



**Testimony of Mark Savage
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**HEARING ON
OPPORTUNITIES AND CHALLENGES IN ADVANCING HEALTH INFORMATION TECHNOLOGY**

**U.S. House of Representatives
Committee on Oversight and Government Reform
Subcommittee on Information Technology and
Subcommittee on Health Care, Benefits, and Administrative Rules
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Good morning, Chairmen Hurd and Jordan, Ranking Members Kelly and Cartwright, and distinguished committee members. Thank you very much for the opportunity to testify here today.

My name is Mark Savage, Director of Health IT Policy and Programs at the National Partnership for Women & Families. I am delighted to be with you today to share the values, needs and experiences of patients and consumers as they use health information technology (or health IT) to improve their health and care. After all, patients and family caregivers are at the center of the health care and information we seek to improve.

The National Partnership is a national, non-profit, non-partisan organization that, for 45 years, has worked to improve the lives of women and families across the country. We represent individuals across the country who are the health care decision-makers for themselves and their families and who want and deserve affordable, high-quality health care services. We are deeply invested in improving the value and experience of health care and committed to ensuring that new models of health care delivery and payment help women and families be partners in their care and have access to the right care at the right time.

Because health IT is now the essential infrastructure for needed improvements in health care quality and value, the National Partnership has a dedicated health IT team and serves as a leading consumer voice with great expertise about patients' and consumers' needs and experiences with health IT. We represented the patient and consumer perspective in development and implementation of the HITECH Act. We lead the Consumer Partnership for eHealth, a coalition of more than 50 leading consumer groups working at the federal, state and local levels to advance private and secure health IT in ways that measurably improve the lives of patients and families.

Today, I am here to speak to the great opportunities that health IT presents to help patients and family caregivers partner with their health care providers to improve care, and to the remaining obstacles to realizing the full potential of an electronic health ecosystem.

Why Health IT Matters to Patients and Consumers

Improving the Quality and Value of Care

Electronic health information exchange is fundamental to improving quality, care coordination and value for our health care system. New models of care require the ability not just to share data, but to integrate relevant individual and population data across various sources (e.g. doctors, hospitals, laboratories, pharmacies, registries and patients).

Patients likewise recognize and value the great benefits of health IT to their clinical care. According to a nationwide survey released by the National Partnership in December 2014, patients overwhelmingly believe that electronic health records (EHRs) are essential to making sure providers have timely access to information that can help avoid medical errors and repeat tests.¹

Engaging Patients as Partners in their Care

Consumers experience significant direct benefits from the use of health IT. Health IT can make it easier for patients and their family caregivers to access care and information, navigate the health system, and communicate with their providers to better manage their own health or care for a loved one.

Health IT is a critical tool for engaging patients in ways that empower them to partner in their health and care. Technology facilitates patient access to their medical information so they and their families can make informed decisions, in partnership with their care providers, about treatment and health that reflect their needs, values and preferences.

Like electronic access in so many other parts of our lives, such as banking and retail, health IT enables real-time access to care and information, providing individuals with the convenience and control they need and expect in the 21st century.

- **Access to CARE:** Health IT transforms the environment, expanding patient access to care from what, for many, was access only during the occasional 10-minute office visit to **access to care anytime and anywhere needed.** For example, the effective use of telehealth services could improve access to care and enhance timely treatment and support. Telehealth is just one example of innovation in health information technology that can support patients and families in their own health and care.

¹ National Partnership for Women & Families, *Engaging Patients and Families: How Consumers Value and Use Health IT* (Dec. 2014), available at <http://www.nationalpartnership.org/research-library/health-care/HIT/engaging-patients-and-families.pdf>.

- **Access to INFORMATION:** Online access to health information helps patients and family caregivers do things like share information with their providers and manage their care across multiple doctors. For example, health IT makes it possible for a patient who needs surgery to send her test results to another doctor for a second opinion. Or a daughter or son caring for parents in another state can keep up-to-date on their medications and treatment recommendations, with health IT.

Patients already recognize and value these benefits. That’s why almost nine in 10 patients who have such access use it. Online access to health information can also help patients set and achieve personal health and wellness goals, which is particularly important for those managing chronic health conditions. Notably, **people who use online access to their health information more frequently are much more likely than infrequent users to report that it motivates them to improve their health.**

Digital Tools that Help Patients and their Providers

Improving Communication and Coordination

Online access to health information improves patients’ ability to communicate with their doctors and improves their knowledge of their health, according to our national survey. Secure email messaging enables patients to communicate with their doctors in timely and efficient ways; to correct inaccurate or outdated information; and to share treatment outcomes, such as pain levels and functional status.

In addition to promoting safe and appropriate care, electronic communication can benefit providers as well as patients by offering more efficient means to address patients’ and caregivers’ questions and concerns electronically, allowing more in-person interaction with providers for patients who need it most.

One program that has helped significantly to bring online access and timely two-way information sharing to patients across the county is the Electronic Health Record (“Meaningful Use”) Incentive Program. In 2017-2018, Stage 3 will provide critical new tools to support coordination and interoperability between patients and their providers—for example, access through Application Programming Interfaces (APIs) so that patients can access and coordinate their health data with new tools such as smartphone applications (apps) and other devices. Private-sector innovators can develop new apps that make patient health data more accessible and useful to patients and providers alike.

