support-affordable-communications>

## Action Item 4.2

### Support initiatives and programs to ensure adequate Internet access for all healthcare providers and organizations.

Healthcare providers and systems must have robust broadband access to optimize connectivity to each other and to the individuals and communities they serve. The need for high-speed broadband will only grow as telemedicine gains traction and increasing quantities of health-related data—including large imaging, pathology, and genomic data files—are collected and shared. Broadband connectivity is particularly challenging for healthcare organizations in rural settings, posing barriers to wider use of telemedicine in these communities. There often are limited broadband options in rural settings, and those available may be prohibitively expensive. An analysis by

the FCC found that Dedicated Internet Access options, which guarantee access to the bandwidth needed for larger healthcare organizations, are as much as three times more expensive in rural areas than in urban areas.<sup>113</sup> Furthermore, high-speed mass-market broadband options, which FCC estimates could meet the needs of offices with four or fewer clinicians, are not even available in some rural areas.<sup>113</sup>

Subsidies for broadband access for public and nonprofit rural healthcare providers are available through FCC's Rural Health Care Program,<sup>116</sup> and some support also is available through other federal programs and initiatives.<sup>117</sup> This support should continue. **In addition, federal, state, local, and private-sector stakeholders should work together to ensure that all healthcare providers and organizations have access to the Internet at speeds that allow them to communicate and exchange data with other institutions and patients.**



## OBJECTIVE 5

### Facilitate data sharing and integration to improve care, enhance surveillance, and advance research.

Over the past 25 years, the U.S. cancer mortality rate has decreased by 23 percent, representing more than 1.7 million cancer deaths averted.<sup>19</sup> These improvements stem from investments in cancer surveillance and research that have led to development of new approaches and wider use of proven strategies to prevent, detect, diagnose, and treat cancers.<sup>19</sup> However, there is remarkable need—and tremendous

opportunity—to reduce the population burden of cancer even further by developing better ways to prevent and treat the hundreds of diseases that make up cancer and ensuring that knowledge is effectively applied.

Unprecedented amounts of data about people at risk of cancer and cancer patients are being collected in medical records, as part of research studies, and by individuals themselves. In the past, health data remained wherever they were collected and generally were used in limited ways to serve the specific needs of whoever collected them. These silos represent a significant missed opportunity, one recently highlighted by the Cancer Moonshot (see *Cancer Moonshot* on page 43). Connected health technologies have an important role to play by facilitating linkages of systems and data sets and creating tools that enable researchers, clinicians, and patients to use data in meaningful ways. Creation

of a national infrastructure to support sharing and processing of cancer data—a National Cancer Data Ecosystem—also is identified as a priority by the Cancer Moonshot Blue Ribbon Panel.<sup>6</sup> To accomplish this, technical and logistical challenges to data integration must be overcome, and the cancer community must foster a culture of collaboration that encourages data sharing and free exchange of ideas. Care also must be taken to ensure that federal, state, and organizational

policies appropriately balance data sharing for research with individuals' privacy and security. HIPAA has received extensive attention in this regard. Concerns raised by the IOM,<sup>118</sup> C-Change,<sup>119</sup> and other stakeholders spurred recent modifications to HIPAA intended to facilitate research.<sup>120-122</sup> Continued attentiveness is needed to ensure that HIPAA and other policies are accurately interpreted and applied and do not unnecessarily deter research.

### Cancer Moonshot

During his State of the Union address in January 2016, President Obama announced the establishment of a new Cancer Moonshot. The initiative—led by Vice President Joseph Biden—aims to accelerate progress in cancer prevention, diagnosis, treatment, and care to make a decade of progress in five years. At the Cancer Moonshot Summit in June 2016, more than 35 new actions and partnerships to advance Cancer Moonshot goals were announced. These include the National Cancer Institute's Genomic Data Commons (see *Genomic Data Commons* on page 50) and the Applied Proteogenomics Organizational Learning and Outcomes (APOLLO) Network, a partnership between NCI, the Department of Defense, and the Department of Veterans Affairs that is using state-of-the-art research methods in proteogenomics to advance understanding of the molecular underpinnings of cancer.

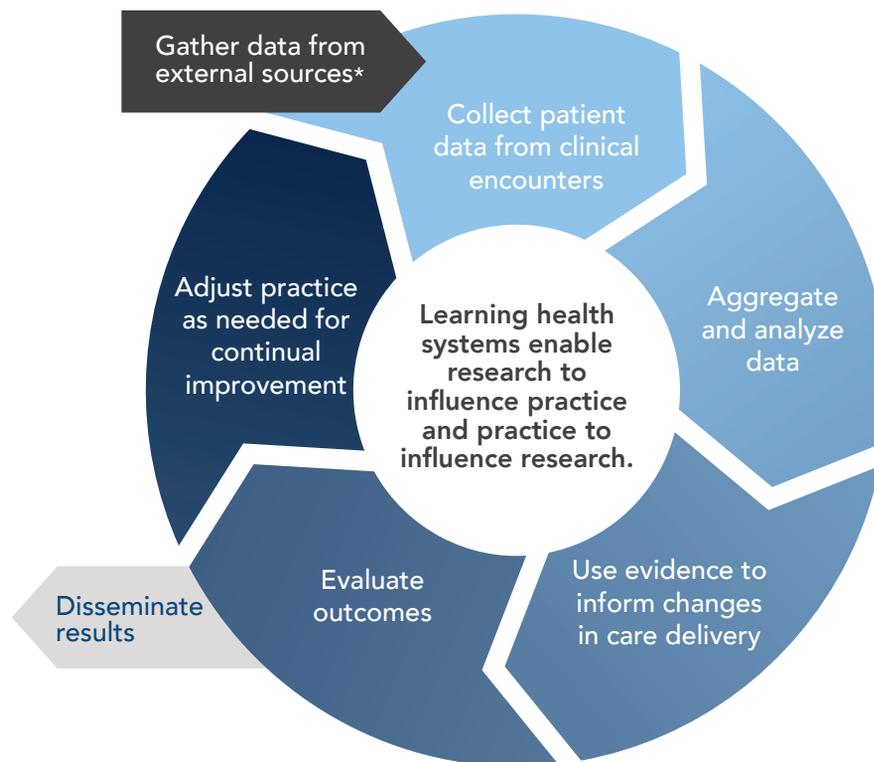
Sources: The White House Office of the Press Secretary. Fact Sheet: Investing in the National Cancer Moonshot [Press Release]. Washington (DC): the White House; 2016 Feb 1. Available from: <https://www.whitehouse.gov/the-press-office/2016/02/01/fact-sheet-investing-national-cancer-moonshot>; National Cancer Institute. NCI-related activities announced at the Moonshot summit [Internet]. Bethesda (MD): NCI; 2016 Jun 29 [cited 2016 Jul 8]. Available from: <http://www.cancer.gov/research/key-initiatives/moonshot-cancer-initiative/milestones/nci-activities>

## Action Item 5.1

### Use learning healthcare systems to support continuous improvement in care across the cancer continuum.

Widespread adoption of health IT and digital capture of health data create opportunities

to develop learning healthcare systems that continuously and iteratively gather and analyze data and use results to transform subsequent care delivery (Figure 8). Although learning healthcare systems integrate data from clinical trials and other research studies, they are set apart by their capacity to conduct powerful new types of observational studies by using data captured during real-world clinical encounters.

