

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



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

Executive Summary



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 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.

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

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.