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A National Action Plan To Support Consumer Engagement Via E-Health

ABSTRACT Patient-centered care is considered one pillar of a high-performing, high-quality health care system. It is a key component of many efforts to transform care and achieve better population health. Expansion of health information technology and consumer e-health tools—electronic tools and services such as secure e-mail messaging between patients and providers, or mobile health apps—have created new opportunities for individuals to participate actively in monitoring and directing their health and health care. The Office of the National Coordinator for Health Information Technology in the Department of Health and Human Services leads the strategy to increase electronic access to health information, support the development of tools that enable people to take action with that information, and shift attitudes related to the traditional roles of patients and providers. In this article we review recent evidence in support of consumer e-health and present the federal strategy to promote advances in consumer e-health to increase patient engagement, improve individual health, and achieve broader health care system improvements.

Patient-centered care is widely considered one pillar of a high-performing, high-quality health care system. It is a key component of many efforts to transform care and achieve better population health. Engaging patients and their caregivers to play an active role in their health is a critical element of patient-centered care, yet patients are an underused resource in the health care system.

Giving patients both access to their health information and electronic tools for using that information can better position them to participate more fully in their care: to self-manage their conditions, coordinate care across multiple providers, and improve communication with their care teams—those directly involved in their care.

The electronic health record (EHR) and consumer e-health tools are changing the ways in which patients and providers interact. We define consumer e-health as a broad category of electronic tools and services that are primarily consumer oriented but that overlap with health information technology, a term more conventionally used in the context of technology for health care providers.

E-health tools include secure Internet portals to enable patients to access information in their EHRs; personal health records; patient-provider secure e-mail messaging; personal monitoring devices; mobile health apps; and Internet-based resources for health education, information, advice, and peer support. The term consumers encompasses patients, families, and caregivers, regardless of health status, whether or not they are actively receiving health care services.

The full potential of consumer e-health is far from realized and may not even yet be fully understood. However, concurrent advancements in health information technology
adoption by providers, the development of consumer technologies, and national health care policy—combined with broader social changes in consumers’ expectations—have created ideal conditions in which to foster its growth.

The Office of the National Coordinator for Health Information Technology, part of the Department of Health and Human Services, is charged with developing and supporting this movement. The Office of the National Coordinator has primarily focused on supporting the adoption and meaningful use of health information technology by health care providers. However, it also seeks to empower individuals to improve their health and health care through health information technology. The Office of Consumer eHealth at the Office of the National Coordinator leads these efforts.

In this article we review the evidence supporting consumer engagement via e-health as a way to achieve better health and health care; explain why now is a critical time to promote advances in e-health; and outline the federal strategy for doing so.

Why Engage Consumers Via E-Health?

Although additional research in this field is needed, surveys indicate that a majority of both patients and providers support using health information technology to improve patient care and prefer computerized means to share patient information with each other. However, relatively low numbers of patients have asked for their information in an electronic format.

A major obstacle to greater use of health information in electronic form appears to be lack of access, not lack of interest. Whereas 65 percent of U.S. adults in one survey considered online access to their health information important, only 17 percent of patients had online access. Also, 85 percent of participants wanted to communicate with their providers by phone or e-mail, yet only 10 percent had the capability to do so. In another survey, two out of three people said that they would even consider switching to a provider who offers online access.

Most adult consumers of health care in the United States are motivated to take on the role of managing their health and health care and are interested in using e-health tools such as personal health records and EHRs to achieve these goals. When given electronic access to health information, the vast majority of people actually use it.

More-Engaged Patients Get Better Outcomes Many studies have shown that engaged patients—those who actively seek to know more about and manage their own health—are more likely than others to participate in preventive and healthy practices, self-manage their conditions, and achieve better outcomes. An AARP study of patients with chronic conditions, found that the more “activated” patients—that is, those with the knowledge, skills, and confidence essential to managing their own health care—were more than three times less likely to suffer a negative health consequence because of poor communication among providers, more than twice as likely to avoid a readmission to the hospital, and nearly half as likely to experience a medical error compared to less activated ones.