**Figure 8. Learning Healthcare System**

\*Examples include clinical trials, observational studies, patient-reported outcomes, surveillance databases, and population-based surveys.

Sources: Abernethy AP, Etheredge LM, Ganz PA, Wallace P, German RR, Neti C, et al. Rapid-learning system for cancer care. *J Clin Oncol.* 2010;28(27):4268-74; Greene SM, Reid RJ, Larson EB. Implementing the learning health system: from concept to action. *Ann Intern Med.* 2012;157(3):207-10.

The vision of a continuously learning healthcare system and the path for achieving this vision are described in detail in the 2012 Institute of Medicine report *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*.<sup>44</sup> The importance of a learning healthcare system for oncology is discussed in the 2013 IOM report *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*.<sup>4</sup> Learning healthcare systems could enhance oncology care and research in several ways.<sup>123</sup> With the emergence of precision medicine, physicians would benefit from clinical decision support tools that help them identify and weigh all available options. Learning healthcare systems provide opportunities to learn from the experiences of a broad array of cancer

patients, including those from populations—such as older adults and racial/ethnic minorities—that are underrepresented in cancer clinical trials.<sup>124,125</sup> They also facilitate comparative effectiveness research and ongoing monitoring of drug safety and efficacy, which is particularly important for drugs receiving accelerated approval from the Food and Drug Administration.

**The President's Cancer Panel reiterates the call by the IOM for a learning healthcare system for cancer.**<sup>4</sup> The Panel also supports efforts by the American Society of Clinical Oncology and others to create learning healthcare systems that will improve cancer prevention, detection, treatment, and survivorship (see *Kaiser Permanente's Learning*

*Healthcare System* below and *CancerLinQ: A Learning Healthcare System for Oncology* on page 46).

Oncology practices and healthcare systems should participate in or implement learning healthcare systems and harness their power to improve cancer care across the continuum. ONC can help address technical barriers by promoting interoperability, as well

as development and adoption of common standards (see *Objective 1*). The Panel is troubled by reports that information blocking (see *Information Blocking* on page 18) has undermined some efforts to create learning healthcare systems and urges all stakeholders to adopt policies and practices that promote the flow of information to support clinical care and learning.

### Kaiser Permanente's Learning Healthcare System

In the mid-2000s, Kaiser Permanente developed and implemented efforts to become a learning organization, capable of continuous improvements in quality, safety, service, and efficiency. Data from Kaiser's integrated EHR system, HealthConnect, play a key role. Among other features, HealthConnect captures quality metrics data and informs clinicians of their concordance with clinical practice guidelines. It also features advanced clinical decision support for oncology that includes 230 standardized protocols for major adult cancers, as well as alerts when patients are eligible for clinical trials.

Studies have shown that Kaiser's commitment to using technology to support care and learning has paid dividends for cancer prevention and care. Rates of colorectal and breast cancer screenings increased following adoption of HealthConnect in Kaiser's Hawaii region. In addition, compared with other colorectal cancer patients in California, patients treated within the Kaiser system were more likely to receive evidence-based care and had higher five-year survival rates. In sharp contrast with the markedly higher colorectal cancer mortality rates observed among African Americans nationwide, racial and ethnic disparities in colorectal cancer survival were absent among Kaiser patients.

**Sources:** Institute of Medicine. *Delivering high-quality cancer care: charting a new course for a system in crisis*. Levit L, Balogh E, Nass S, Ganz P, editors. Washington (DC): The National Academies Press; 2013 Sep 10. Available from: <https://www.nap.edu/18359>; Kaiser Permanente. *How Kaiser Permanente became a continuous learning organization* [Press Release]. Oakland (CA): Kaiser Permanente; 2011 Nov 17. Available from: <https://share.kaiserpermanente.org/article/how-kaiser-permanente-became-a-continuous-learning-organization>; Kemp K. *Research insights: using evidence to build a learning health care system*. Washington (DC): Academy Health; 2012. Available from: <http://www.academyhealth.org/publications/2012-08/research-insights-using-evidence-build-learning-health-care-system>; Shah NR. *Supporting population health through integrated healthcare systems, patient engagement, and transparency*. Presented at: President's Cancer Panel meeting; 2015 Mar 26; San Francisco, CA; Chen C, Garrido T, Chock D, Okawa G, Liang L. *The Kaiser Permanente Electronic Health Record: transforming and streamlining modalities of care*. *Health Aff (Millwood)*. 2009;28(2):323-33; Rhoads KF, Patel MI, Ma Y, Schmidt LA. *How do integrated health care systems address racial and ethnic disparities in colon cancer?* *J Clin Oncol*. 2015;33(8):854-60; Schilling L, Dearing JW, Staley P, Harvey P, Fahey L, Kuruppu F. *Kaiser Permanente's performance improvement system, Part 4: Creating a learning organization*. *Jt Comm J Qual Patient Saf*. 2011;37(12):532-43.

## CancerLinQ: A Learning Healthcare System for Oncology

The American Society of Clinical Oncology has developed a learning healthcare system for oncology called the Cancer Learning Intelligence Network for Quality, or CancerLinQ. CancerLinQ gathers data through automated feeds from EHRs and practice management systems of participating oncology practices, so practice staff do not need to manually extract data for submission. The primary goals of CancerLinQ are to:

- Provide real-time quality feedback to practices to foster a culture of self-examination and improvement.
- Provide personalized insights to help physicians choose the right therapy at the right time for each patient, based on published treatment guidelines and other knowledge bases.
- Uncover patterns that can improve care using analytical tools.

CancerLinQ was launched in 2016 and, to date, more than 58 practices ranging from small private practices to cancer centers have joined. CancerLinQ also has formed a collaboration with Cancer Informatics for Cancer Centers, a consortia of senior cancer informatics leaders from the 70 NCI-funded cancer centers and other cancer centers around the world.

**Sources:** Sledge GW, Hudis CA, Swain SM, Yu PM, Mann JT, Hauser RS, et al. ASCO's approach to a learning health care system in oncology. *J Oncol Pract.* 2013;9(3):145-8; American Society of Clinical Oncology. CancerLinQ health information technology (HIT) platform [Internet]. Alexandria (VA): ASCO; [cited 2015 Aug 28]. Available from: <http://www.instituteforquality.org/cancerlinq>; American Society of Clinical Oncology. CancerLinQ completes agreements with thirty-six "vanguard" practices. Alexandria (VA): ASCO; 2016 Apr 21. Available from: <https://www.asco.org/latest-news-releases/cancerlinq-completes-agreements-over-thirty-five-vanguard-practices>; Schilsky RL, Miller RS. Creating a learning health care system in oncology. In: Hesse BW, Ahern D, Beckjord E, editors. *Oncology informatics: using health information technology to improve processes and outcomes in cancer.* San Diego (CA): Elsevier; 2016; American Society of Clinical Oncology. ASCO's CancerLinQ™ extends its reach—58 oncology practices, 750,000 patient records, 1,000 providers under contract, new partnership launched with the nation's leading cancer informatics association [News Release]. Alexandria (VA): ASCO; 2016 Jun 5. Available from: <https://www.asco.org/about-asco/press-center/news-releases/asco%E2%80%99s-cancerlinq%E2%84%A2-extends-its-reach-%E2%80%93-58-oncology-practices>

