ENHANCING PATIENT NAVIGATION WITH TECHNOLOGY TO IMPROVE EQUITY IN CANCER CARE

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

The President's Cancer Panel

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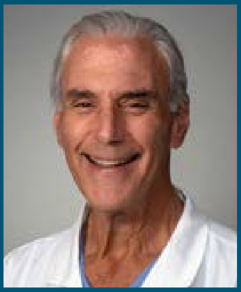

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This report is submitted to the President of the United States in fulfillment of the obligations of the President's Cancer Panel to appraise the National Cancer Program as established in accordance with the National Cancer Act of 1971 (P.L. 92-218), 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 President Biden,

We are deeply grateful for your and Dr. Biden's steadfast commitment to end cancer as we know it and for the hope you have imparted to the cancer community. Through the Cancer Moonshot and other efforts, your leadership has served as a powerful catalyst in improving outcomes through advances in cancer care and research.

Unfortunately, disparities in cancer care persist, and many have been increasing. Patients, including individuals from under-resourced and marginalized communities, continue to experience dangerous delays in cancer treatment, struggle with unmet social needs, and face decisions about their care without support. This must change.

Patient navigation is an evidence-based approach to improving health equity by supporting patients' social and care needs so that they can focus on their health. Your effort to expand access to patient-centered, high-quality care by allowing the Centers for Medicare & Medicaid Services to pay for navigation services for cancer and other serious illnesses is an important step, but there is more work to do to ensure that we reach all cancer patients in need of support.

In late 2023, we convened a series of meetings to explore opportunities for technology to support patient navigation. **We concluded that technology, when responsibly used, holds promise to extend the reach of navigation resources to empower patients and enable navigators and other care team members to work more efficiently so they can focus on the most important part of their jobs—directly caring for their patients.** However, this potential hinges on the ability of patients, navigators, and care teams to access and use the technology they need. The recent decision to allow funding for the Affordable Connectivity Program to lapse has left millions of low-income Americans with limited or no access to digital healthcare platforms such as telehealth appointments and patient portals. Sustained federal government support for broadband subsidies and infrastructure is crucial to expanding the reach of navigation using technology. We must also do a better job protecting the health information of the American people through cohesive laws and regulations that reflect the modern technology landscape. In addition, it is critical that we prioritize interoperability so that patients and their care teams have access to all of the information they need, whenever they need it.

This report outlines four priorities and our recommendations for how stakeholders from multiple sectors can support the effective and responsible use of technology to extend the reach of cancer patient navigation and improve the delivery of high-quality cancer care to all patients throughout their cancer journey.

Mr. President, your compassion and unwavering support have bolstered the entire cancer community; however, there is more work to do. Too many cancer patients and their families are left without support at a time when they need it most. This has led to disparities in cancer care and outcomes, many of which have been exacerbated by the COVID-19 pandemic. We hope that you and the rest of the country will join us to create a future in which every patient has access to the care and resources they deserve.

Sincerely,

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Contents

Executive Summary

Despite advances in cancer screening, detection, diagnosis, and management, many patients face challenges in accessing patient-centered, high-quality care in the United States due to systemic, cultural, and individual barriers. One evidence-based method for overcoming these obstacles is patient navigation, which aims to improve cancer outcomes and equity by reducing barriers and facilitating patients' access to care.

In late 2023, the President's Cancer Panel (the Panel) held a series of meetings on opportunities to enhance patient navigation with technology to improve equity in cancer care. The Panel concluded that health technology provides both new solutions and new challenges and that healthcare organizations, policy, and research must keep pace with technology's rapid advancement and adoption in order to minimize cancer disparities and improve health outcomes for all.

PART I. Achieving Equity in Cancer Care: The Need for Navigation and the Promise of Technology

The burden of cancer does not fall equally across all segments of the U.S. population. Some demographic groups—particularly people of color; those living in rural areas; those with limited educational attainment or economic resources; lesbian, gay, bisexual, and transgender people; and those with disabilities—experience disproportionate rates of poor health and worse outcomes. Yet despite the evidence supporting its effectiveness in improving equity, patient navigation does not reach all patients who would benefit from it. Technological tools present one possible path to filling these gaps. Technology also has the potential to streamline cancer patient navigation and improve outcomes. The barriers to and risks of using technology to enhance cancer patient navigation are complex and are outlined in more detail in the priority area descriptions below.

PART II. Taking Action to Improve Equity with Technology-Supported Navigation

In this report, the Panel identifies four priorities and related recommendations regarding the development and use of technology for cancer patient navigation. Implementation of these recommendations should align with two foundational values: first, that technology should be used to augment, not replace, human interaction; and second, that access to or use of technology should not be a requirement for accessing high-quality cancer care and patient navigation.

PRIORITY 1

Use Technology to Support Navigation Activities to Achieve Equitable Outcomes for People with Cancer

Navigation programs that spend more direct time with patients or with care team members on behalf of patients (as opposed to working in electronic health records [EHRs]) are more effective at improving access to timely care. Technology can help automate certain aspects of navigation and/or increase the efficiency of navigation processes so that care teams, including navigators, can spend more of their time caring for and interacting with patients.

Recommendation 1.1: Develop and implement tools that facilitate efficient, patient-centered coordination of cancer care.

Technology can help healthcare organizations address both systems and individual barriers to the delivery of timely, high-quality care. EHR vendors and healthcare organizations should assess the choice architecture of their EHR systems and implement and evaluate changes to improve workflow and delivery of care. Automatic referrals to appropriate providers and prompts for follow-up with patients who miss or are behind on recommended care could help ensure that no patient falls through the cracks. Technology in the form of automated tools embedded within EHRs could help more efficiently identify cancer patients who would benefit most from additional resources and services and ensure that those connections are made. Healthcare organizations should invest in and implement these tools and ensure that patients in need are referred to navigation services.

Recommendation 1.2: Develop and implement technologies to help navigators connect cancer patients with organizational and local resources.

Navigators are skilled at determining patients' needs and how to meet them, yet this knowledge is often not shared in any centralized way. Healthcare organizations should establish navigator resource dashboards within EHR systems that allow navigators to link patients with resources that address their unique clinical and social needs. These dashboards should include a living and searchable database of institutional and local resources. This type of tool could significantly reduce administrative burden and streamline referrals, allowing navigators to spend more time directly supporting patients.

Recommendation 1.3: Develop and implement tools that provide vetted, personalized cancer-related information for patients and caregivers.

Patients should be able to easily conduct targeted searches and find results relevant to their specific diagnosis, treatment plan, and circumstances. This could be achieved through the creation of vetted search platforms; such tools would be even more powerful and precise if they were integrated with a patient's own EHR data. Technology can also link patients with resources to meet nonclinical needs that arise over the course of their cancer diagnosis and treatment. Technology developers, advocacy organizations, and research funding organizations should invest in technology tools—such as patient-facing apps and decision support tools—that empower patients to navigate their cancer journey.

PRIORITY 2

Ensure Equitable Patient Access to Technology That Supports Cancer Navigation

The communities most likely to experience health disparities are often also the ones with the least access to technology, including devices and broadband internet. These disparities occur at both the individual and collective levels and can limit patients' access to care. The government approach to filling these gaps is complex and dispersed across numerous agencies and programs at the state and federal levels.

Recommendation 2.1: Provide sustainable funding for federal programs that facilitate access to broadband internet.

Ensuring equitable access to broadband internet will require both short-term and long-term funding mechanisms. The Panel has identified two actions to support this goal.

The Federal Communications Commission's (FCC's) Affordable Connectivity Program (ACP) provided crucial financial support to help households afford internet access, but funding for this program concluded in May 2024. Bipartisan efforts to renew the program have stalled, leaving millions of Americans with limited or no digital access to healthcare, work, school, and benefits. The Panel recommends that Congress and the President renew funding for the ACP, with the understanding that a longer-term mechanism will be required to provide ongoing funds.

The Universal Service Fund, also overseen by the FCC, enhances telecommunication access in low-income areas and aims to deliver service where it is needed most. Digital inclusion experts and the bipartisan Universal Service Fund Working Group in Congress are advocating for the modernization of this program to reflect the ways Americans use telecommunications today. The Panel urges continued work by the Universal Service Fund Working Group and recommends that reformation of the Fund include ongoing support for equitable broadband internet access through the ACP as well as sustainable funding for existing programs.

Recommendation 2.2: Increase patient access to devices and private space through community sites to facilitate access to telehealth appointments.

Patients need internet-connected devices and private, secure settings to comfortably and effectively access telehealth appointments, patient portals, and health information. A practical and relatively low-lift solution to this need is to create dedicated telehealth spaces within public places in the community. The Panel encourages continued support of telehealth access efforts in public libraries and other community settings, including through local, state, and federal funding. States and territories should make telehealth access a priority as they implement their Broadband Equity, Access, and Deployment (BEAD) Program plans in the coming years.

PRIORITY 3

Promote Responsible Development and Use of Technology to Support Navigation

Technology does not automatically lead to increased efficiency or improved outcomes. Poorly designed and implemented health technology solutions can result in frustration, wasted resources, diminished trust, and even serious harm through medical errors or exacerbation of health disparities. Consensus-based frameworks are needed to ensure that the technologies used for cancer patient navigation are developed and used in ways that serve, protect, and build trust with patients. All frameworks and guidelines should adhere to a set of core principles, including:

- A people-first approach
- Equity
- User-centered design
- Effectiveness and validity
- Use of high-quality source data
- Transparency
- Privacy
- Interoperability
- Ongoing assessment and improvement

Recommendation 3.1: Adhere to core principles for responsible development and use of technologies that support cancer patient navigation.

All organizations that develop and use technology for cancer patient navigation should adhere to the core principles for navigation technology and use to ensure optimal benefit and return on investment. Organizations that purchase or fund development of technology for cancer patient navigation must take the lead in ensuring that technology is responsibly developed and implemented. Healthcare organizations should establish clear and binding expectations that all products purchased from or developed in partnership with third parties be responsibly developed, implemented, and assessed. Research funding organizations should include core principle requirements in the terms of award for any grant that involves development of a technology tool for patient navigation.

Recommendation 3.2: Support research to ensure that technology to support navigation achieves its goals.

Research is needed to explore new types of technology and new applications of existing technology that could be used to support navigation. Research funding organizations should provide funding for the development and testing of patient navigation technologies with a focus on tools that will address health disparities. Implementation research is also needed to determine the best ways to implement navigation-supporting technologies in real-world settings. The Agency for Healthcare Research and Quality (AHRQ) Digital Healthcare Research Program—which aims to produce and disseminate evidence about how the evolving digital healthcare ecosystem can best advance the quality, safety, and effectiveness of healthcare for patients and their families—is well suited to conduct this research. The Panel encourages AHRQ to assess technologies used by cancer patient navigators and care teams as well as those used by patients and caregivers.

Recommendation 3.3: Incorporate technology knowledge and skills into patient navigator training and core competencies.

The potential of technology-based tools for navigation can only be realized if navigation professionals understand and feel comfortable with using these tools. Navigator training programs should also incorporate learning objectives so that navigators understand how to use technology effectively and responsibly. As navigation technologies become more commonplace, digital skills should be included among oncology navigator core competencies such as those developed by the National Navigation Roundtable and Professional Oncology Navigation Task Force. Healthcare organizations must provide training for their navigators on any technology tool that is implemented within their system.

PRIORITY 4

Maintain Privacy and Security While Facilitating Data Sharing to Support Cancer Patient Navigation

Effective cancer care delivery depends on the timely exchange of patient health data. At the same time, sensitive health information must be kept both private and secure. In an ideal world, data sharing would protect patient information without impeding its access and use by appropriate parties, including patients themselves. To create a seamless workflow for cancer patient navigation, patients and care teams—including navigators—need access to different types of data from different sources.

Recommendation 4.1: Improve and incentivize interoperability to enable portability of patient data across health IT platforms and systems in order to improve navigation.

The need for interoperability in health information technology has been a topic of discussion in the cancer community for some time. The federal government has made significant progress toward this aim, but there is significant work still to do. Continued progress toward interoperability and the seamless and secure exchange of health data to support cancer patient navigation and care will depend not only on regulations and guidance but also on cultural shifts within individual institutions and across the healthcare industry. The Panel acknowledges the many strides taken toward interoperability to date and encourages continued progress at the federal, industry, and health-system levels. Future efforts should include targeted investments to support participation of small practices in health information exchanges.