The National Partnership asked people to share in just six words why all patients need easy online access to health information and secure ways to email their doctors. People across America shared their six-word stories. Here are three:

- **“Second opinions matter. Information prevents redoing.”**
Kathryn B., California
- **“Had cancer. Information helpful. Removed doubt.”**
Debbie G., Illinois
- **“Shared accurate records save patients' lives.”**
Eloise D., Pennsylvania

Enhancing Privacy Protections

A foundation of strong security and privacy protections is essential to public trust and the ultimate success of health IT. While people continue to be concerned about the privacy of their health information, those concerns are increasingly understood in the fuller context of the benefit of EHRs and electronic health information exchange. Indeed, health IT provides opportunities for *enhancing* the privacy and security of patient data, including encryption of electronic personal health information and electronic audit trails.

Health IT can also give patients more control over how their personal medical information is used. Different people may deem different kinds of health information to be especially sensitive, such as psychotherapy notes or substance abuse information. Continued development and testing of approaches that enable patients to segment their data and direct which care team members can see certain information can enhance consumer trust and use of electronic health information exchange.

Patients' online access to their health information can also improve trust. Our survey found that patients who use online access more frequently have significantly greater trust that their providers will protect their privacy and other rights than patients who use online access infrequently or never use it. Accessing and seeing one's electronic medical information is a significant factor in increasing patients' trust that their information is safe and that their doctors are protecting their privacy.

Key Actions to Leverage Health IT and Improve Health Care

The country has made substantial progress in the past few years, including a rapid increase in adoption and use of certified electronic health records (97 percent of hospitals, and 74 percent of office-based physicians through 2014²). For patients, their online access to their health information has doubled in three years, increasing from 26 percent in 2011 to 50 percent in 2014, according to our national survey. This adds up to profound and very welcome change. However, much more work remains before the benefits and opportunities of health IT will reach all patients.

To move to a system where patients' access to and use of their health care information is the norm, we must break down barriers on a variety of fronts. None of these actions require legislation; they can be done through federal guidance or assistance that further spurs private sector innovation, by public-private collaboration and by industry advancements. The following recommendations reflect what we have heard from consumers across the nation about their experiences getting and using their health information.

(1) Address barriers to access to important health information

Consistent with our commitment to improve consumer and patient access to their health information, we worked with leading technology, consumer and provider organizations to convene the GetMyHealthData campaign. GetMyHealthData is

² Office of the National Coordinator for Health Information Technology, *Report to Congress on the Adoption of Health Information Technology and Related Efforts to Facilitate the Electronic Use and Exchange of Health Information* (Feb. 2016), pp. 27-28.

dedicated to making it easier for patients and families to request their medical records and other health information, and to use their data to improve their care and health. In leading the campaign, the National Partnership has learned a lot about what the process of getting and using health data is like in the real world. We have learned from our volunteers that, despite longstanding policies designed to improve access to health information, patients continue to face many barriers to getting electronic copies of their medical records and other health data. Too often:

- Accessing health information is a confusing and difficult process for patients.
- Confusion surrounding HIPAA persists, and both providers and patients misunderstand patients' rights to access their health information. This often means that patients do not get the access to information they need for themselves or a loved one, despite their rights to their health data.
- Unreasonable fees for copies of health records pose barriers to patient access, further impeding their ability to get and use their health data.

Accordingly, the campaign has worked to bridge these gaps by developing innovative tools and guidance to make it easier for patients and families to request access to and use their health information.

Key actions to remove barriers to access:

- Public and private-sector efforts need to advance policies and practices that promote patients' online access to and use of their health information.
- Public and private-sector efforts to address interoperability among health IT systems and users must **explicitly include consumers as equal users** and address operational and technical barriers that impede the ability of patients and family caregivers to send, receive, find and use their health data.

(2) Clarify privacy and security requirements for sharing health data

One significant point of friction in patients' access to their health information is providers' and patients' **misunderstanding of patients' access rights**.

Key actions to clarify privacy and security requirements:

- Policies to promote patient access must be supplemented with comprehensive and proactive education initiatives to enhance understanding of patients' rights to their electronic health information and providers' responsibilities when responding to patient requests.
- Mobile app developers and other technology vendors should join voluntary efforts to post their privacy policies and data sharing practices embedded in their products in standardized ways. This will help consumers quickly and easily compare such policies and practices (such as whether the developer sells consumer data for marketing or pharmaceutical research).

(3) Enhance the Usability of Access to Health Information

Even when patients can access their medical data, the data may be difficult to interpret, use and translate into meaningful and actionable information that can inform their care or the care of loved ones. Does a particular blood test value mean that one is healthy or that one needs care? Health data often need context, explanation or interpretation to help consumers understand their meaning.

Key actions to improve usability:

- Public and private entities, including technology and app developers, should work together to improve the usability of patient health data so that, for example, consumers and patients can incorporate their data into apps that display the data in formats and with options that consumers find meaningful, useful and actionable.

(4) Bridge the Digital Divide

Barriers to electronically connected and coordinated care tend to be even greater, for example, in rural and underserved communities, and for the 60 million Americans with disabilities and the 60 million who speak languages other than English. We need to design and build digital health tools for patients that reflect their diverse needs and bridge existing digital divides.

Key actions to bridge digital divides:

- The public and private sectors should improve and promote online access to patient health information across all communities, and remove the barriers that impede access and use for too many people today. Innovation in mobile apps can help. The more consumers across diverse communities can share information that reflects their needs and experiences, the greater potential we have to identify and ultimately reduce disparities in care. Additionally, public-private partnerships are an important component of increasing broadband adoption.

Patients have a unique vantage point: They see multiple providers and thus know whether their care is being coordinated. They know whether they have to provide the same information over and over again, or whether tests have to be repeated because the results were lost or inaccessible. They can spot and correct errors in their medical records. They know and can report the many factors outside the clinical setting that are integral parts of their health and care, such as the family caregivers who assist them, the community resources they access and the social determinants that affect their health. **Taking the steps described above, we can leverage health IT to enable patients to contribute all of these critical resources as partners in their care.**