## Action Item 5.2

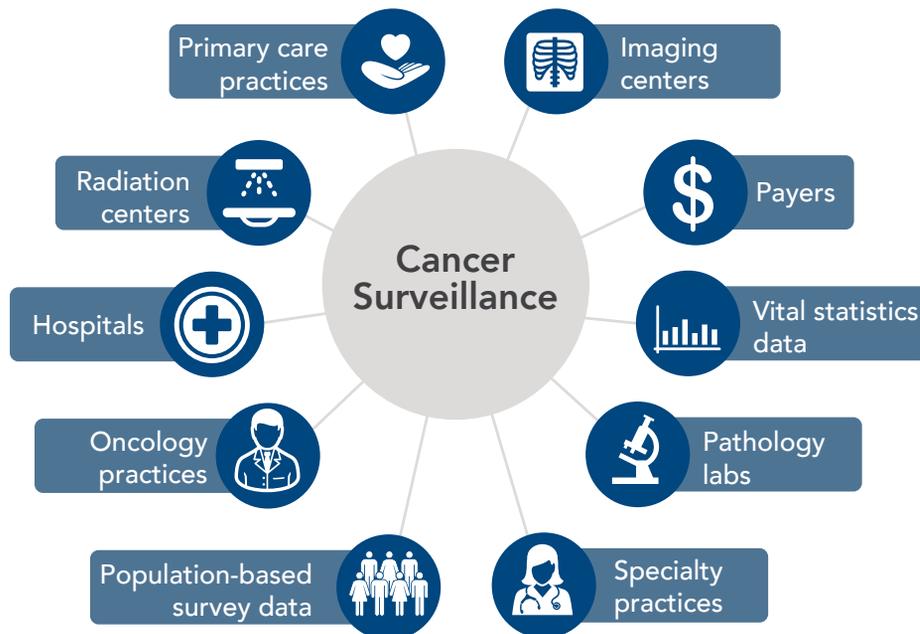
### Use health information technologies to enhance cancer surveillance.

Cancer registries provide invaluable data that are used to inform cancer prevention and control efforts, as well as to support a broad variety of research activities. Healthcare providers in each state are required to report all cancer cases, treatments, and outcomes to state cancer registries. National cancer statistics are generated by combining data collected by the CDC National Program of Cancer Registries (NPCR) and the NCI Surveillance, Epidemiology, and End Results (SEER) Program.

Modern cancer surveillance faces several challenges that could be addressed through connected

health. Cancer surveillance data traditionally have been submitted to central registries by hospitals and, more recently, pathology laboratories. However, the number of patients being diagnosed and treated in non-hospital settings is growing, resulting in underreporting of incidence for certain cancers and incomplete information on treatments administered.<sup>126-129</sup> Many patients also receive therapies in multiple locations—sometimes in different states—over long periods of time, which complicates reporting. Cancer surveillance could be strengthened if health IT were used to create and enhance linkages across state registries, as well as between registries and all providers, laboratories, and institutions involved in diagnosing and treating cancers. Ideally, surveillance data also could be supplemented with information from payers, government data systems for vital statistics, population-based surveys, and patients themselves (Figure 9).

**Figure 9. Sources of Cancer Surveillance Data**



**Source:** Penberthy LT, Winn DM, Scott SM. Cancer surveillance informatics. In: Hesse BW, Ahern D, Beckjord E, editors. *Oncology informatics: using health information technology to improve processes and outcomes in cancer*. San Diego (CA): Elsevier; 2016.

One way to enhance linkages between registries and providers would be to promote automatic reporting of data from EHRs to central cancer registries. CDC, in collaboration with other stakeholders, has developed and published guidance for EHR-based data submission to cancer registries by ambulatory healthcare providers, a group that traditionally has underreported to cancer registries.<sup>38</sup> The ONC 2015 Health IT Certification Criteria require EHRs to be capable of compiling cancer case information for transmission to central cancer registries<sup>29</sup> and identify the CDC guidance as the standard for this transmission. However, implementation of processes that enable automatic transmission of cancer data from EHRs to central registries has been slow. Barriers to more widespread implementation include lack of cancer-reporting functionality in many EHRs; EHR workflows that are not conducive to entering data elements needed by cancer registries; limited resources within central cancer registries for receiving, validating, and processing EHR data; and issues with quality and completeness of data transmitted from EHRs.

Currently, some of the EHR-derived data submitted to central registries are in unstructured formats, requiring manual extraction and interpretation that are both time-consuming and prone to errors. Non-standardized data from laboratories for cancer biomarkers and diagnostic test results pose a particular challenge for registries. CDC and the College of American Pathologists have collaborated to develop protocols and tools for pathologists to collect cancer pathology and biomarker data in standardized, coded templates.<sup>130</sup> However, pathologists and laboratories have been slow to

implement these standards within their laboratory information systems.

**The President's Cancer Panel encourages national and state registry representatives, health IT developers, and federal agencies to collaborate in using connected health tools to improve cancer surveillance. Moreover, innovations in tool development should be encouraged.** ONC should continue its work with registry stakeholders to ensure that the health information technologies used by all providers and institutions involved in treating and diagnosing cancer are capable of automatically transmitting high-quality data in a consistent format to central cancer registries. Federal agencies supporting surveillance should ensure that the states' central registries have the resources and technical support necessary to receive, validate, and process automated data transmissions from a variety of sources. As technical standards emerge for cancer-related data, structured data elements should be incorporated into registry submissions whenever appropriate. Federal agencies should continue to work with laboratories, pathologists, and laboratory information system vendors to implement standardized collection and reporting of cancer pathology and biomarker data using the College of American Pathologists protocols and tools. Registry stakeholders also should continue to collaborate with computer scientists to pursue other strategies, such as natural language processing (see *Natural Language Processing* on page 49), that facilitate extraction of meaningful information from unstructured data. This will be particularly important in an era of precision medicine in which registries seek to integrate more sophisticated molecular and genomic information about patients and their tumors to provide insights into how these factors influence prognosis and treatment responses.

## Natural Language Processing

Most information in health records is entered as free text. Free text may be an effective way for members of an individual's care team to communicate, but it is difficult to search, summarize, and analyze for secondary purposes, such as research or quality improvement. Natural language processing, or NLP, is any computer-based algorithm that handles, augments, or transforms natural language—such as a doctor's notes—so that it can be represented for computation. NLP is one strategy being explored to make data more usable for cancer registries and other applications.

Source: Yim WW, Yetisgen M, Harris WP, Kwan SW. Natural language processing in oncology: a review. *JAMA Oncol.* 2016;2(6):797-804.

### Action Item 5.3

#### Integrate data from various sources to create knowledge networks for cancer research.

Researchers, clinicians, and patients have accumulated vast amounts of cancer-related data. Far greater insights would be possible if data from various sources were integrated and made broadly available to researchers. A number of recommendations in the Cancer Moonshot Blue Ribbon Panel report focused on the challenges in and opportunities for new discoveries and insights that could emerge from greater data sharing.<sup>6</sup> Examples could include combining similar data sets collected at different institutions and/or through different research projects to generate larger data sets for analysis. Multiple initiatives are under way to facilitate this type of data sharing among researchers (see *Genomic Data Commons* on page 50 and *Oncology Research Information Exchange Network* on page 51). Rich data sets also could be created by linking large databases housing different types of data, such as clinical data from EHRs, population-based health survey

results, cancer surveillance data, behavioral data, environmental data, and payer claims. Integration of these complementary data can facilitate more meaningful and comprehensive analyses of outcomes, patterns of care, cost-effectiveness, social determinants of health, health services, and other factors. However, the barriers to conducting these linkages can be daunting. Among other challenges, data from different sources may be covered by different policies and regulations (e.g., HIPAA, informed consent, state laws), negotiation of Data Use Agreements can be time-consuming, and matching of individual records often is difficult. Despite these barriers, integration of data is being achieved in some cases (see *Integrated Cancer Information and Surveillance System* on page 51).