Recommendation 4.2: Evaluate existing privacy and security regulations and laws and identify opportunities for a national legal framework to protect patients while fostering technological innovation to support patient navigation.

The technological landscape has changed significantly since the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act were enacted; for example, more than half of U.S. adults report having used a mobile health application within the past 12 months. Although these apps generate, store, and use individuals' health data, in most cases they are not considered covered entities or business associates under HIPAA and therefore are not subject to HIPAA standards of privacy and security.

There have been efforts to address these limitations and to protect the large and growing body of health data that falls outside the purview of HIPAA, and the federal government is working to address this gap from multiple perspectives. The Panel encourages continued discussion on this topic within and between all branches of the federal government. Mechanisms should be explored to protect patient data without obstructing data sharing and integration that support cancer care and research. The Panel recommends commissioning the National Academies of Sciences, Engineering, and Medicine to evaluate the current regulatory landscape and provide guidance to legislators on next steps to improve policies to better serve patients.

PART III. Conclusions

Patient navigation has been proven to reduce cancer disparities—a critical problem facing the National Cancer Program—by addressing individual and systemic barriers to accessing timely and high-quality care. In this report, the Panel identifies ways technology could be used to enhance evidence-based patient navigation for people with cancer.

The Panel has defined four priority areas and provided recommendations in each area to promote effective and appropriate use of technology for cancer navigation. These recommendations should be implemented in alignment with the following principles: first, that technology should augment, not replace, people; second, that technology must be responsibly developed and used; and third, that technology should help achieve equity, not exacerbate disparities.

Preface

The President's Cancer Panel (the 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 progress. 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.

A key theme across many of the Panel's prior meeting series and reports has been the importance of acknowledging and overcoming disparities in cancer risk, diagnosis, treatment, and outcomes among different populations in the United States. For its 2023 series of meetings, the Panel continued its focus on inequities, this time through the lens of cancer patient navigation and technology. The Panel convened three public meetings to gather information from many stakeholders in this area, including patient advocates, community health organizations, professional associations, patient navigators, academia, technology innovators, government, and healthcare. Meeting summaries and recordings are available on the Panel website (https://prescancerpanel.cancer.gov).

Patient navigation is known to reduce cancer health disparities and help patients access care. The Panel applauds ongoing work by many organizations—including the National Navigation Roundtable, Academy of Oncology Nurse & Patient Navigators, Oncology Nursing Society, and others—to advance patient navigation programs and services through research, creation of best practices, workforce development, and policy. The Panel urges policymakers and healthcare organizations to expand access to navigation services for cancer and other complex health situations, while recognizing that resource constraints prevent offering comprehensive navigation services to all patients.

Rapid advancements in technology have ushered in a new era of digital and connected health. The Panel sees exciting opportunities for technology to extend the reach of patient navigation, support cancer patients, and reduce health disparities. However, in some cases, the rapid proliferation and adoption of new technologies has outpaced federal guidance and equitable access, creating gaps that can interfere with care, exacerbate inequities, and leave many patients behind.

In this report, the Panel presents principles, priorities, and recommendations to address these areas of need. The Panel urges all stakeholders—healthcare providers, cancer patient navigators, researchers, patient advocacy groups, healthcare organizations, government agencies, technology leaders, and others—to collaborate to ensure that health technologies enable better cancer care, advance health equity, and reduce the burden of cancer on patients, families, and their communities.

PART I

Achieving Equity in Cancer Care: The Need for Navigation and the Promise of Technology

Achieving Equity in Cancer Care: The Need for Navigation and the Promise of Technology

Disparities in Cancer Care Access and Outcomes

The burden of illness does not fall equally across all segments of the U.S. population. Some demographic groups—particularly people of color; those living in rural or remote areas; those with limited educational attainment or economic resources; lesbian, gay, bisexual, and transgender people; and those with disabilities—experience disproportionate rates of poor health and worse outcomes. Disparities such as these are evident in cancer.[1-6] Advances in cancer detection and treatment are not reaching these populations at the same rate as for those with greater socioeconomic privilege, resulting in higher rates of morbidity and mortality. Disabled women with breast cancer, for example, are less likely than nondisabled women to be offered standard treatment.[3] Black patients, people with lower education levels, and those living in rural areas also have higher cancer-related mortality rates than members of other groups.[1,7]

Improving Equity with Cancer Patient Navigation

Despite advances in cancer screening, detection, diagnosis, and management, many patients face challenges in accessing patient-centered, high-quality care in the United States due to systemic, cultural, and individual barriers.[1,7] Navigating the cancer care journey is burdensome for patients due to a complex and fragmented healthcare system, and many patients are left behind. Major issues include delays in care, unmet social support needs, financial toxicity, reactive symptom management, high acute care utilization, and misaligned end-of-life care. Each of these issues has a disproportionate impact on under-resourced communities and marginalized populations.[8]

Patient navigation is an evidence-based intervention that was developed specifically to address these inequities (Figure 1). Navigation can include one or more of a variety of services and activities such as coordinating multidisciplinary care across the cancer continuum, including referrals to clinical trials; identifying and addressing barriers to care; and providing health education. The aim of patient navigation is to reduce barriers and facilitate a patient's access to care by providing needed support services throughout the cancer journey. Each person's navigation needs are unique; some patients require very little to no intervention, while others may need more support.

The first patient navigation program in the United States was developed by former President's Cancer Panel Chair Dr. Harold Freeman in 1990.[9] Dr. Freeman's program focused on using navigation to increase the uptake of cancer screening and early detection in his Harlem, New York, community. The program's success inspired Dr. Freeman and others to expand the scope of patient navigation to encompass the entire cancer continuum.[10]

In the intervening decades, cancer patient navigation has consistently been demonstrated to improve outcomes; reduce disparities in cancer care; and lower costs for patients, healthcare organizations, and payors. Patients who receive navigation services have a shorter time to diagnosis and treatment, are more likely to complete their course of treatment, and report better understanding of their condition and the treatment process, as well as an overall higher quality of life.[9-11] However, patient navigation programs continue to face challenges (see *Cancer Patient Navigation: Building Sustainable Programs* on page 5).

The President's Cancer Panel (the Panel) recognizes that navigation is invaluable for cancer patients and their families and endorses efforts to expand access to these services. The Panel is encouraged by progress being made in patient navigation and urges continued energy and advocacy in this area. Ideally, all patients with cancer would have access to comprehensive navigation services; however, this is not realistic in the current healthcare landscape. There are not

Figure 1. Patient Navigation

EXAMPLES OF NAVIGATION ACTIVITIES

- Coordinating care
    - Connecting patients with providers
    - Providing appointment reminders
    - Matching patients with clinical trials
- Providing or connecting with resources to address:
    - Social needs
    - Psychosocial care
    - Financial support
- Providing health education

WHAT IS NAVIGATION?

Navigation is a **person-centered healthcare service delivery model** that aims to overcome individual and systemic barriers to accessing timely and quality cancer care.

WHO CAN PERFORM NAVIGATION?

- Patient navigators
- Community health workers
- Social workers
- Physicians
- Nurses
- Other members of the healthcare team

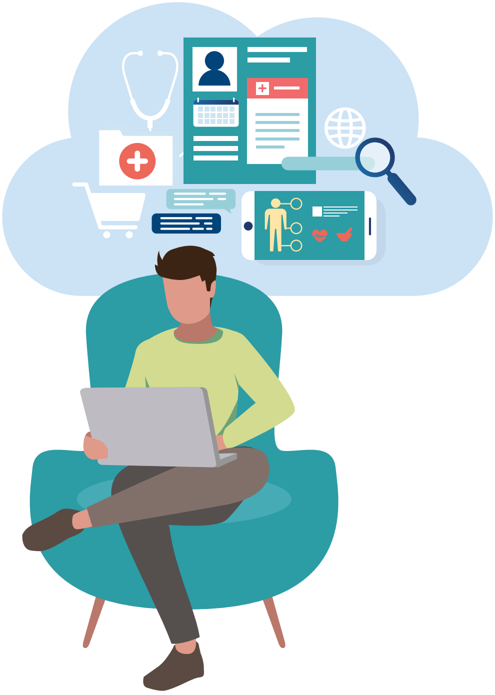
Cancer Patient Navigation: Building Sustainable Programs

Despite the many success stories, development and implementation of cancer patient navigation programs continue to be challenging for a variety of reasons. Cancer patient navigation programs and efforts across the country vary considerably in their structure, scale, target populations, and goals. This has made it difficult to standardize training and design studies that yield generalizable results. In addition, navigation programs have historically been supported with grant funding, which has undermined sustainability.

Several organizations are working to address these and other challenges and promote sustainable models for cancer patient navigation. The American Cancer Society National Navigation Roundtable, which was established in 2017, brings together more than 200 member organizations to advance navigation and promote health equity across the cancer continuum. In 2022, the Professional Oncology Navigation Task Force—a collaborative effort of professional organizations—released a set of oncology navigation standards that describes the qualifications, roles, and needs of clinical and nonclinical navigators. Multiple organizations have developed navigation training and credentialing programs to improve the knowledge and skills and increase the credibility of those performing navigation.

The federal government is working to make navigation more accessible for patients with cancer and other serious conditions by updating Medicare policy to allow reimbursement for navigation services and securing commitments from insurance companies and cancer centers to provide these services. This policy change is a step in the right direction; however, many stakeholders have expressed uncertainty about how to implement it. The Panel encourages the Centers for Medicare & Medicaid Services (CMS) to gather feedback on this policy and develop guidance so that it can be used effectively for its intended purpose—to help patients and families facing significant challenges.

Sources: Dwyer A, Wender R, Weltzien E, et al. Collective pursuit for equity in cancer care: The National Navigation Roundtable. Cancer. 2022;128 (13 Supp):2561-7. Available from: http://www.doi.org/10.1002/cncr.34162; The Professional Oncology Navigation Task Force. Oncology navigation standards of professional practice. Clin J Oncol Nurs. 2022;26(3):E14-E25. Available from: https://doi.org/10.1188/22.CJON.E14-E25; American Cancer Society. Leadership in oncology navigation [Internet]. Atlanta (GA): ACS; n.d. [cited 2024 June 18]. Available from: https://www.cancer.org/health-care-professionals/resources-for-professionals/patient-navigator-training.html; George Washington Cancer Center. Oncology patient navigator training: the fundamentals [Internet]. Washington (DC): The George Washington University School of Medicine and Health Sciences; 2024 [cited 2024 June 18]. Available from: https://cme.smhs.gwu.edu/gw-cancer-center-/content/oncology-patient-navigator-training-fundamentals; Centers for Medicare & Medicaid Services. CMS finalizes physician payment rule that advances health equity [Press Release]. Baltimore (MD): CMS; 2023 Nov 2. Available from: https://cms.gov/newsroom/press-releases/cms-finalizes-physician-payment-rule-advances-health-equity; The White House. Biden Cancer Moonshot announces commitments from leading health insurers and oncology providers to make navigation services accessible to more than 15 million Americans [Fact Sheet]. Washington (DC): The White House; 2024 Mar 8. Available from: https://www.whitehouse.gov/ostp/news-updates/2024/03/08/fact-sheet-biden-cancer-moonshot-announces-commitments-from-leading-health-insurers-and-oncology-providers-to-make-navigation-services-accessible-to-more-than-150-million-americans



enough resources or navigators to accomplish this even in high-resource settings, let alone in lower-resource settings in which navigation is even more critical.[11] Technology has the potential to support the professionals providing navigation services. If implemented thoughtfully, technological tools could extend the reach of limited navigation resources to more patients and help reach the goal of eliminating inequities in cancer care and outcomes.

There are many definitions of patient navigation. For the purposes of this report, the Panel is using the following definition:

> ***Navigation is a person-centered healthcare service delivery model that aims to overcome individual and systemic barriers to accessing timely and quality cancer care. Navigation may be carried out by various members of the healthcare team, including, but not limited to, patient navigators, community health workers, social workers, physicians, and nurses. Navigation may also be achieved through systems and resources that are not directly managed or delivered by a member of the healthcare team.***

Patient navigation is critical across the entire cancer continuum. Community-oriented outreach and support services, including those provided by community health workers (CHWs), were identified as an important priority for cancer screening and follow-up in the 2022 Panel report *Closing Gaps in Cancer Screening: Connecting People, Communities, and Systems to Improve Equity and Access.*[12] The Panel reaffirms its recommendation that navigation services be available for cancer screening; however, the current report focuses on navigation *after* screening, from the time of diagnosis through treatment and beyond.