The appeal, reach, and potential of e-health to engage diverse populations appear strong. Despite concerns about the “digital divide,” a 2012 study found that age, education, and income levels are not accurate indicators of patients’ willingness to adopt personal health records. Contrary to stereotypes, 17 percent of seniors use personal health records—the highest proportion of any age group. Use is also relatively common among consumers with chronic conditions, who are also active users of online resources such as discussion forums and chat rooms.

Patient engagement via e-health may be an undervalued tool for reducing health disparities. A recent study suggested that raising patient activation rates among Hispanic Americans to the level of those rates among white Americans would decrease the percentage of unmet medical need within the Hispanic population by about a fifth.

In addition, one national survey showed that low-income, chronically ill people who used personal health records reported a greater sense of connection with their providers and more positive behavior changes than members of other demographic groups.

Growing Evidence Base Supports Consumer Engagement Via E-Health A 2012 report on the evidence for the use of health information technology to enable patient-centered care—improving shared decision making, patient-clinician communication, and access to medical information by patients—found important evidence that these applications have an overall positive effect on several types of health care outcomes. People who use e-health resources feel better prepared for clinical encounters, ask more-relevant questions, know more about their health care, and are more likely to take steps to improve their health, compared to those who do not. The OpenNotes initiative, which gives patients online access to physicians’ visit notes, reported that patients felt more in control
of their care and demonstrated increased medication adherence, while providers’ concerns about increased workload and confused or offended patients were largely unwarranted.7

Use of secure patient-physician e-mail has been associated with improved quality outcomes19 and excellent patient satisfaction.20,21 Personal health records have also proved to be effective tools for increasing use of preventive services,22 improving self-management of blood pressure,23 and controlling blood glucose.24

When patients participate in online health communities, they report gains in knowledge, self-efficacy, and social support. In a survey of members of PatientsLikeMe.com, an online patient community, 76 percent agreed that the site helped them better understand their prognosis, and 59 percent found it helpful in managing symptoms.25

Why Act Now?
Several current trends suggest a strong potential for growth in the area of consumer e-health.

TECHNOLOGY IS RAPIDLY DEMOCRATIZING INFORMATION We anticipate that the trends toward democratization and consumer engagement evident today in areas such as banking, travel planning, and shopping will expand to health care as consumers grow to expect a similar level of access, control, accountability, and transparency related to health services.

Already 80 percent of US Internet users have searched for health information online.26 Patients and caregivers are also finding each other online: 34 percent of Internet users have read about other people’s health and medical experiences online, and 18 percent of Internet users have gone online to find others who share their health condition or concern.24

There is also a recent explosion of new products and services designed to engage consumers by simplifying the collection, integration, analysis, and sharing of health data, bolstered by the proliferation of cheaper, smaller, and faster electronic devices.27

HEALTH INFORMATION TECHNOLOGY ADOPTION IS INCREASING In a recent national study, 72 percent of physicians reported that they had adopted some type of electronic health record system.28 Also, the percentage of hospitals with such systems more than doubled from 16 percent in 2009 to 35 percent in 2011.29

Increased provider use of EHRs—prompted in part by incentive programs—is likely to catalyze consumer engagement as health information becomes more readily available in electronic form and directly accessible to patients. In one study, six of ten consumers without a personal health record reported interest in using one if it were connected to their doctor’s office.15

CONSUMERS’ FINANCIAL RESPONSIBILITY IN HEALTH CARE IS RISING The shift toward new payment models such as bundled payment and accountable care organizations that reward providers based on health outcomes rather than volume of transactions puts a greater emphasis on prevention and wellness relative to sickness care. To achieve that goal, these approaches encourage providers to enlist their patients as partners in care and to use technology to access and analyze information about health care treatments and costs.

The Federal Strategy For Consumer E-Health
The role of the Office of the National Coordinator in advancing consumer e-health is primarily as a catalyst and coordinator, providing incentives and support to others—such as patients, providers, and technology developers—who are at the forefront of furthering consumer engagement via e-health. The office also coordinates federal policies, investments, and activities to advance this goal.