Connected health also has created opportunities to enhance biomedical research through increased public participation in research. Individuals increasingly have electronic access to their medical records and also are collecting their own data using mobile and wearable devices. In addition to using these data to support their own health goals, individuals should be empowered to share their data with researchers, with appropriate safeguards for sensitive data. The Sync for Science pilot program

recently launched by ONC and the National Institutes of Health will facilitate this by promoting development of apps that link to individuals' electronic health information and facilitate donation of data to the Precision Medicine Initiative.<sup>131</sup> A public-facing portal that enables patients and healthy individuals to contribute their data for scientific research is a flagship feature of the Cancer Data Ecosystem envisioned by the Cancer Moonshot Blue Ribbon Panel.<sup>6</sup> Patient-driven knowledge networks, such as PatientsLikeMe (see *Tools Supporting Consumer Engagement* on page 25),<sup>132</sup> also are making contributions to research. In addition, there are opportunities for researchers to incorporate person-generated data into their studies (see *Using Person-Generated Data in Cancer Research* on page 52).

Biomedical research has revealed the vast complexity of the hundreds of diseases that collectively are called cancer. Numerous genetic, environmental, and lifestyle factors determine cancer risk, as well as response to treatment. Research is needed to identify ways to reduce the population burden of cancer by tailoring risk reduction and treatment strategies to patients' circumstances. This will be accomplished faster and more effectively if data are shared openly and all stakeholders collaborate. There has been progress in this area, but there is more to be done. **The President's Cancer Panel urges continued public-private collaboration to facilitate the efficient and effective flow of health information for cancer research.** Members of the public also should be engaged throughout the research process.<sup>133</sup>

### Genomic Data Commons

The Cancer Moonshot, along with the Precision Medicine Initiative, helped launch the NCI Genomic Data Commons (GDC), a database that promotes sharing of genomic and clinical data among researchers to advance precision medicine for cancer. The GDC provides a resource for depositing, standardizing, harmonizing, and sharing cancer genomic and clinical data. The GDC also provides tools for finding genomic and clinical data sets, as well as a growing palette of tools for sharing, analyzing, and visualizing cancer genomic and phenotypic data. The GDC has data from The Cancer Genome Atlas, TARGET (Therapeutically Applicable Research to Generate Effective Treatments), and other genomic data sets. As part of a recently announced partnership, Foundation Medicine, Inc., will provide the GDC with molecular and genomic profiles of 18,000 patients with various cancers generated by the company's proprietary genomic profiling assay. Research institutions are encouraged to submit data via a portal to enable sharing and analysis with other data sets to build on an expandable knowledge network of clinical and genomic data for use by cancer research programs. In addition to the GDC, NCI has three Cloud Pilots designed to take data from the GDC and make those data available in a commercial cloud computing infrastructure.

Source: National Cancer Institute. Genomic Data Commons [Internet]. Bethesda (MD): NCI; [cited 2016 Oct 4]. Available from: <https://gdc.cancer.gov>

## Oncology Research Information Exchange Network

Numerous cancer centers and private companies have formed a research partnership called the Oncology Research Information Exchange Network (ORIEN) to collaborate on precision cancer medicine efforts and to accelerate the development of targeted treatments. ORIEN uses a common protocol to prospectively collect and share clinical, molecular, and epidemiological data on more than 100,000 consenting patients. These data can be used to efficiently match patients, based on molecular profiles, to clinical trials for targeted therapies. ORIEN's shared data repository also can facilitate cross-institutional collaborations, such as biomarker discovery projects, and serve as a rapid-learning environment for researchers to analyze data and share findings among member organizations.

**Source:** Oncology Research Information Exchange Network. Home page [Internet]. Tampa (FL): ORIEN; [cited 2016 Sep 8]. Available from: <http://oriencancer.org>

## Integrated Cancer Information and Surveillance System

The Integrated Cancer Information and Surveillance System (ICISS), a component of University of North Carolina Lineberger Comprehensive Cancer Center's Outcomes Research Program, uses a "team science" approach to build data systems and methods to support researchers in leveraging big data to enhance population health in North Carolina. ICISS links and manages large data sets from multiple state sources, including cancer registries, private and public payers, and geospatial resources. Researchers, with the help of innovative analytical tools and expert technical support, can use these data to describe clinical, social, and environmental factors that influence health outcomes among the state's cancer population. This big data resource is particularly useful in answering questions regarding health inequities. For example, a study analyzing ICISS data found that black women were 25 percent less likely to receive trastuzumab, a key adjuvant treatment for HER2-positive breast cancer, within one year of diagnosis than were white women.

**Sources:** University of North Carolina at Chapel Hill, Lineberger Comprehensive Cancer Center. Integrated Cancer Information and Surveillance System [Internet]. Chapel Hill (NC): UNC Lineberger [cited 2016 Oct 3]. Available from: <https://iciss.unc.edu>; Meyer AM, Olshan AF, Green L, Meyer A, Wheeler SB, Basch E, et al. Big data for population-based cancer research: the Integrated Cancer Information and Surveillance System. *N C Med J.* 2014;75(4):265-9; Reeder-Hayes K, Peacock Hinton S, Meng K, Carey LA, Dusetzina SB. Disparities in use of human epidermal growth hormone receptor 2-targeted therapy for early-stage breast cancer. *J Clin Oncol.* 2016;34(17):2003-9.

## Using Person-Generated Data in Cancer Research

The emergence of smartphones and a variety of wearable technologies (e.g., Fitbit) has created new ways to collect person-generated data for cancer research. These tools can help gain a more comprehensive picture of the biological, social, behavioral, and environmental factors that influence health, as well as the impact of disease and treatment on people's everyday lives.

Mobile and wearable technologies offer a number of advantages for research. Data can be collected more frequently—sometimes even continuously—and are gathered as people live their everyday lives, rather than in controlled clinical or laboratory environments. Remote data collection also means fewer trips to the research site, which should result in cost savings and make it easier for people to participate. Mobile devices also can be used to prompt participants to take medications, record information, or carry out research-related tasks.