Potential for Technology-Supported Navigation

Nearly every aspect of daily life in the 21st century is shaped by technology. Computers, mobile devices, and the internet have revolutionized how people work, learn, play, interact, and care for their homes, their families, and themselves.

Technological tools—from electronic health records (EHRs) to telemedicine platforms—are now an integral part of healthcare. For the purposes of this report, the term "technology" refers to digital health technologies, a subset of tools that use computing platforms, connectivity, and software to support health and healthcare. Integrating technology into healthcare can result in increased health-related quality of life, fewer emergency department visits, reduced length of hospital stays, and reduced treatment-related toxicities.[13-17]

Technology also has the potential to streamline cancer patient navigation and improve outcomes (Figure 2). Today, healthcare providers, navigation professionals, and patients rely on a patchwork of technologies to support the cancer journey. Meeting attendees listed the health technologies most commonly used for navigation today as EHRs, digital screening tools, and patient portals.[18] Many patients also are seeking out information and tools outside of the healthcare system, including direct-to-consumer products designed to help patients manage and track their care. Technology-savvy patients may use smartwatches and other wearable devices to monitor vital signs and activity and/or download mobile applications (apps) to log their diet, exercise, symptoms, and medications or seek

Figure 2. Technology for Navigation

Adapted with permission from a figure by Kingsley Ndoh.

health advice.[19] Over the last few years, some health systems have begun to integrate various types of artificial intelligence (AI) into their workflows (see *Artificial Intelligence to Support Patient Navigation: Opportunities and Concerns* on page 8).

Technology applications will undoubtedly continue to expand into additional areas of health and healthcare in the coming years. Areas of opportunity for technology to support navigation of cancer patients and their families range from patient education to improved data collection and sharing, clinical trial matching, and more. The barriers to and risks of using technology to enhance cancer patient navigation are complex and are outlined in more detail in the priority area descriptions below. During the meeting series, stakeholders agreed that broad and successful implementation of digital solutions will require acknowledging and addressing barriers at the organizational, care team, and patient levels, including resource limitations; lack of payment models for training and tools, including mobile apps; technology fatigue; gaps in technological and health literacy; and limited interoperability among data platforms.[18]

In this report, the President's Cancer Panel identifies four priorities and related recommendations to promote effective and responsible development and use of technology to support cancer patient navigation. Implementation of these recommendations will help extend the reach of patient navigation and improve the delivery of high-quality cancer care to all patients.

Artificial Intelligence to Support Patient Navigation: Opportunities and Concerns

Large Language Model (LLM): An LLM is a type of artificial intelligence that is trained on a large dataset to understand, summarize, translate, predict, and generate human language, enabling it to communicate and provide information in a way that mimics human interaction. One common example of an LLM is a customer service chatbot; another is OpenAI's ChatGPT.

Machine Learning (ML): ML is a subset of AI focused on the study and development of algorithms that can learn from data and improve autonomously (without additional programming). ML works by recognizing patterns in data to improve over time.

AI-based tools have exploded onto the scene over the past few years, and many sectors see the potential to integrate these tools into healthcare. AI has the potential to support some of the Panel's recommendations. For example, ML and deep learning could analyze large datasets—from EHRs, public databases, and other sources—to find new and better ways to predict which patients are most likely to need additional support throughout their cancer journey. Generative AI tools could help busy care teams by summarizing treatment plans (or other information) in language tailored to the needs of individual patients. They could support providers by creating draft responses to questions submitted via a patient portal. Chatbots may be able to guide patients through simple administrative tasks, such as appointment scheduling, or facilitate access to information through apps or care platforms. AI-guided web searches could help patients and caregivers find information and resources relevant to their situations. Many of these types of AI applications are already being pursued. Major EHR vendors are working to integrate provider- and patient-facing AI functionality into their software, and many cancer patients are undoubtedly already using large language models like ChatGPT to answer questions about their diagnosis and care.

However, excitement about the power of AI has been tempered by concerns about its limitations and potential harms. Algorithms are built by human beings and trained using data that humans have selected. While developers may consider themselves objective, their personal biases can and do influence how algorithms are built and trained, resulting in algorithms that perpetuate and magnify the discrimination held unconsciously by their creators. Training of AI algorithms on limited datasets—such as those from a single organization's EHR—can limit their generalizability. Latent bias can also develop in the case of adaptive AI algorithms that continue to be updated after deployment if ongoing learning is based on nonrepresentative patient populations. In addition, studies have found that LLMs are inconsistent in their responses to questions and often perpetuate race and gender bias. Some examples include:

- Training a diagnostic algorithm meant for all demographic groups exclusively on cases from a single hospital in a wealthy area where most patients are highly educated and have access to healthcare.
- Using only photographs of people with lighter skin while developing facial recognition software, leading to a higher error rate when identifying people with darker skin.

Algorithmic flaws in health settings have the potential to result in medical errors and inappropriate denials of care. The occurrence of AI "hallucinations"—content generated by an ML model that is not based on existing data and does not make sense—raises particular concern for patient-facing applications. The stakes of unintended consequences are high in cancer care, particularly when working with vulnerable populations. In addition, the use of AI is accompanied by a staggering, if hidden, environmental cost, further limiting resources in communities that already experience significant strain and health inequities. It is imperative that AI integration into healthcare be done thoughtfully and cautiously with a commitment to core principles of the responsible development and use of technology (see *Priority 3* and *Core Principles for Navigation Technology Development and Use* on page 26).

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PART II

Taking Action to Improve Equity with Technology-Supported Navigation

Taking Action to Improve Equity with Technology-Supported Navigation

Technology has potential to extend the reach of navigation to relieve the burden of cancer for patients, caregivers, and families and help eliminate inequities in care and outcomes. While the expansion of technology in healthcare is a near certainty, there is no guarantee that the full potential benefits of these tools will be realized. Technologies—particularly those that will be used to support direct patient care—must be developed and deployed with forethought and care to optimize benefit and avoid harm. In this report, the Panel identifies four priorities and related recommendations to promote effective and responsible development and use of technology for cancer patient navigation (Figure 3). All of these recommendations should be implemented in ways that align with the following foundational values:

- Technology should be used to augment patient navigation. It should not replace personal interactions or the people providing navigation services but, rather, should be applied in ways that allow more patients to be navigated more effectively and efficiently.
- Access to or use of technology should not be a requirement for accessing high-quality cancer care and patient navigation. Patients should always be able to opt out of technology without compromising their care.

Figure 3. President's Cancer Panel Priorities and Recommendations

USE TECHNOLOGY TO SUPPORT NAVIGATION AND ACHIEVE EQUITY

- Facilitate patient-centered care coordination.
- Link navigators and patients to resources.
- Inform and empower patients.

ENSURE EQUITABLE ACCESS TO TECHNOLOGY

- Fund federal programs for broadband access.
- Increase telehealth access in community places.

PROMOTE RESPONSIBLE DEVELOPMENT AND USE OF TECHNOLOGY

- Adhere to core principles.
- Support research to confirm goals are met.
- Ensure navigators have technology knowledge and skills.

MAINTAIN PRIVACY AND SECURITY WHILE PROMOTING DATA SHARING

- Improve and incentivize interoperability.
- Identify opportunities for a national legal framework.

PRIORITY 1

Use Technology to Support Navigation Activities to Achieve Equitable Outcomes for People with Cancer

Patients who have been diagnosed with cancer face innumerable challenges. These challenges may be due to personal circumstances, suboptimal systems, or both. The healthcare system and the organizations comprising it are complex, and this is particularly true for oncology care. Patients with cancer receive care from multiple types of providers—including their primary care providers, specialists, and other care team members—and sometimes through multiple healthcare organizations as they progress from a suspicious finding or symptom to diagnosis and treatment and into survivorship, palliative care, and/or end-of-life care.[20,21] This process requires frequent handoffs and integration of information from myriad tests, procedures, and appointments. These handoffs should be seamless, and all patients and members of their care teams should have accurate and complete information at their fingertips when they need it. Unfortunately, the U.S. healthcare system is fragmented. Despite the best intentions of cancer care teams to provide the best care to all of their patients, this fragmentation often results in unnecessary delays and inefficient delivery of care.

In addition to moving through cumbersome systems, patients face many personal obstacles, both medical and nonmedical. At each step of their cancer journey, they are presented with new information and treatment options, which can be confusing and overwhelming. Many of these treatments come with side effects that impact quality of life. The physical and emotional burden of cancer may make it difficult for patients to balance their care with other aspects of their lives, including work and family responsibilities. Many patients experience significant financial strain as they face high costs for care and reduced capacity to work, which may lead to housing and food insecurity.

These challenges, coupled with the labyrinthine nature of cancer care, create many vulnerable inflection points at which any barrier—administrative burden, socioeconomic obstacles, health or digital literacy needs, or lack of other forms of support—could result in losing a patient to follow-up or delays in life-saving care.[10] There often are institutional and community resources available to address patients' personal needs, but patients may not be aware of them or have the capacity to seek them out amidst the other demands of managing their disease and care. Some examples of these social supports include public housing, transportation (e.g., gas cards, taxis, van service), and food assistance; financial counseling and support; behavioral health services; and childcare, eldercare, or other family services.

Evidence suggests that navigation programs that spend more direct time with patients or with care team members on behalf of patients (as opposed to working in EHRs) are more effective at improving access to timely care.[22] Technology can help automate certain aspects of navigation and/or increase the efficiency of navigation processes so that care teams, including navigators, can spend more of their time caring for and interacting with patients. The Panel recommends using specific technologies to enhance navigation in the following three areas: coordinating cancer care, connecting patients with community and organizational resources, and informing patients and caregivers.

Recommendation 1.1: Develop and implement tools that facilitate efficient, patient-centered coordination of cancer care.

Technology can help healthcare organizations address both systems and individual barriers to the delivery of timely, high-quality care. Two key opportunities are: (1) increasing the efficiency of care delivery and coordination and (2) analyzing data in real time to identify patients most likely to benefit from additional support services.

Facilitate Efficient Workflow and Handoffs

In the early years of EHRs, there was hope that transitioning to digital systems would improve the safety and delivery of evidence-based care. While there have been successes, the design and implementation of effective EHR-based tools remain challenging.[23,24] Many clinical decision support systems have relied on alerts that must be resolved before clinicians can continue using the EHR. Overuse of these alerts has led to "alert fatigue." A systematic review in 2020 found that between 46% and 100% of these alerts are overridden, often appropriately, which undermines their effectiveness and leads to dissatisfaction with EHRs.[25]

Behavioral science experts have begun to promote changes in EHR choice architecture rather than interruptive alerts to encourage best practices and help reduce unnecessary delays in care. This approach aims to understand how people use systems, then change the way information and options are presented to make desirable behaviors easier. These noninterruptive nudges can include things like designating the optimal or most commonly selected options as preset defaults, making relevant information more visible, changing the range or composition of options, and reducing effort through use of automatic orders or referrals for guideline-concordant care.

What is a nudge?

In behavioral economics, the term "nudge" refers to any aspect of choice architecture that alters people's behavior in a predictable way without forbidding any options or significantly changing economic incentives. In healthcare, nudges can be used to increase the likelihood that care team members or patients will make choices aligned with evidence and best practices.

Source: Thaler RH, Sunstein CR. Nudge: improving decisions about health, wealth, and happiness. New Haven (CT): Yale University Press; 2008.

Timely handoffs between providers are of utmost importance throughout the cancer journey, including at the very beginning. Unfortunately, it sometimes takes months after a confirmed or suspected cancer diagnosis for patients to find an oncology team. This delay in care—which happens more commonly among vulnerable populations—can impact treatment outcomes and survival.[2] Nudges such as default conditional orders, in which the outcome of a screening or test can prompt an automated order for the next diagnostic step, can help make time-sensitive diagnostic workflows more efficient. An ongoing project at the University of Pennsylvania is testing whether this type of approach can reduce racial disparities in the time between an abnormal breast cancer screening result and biopsy.[26] Automatic referrals to appropriate providers and prompts for follow-up with patients who miss or are behind on recommended care could help ensure that no patient falls through the cracks.