In some cases, such as the Centers for Medicare and Medicaid Services’ EHR Incentive Programs—also known as “meaningful use”—providers must demonstrate that they are engaging patients and family members in their health care in order to qualify for financial incentives to support the adoption of EHRs.

The Office of the National Coordinator has developed the “Three A’s” strategy to fulfill its goal to empower people to improve their health and health care through health information technology. The three prongs of the strategy are to increase patients’ Access to their health information; to enable consumers to take Action with that information; and to shift Attitudes so that patients and providers think and act as partners in managing health and health care using health information technology. These three elements of the strategy are interdependent.

INCREASE ACCESS Of the three strategic elements, the Office of the National Coordinator has the greatest direct influence on consumers’ access to their health data, which it supports through the Medicare and Medicaid EHR Incentive Programs and the Blue Button Pledge Program.

EHR INCENTIVE PROGRAMS (MEANINGFUL USE): The Medicare and Medicaid EHR Incentive Programs provide billions of dollars in financial incentives to eligible professionals and hospitals that demonstrate “meaningful use” of certified EHR technology in specified
ways that improve patient care. Compliance with rules for meaningful use of EHRs is voluntary, and incentives are available only to eligible providers and hospitals. However, the impact of the program is significant. In 2012 two-thirds of office-based physicians reported that they planned to apply, or already had applied, for meaningful-use incentives, and 85 percent of hospitals surveyed indicated that they plan to attest.

Meaningful-use requirements are being developed through several stages. The first stage, effective for hospitals in October 2010 and for eligible professionals in January 2011, required health care providers to give patients paper or electronic access to clinical summaries of their office visits, access to an electronic copy of their health information, and hospital discharge instructions.

The second-stage requirements, effective in October 2013 for hospitals and in January 2014 for eligible physicians, require providers to use secure e-mail with patients and to provide patients with a way to view, download, and transmit their health information to a third party. Under this provision, patients will be able not only to view their health information online, but also to export their data from EHRs in structured and human-readable formats; share those data with others; and use tools and applications to store, analyze, or otherwise make use of their information. The second stage also establishes thresholds for the proportion of patients using these functions, which will encourage providers to promote their use.

For the third stage, the Office of the National Coordinator is exploring ways for providers to incorporate data from patients, including data from remote devices, back into the EHR, and to enable patients to request amendments to their records online.

**Blue Button Pledge Program:** The Blue Button Pledge Program is a voluntary mechanism for supporting consumers’ access to their health data. The Blue Button icon, used in a large community of organizations including those eligible for the EHR Incentive Programs, signals that consumers can download their health data at the site that displays this icon. Clicking the Blue Button icon provides a way for patients to view and download digital health records or insurance claims.

First deployed within the Department of Veterans Affairs in 2010, Blue Button is now used by the Department of Defense; Medicare; and numerous private health insurance providers including Aetna, UnitedHealthcare, and other participants in the Federal Health Employee Benefits program. At the Department of Veterans Affairs, more than one million people have already used Blue Button to download their health data. To help the Office of the National Coordinator and its partners expand Blue Button nationwide, the White House designated Blue Button as one of five high-impact projects and allocated several Presidential Innovation Fellows to support it.

The Blue Button Pledge Program now includes more than 450 organizations that are committed to learning and collaborating in efforts to increase patient access to, and use of, health data. The Pledge Program, launched in 2011, includes “data holders”—such as health care providers and insurers—who pledge to liberate health data, and “non-data holders”—such as software developers and consumer advocacy organizations—who pledge to educate consumers about the value of getting and using their health data.

For example, two organizations—the Alliance for Nursing Informatics and the American Nurses Association—teamed up in 2012 to host “Ask for Your Record Week,” a campaign to encourage nurses to adopt personal health records for themselves and to equip them to talk with patients about their own experiences using e-health.

**Enable Action** Initiatives in this second element of the “Three A’s” support the development of an ecosystem of tools and services that help consumers take action using their health information. The liberation of electronic health information, bolstered by the Office of the National Coordinator’s access-related initiatives, has the potential to create an expanded market for tools that empower patients.