Smartphones and wearables already have been incorporated into a number of research studies relevant to cancer, including:

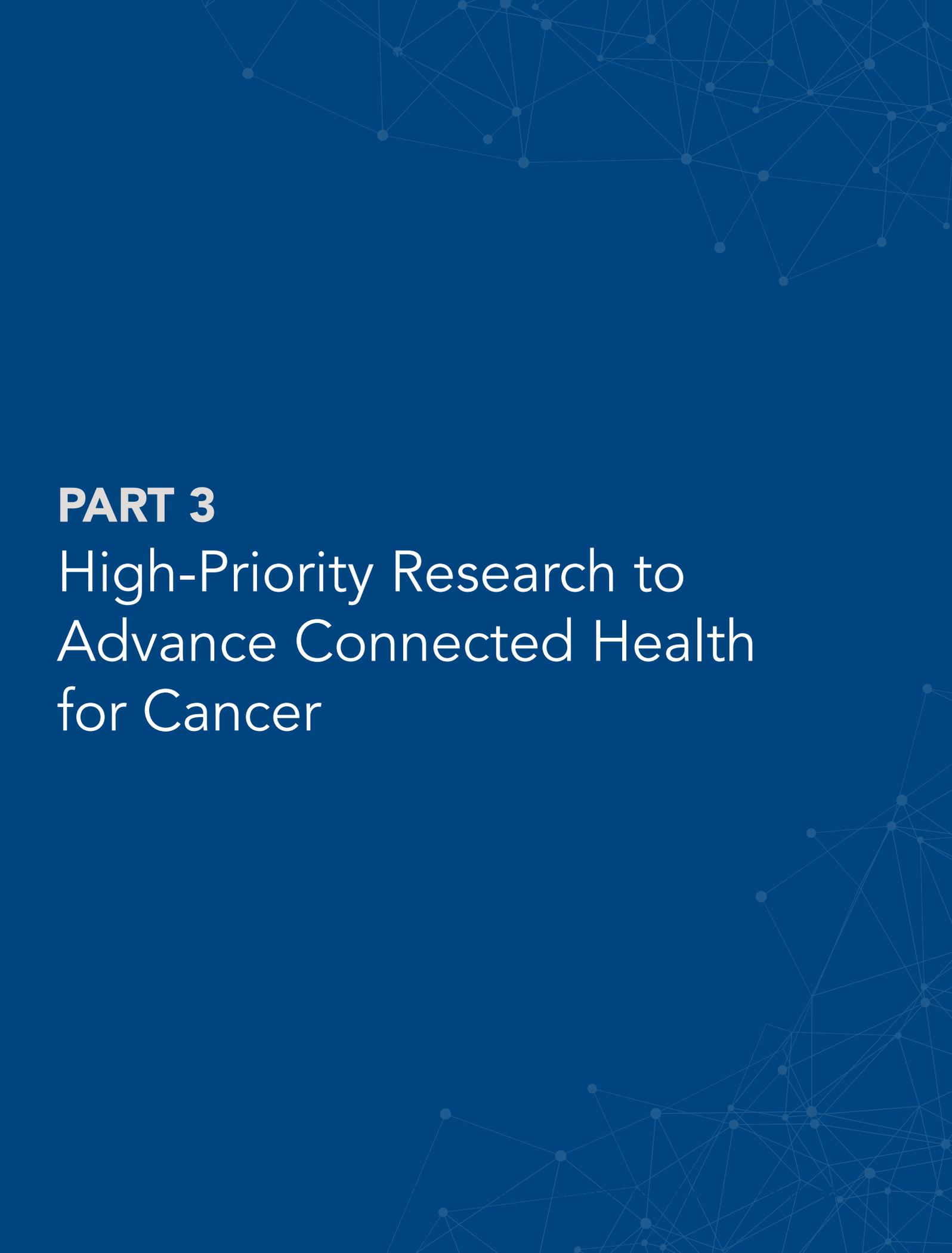
- **Breast Cancer Weight Loss (BWEL) study:** Researchers at Dana-Farber Cancer Institute have partnered with Fitbit to find out whether losing weight can reduce the likelihood of recurrence among overweight or obese women recently diagnosed with early-stage breast cancer. The 3,200 participants from across the United States and Canada all will receive health education about breast cancer, as well as Fitbit devices donated by the company. These devices will enable measurement of activity, heart rate, body weight, body mass index, lean mass, and body fat. Some women also will have a health coach who can access their Fitbit data and will communicate with them by phone to help them reach their goals.
- **Share the Journey:** Sage Bionetworks, a nonprofit research organization, has used Apple's ResearchKit (see *Apple ResearchKit and CareKit* on page 26) to create an app that enables breast cancer survivors to record and track their health and symptoms in real time on their iPhones. They also can share their data with researchers, who plan to use the data to enhance understanding of the symptoms that occur after breast cancer treatment, determine why these symptoms vary over time, and help identify ways to improve them.
- **Keeping Pace:** With funding from the Health Data Exploration Project, a New York University research laboratory is using personal sensor data to investigate how the built environment influences exercise behaviors over time. Participants share their RunKeeper data, along with basic demographic information, with the researchers. The use of personal sensors in mobile devices avoids the recall bias that is a drawback of using surveys for this type of research.

There also may be opportunities to learn from the vast quantities of data being captured by individuals' personal devices. The Health Data Exploration project found that individuals have a strong interest in contributing their personal health data and researchers are enthusiastic about using it, but additional work is needed related to privacy and data ownership, informed consent, the validity of personal health data collected by consumer devices, and the lack of standardization among devices. Consumers' role in data generation is paving the way for new models that regard personal health data as a natural resource and provide individuals with more control over how their data are accessed and used.

The research community should continue to identify ways to use connected health tools to gather person-generated data for cancer-related studies, as well as generate data that will help elucidate the value of sensors and mobile devices for clinical care (see *Part 3*). Connected health tools could be particularly useful for implementing the Cancer Moonshot Blue Ribbon Panel recommendation to accelerate research for monitoring and managing patient-reported symptoms. The NIH Toolbox, which is available as an iPad app, is one resource that can help researchers assess functional changes in patients as part of research studies.

**Sources:** Pai A. Dana Farber, Fitbit to study the impact of weight loss on breast cancer recurrence. *mobihealthnews* [Internet]. 2016 Apr 27 [cited 2016 Jul 27]. Available from: <http://mobihealthnews.com/content/dana-farber-fitbit-study-impact-weight-loss-breast-cancer-recurrence>; Rabin RC. Putting breast cancer on a diet. *The New York Times* [Internet]. 2016 Jun 27 [cited 2016 Jul 27]. Available from: <http://nyti.ms/28Zw5Uk>; Dana-Farber Cancer Institute. Dana-Farber and Fitbit partner to test if weight loss can prevent breast cancer recurrence. Boston (MA): Dana-Farber Cancer Institute; 2016 Apr 27. Available from: <http://www.dana-farber.org/Newsroom/News-Releases/dana-farber-cancer-institute-and-fitbit-partner-to-test-if-weight-loss-prevent-breast-cancer-recurrence.aspx>; Dana-Farber Cancer Institute. App developed in collaboration with Dana-Farber researchers allows breast cancer survivors to share symptoms instantly [News Release]. Boston (MA): Dana-Farber Cancer Institute; 2016 Mar 9. Available from: <http://www.dana-farber.org/Newsroom/News-Releases/app-developed-in-collaboration-with-dana-farber-researchers-allows-breast-cancer-survivors-to-share-symptoms-instantly.aspx>; Share the Journey. Home page [Internet]. Seattle (WA): Sage Bionetworks; [cited 2016 Jul 28]. Available from: <http://sharethejourneyapp.org>; Dorsey ER, Yvonne Chan YF, McConnell MV, Shaw SY, Trister AD, Friend SH. The use of smartphones for health research. *Acad Med*. 2016 [Epub 2016 Apr 26]; Health Data Exploration Project. Personal data for the public good: new opportunities to enrich understanding of individual and population health. Princeton (NJ): Robert Wood Johnson Foundation; 2014 Mar. Available from: <http://www.rwjf.org/content/dam/farm/reports/reports/2014/rwjf411080>; Bietz MJ, Bloss CS, Calvert S, Godino JG, Gregory J, Claffey MP, et al. Opportunities and challenges in the use of personal health data for health research. *J Am Med Inform Assoc*. 2016;23(e1):e42-8; Evans BJ. Barbarians at the gate: consumer-driven health data commons and the transformation of citizen science. *Am J Law Med*. 2016;42(4). Available from: [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=2750347](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2750347); Cancer Moonshot Blue Ribbon Panel. Cancer Moonshot Blue Ribbon Panel Report 2016. Bethesda (MD): National Cancer Institute; 2016 Oct 17. Available from: <https://www.cancer.gov/research/key-initiatives/moonshot-cancer-initiative/blue-ribbon-panel>; NIH Toolbox [Internet]. National Institutes of Health and Northwestern University [cited 2016 Sep 28]. Available from: <http://www.nihtoolbox.org>