EHR vendors and healthcare organizations should assess the choice architecture of their EHR systems and implement and evaluate changes to improve workflow and delivery of care. EHR vendors should integrate research-based design improvements—particularly those shown to increase health equity—into standard EHR systems so that all healthcare organizations benefit. Healthcare organizations should continually strive to identify opportunities to improve their health information technology (IT) interfaces to make it easier for care teams to deliver the best possible care to their patients. Research funding organizations such as the Agency for Healthcare Research and Quality (AHRQ) should support efforts to refine navigation-supporting technologies as part of their investments in digital healthcare and learning health systems (see *Recommendation 3.2*).

In addition to these nudges, technology—including, but not limited to, tools embedded in EHRs—could help providers identify the best physician or healthcare center to address the next step in their patients' cancer journey. This can often be a challenge for providers not embedded within large healthcare organizations and for providers whose patients have rare cancers or complicated health needs. **State medical boards, accreditation bodies (e.g., Commission on Cancer), and CMS should develop and maintain databases of oncology providers that can be searched based on location, specialty and subspecialty, and insurance accepted. These databases should be made available to EHR systems and third parties through application programming interfaces (APIs) so that they are easily accessible to providers in different settings, as well as to patients (see *Recommendation 1.3*).**

Using Technology to Improve Referrals to Patient Navigation Programs

Currently, referrals to navigation services often are based on conversations with care team members, including clinicians and patient navigators; distress screenings and other structured assessments; and manual review of EHRs by patient navigators and CHWs. These approaches are time- and labor-intensive, yet fail to reach many patients in need. A technology-based, systematic, evidence-based tool that identifies patients most in need and triggers an automated referral to a patient navigator could help prevent patients from falling through the cracks. Because each health system's patient population is unique, administrators should select approaches that best suit their community's needs and experience. The algorithms could take into account factors such as missed appointments, unmet care milestones, changes in insurance status, psychosocial distress, or other social determinants of health (SDOH). The information could also flow into equity dashboards (also called disparity dashboards), which capture and present real-time data on health disparities.

Once a referral is initiated, a tracking system and follow-up message could ensure that the patient and care team members complete the referral and close the loop. Assessments should occur periodically throughout patients' cancer journey, as their needs change over time. It is important to note that this digitized referral process would not preclude or replace interactions with human navigators; automated triage would simply reduce their workload, enabling these professionals to spend their time most efficiently with the patients who need it most.

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Use Analytics to Link Patients with Resources

To achieve cancer equity, care must be delivered equitably (as opposed to equally) to meet the needs of the individual patient. This is true of navigation services as well. Technology can help healthcare organizations analyze patient data to identify those who would benefit most from additional care or support services. Depending on the goal and inequities within a given community or health system, analyses could include clinical data, information on social determinants of health (SDOH) collected via screening tools, or other patient-reported outcomes. Analytical methods could range from simple filters to complex AI tools that predict need based on known risk factors or observed patterns of care. Regardless of the approach, all technology-based tools must follow guidelines for responsible development and use (see *Priority 3*).

Automated tools embedded within EHRs could help more efficiently identify cancer patients who would benefit most from additional resources and services and ensure that those connections are made. One key area of opportunity is triaging referrals to patient navigation services. **Healthcare organizations should invest in and implement tools to identify patients who would benefit most from navigation and ensure that these patients are referred to navigation services (see *Using Technology to Improve Referrals to Patient Navigation Programs* on page 16)**. Other areas of opportunity for automated tools include clinical trial matching and financial counseling referrals.[27]

Healthcare organizations need to make sure they have the data they need to conduct these assessments. In many cases, this includes information on SDOH. Many institutions use screening tools to monitor patient distress and identify unmet SDOH needs. The precise language and approach to capturing SDOH data vary by organization, community demographics, and location; this is fitting, as screenings should be tailored for the specific audience.[28] At the same time, it is important for all systems to capture a minimum common set of data elements for the purposes of consistency, interoperability, and research.

Patient-reported data may also be captured using outreach through portal messages or text messaging. Many patients who do not feel fluent with technology or who lack access to broadband internet (see *Priority 2*) are still comfortable sending and responding to text messages, making this an accessible format for short-form communications like well-being checks. This approach has its limitations: text messaging is not end-to-end secure, which may raise privacy concerns in the exchange of health information, and any data captured through text message must be manually integrated with EHR data and followed by action.[29]

Recommendation 1.2: Develop and implement technologies to help navigators connect cancer patients with organizational and local resources.

Patient navigators' time is at a premium, yet many professionals must dedicate hours each week to creating and maintaining an up-to-date portfolio of supportive resources for patients. Approaches to managing this information vary across and even within health systems, clinics, and institutions. In some locations, care teams collaborate to compile useful references and services; elsewhere, navigators keep their own lists of resources, often in a physical document like a binder or in a spreadsheet on their personal computers or devices. Navigators are skilled at determining patients' needs and how to meet them, yet this knowledge often is not shared in any centralized or consistent way. This is both inefficient, as it involves significant duplication of effort and use of navigators' time, and risky, as the departure of a single care team member could result in a great loss of institutional knowledge. The information also typically is stored in a separate location than other patient data, which may contribute to patients' falling through the cracks.

Healthcare organizations should establish navigator resource dashboards that allow navigators to link patients with appropriate and available resources that address their unique clinical and social needs. These dashboards should draw on the results of the EHR triage function outlined in Recommendation 1.1 to flag patients in need of navigation and include a living and searchable database of institutional and local resources. This type of tool could significantly reduce administrative burden and streamline referrals, allowing navigators to spend more time directly supporting patients. The resource dashboard should be integrated directly into the EHR. Healthcare organizations could leverage existing databases of local resources, such as Findhelp.org and Unite Us,[30,31] which already are used by many navigators and health systems. State departments of public health could also maintain databases of services. While the Panel does not specifically endorse any organization's product, incorporating an information resource of this kind into an EHR-connected navigator platform is an important next step.

Recommendation 1.3: Develop and implement tools that provide vetted, personalized cancer-related information for patients and caregivers.

Every stage of the cancer journey presents patients with new information and support needs, from understanding treatment options and managing side effects to exploring clinical trials and addressing SDOH needs. Internet searches open the door to virtually endless amounts of information, much of it inaccurate, out of date, or intended to sell a product. Patients may become overwhelmed by the task of sifting through pages and pages of information to find what they need, and even the savviest may be unable to distinguish which sources are trustworthy and up to date.

Technology has potential to facilitate access to evidence-based information and reliable resources through patient portals, trusted websites, and mobile health apps. From 2020 to 2022, more than 6 in 10 people who had recently been diagnosed with cancer were offered and accessed their EHRs, a significant increase from prior years.[32] Healthcare organizations should ensure that their patient portals provide information important to patients—such as treatment plans and test results—in plain language. Use of live chat or chatbots could help answer patient questions, including outside of office hours. Whenever possible, patient-facing information and resources should be available in patients' preferred language.

Many patients and caregivers look beyond their healthcare organizations for information and support. Patients should be able to conduct targeted searches easily and find results relevant to their specific diagnosis, treatment plan, and circumstances. This could be achieved through manual entry of terms into a vetted search platform; such tools would be even more powerful and precise if they were integrated with a patient's own EHR data (see *Recommendation 4.1*). This personalized information could also help explain treatment options and identify clinical trials for which the patient may be eligible. The information presented should be in plain language, although patients should be able to dig deeper, as desired, to find more detailed medical and scientific information on specific drugs, procedures, side effects and symptoms, and other

concerns. Importantly, patients should be able to find the information in their preferred language.

Technology can also link patients with resources to meet nonclinical needs that arise over the course of their cancer diagnosis and treatment. This could include connecting patients with peer support, behavioral health and social work professionals, and linkages to local services for help with transportation, housing, childcare, food, or financial assistance. Similar to the navigation resource dashboards described above, patient-facing tools and apps could include integrations with databases like Findhelp or Unite Us. They also could help connect patients to each other for peer-to-peer learning and support. For patients in active treatment, technology could incorporate features such as medication and appointment reminders and symptom trackers. In addition to helping patients manage their disease, these tools could also facilitate communication with care teams about patients' day-to-day experiences.

If technology can be used to help some patients answer questions or access resources on their own, navigators and other care team members will have additional time to focus on more complex issues and possibly serve more patients. Patient-facing technologies that provide information can also lead to more meaningful conversations with providers and support shared decision-making.

Technology developers, advocacy organizations, and research funding organizations should invest in technology tools—such as patient-facing apps and decision support tools—that empower patients to navigate their cancer journey. The Panel envisions a suite of tools that can serve a range of patient needs during different phases of their cancer experience. All health technology tools, especially those intended for use by patients, must adhere to principles for responsible development and use (see *Core Principles for Navigation Technology Development and Use* on page 26). Key among these principles is that tools should be easy to access and use through a variety of devices and platforms. It is also critical that patient-facing tools draw from trusted sources of information (e.g., National Cancer Institute [NCI], American Cancer Society [ACS]) and peer-reviewed clinical guidelines published by professional organizations and that they are updated regularly. Promising tools that meet many of these standards—including Outcomes4Me—are available and used today. However, additional investment and effort are needed to ensure that all patients with cancer have tools that can guide them along the cancer journey.

The **NCI Cancer Information Service** and the **American Cancer Society** provide patients with free, personalized support—including information on treatment options, clinical trials, support groups, social services, and more—via phone and live chat. Both NCI and ACS offer extensive information on their websites.

Outcomes4Me is a free app that aims to empower patients to make informed decisions about their care. Features include information on evidence-based treatment options, access to clinical trials, and tools for symptom tracking and management.

As an extension of cancer care, patient-facing navigation technologies should be free to patients. Currently, making these tools free to patients requires that development and maintenance costs be covered by philanthropic funds or commercial sponsors (e.g., pharmaceutical companies). Funding sources for tools must be clearly disclosed to make users aware of their potential influence on the content or perspective of the tool (e.g., potential conflicts of interest or bias). As the evidence base for patient-facing technologies grows (see *Recommendation 3.2*), the cost of these tools could be covered through insurance, including by CMS, either directly or as part of an oncology care model. CMS should consider supporting pilot programs to determine whether patient-facing technologies can increase care quality and health equity.

PRIORITY 2

Ensure Equitable Patient Access to Technology That Supports Cancer Navigation

The communities most likely to experience health disparities are often also the ones with the least access to technology;[33] these disparities occur at both the individual and collective levels. Many patients in under-resourced communities lack access to computing devices beyond smartphones, but even households that can afford the latest devices cannot use them without crucial infrastructure like broadband internet, the absence of which can limit access to patient portals, participation in telehealth appointments, and the use of other tools. Adults over the age of 65, Black people, people with lower income and education, and those in rural communities are the least likely to have broadband access at home.[34]

The government approach to filling these gaps is complex and dispersed across numerous agencies and programs, including the Internet for All initiative.[35] While these efforts are commendable, some crucial programs lack consistent funding and implementation and are currently failing to reach large segments of the population.

Another barrier to accessing navigation and other medical care is privacy. In many communities, large households are common. Sharing a home may make it difficult to keep telehealth appointments and make private phone or video calls. Household members may also share devices, making it challenging for a patient to consistently use a device to access care.[18]

Recommendation 2.1: Provide sustainable funding for federal programs that facilitate access to broadband internet.

Access to broadband internet is significantly correlated with improved health outcomes. A 2019 report by the Federal Communications Commission's (FCC's) Connect2Health Task Force found that broadband connectivity is a social determinant of health, akin to safe housing and clean air and water.[36] Because other SDOH such as education, job opportunities, and trainings are increasingly dependent on internet access, the Task Force deemed broadband connectivity a *super* determinant of health—a gateway to other activities that make a healthy life more possible.[37] Not surprisingly, limited broadband access is also linked to lower utilization of telehealth.[38]

Unfortunately, broadband internet access is currently out of reach for many Americans, particularly those in rural and inner-city communities.[34,39,40] This undermines health and makes it harder for people to take advantage of telehealth and other digital tools to access care. Ensuring equitable access to this crucial resource will require both short-term and long-term funding mechanisms. The Panel has identified two actions to support this goal.