**SUPPORTING DEVELOPERS WHO BUILD E-HEALTH TOOLS:** The Office of the National Coordinator, the White House, and the Department of Veterans Affairs are collaborating to encourage technology developers to build tools that enable consumers to use Blue Button health data, and to grow a new market for these applications. Through the Automate Blue Button Initiative, the Office of the National Coordinator is providing a forum for open collaboration with more than sixty-eight organizations—ranging from Microsoft, GE, and other large corporations to smaller start-ups such as Humetrix and Kinergy—to establish common industry approaches and standards for automatically updated health data, supplied in both machine- and human-readable formats.

In addition, the Office of the National Coordinator is working with other agencies and offices, including the Food and Drug Administration and Federal Trade Commission, to ensure that regulations and policies support innovation of consumer e-health tools and to help innovators better understand relevant
regulatory requirements.

Periodic “challenges” issued by the Office of the National Coordinator reward innovators who develop solutions to specific health information technology or data exchange, presentation, and access obstacles. Recent challenges include a Health Record Design contest that invited designers to rethink how the medical record is presented visually; and a Blue Button Mash-Up Challenge to create mobile applications that combine an individual’s Blue Button health data with other types of data to make the information more usable and meaningful. For example, the winning iBlueButton app includes features such as optimized displays and dashboards, medication look-up, and new tools to download or print health information.

▸Fostering Trust and Protecting Privacy in E-Health Tools: To help consumers understand and compare how companies offering personal health records protect individual health information, the Office of the National Coordinator developed a web-based Model Privacy Notice for personal health records that companies may use to describe their own practices. Similar to a “Nutrition Facts” or “Drug Facts” label, the Model Notice is intended to present complex information about the privacy of health data in an accessible, standardized, and transparent way. Although use of the notice is voluntary, the Federal Trade Commission has authority to make sure that companies engage in actions that are consistent with those they describe via the notice. Microsoft HealthVault and NoMoreClipboard are voluntarily using the Model Notice.

▸Pilot Programs: The Office of the National Coordinator has provided funding to seventeen so-called Beacon communities around the country that are working to increase the use of health information technology to achieve specific population health goals and to evaluate those efforts. Through this program, the office piloted a text-messaging tool called Txt4Health that consumers can use to assess their individual risk of diabetes and guide them in obtaining follow-up care.

The Office of the National Coordinator also conducted a pilot at Geisinger Health System to evaluate the role of patients in improving the accuracy of the information in their medical records. Preliminary findings suggest that patients’ feedback is valuable and does improve the accuracy of the information.

▸Shift Attitudes: This final part of the Three A’s strategy supports the evolution of consumers’ and providers’ expectations about roles relative to each other, leading toward a less hierarchical, more collaborative partnership, enabled by e-health. For example, patients need to feel comfortable requesting electronic access to their health records, asking providers questions, sharing their own health knowledge, and weighing in on treatment options. A cultural shift among patients and providers—is necessary to support these kinds of behavior.

▸Clarifying Patients’ Right to Access Health Information: The Office for Civil Rights in the Department of Health and Human Services recently launched a campaign to build public awareness of individuals’ legal right to access their own health information under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule, in the format in which they request it—including electronic, if available. In May 2012 the Office for Civil Rights released a memo detailing these rights and directing consumers to educational resources.

Failure to respect these rights can lead to substantial fines. For example, one health care provider company, Cigna Health of Maryland, was fined $4.3 million for failing to provide patients with access to their medical records.

▸Educational Resources: The HealthIT.gov website serves as a “one-stop shop” for patients and families to learn about health information technology and e-health tools, and to share experiences about how e-health has benefited real patients. The site also offers a tool kit for organizations to use in their outreach efforts, including an animated video intended to make learning about health information technology fun and accessible.

▸The Power of Storytelling: Just as providers, patients, and families often find valuable health information through peer-to-peer connections, they can also gain insight into health information technology through personal narratives and connections. The Office of the National Coordinator ran a series of video contests throughout 2012 encouraging consumers to share their stories about how health information technology improved their health and increased involvement in their own care.