**PART 3**

High-Priority Research to  
Advance Connected Health  
for Cancer

Additional research in several areas could increase the benefits of connected health for cancer. Better tools and interfaces could be developed if more were known about how healthcare providers work collaboratively and the factors that enhance people's engagement with their health and healthcare. Research also is needed to ensure that the vast quantities of data being generated can be used in meaningful ways to support patient-centered care.

### **1. Improve understanding of how connected health can enable effective teamwork in healthcare.**

Cancer care routinely is delivered by diverse teams of professionals working collaboratively with patients and caregivers across numerous medical and community settings.<sup>134,135</sup> Effective and efficient communication among team members is essential to achieve care goals and accurately relay information such as test results, treatment plans, or referrals for specialized services. Health IT tools can extend the reach and effectiveness of care teams and support team communication across the cancer continuum.<sup>4</sup> For example, an EHR-based tool can connect

patients to community-based tobacco cessation services and, using a "closed-loop" function, send a notification back to the provider on the referral's outcome (see *Connecting Primary Care Patients to Tobacco Cessation Quit Line Services* on page 57). Although this and other emerging examples of tools to support delivery of team-based care are encouraging, a more complete understanding is needed regarding how to improve team performance through connected communication channels across care settings, including into the home through patient portals and smart devices. A particular research focus should be on enhancing continuity of care and reducing the types of medical errors that occur when information is "handed off" from one member of the care team to the other. Understanding how to improve communication effectiveness within teams should have the added benefit of improving efficiency and the experience of care for both patients and healthcare providers. In addition, efforts are needed to describe cognitive, motivational, and behavioral influences on care teams and to characterize complex team structures and communication processes.<sup>134,136</sup> Methods to best engage patients and caregivers as active team members also should be explored.<sup>137</sup>

### Connecting Primary Care Patients to Tobacco Cessation Quit Line Services

Researchers at the University of Wisconsin-Madison teamed up with Dean Health Systems and its EHR vendor, Epic Systems Corporation, to create a closed-loop EHR tool called eReferral. Once patients are identified as tobacco users as part of the standard EHR clinic workflow, eReferral prompts providers to offer tobacco cessation quit line telephone services to those patients. If the patients express interest, electronic referrals are sent to the Wisconsin Tobacco Quit Line. Quit Line staff contact the patients, provide counseling and over-the-counter cessation medication, and send documentation of the outcome of the referrals back to patients' EHRs so providers are aware of the key outcomes. Quit Line referrals increased dramatically when eReferral was implemented. Importantly, feedback from key stakeholders, including clinicians, was integrated during the development process.

**Sources:** Adsit RT, Fox BM, Tsiolis T, Ogland C, Simerson M, Vind LM, et al. Using the electronic health record to connect primary care patients to evidence-based telephonic tobacco quitline services: a closed-loop demonstration project. *Transl Behav Med.* 2014;4(3):324-32; Lindholm C, Adsit R, Bain P, Reber PM, Brein T, Redmond L, et al. A demonstration project for using the electronic health record to identify and treat tobacco users. *WMJ.* 2010;109(6):335-40.

## 2. Identify strategies to enhance individuals' engagement in their healthcare.

Understanding patients' and families' interactions with health systems is now recognized as an important area of health services research. The potential benefits of individuals' active participation in their own healthcare is well documented (see *Objective 2*), but cancer patients continue to have unmet information needs and frequently are not fully connected to their care teams.<sup>138</sup> Although existing connected health tools address some patient needs, the tasks, technologies, responsibilities, and expectations involved in personal health management continue to increase in complexity.<sup>139</sup> Researchers are applying methods from a wide range of fields—from behavioral psychology to economics—to explore

factors that influence active participation at various points across the care continuum. For example, a framework developed in partnership with patients describes ways that patients and families can be involved in healthcare decisions in multiple areas, including at the point-of-care, organizational, and policy levels.<sup>140</sup> Further research is needed to understand factors influencing whether and to what extent patients and families participate in healthcare (see *Patient Engagement: Key Knowledge Needs* on page 58). Solutions for addressing knowledge, skill, and technological barriers, among others, should be explored.<sup>44,59,140,141</sup> An enhanced evidence base could inform development of improved tools and strategies for achieving and sustaining engagement, and, ultimately, improving cancer-related and other health outcomes in line with the needs and preferences of patients and families.

### Patient Engagement: Key Knowledge Needs

- Define full range of actions that individuals have the option to perform to achieve maximum benefit from healthcare.
- Identify factors, or combination of factors, that have greatest impact on patient engagement.
- Identify optimal, effective methods that organizations and policy makers can use to enhance opportunities for meaningful participation.
- Determine best practices for translating research findings into routine care in ways that benefit patients and healthcare providers.

Sources: Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff (Millwood)*. 2013;32(2):223-31; Center for Advancing Health. A new definition of patient engagement: what is engagement and why is it important? Washington (DC): CFAH; 2010. Available from: [http://www.cfah.org/pdfs/CFAH\\_Engagement\\_Behavior\\_Framework\\_current.pdf](http://www.cfah.org/pdfs/CFAH_Engagement_Behavior_Framework_current.pdf)

### 3. Develop approaches for using data from connected devices in meaningful ways to enhance clinical care.

Individuals increasingly are using wearable devices and smartphone apps to collect health-related data and help them reach personal health goals. These person-generated health data provide valuable insights into people's everyday lives—including factors that influence cancer risk and outcomes—and have potential to help healthcare providers deliver more patient-centered care. Among other things, personal devices can be used to gather patient-reported outcomes (e.g., symptom self-reporting), which can enhance quality of care.<sup>142-144</sup> However, additional research is needed to determine how to integrate person-generated health data collected by connected devices into clinical care. This includes research on ways to

monitor and manage symptoms of cancer patients and cancer survivors, a recommendation of the Cancer Moonshot Blue Ribbon Panel.<sup>6</sup> Devices and tools must be validated to ensure that they provide clinically useful information (see *Validating New Tools to Inform Chemotherapy Decisions* on page 59), and feasibility studies are needed to determine whether patients' use of connected devices in real-world settings yields meaningful data. Work also must be done to determine which devices, channels, and types of data are most relevant for various populations and situations. Researchers are beginning to explore this area (see *Using Person-Generated Data in Cancer Research* on page 52), but a broader array of studies is needed. Methodologies and tools also should be developed to ensure that the vast amounts of data collected are provided to healthcare providers and individuals in meaningful and actionable formats.