Renew Funding for the Affordable Connectivity Program

The FCC's Affordable Connectivity Program (ACP) provided crucial financial support to help households afford internet access, but funding for this program concluded in May 2024.[41]

The ACP was funded as part of the Bipartisan Infrastructure Law and falls under the umbrella of the Internet for All initiative.[42] For years, the ACP provided eligible American households with a $30-per-month subsidy for high-speed internet service and a one-time subsidy of up to $100 for an internet-connected device.

The Program brought critical support to more than 23 million, or 1 in 6, households across the country (Figure 4).[43,44] In an FCC survey, 72% of respondents said they used the internet to schedule or attend telehealth appointments. Other top responses included looking for jobs, accessing government benefits, and doing schoolwork. In the months since funding for the ACP expired, these households have had to make difficult decisions. More than three-quarters of respondents to an FCC survey said the end of the ACP would either disrupt their internet access or end it entirely. Others said they would “take money from other bills” or “cut other basic expenses” like food and gas in order to pay for the internet.[45]

Bipartisan efforts to renew the Program have stalled, leaving millions of Americans with limited or no access to healthcare, work, school, and benefits.

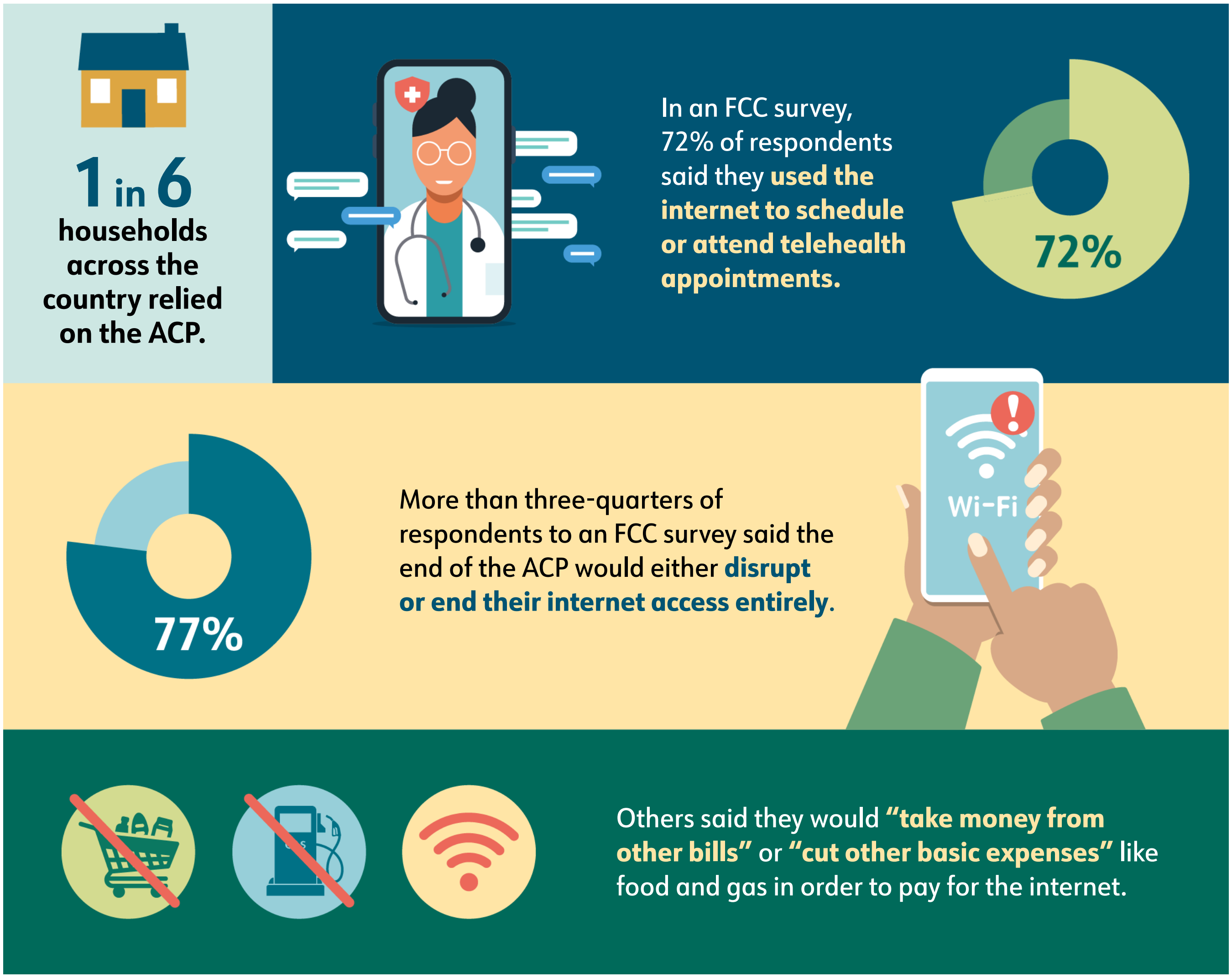
The Panel recommends that Congress and the President renew funding for the Affordable Connectivity Program, with the understanding that a longer-term mechanism will be required to provide ongoing funds.

Reform the Universal Service Fund

The Universal Service Fund (USF), also overseen by the FCC, enhances telecommunication access in low-income areas. The Fund was created in response to the Communications Act of 1934, which stated that all people in the United States shall have access to rapid, efficient, nationwide communications service with adequate facilities at reasonable charges, and then expanded with the Telecommunications Act of 1996.[46]

The USF collects fees from telecommunications carriers, including wireline and wireless telephone

Figure 4. Affordable Connectivity Program



1 in 6 households across the country relied on the ACP.

In an FCC survey, 72% of respondents said they **used the internet to schedule or attend telehealth appointments.**

More than three-quarters of respondents to an FCC survey said the end of the ACP would either **disrupt or end their internet access entirely**.

Others said they would **“take money from other bills”** or **“cut other basic expenses”** like food and gas in order to pay for the internet.

companies, and interconnected Voice over Internet Protocol providers, including cable companies that provide voice service. Carriers are required by law to make contributions to the USF, paying a percentage of their end-user interstate and international revenues. The USF disburses funds through the Universal Service Administrative Company, while the FCC ensures rule compliance.[47,48]

The FCC established four programs within the USF: the Connect America Fund, to build broadband infrastructure in rural areas; Lifeline, for low-income consumers, including initiatives to expand telephone service on Tribal lands; Schools and Libraries (E-Rate), which makes telecommunications and information services more affordable for eligible schools and libraries; and Rural Health Care. The Rural Health Care program provides important funding for telecommunications and broadband internet to healthcare providers, such as medical schools, hospitals, and community health centers, but not directly to patients or consumers.[46]

The USF was created before the digital age and, consequently, is both limited and outdated, yet the mechanism has great potential to deliver service where it is needed most. Today, digital inclusion experts and the bipartisan Universal Service Fund Working Group in Congress are advocating for the modernization of this program. An updated version of the Fund could incorporate the collection of fees from internet service providers as well as heavy users of the networks like digital advertisers and content providers.[49]

Updating the Universal Service Fund to reflect the ways Americans consume and pay for telecommunications today could ensure sustainable funding not only for existing programs but for equitable broadband internet access through the ACP.

The Panel urges continued work by the Universal Service Fund Working Group and recommends that reformation of the Fund include ongoing support for the Affordable Connectivity Program.

Recommendation 2.2: Increase patient access to devices and private space through community sites to facilitate access to telehealth appointments.

Internet access is vital, but it is only part of the digital equity equation. Patients need internet-connected devices and private, secure settings to comfortably and effectively access telehealth appointments, patient portals, and health information. A practical and relatively low-lift solution to this need is to create dedicated telehealth spaces within public places in the community.[50] An effective telehealth space has four components:

- **Privacy:** a private room with a door or a soundproofed cubicle where a computer screen will not be visible to passersby
- **Technology:** an up-to-date desktop computer or other device that can support video calls, patient portal access, and other patient-facing technology needs
- **Internet access:** high-speed access to ensure an appointment will not be disrupted by outages or lagging audio or video
- **Support:** staff available to demonstrate how to use the space and to answer equipment-related questions as needed

Public libraries are a natural fit for this type of resource, as these settings already are oriented toward helping patrons meet their information needs, supplying computers and digital education, and providing private meeting spaces. Libraries are trusted anchors in their communities and are known as safe places to find information and get help, especially for those in need of social services or financial support.

The Network of the National Library of Medicine (NNLM) has led the charge to raise awareness of the need for and value of telehealth spaces in public libraries. NNLM's Bridging the Digital Divide initiative and Telehealth Interest Group have designed courses and webinars and collaborated with libraries, healthcare providers, and other community institutions to implement the concept. Libraries across the United States have taken an interest in the idea, and telehealth programs are already under way at many sites.[50] One of the many benefits of this type of resource is its versatility; patrons and community members often need access to a private, internet-connected computer for non-health-related reasons. Labeling the private space a "meeting room" simultaneously increases the number of people who might benefit and eliminates any potential concerns about stigma related to being seen accessing healthcare.

Telehealth access points in public libraries may be funded through multiple mechanisms, including local, state, and federal funding. NNLM provides funding opportunities for libraries and library professionals to increase access to health information and improve equity.[51] At NCI, the Division of Cancer Control and Population Sciences supports healthcare delivery research and implementation.[52] **The Panel encourages continued support of telehealth access efforts in libraries. Support should include funding for telehealth access spaces, outreach and education to libraries, and public training in digital skills. In addition, research should be done to evaluate the feasibility and impact of facilitating access to telehealth in libraries, and best practices in telehealth access methods and digital health literacy should be developed and disseminated.**

Other community settings should also be considered as possible telehealth and digital healthcare access sites. Senior living facilities, housing shelters, and schools are trusted institutions accustomed to providing practical, technical, and health-related support for their residents, families, and visitors. Enabling private device access in these settings would offer a safe and convenient way for community members to meet their healthcare needs even amidst life changes or disruptions.

The federal Broadband Equity, Access, and Deployment (BEAD) Program was created to support high-speed internet access and use in all 50 states; Washington, D.C.; Puerto Rico; the U.S. Virgin Islands; Guam; American Samoa; and the Commonwealth of the Northern Mariana Islands.[53] To date, all eligible entities have submitted Five-Year Action Plans, which will form the basis for how BEAD-allocated funds will be used. In addition, under the Digital Equity Act–funded State Digital Equity Planning Grant Program, each of the 56 eligible states and territories submitted a Digital Equity Plan.[54] Despite the established link between internet access and health disparities, the grant program did not require that plans include a health equity component. Once the Digital Equity Plans are accepted, states and territories will be able to apply for funds through the State Capacity Grant Program. **As the BEAD and Digital Equity Act Programs move into the implementation and capacity-building phase, the Panel recommends that states and territories make access to telehealth a priority.**[55]

PRIORITY 3

Promote Responsible Development and Use of Technology to Support Navigation

Technology does not automatically lead to increased efficiency or improved outcomes. Poorly designed and implemented technological solutions can result in frustration, wasted resources, diminished trust, and even serious harm. This is particularly true in the setting of healthcare, where sensitive information is collected and patients and providers are making decisions with profound implications. The unchecked use of technology in healthcare may result in negative consequences to patients, including increasing health disparities and medical errors.

Consensus-based frameworks are needed to ensure that the technologies used for cancer patient navigation are developed and used in ways that serve, protect, and build trust with patients. Thoughtful consideration is particularly important for new approaches, such as those that include AI (see *Artificial Intelligence to Support Patient Navigation: Opportunities and Concerns* on page 8).

Furthermore, ensuring that technology mitigates rather than exacerbates health disparities is essential. Public and private stakeholders in the health technology development space are working to address the responsible development and use of technology, including artificial intelligence (see *Activities to Address Responsible Use of Technology* on page 25).

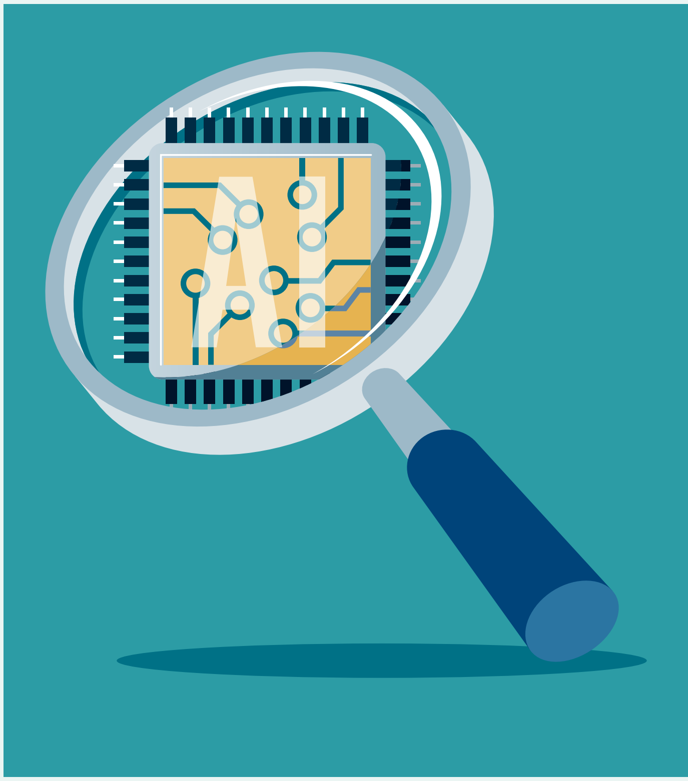
It would be impossible to develop a single framework able to address all types of technologies and applications. However, all frameworks and guidelines should adhere to a set of core principles (see *Core Principles for Navigation Technology Development and Use* on page 26). First and foremost, health technology—and technology that will be used for navigation in particular—must be developed using a people-first approach that aims to augment rather than replace interactions between patients and their care teams. Equity must be considered throughout development and implementation, as the inequitable distribution of technology in healthcare has in some cases widened, rather than narrowed, gaps in access and outcomes. For example, although the rapid pivot to telemedicine at the beginning of the COVID-19 pandemic was a testament to the power of technology, the benefits were not evenly distributed. Women, people without a high school diploma, people who were ages 65 years and older, and those who identified as Latino, Asian, or Black were even less likely to be able to get the care they needed than when all visits were in person.[56,57] At a minimum, care must be taken to ensure that new technologies do not exacerbate disparities. Ideally, technology would be intentionally designed and implemented to close gaps in care and outcomes.

User-centered design is essential for the success of any technology. To be effective, technological solutions must be both useful to and usable by the intended users.[58] Poorly designed tools increase burden on providers, including navigators, contributing to burnout. EHR-related burnout has been a significant issue[59] and provides a cautionary tale for health technologies. Thus, it is crucial that technological tools for cancer care and navigation are developed with input from end users, including patients and caregivers, providers, and navigation professionals. These stakeholders should be included from the earliest stages of development through testing and implementation. Patients and caregivers involved in this process should be representative of the target populations with respect to culture, age, educational attainment, and digital literacy. Failure to include those groups may result in low uptake, limiting real-world impact.[60-62] Technology should be thoroughly tested in each new setting and population prior to implementation to optimize benefits and reduce the risk of negative unintended consequences.

Technology can only be as good as its source data. Technology developers should use evidence-based information whenever possible. For AI-based tools, use of large, representative datasets for training models is critical (see *Artificial Intelligence to Support Patient Navigation: Opportunities and Concerns* on page 8). Training data must also be evidence based and peer reviewed. LLMs consistently recapitulate any problematic attitudes and beliefs inherent in the texts upon which they are trained. One study of AI for healthcare found that four major LLMs promoted racist stereotypes and previously debunked race-related claims, providing inaccurate and dangerous medical advice.[63] Concerns have also been raised about algorithmic bias negatively influencing clinicians from the very beginning of their careers as medical schools may begin to utilize LLMs in the development of clinical training vignettes and other educational resources.[64-66] New biases may also be inadvertently introduced over time as models incorporate additional data.[67] While elimination of algorithmic bias may be impossible, being transparent about design and data sources can help troubleshoot and mitigate problems, including bias.

Health technology must protect the privacy of patient information through robust security practices. Health systems' increasing reliance on technology has created a significant vulnerability to cyberattacks. Over the last few years, cyber criminals have turned their focus on hospitals and payors, with 46 attacks on health systems in 2023 alone.[68,69] These attacks not only expose patients' sensitive data but also bring hospital operations to a halt, causing dangerous disruptions in care.[70]

Activities to Address Responsible Use of Technology



The Biden White House has initiated a number of actions, including releasing a Blueprint for an AI Bill of Rights in 2022 and issuing two Executive Orders on responsible AI in 2023. Following the Executive Orders, agencies across the government have acted to address the promise and risks of AI. The Administration has also secured voluntary commitments from 16 major technology companies to move together toward the safe, secure, and transparent development of AI technology. The U.S. Department of Health and Human Services (HHS) Health IT Alignment Policy was adopted in 2022 to align information technology activities across the Department. An AI risk management framework developed by the National Institute of Standards and Technology will help guide technology development within the government and industry. More broadly, the U.S. Food and Drug Administration's Digital Health Center of Excellence provides guidance and support for the development of health-related technologies. In the private sector, the Coalition for Health AI is currently developing a consensus-driven framework to improve the quality of healthcare by promoting the adoption of credible, fair, and transparent AI systems.

Sources: The White House. President Biden issues Executive Order on safe, secure, and trustworthy artificial intelligence [Fact Sheet]. Washington (DC): The White House; 2023 Oct 30. Available from: https://www.whitehouse.gov/briefing-room/statements-releases/2023/10/30/fact-sheet-president-biden-issues-executive-order-on-safe-secure-and-trustworthy-artificial-intelligence; The White House. Biden-Harris Administration announces key AI actions following President Biden's landmark Executive Order [Fact Sheet]. Washington (DC): The White House; 2024 Jan 29. Available from: https://www.whitehouse.gov/briefing-room/statements-releases/2024/01/29/fact-sheet-biden-harris-administration-announces-key-ai-actions-following-president-bidens-landmark-executive-order; The White House. Executive Order on further advancing racial equity and support for underserved communities through the federal government [Internet]. Washington (DC): The White House; 2023 Feb 16 [cited 2024 Mar 29]. Available from: https://www.whitehouse.gov/briefing-room/presidential-actions/2023/02/16/executive-order-on-further-advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government; White House Office of Science and Technology Policy. Blueprint for an AI bill of rights: making automated systems work for the American people. Washington (DC): OSTP; 2022 Oct. Available from: https://www.whitehouse.gov/wp-content/uploads/2022/10/Blueprint-for-an-AI-Bill-of-Rights.pdf; The White House. Biden-Harris Administration secures voluntary commitments from leading artificial intelligence companies to manage the risks posed by AI [Fact Sheet]. Washington (DC): The White House; 2023 Jul 21. Available from: https://www.whitehouse.gov/briefing-room/statements-releases/2023/07/21/fact-sheet-biden-harris-administration-secures-voluntary-commitments-from-leading-artificial-intelligence-companies-to-manage-the-risks-posed-by-ai; The White House. Biden-Harris Administration announces new AI actions and receives additional major voluntary commitment on AI [Fact Sheet]. Washington (DC): The White House; 2024 Jul 26. Available from: https://www.whitehouse.gov/briefing-room/statements-releases/2024/07/26/fact-sheet-biden-harris-administration-announces-new-ai-actions-and-receives-additional-major-voluntary-commitment-on-ai; Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology. HHS Health IT Alignment Policy [Internet]. Washington (DC): ASTP/ONC; n.d. [updated 2024 Jul 5; cited 2024 Sep 8]. Available from: https://www.healthit.gov/topic/hhs-health-it-alignment-policy; National Institute of Standards and Technology. AI risk management framework [Internet]. Gaithersburg (MD): NIST; 2023 [cited 2024 Mar 29]. Available from: https://www.nist.gov/itl/ai-risk-management-framework; U.S. Food and Drug Administration. Digital Health Center of Excellence [Internet]. Silver Spring (MD): FDA; 2024 [cited 2024 March 8]. Available from: https://www.fda.gov/medical-devices/digital-health-center-excellence; Coalition for Health AI. Blueprint for trustworthy AI implementation guidance and assurance for healthcare (version 1.0). McLean (VA): The MITRE Corporation; 2023 Apr 4. Available from: https://www.coalitionforhealthai.org/papers/blueprint-for-trustworthy-ai_V1.0.pdf

Core Principles for Navigation Technology Development and Use

- **People-first approach:** Augment, rather than replace or diminish, human interactions between patients and their care teams.
- **Equity:** Take an equity-first approach that incorporates insights from marginalized communities into every stage of the process and takes care not to exacerbate existing disparities.
- **User-centered design:** Address an area of need and reduce burden for patients, caregivers, navigators, and other members of the care team. Ensure that tools are easy to use.
- **Effectiveness and validity:** Conduct testing to confirm validity and benefits for the intended settings and populations.
- **Use of high-quality source data:** Rely on evidence-based information and trusted sources. Train LLMs and other algorithms using accurate and inclusive datasets.
- **Transparency:** Navigation technologies and the process of their development should be transparent and explainable. Human users must be able to troubleshoot and understand the systems they are using.
- **Privacy:** Health technologies, including third-party and direct-to-consumer products, must balance utility and the secure exchange of data with the protection of patients' privacy.
- **Interoperability:** Incorporate a minimum set of common data elements and facilitate the secure exchange of health information between appropriate parties like healthcare organizations, navigators, and cancer patients.
- **Ongoing assessment and improvement:** Develop a plan for evaluation and improvement that incorporates outcomes data. Enable continual updates and improvements, and discontinue use of ineffective tools.

Interoperability is also essential to allow integration of data across healthcare organizations and platforms. Ongoing evaluation and continual improvement are important to ensure that technology is achieving its goals without creating undue burden. Developers and implementers should establish evaluation metrics and plans and ensure that updates and improvements can be implemented as needed. Use of any technology that is not achieving its goals or is causing harms that outweigh its benefits should be discontinued.

Recommendation 3.1: Adhere to core principles for responsible development and use of technologies that support cancer patient navigation.

All organizations that are developing and using technology for cancer patient navigation—including healthcare organizations, EHR vendors, third-party developers, and others—should adhere to the core principles for navigation technology development and use to ensure optimal benefit and return on investment (see *Core Principles for Navigation Technology Development and Use* above). For technologies and applications for which there are more detailed guiding frameworks, these should also be referenced and followed. The risks of implementing technology that does not meet these standards are dire. In addition to potentially worsening health outcomes and widening disparities, security breaches, perpetuation of bias, and creation of tools with limited value will diminish patient and provider trust in both new technology and the healthcare system.[71]

Developers have an ethical responsibility to create tools that are aligned with these core principles. Potential short-term profits should not trump the importance of long-term benefits, trust, and value.

Organizations that are purchasing or funding development of technology for cancer patient navigation must take the lead in ensuring that technology is responsibly developed and implemented. Healthcare organizations should establish clear and binding expectations that all products purchased from or developed in partnership with third parties be responsibly developed, implemented, and assessed. Research funding organizations—including, but not limited to, the National Institutes of Health (NIH) and AHRQ—should include core principle requirements in the terms of award for any grant that involves development of a technology tool for patient navigation.

Recommendation 3.2: Support research to ensure that technology to support navigation achieves its goals.

Research is needed to explore new types of technology and new applications of existing technology that could be used to support care teams, navigators, patients, and caregivers. **Research funding organizations should provide funding for the development and testing of cancer patient navigation technologies with a focus on tools that will address health disparities.**

Implementation research is also needed to determine the best ways to implement navigation-supporting technologies in real-world settings. The AHRQ Digital Healthcare Research Program—which aims to produce and disseminate evidence about how the evolving digital healthcare ecosystem can best advance the quality, safety, and effectiveness of healthcare for patients and their families—is well suited to conduct this research.[72] **The Panel encourages AHRQ to assess technologies used by cancer patient navigators and care teams as well as those used by patients and caregivers.** Research questions could include the impact of navigation technologies on patient outcomes (e.g., time to treatment initiation, successful resolution of SDOH-related challenges), disparities in healthcare access within an institution, or navigator capacity and effectiveness. AHRQ should develop and disseminate best practices and lessons learned to guide development, implementation, and evaluation of technology for navigation.