## Validating New Tools to Inform Chemotherapy Decisions

Individuals with cancer who are active are better able to tolerate and benefit from chemotherapy than are those who are sedentary. Currently, oncologists assess patients' activity levels and overall wellness by asking a set of defined questions during appointments, but there are drawbacks to this approach—it depends on patients' ability to remember, is subject to patient and physician bias, and does not capture how patients are doing outside the clinic. Wearable sensors that collect information about patients' daily activities may provide more accurate and comprehensive insights. Oncologists at Cedars-Sinai Samuel Oschin Comprehensive Cancer Institute are conducting a validation study to determine whether Fitbits can provide useful information on patients with cancer. To do this, Fitbit data will be compared with data from traditional functional status assessment tools and correlated with patient toxicity and survival outcomes.

**Sources:** Cedars-Sinai trial uses Fitbit to better understand patients' functional status. HemOnc today [Internet]. 2016 Mar 15 [cited 2016 Aug 9]. Available from: <http://www.healio.com/hematology-oncology/breast-cancer/news/online/%7B24968163-c464-485a-9b88-068959cd78fc%7D/cedars-sinai-trial-uses-fitbit-to-better-understand-patients-functional-status>; Shinde AM, Gresham GK, Hendifar AE, Tuli R, Spiegel B, Figlin RA. Biosensors to assess performance status in cancer (BioAPS Study). J Clin Oncol (Meeting Abstracts). 2016;34(15):TPS6631.



# CONCLUSIONS

Connected health is creating significant new opportunities to improve the quality and experience of health and healthcare in the United States and around the world. Cancer—with its complex biology, multispecialty care teams, transitions between treatment phases, and profound impact on the lives of patients and families—is an area of healthcare likely to benefit especially from improved coordination, communication, information access, and health behavior change facilitated by connected health. The capacity to share and integrate data also has the potential to expedite scientific discovery, enabling identification and development of strategies to more effectively prevent and treat cancers.

Technologies with potential to support connected health have been adopted widely by individuals, healthcare providers, healthcare organizations, researchers, and other National Cancer Program stakeholders. These technologies have yielded some positive results, but the full vision of connected health for cancer has not yet been achieved. Technological and cultural barriers to information sharing persist, and apps and tools intended to support individuals and providers often fall short. **The challenges to connected health are considerable, but they can be overcome.** While technologies play a fundamental role in connected health, the actions recommended by the President's Cancer Panel in this report reflect the Panel's view that a clear and unwavering focus on the following guiding principles is even more important.

**People, not technologies, must be at the center of connected health for cancer.** The promise of connected health will be realized only if technologies are designed and implemented to meet the needs, preferences, and values of *people*—healthy individuals, patients, caregivers, healthcare delivery team members, and others. Ideally, technologies will be seamlessly embedded into people's lives, providing access to information, supporting engagement, and bolstering productivity without imposing additional burden or causing frustration. The opportunity to participate in connected health must be available to *everyone*, regardless of income, education, race, or geography. Uneven dissemination of technology, as has been the case to date, could exacerbate existing inequities in health and health outcomes in the United States. Extraordinary efforts are needed to assure that the benefits of connected health extend to all populations.

**Timely access to data is imperative.** Everyone involved in an individual's care—the person, designated caregivers, and all healthcare providers—must have timely access to data in meaningful and usable formats. Currently, lack of interoperability among health IT systems impedes the effective and efficient flow and use of health information. Barriers to interoperability must be overcome, and individuals and designated caregivers must be provided the means to access and share their information.

**A culture of collaboration will accelerate progress.** Overcoming technical barriers to information exchange is critical but is insufficient. Providers, healthcare organizations, researchers, and other stakeholders should collaborate and freely share clinical and research data to support patient-centered clinical care and drive discovery within the bounds of privacy rules. Patients and members of the public should be engaged as important partners in their care and in cancer research, and encouraged to provide input on research priorities as well as contribute data.

The challenges facing connected health cannot be addressed by any single organization or agency. The President's Cancer Panel agrees with Vice President Biden that progress in cancer can be accelerated if collaboration becomes the norm. **The Panel urges all stakeholders—health IT developers, healthcare organizations, healthcare providers, researchers, government agencies, and individuals—to collaborate in using connected health**

**to reduce the burden of cancer through prevention and improve the experience of cancer care for patients and providers.** In the end, the purpose of connected health is to improve knowledge, engagement, processes, and quality of cancer care, and, thereby, to save lives and improve quality of life for millions of people living with cancer.

“[The fight against cancer] requires a lot more openness. Open data, open collaboration, and above all, open minds.”

— Vice President Joseph Biden, June 6, 2016, Chicago, IL



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# APPENDIX A: Workshop Dates and Roster of Participants

MEETING DATE	LOCATION
December 11, 2014	Cambridge, MA
March 26, 2015	San Francisco, CA
July 9, 2015	Chicago, IL

MEETING PARTICIPANTS	AFFILIATIONS
David K. Ahern, PhD	National Cancer Institute
Neeraj K. Arora, PhD	Patient-Centered Outcomes Research Institute
Ethan Basch, MD	University of North Carolina, Chapel Hill
Donald M. Berwick, MD, MPP, FRCP*	Institute for Healthcare Improvement
Christopher Boone, PhD	Health Data Consortium
Wen-ying Sylvia Chou, PhD, MPH	National Cancer Institute
Heather Cooper Ortner	Dr. Susan Love Research Foundation
Robert T. Croyle, PhD	National Cancer Institute
Marcia R. Cruz-Correa, MD, PhD	University of Puerto Rico Comprehensive Cancer Center
Gabriel Eichler, PhD	PatientsLikeMe
Karen Emmons, PhD	Kaiser Foundation Research Institute
Joshua Feast, MBA	Cogito Health
Janet Freeman-Daily, MS, ENG	Addario Lung Cancer Foundation
Stephen H. Friend, MD, PhD	Sage Bionetworks
Gilles J. Frydman	Smart Patients
M. Christopher Gibbons, MD, MPH	Johns Hopkins University
Thomas Goetz, MPH	Iodine
Sarah Greene, MPH	Patient-Centered Outcomes Research Institute
David Gustafson, PhD	University of Wisconsin-Madison
Hill Harper, JD	President's Cancer Panel Author, Actor, and Philanthropist
Bradford W. Hesse, PhD	National Cancer Institute
Matthew Holt, MS	Health 2.0
Kamal Jethwani, PhD, MPH	Partners Healthcare
Warren A. Kibbe, PhD	National Cancer Institute