Recommendation 3.3: Incorporate technology knowledge and skills into patient navigator training and core competencies.

Technology-based tools have potential to increase the efficiency and effectiveness of patient navigators. However, realizing this potential depends on navigators' understanding and feeling comfortable with using these tools. As noted in the core principles, navigators should be included in the design of any technology intended for their use. In addition, navigators may need training to ensure that they are able to effectively use these tools once implemented. Navigators come from a range of backgrounds and will have a range of experience with technology.

Healthcare organizations must provide training for their navigators on any technology tool that is implemented within their system. This could include up-front training as well as a mechanism for continued support as needed during rollout.

Several navigator training programs have been developed to provide navigators with the knowledge and skills they need to carry out their jobs. **Navigator training programs should incorporate learning objectives so that navigators understand how to use technology effectively and responsibly. As navigation technologies become more commonplace, digital skills should be included among oncology navigator core competencies such as those developed by the National Navigation Roundtable and Professional Oncology Navigation Task Force.**[73,74]

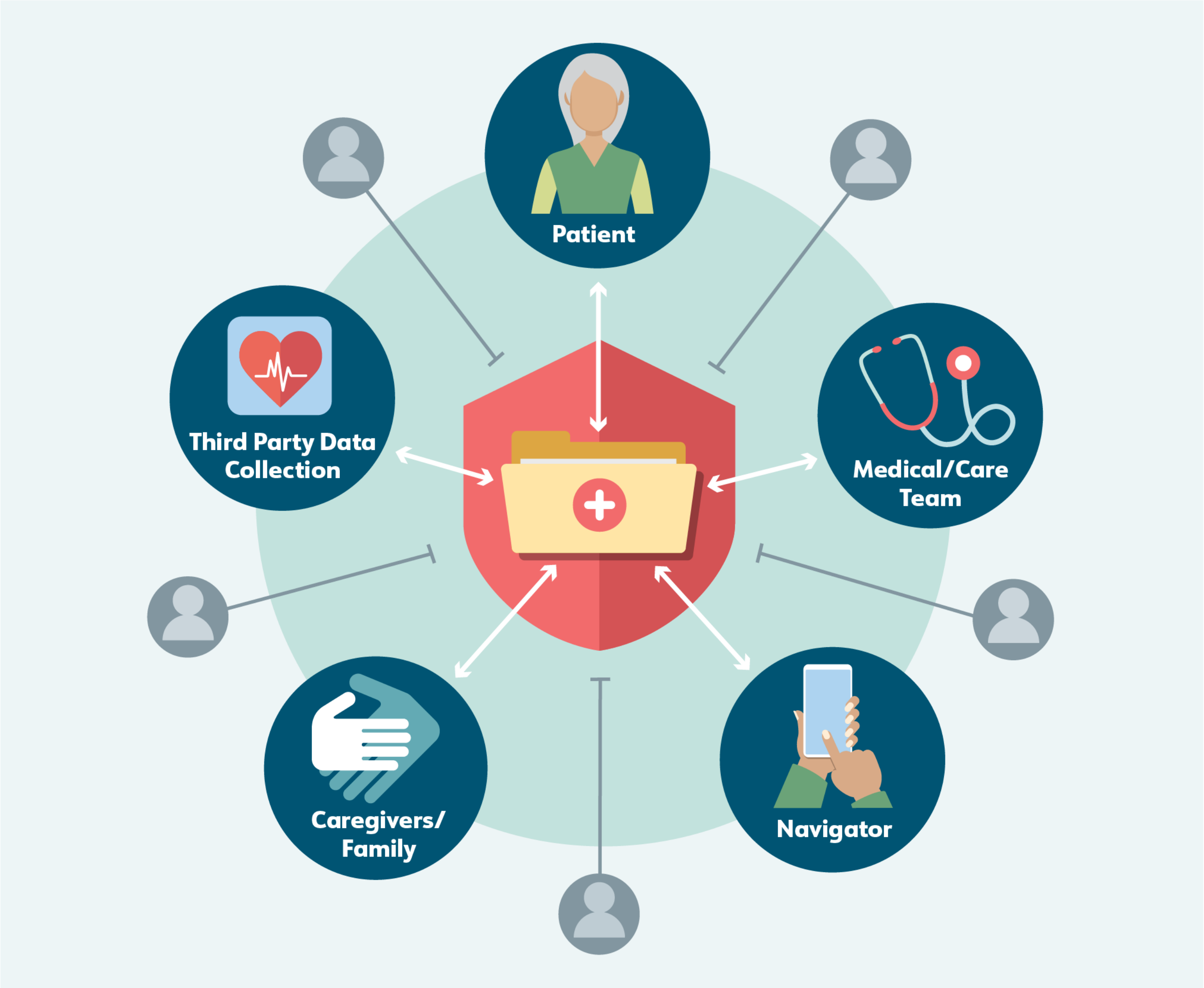
PRIORITY 4

Maintain Privacy and Security While Facilitating Data Sharing to Support Cancer Patient Navigation

The cancer journey creates vast quantities of patient health data, including test results, referrals, prescriptions, visit summaries, and communications between patients and caregivers and their care teams. Effective cancer care delivery depends on the timely exchange of these data. At the same time, sensitive health information must be kept both private and secure. In an ideal world, data sharing would protect patient information without impeding its access and use by appropriate parties, including patients themselves (Figure 5).

Current circumstances are far from ideal. Patients, caregivers, navigators, and clinicians all experience significant obstacles in accessing and sharing health-related data. Even within a health system, technological or logistical barriers can prevent team members from exchanging vital patient information.[75,76] The challenges are often even greater when trying to share between healthcare organizations, with patients directly, or with third parties. Yet, outside the healthcare setting,

Figure 5. Balancing Data Sharing with Privacy and Security



individuals' health-related data can be shared too freely, without appropriate protections (see *Recommendation 4.2*).

To create a seamless workflow for cancer patient navigation, patients and care teams—including navigators—need access to different types of data from different sources. These data are currently collected through and stored in many discrete streams, each with its own format and exclusive audience; in some settings, for example, CHWs may not be able to access their patients' EHRs, while clinicians may not be able to view patient navigators' notes or referrals to resources.

Recommendation 4.1: Improve and incentivize interoperability to enable portability of patient data across health IT platforms and systems in order to improve navigation.

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. A recent survey found that more than half of people who had recently been diagnosed with cancer had multiple patient portals or EHRs; patients with cancer also had a higher average number of EHRs and patient portals compared with people who had never been diagnosed with cancer.[32] The need for interoperability in health information technology has been a topic of discussion in the cancer community for some time and was even identified as an urgent priority in the 2016 President's Cancer Panel report, *Improving Cancer-Related Outcomes with Connected Health.*[75]

Since the publication of that report, the federal government has made significant progress toward this aim. The Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology (ASTP/ONC) within HHS leads and coordinates interoperability efforts, including standards development and health information technology certification, as well as policy and programmatic initiatives in partnership with the healthcare industry.[77] ASTP/ONC is charged with providing technical assistance across the Department under the HHS Health IT Alignment Policy, which requires HHS-funded initiatives to use aligned standards for health IT with the goal of advancing interoperability between and among all parts of the healthcare and public health community.[78] ASTP/ONC also defines functional requirements for the voluntary certification of health information technology. This certification has great influence; as of 2017, more than 96% of nonfederal acute care hospitals were using certified health information technology.[79] In January 2024, ASTP/ONC finalized its Health Data, Technology, and Interoperability: Certification Program Updates, Algorithm Transparency, and Information Sharing (HTI-1) rule. The final rule advances core data standards for interoperability and requires developers of certified health information technology to report on metrics related to interoperability.[80,81]

In addition, ASTP/ONC oversees the Trusted Exchange Framework and Common Agreement (TEFCA), which was described in the 21st Century Cures Act. The goals of TEFCA are to establish a universal governance, policy, and technical floor for nationwide interoperability; simplify connectivity for the secure exchange of clinical information; and enable individuals to access their own health data. Version 2.0 of the Common Agreement was released by ASTP/ONC in April 2024.[82] The updated agreement defines baseline legal and technical requirements for secure information sharing nationwide and lays out a common set of principles to facilitate trust.[83] TEFCA aims to help address impediments to electronic information exchange, including for small and rural healthcare providers, many of whom still use mail or fax more frequently than electronic means to share data.[84]

Continued progress toward interoperability and the seamless and secure exchange of health data to support cancer patient navigation and care will depend not only on regulations and guidance but also on cultural shifts within individual institutions and across the healthcare industry. For many years, health systems have focused more on cost

Figure 6. mHealth Apps

More than HALF
of U.S. adults report having used an mHealth app within the past 12 months

mHealth apps can collect patient data, including clinical data from EHRs and patient-generated data.

conservation and data security, a perspective that shapes their interpretation of laws and policies like the Health Insurance Portability and Accountability Act of 1996 (HIPAA).[85] This orientation is understandable but can result in the unintended consequence of deprioritizing the most important aspect of healthcare: ensuring that patients get the care they need. The federal government can support these shifts by continuing to incentivize collaboration. **The Panel acknowledges the many strides taken toward interoperability to date and encourages continued progress at the federal, industry, and health system levels. Future efforts should include targeted investments to support participation of small practices in health information exchanges.**

Recommendation 4.2: Evaluate existing privacy and security regulations and laws and identify opportunities for a national legal framework to protect patients while fostering technological innovation to support patient navigation.

The HIPAA Privacy Rule, adopted in 2000, established the first national standards to protect individuals' medical records and other individually identifiable health information.[86] The 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act and the subsequent HHS rule amended HIPAA, created a breach notification rule, and incentivized the adoption of EHRs.[87,88] With these modifications, HIPAA rules apply to covered entities—including health plans, healthcare clearinghouses, and healthcare providers who transmit health information in electronic form*— as well as business associates of the covered entities.[89]

The technological landscape has changed significantly since HIPAA and HITECH were enacted. As of 2021, more than 350,000 mobile health (mHealth) apps were available for smartphones, tablets, and other devices.[90] More than half of U.S. adults report having used an mHealth app within the past 12 months (Figure 6).[91] Although these apps generate, store, and use individuals' health data, in most cases they are not considered covered entities or business associates under HIPAA and therefore are not subject to HIPAA standards of privacy and security.[19,92] Standard modes of communication have also shifted. Many people prefer to communicate and receive information via social media and text messages, which are generally not considered to be secure.

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* Healthcare providers are covered entities only if they transmit information in an electronic form in connection with a transaction for which HHS has adopted a standard. Source: Centers for Medicare & Medicaid Services. Transactions overview [Internet]. Baltimore (MD): CMS; n.d. [updated 2024 Aug 8; cited 2024 Sep 9]. Available from: https://www.cms.gov/priorities/key-initiatives/burden-reduction/administrative-simplification/transactions

Many organizations and individuals, including from the President's Cancer Panel,[93] have raised concerns that HIPAA impedes biomedical research and healthcare and inadequately protects patient data. A 2009 report from the Institute of Medicine noted that different interpretations of HIPAA requirements across institutions created barriers to research and urged HHS to provide clearer guidance to address this.[94] Although the HHS Office for Civil Rights provides extensive information on HIPAA interpretation and compliance,[95] overly cautious interpretations of HIPAA and fear of lawsuits are still cited as barriers to data sharing.[96] Efforts to follow the letter of the law and avoid data breaches are commendable but result in considerable data access challenges for health systems, care teams, researchers, and patients and their families. These challenges will only grow as patients increasingly want to integrate their health information across healthcare organizations and platforms.

There have been efforts to protect the large and growing body of health data that falls outside the purview of HIPAA. Some states have enacted their own privacy rules to provide additional protections. These state-level laws are designed to help patients and can close gaps in information-sharing that could expose individuals' information. Unfortunately, the resulting inconsistency across state lines creates significant compliance and cost challenges for health information technology developers and for institutions.[97]

The federal government also is working to address this gap from multiple perspectives. The Federal Trade Commission's (FTC) Health Breach Notification Rule, which applies to mHealth apps and similar technologies, requires companies to notify consumers following breaches that may involve unauthorized disclosures of their health information.[92] Section 5 of the FTC Act prohibits unfair or deceptive acts or practices in or affecting commerce, including those relating to the privacy and security of personal information in mHealth apps, while Section 12 prohibits false advertising.[92] The U.S. Food and Drug Administration enforces the Federal Food, Drug, and Cosmetic Act, which, among other things, regulates the safety and effectiveness of medical devices, including some mHealth apps.[92] A 2019 report from the National Committee on Vital and Health Statistics offered a new framework for the protection of health information not covered by HIPAA.[98] There are also ongoing efforts—including the National Science Foundation's Safeguarding the Entire Community of the U.S. Research Ecosystem (SECURE) Center[99]—to ensure that data collected for research, including clinical trials, are secure. The proposed American Privacy Rights Act of 2024, first introduced to Congress in April 2024, aims to create a comprehensive framework to protect individuals' privacy rights, including those related to health and other sensitive data.[49]

The Panel encourages continued discussion on this topic within and between all branches of the federal government. **Mechanisms should be explored to protect patient data without obstructing data sharing and integration that support cancer care and research. The Panel recommends that Congress commission the National Academies of Sciences, Engineering, and Medicine to evaluate the current regulatory landscape and provide guidance to legislators on next steps to improve policies to better serve patients.**

PART III

Conclusions

Conclusions

Patient navigation has been proven to reduce cancer disparities—a critical problem facing the National Cancer Program—by addressing individual and systemic barriers to accessing timely and high-quality care. In this report, the Panel identifies ways that technology could be used to enhance evidence-based patient navigation for people with cancer. The Panel has defined four priority areas and provided recommendations in each area to promote effective and appropriate use of technology for cancer navigation. These recommendations should be implemented in alignment with the following principles.

Technology should augment, not replace, people. Human connection is essential, particularly when people are overwhelmed and vulnerable, as people dealing with cancer often are. Technology should not replace personal connections; rather, it should make those connections easier, more efficient, and more meaningful.

Technology must be responsibly developed and used. Care must be taken that health technologies—including those used by organizations, care teams, and individuals—be developed and used in ways that optimize benefit and avoid harm, particularly for patients. User-centered design is a key component of this; user input must be gathered throughout the development process to ensure that tools address actual needs and that they are usable and accessible. Ongoing assessment is necessary to ensure that goals are being met and that any negative unintended consequences are identified and addressed in a timely manner. Technology presents many opportunities, but it is important that innovation—including, but not limited to, the use of AI in health technologies—be balanced with the critical need for data security and patient privacy.

Technology should help achieve equity, not exacerbate disparities. The elimination of disparities in cancer care and outcomes must be among the highest priorities of the National Cancer Program. Technology can help achieve this goal, but only if traditionally underserved populations have access to broadband, devices, and digital skills. The impact of technology on disparities must be continually monitored, and both technological and nontechnological solutions must be pursued to address this pressing problem.

Effective use of technology to support cancer patient navigation requires cross-sector commitment and action. The Panel urges all stakeholders in the National Cancer Program—federal, state, and local governments; healthcare organizations; healthcare providers; EHR vendors and health IT developers; insurance companies; patients, families, and caregivers; and others—to work together to find the best ways to incorporate technology into cancer navigation to ensure that everyone facing a diagnosis of cancer has access to the best possible treatment and support.

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Appendix A: Meeting Dates and Roster of Participants

MEETING DATE	LOCATION
October 17, 2023	New Orleans, Louisiana
November 2–3, 2023	Virtual Meeting
December 7, 2023	Bethesda, Maryland

MEETING PARTICIPANT	AFFILIATION
Tracy Battaglia, MD, MPH	Boston University Chobanian & Avedisian School of Medicine and School of Public Health
Luis Belén	The National Health IT Collaborative for the Underserved, Inc. (NHIT®)
Valerie D. Bouldin, MEd	City of New Orleans
Wout Brusselaers, MA, MFA	Deep 6 AI
Paige Butler	Lymphoma Research Foundation
Elizabeth Calhoun, PhD, MEd	University of Illinois at Chicago
Kevin Chaney, MGS	Agency for Healthcare Research and Quality
Irene Chen, PhD	University of California, Berkeley
Heather Ciccarelli, MSW	American Cancer Society
Mary Cosper, LCSW-BACS, MPH	Cancer Association of Greater New Orleans/Cancer Association of Louisiana
Jennifer Couch, PhD	National Cancer Institute
Irene Dankwa-Mullan, MD, MPH	Marti Health
Ethan Davidoff	Atlas Health
Monica Dean	Academy of Oncology Nurse & Patient Navigators
Crystal S. Denlinger, MD	National Comprehensive Cancer Network
Megan Doerr, MS, LGC	Sage Bionetworks
Andrea "Andi" Dwyer, MPH	University of Colorado
Chris Dymek, EdD	Agency for Healthcare Research and Quality
Bilikisu "Reni" Elewonibi, PhD, MPH	Louisiana State University Health Science Center New Orleans
Ricki Fairley, MBA	TOUCH, The Black Breast Cancer Alliance
Tamika Felder	Cervivor, Inc.
Linda Fleisher, PhD, MPH	Fox Chase Cancer Center
Paul Friedlander, MD	Tulane University School of Medicine, Southeast Louisiana Veterans Healthcare System
Sharon Gentry, MSN, RN, HON-ONN-CG, AOCN, CBCN	Academy of Oncology Nurse & Patient Navigators
Sara Gerke, Dipl-Jur Univ, MA	Penn State Dickinson Law
Jennifer C. Goldsack, MChem, MA, MBA, OLY	Digital Medicine Society (DiMe)

MEETING PARTICIPANT	AFFILIATION
Darcie Green	Latinas Contra Cancer
Angela Hammett, MSN, RN	Mary Bird Perkins Cancer Center
Jonathan A. Handler, MD, FACEP, FAMIA	OSF HealthCare
Ivor Braden Horn, MD, MPH	Google
Melanie K. Infinger	Nursenav
Doug Jacobs, MD, MPH	Centers for Medicare & Medicaid Services
Maureen R. Johnson, PhD	National Cancer Institute
Katherine Kim, PhD, MPH, MBA, FAMIA	MITRE Corporation
Ron Kline, MD, FAAP	Centers for Medicare & Medicaid Services
Tatjana Kolevska, MD	Kaiser Permanente
Dinesh Kotak, MD	The Permanente Medical Group, Kaiser Permanente
Mei Wa Kwong, JD	Center for Connected Health Policy
Eugene Lengerich, VMD, MS	Penn State University, Penn State Cancer Institute
Melissa D. McCradden, PhD, MHSc	The Hospital for Sick Children
Gina McWhirter, RN, MSN, MBA	Department of Veterans Affairs
Michelle Mollica, PhD, MPH, RN, OCN	National Cancer Institute
Samyukta Mullangi, MD	Thyme Care
Timothy Mullett, MD, MBA, AFCS	Markey Cancer Center Network, University of Kentucky
Phyllis Pettit Nassi, MSW	University of Utah
Kingsley I. Ndoh, MD, MPH	Hurone AI, University of Washington
Augusto Ochoa, MD	LSU Health New Orleans
Kellie Owens, PhD	NYU Grossman School of Medicine
Ravi B. Parikh, MD, MPP	University of Pennsylvania
Amila Patel, PharmD, BCOP	Navigating Cancer
Timil Patel, MD	U.S. Food and Drug Administration
Steven R. Patierno, PhD	Duke Cancer Institute, Duke University School of Medicine
Hoifung Poon, PhD	Microsoft Research
Mandi Pratt-Chapman, PhD	George Washington University Cancer Center
Gabrielle Rocque, MD, MSPH	University of Alabama at Birmingham
Elizabeth A. Rohan, PhD, MSW	Centers for Disease Control and Prevention
Traudi Rose, DNP, RN, MBA, OCN, NEA-BC	VA Portland Health Care System
Maya R. Said, ScD	Outcomes4Me Inc.
Alyssa Schatz, MSW	National Comprehensive Cancer Network
Wade Shen, MS	White House Office of Science and Technology Policy
Amy R. Sheon, PhD, MPH	Public Health Innovators, LLC; Case Western Reserve University; and Arizona State University
Ya-Chen Tina Shih, PhD	University of California, Los Angeles
Anne W. Snowdon, PhD	HIMSS
Arti Patel Varanasi, PhD, MPH, CPH	Johns Hopkins University

MEETING PARTICIPANT	AFFILIATION
Lisa A. Wagner, MPA	U.S. Department of Health and Human Services
Shinobu Watanabe-Galloway, PhD, MPH	University of Nebraska Medical Center
Stephanie Wheeler, PhD, MPH	University of North Carolina at Chapel Hill
Valarie Worthy, MSN, RN	TOUCH, The Black Breast Cancer Alliance
Tingting Zhang, PhD	Hear2Care

Appendix B: Recommendations Table

PRIORITY/RECOMMENDATION	RESPONSIBLE STAKEHOLDER(S)
PRIORITY 1: Use Technology to Support Navigation Activities to Achieve Equitable Outcomes for People with Cancer	
Recommendation 1.1: Develop and implement tools that facilitate efficient, patient-centered coordination of cancer care.	Healthcare organizations EHR vendors
Recommendation 1.2: Develop and implement technologies to help navigators connect cancer patients with organizational and local resources.	Healthcare organizations EHR vendors
Recommendation 1.3: Develop and implement tools that provide vetted, personalized cancer-related information for patients and caregivers.	Technology developers Advocacy organizations Research funding organizations
PRIORITY 2: Ensure Equitable Patient Access to Technology That Supports Cancer Navigation	
Recommendation 2.1: Provide sustainable funding for federal programs that facilitate access to broadband internet.	U.S. Congress President
Recommendation 2.2: Increase patient access to devices and private space through community sites to facilitate access to telehealth appointments.	State and local governments Network of the National Library of Medicine
PRIORITY 3: Promote Responsible Development and Use of Technology to Support Navigation	
Recommendation 3.1: Adhere to core principles for responsible development and use of technologies that support cancer patient navigation.	Technology developers Healthcare organizations and providers Research funding organizations
Recommendation 3.2: Support research to ensure that technology to support navigation achieves its goals.	Research funding organizations (e.g., NIH, ACS, AHRQ)
Recommendation 3.3: Incorporate technology knowledge and skills into patient navigator training and core competencies.	Navigation training programs National Navigation Roundtable Professional Oncology Navigation Task Force
PRIORITY 4: Maintain Privacy and Security While Facilitating Data Sharing to Support Cancer Patient Navigation	
Recommendation 4.1: Improve and incentivize interoperability to enable portability of patient data across health IT platforms and systems in order to improve navigation.	Assistant Secretary for Technology Policy/Office of the National Coordinator for Health IT Healthcare organizations and providers
Recommendation 4.2: Evaluate existing privacy and security regulations and laws and identify opportunities for a national legal framework to protect patients while fostering technological innovation to support patient navigation.	U.S. Congress National Academies of Sciences, Engineering, and Medicine

Appendix C: Abbreviations and Acronyms

ACRONYM	DEFINITION
ACP	Affordable Connectivity Program
ACS	American Cancer Society
AHRQ	Agency for Healthcare Research and Quality
AI	Artificial intelligence
API	Application programming interface
ASTP	Assistant Secretary for Technology Policy
BEAD	Broadband Equity, Access, and Deployment Program
CHW	Community health worker
CMS	Centers for Medicare & Medicaid Services
COVID	Coronavirus disease
EHR	Electronic health record
FCC	Federal Communications Commission
FTC	Federal Trade Commission
HHS	U.S. Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HITECH	Health Information Technology for Economic and Clinical Health Act
HTI-1	Health Data, Technology, and Interoperability: Certification Program Updates, Algorithm Transparency, and Information Sharing rule
IT	Information technology
LLM	Large language model
mHealth	Mobile health
ML	Machine learning
NCI	National Cancer Institute
NIH	National Institutes of Health
NNLM	Network of the National Library of Medicine
ONC	Office of the National Coordinator for Health Information Technology
SDOH	Social determinants of health
SECURE	Safeguarding the Entire Community of the U.S. Research Ecosystem
TEFCA	Trusted Exchange Framework and Common Agreement
USF	Universal Service Fund

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