## PRESIDENT'S CANCER PANEL

Katherine Kim, PhD, MPH, MBA	University of California, Davis
George Komatsoulis, PhD	National Center for Biotechnology Information
Joseph C. Kvedar, MD	Massachusetts General Hospital Harvard Medical School
Kenneth D. Mandl, MD, MPH	Boston Children's Hospital Harvard Medical School
Thomas A. Mason, MD	Office of the National Coordinator for Health Information Technology
Blackford Middleton, MD, MPH, MSc	Vanderbilt University School of Medicine
Judy Murphy, RN, FACMI, FHIMSS, FAAN	IBM Healthcare
Elizabeth D. Mynatt, PhD	Institute for People and Technology
Wendy Nilsen, PhD	National Institutes of Health National Science Foundation
Olufunmilayo "Funmi" I. Olopade, MD	The University of Chicago
Aydogan Ozcan, PhD	University of California, Los Angeles
Corrie Painter, PhD	Broad Institute Angiosarcoma Awareness
Kevin Patrick, MD, MS	University of California, San Diego The Qualcomm Institute/Calit2
Rosalind W. Picard, ScD	Massachusetts Institute of Technology Media Lab
Ruth Rechis, PhD	LIVESTRONG Foundation
Barbara K. Rimer, DrPH	President's Cancer Panel University of North Carolina Gillings School of Global Public Health
Abby B. Sandler, PhD	President's Cancer Panel National Cancer Institute
Urmimala Sarkar, MD, MPH	University of California, San Francisco
Richard L. Schilsky, MD	American Society of Clinical Oncology
Nirav R. Shah, MD	Kaiser Permanente Southern California
Erin Siminerio, MPH	U.S. Department of Health and Human Services
Paul Tarini, MA	Robert Wood Johnson Foundation
Stacey Tinianov	Community Engagement & Patient Advocacy Consultant
Emily S. Van Laar, MS	WebMD/Medscape
Kasisomayajula "Vish" Viswanath, PhD	Harvard School of Public Health Dana-Farber Cancer Institute
John T. Wald, MD	Mayo Clinic
Owen N. Witte, MD	President's Cancer Panel University of California, Los Angeles

\*Dr. Berwick was not in attendance but participated via prerecorded presentation.

# APPENDIX B: President's Cancer Panel

## Action Items and Responsible Stakeholders

ACTION ITEMS	RESPONSIBLE STAKEHOLDER(S)
<b>Objective 1: Enable interoperability among institutions and individuals that support care delivery across the cancer continuum, from prevention through treatment, survivorship, and end-of-life care.</b>	
<b>Action Item 1.1: Health IT stakeholder groups should continue to collaborate to overcome policy and technical barriers to a nationwide, interoperable health IT system.</b>	Government agencies Healthcare systems Healthcare providers Standards development organizations Public- and private-sector health IT developers
<b>Action Item 1.2: Technical standards for information related to cancer care across the continuum should be developed, tested, disseminated, and adopted.</b>	ASCO Standards development organizations Health IT vendors Healthcare organizations ONC
<b>Action Item 1.3: Standard, open API platforms should be developed and used to facilitate development of cancer-related apps.</b>	ONC Public- and private-sector health IT developers
<b>Objective 2: Enable individuals to manage their health information and participate in their care across the cancer continuum.</b>	
<b>Action Item 2.1: Develop and validate interfaces and tools that support individuals' engagement in their care across the cancer continuum.</b>	Healthcare organizations Public- and private-sector health IT developers Public and private research funding organizations Patient advocacy organizations
<b>Action Item 2.2: Organizations should develop processes that enable individuals to flag perceived errors in their medical records and ensure that responses are provided and appropriate changes are made in a timely manner.</b>	Healthcare organizations Public- and private-sector health IT developers
<b>Action Item 2.3: Create tools and services that help individuals identify cancer-related clinical trials appropriate for their particular situations.</b>	Research institutions NIH/NCI Public- and private-sector health IT developers Patient advocacy organizations
<b>Objective 3: Ensure that federal programs and health IT tools support the oncology workforce as it delivers care.</b>	
<b>Action Item 3.1: Federal incentive programs should promote use of health IT to enhance provider delivery of high-quality, patient-centered care.</b>	ONC CMS
<b>Action Item 3.2: EHR vendors and healthcare organizations should employ human-centered design principles to ensure that EHR interfaces are intuitive and aligned with providers' workflows.</b>	Public- and private-sector health IT developers Healthcare organizations

<b>Action Item 3.3: Develop and test tools and interfaces, including apps, tailored to needs of the oncology workforce.</b>	Public and private research funding organizations Public- and private-sector health IT developers Healthcare organizations Professional organizations
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**Objective 4: Facilitate health information access and sharing by ensuring adequate Internet access.**

<b>Action Item 4.1: Support initiatives and programs to ensure that everyone in the United States has adequate Internet access if so desired.</b>	FCC Internet service providers Nonprofit organizations
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<b>Action Item 4.2: Support initiatives and programs to ensure adequate Internet access for all healthcare providers and organizations.</b>	FCC Public and private stakeholders
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**Objective 5: Facilitate data sharing and integration to improve care, enhance surveillance, and advance research.**

<b>Action Item 5.1: Use learning healthcare systems to support continuous improvement in care across the cancer continuum.</b>	ASCO Healthcare organizations ONC
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<b>Action Item 5.2: Use health information technologies to enhance cancer surveillance.</b>	ONC NCI SEER CDC NPCR State cancer registries Public- and private-sector health IT developers
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<b>Action Item 5.3: Integrate data from various sources to create knowledge networks for cancer research.</b>	NIH/NCI Patient-driven knowledge networks Other public and private stakeholders
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**High-Priority Research to Advance Connected Health for Cancer**

<b>1. Improve understanding of how connected health can enable effective teamwork in healthcare.</b>	NIH/NCI CDC
<b>2. Identify strategies to enhance individuals' engagement in their healthcare.</b>	PCORI Healthcare organizations Professional organizations Patient advocacy organizations Research institutions Other public and private research organizations
<b>3. Develop approaches for using data from connected devices in meaningful ways to enhance clinical care.</b>	

**Note:** ASCO = American Society of Clinical Oncology; CDC = Centers for Disease Control and Prevention; CMS = Centers for Medicare & Medicaid Services; FCC = Federal Communications Commission; NCI = National Cancer Institute; NIH = National Institutes of Health; NPCR = National Program of Cancer Registries; ONC = Office of the National Coordinator for Health Information Technology; PCORI = Patient-Centered Outcomes Research Institute; SEER = Surveillance, Epidemiology, and End Results Program

## APPENDIX C: Acronyms

ACRONYM	DEFINITION
API	Application programming interface
APOLLO	Applied Proteogenomics Organizational Learning and Outcomes Network
ASCO	American Society of Clinical Oncology
BWEL	Breast Cancer Weight Loss study
CancerLinQ	Cancer Learning Intelligence Network for Quality
CDC	Centers for Disease Control and Prevention
CHIP	Children's Health Insurance Program
CMS	Centers for Medicare & Medicaid Services
COTPS	Clinical Oncology Treatment Plan and Summary
EHR	Electronic health record
FCC	Federal Communications Commission
FHIR	Fast Healthcare Interoperability Resources
GDC	Genomic Data Commons
HIPAA	Health Insurance Portability and Accountability Act
HITECH	Health Information Technology for Economic and Clinical Health
ICISS	Integrated Cancer Information and Surveillance System
IOM	Institute of Medicine
IT	Information technology
MACRA	Medicare Access and CHIP Reauthorization Act of 2015
NCI	National Cancer Institute
NIH	National Institutes of Health
NLP	Natural language processing
NPCR	National Program of Cancer Registries
ONC	Office of the National Coordinator for Health Information Technology
OPeN	Oncology Precision Network
ORIEN	Oncology Research Information Exchange Network
PCM	Precision Cancer Medicine
PCORI	Patient-Centered Outcomes Research Institute
PMI	Precision Medicine Initiative
SEER	Surveillance, Epidemiology, and End Results Program
SMART	Substitutable Medical Applications and Reusable Technology
TARGET	Therapeutically Applicable Research to Generate Effective Treatments