Conclusion
Growing evidence supports the use of e-health to support consumer engagement to improve health and health care. The Office of the National Coordinator coordinates and catalyzes its growth both within the government and the private sector, capitalizing on the confluence of several trends related to information technology and health care policy, as well as broader social trends in communication and information technology adoption.
In the short term, the Office of the National Coordinator will measure its success in relation to progress on its “Three A’s” strategy, according to the number and proportion of Americans with access to electronic health information, the proliferation and use of tools and apps that enable people to take action using health information, and the extent of changes in attitudes related to the evolving roles of patients and providers. Additional research will be necessary to measure and track these metrics accurately, and the Office of the National Coordinator will collaborate with its partners to define research priorities.

Over the longer term, the success of consumer e-health will be measured according to the extent that it becomes an integral part of health care transformation, contributing to better health, better health care, and lower costs.

In the coming months and years, the Office of the National Coordinator will continue to refine and realize a vision in which the individual patient or consumer is genuinely at the center of his or her own health and health care, supported by health information technology. The work will include diverse stakeholders, including an expanding circle of federal partners.

The Office of the National Coordinator will work to provide the policy and technical building blocks needed to achieve such a vision, by tracking and responding to trends such as the growing role of social media in health, the integration of personalized medicine and genomic data into clinical care, and the analysis and application to health and health care of ever-increasing volumes of data from diverse sources—all through the lens of the individual health care consumer’s needs.

NOTES


information-technology-a-national-survey
32 Medicare and Medicaid Programs; Electronic Health Record Incentive Program—Stage 2. 45 CFR, Sec. 170 (2012).
33 Department of Health and Human Services, Office of the National Coordinator for Health Information Technology. Request for comment regarding the stage 3 definition of meaningful use of electronic health records (EHRs) [Internet]. Washington (DC): ONC; [cited 2012 Dec 20]. Available from: http://www.healthit.gov/sites/default/files/https_stage3_rfc_final.pdf
35 For a list of organizations that have pledged, see HealthIT.gov, Blue Button Pledge Program [Internet]. Washington (DC): Department of Health and Human Services; [cited 2013 Jan 11]. Available from: http://www.healthit.gov/bluebutton
40 ONC and other federal agencies promote these challenges on http://Challenge.gov.
48 Health IT video contests include the Healthy New Year Challenge (http://healthynewyear.challenge.gov/).
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Lygeia Ricciardi

Lygeia Ricciardi is the director of the Office of Consumer eHealth, Office of the National Coordinator for Health Information Technology. In this month’s Health Affairs, Lygeia Ricciardi and coauthors, all with the Office of the National Coordinator for Health Information Technology (ONC) in the Department of Health and Human Services, describe the federal government’s strategy to increase electronic access to health information and use of e-health. The term refers to electronic tools and services such as secure e-mail messaging between patients and providers or mobile health apps that people use to take action on the basis of health information. The authors also review recent evidence in support of consumer e-health as a means of increasing patient engagement and achieving improvements in health and health care at the individual and system levels.

Ricciardi is the director of the Office of Consumer eHealth within the ONC. She established the Consumer eHealth Program and continues to define its strategic and tactical approach. She also supports the development of meaningful-use policy to enable greater patient and family engagement.

Ricciardi has worked to further patient engagement through technology in both the public and private sectors. In the federal government, she served as a policy adviser at the Federal Communications Commission and also provided expert policy input to the Obama administration’s 2008 Transition Team. In the private sector, she was a director of the Markle Foundation’s Health Program and ran her own consulting firm that advised clients, including the State of New York and the Robert Wood Johnson Foundation, on policy and implementation aspects of consumer e-health. She received a master’s degree in technology in education from Harvard University.

Farzad Mostashari

Farzad Mostashari is the national coordinator for health information technology at the ONC. Previously, Mostashari was assistant commissioner for the Primary Care Information Project at the New York City Department of Health and Mental Hygiene. He also led the New York City Center of Excellence in Public Health Informatics, which was funded by the Centers for Disease Control and Prevention, and a project focused on quality measurement at the point of care, which was funded by the Agency for Healthcare Research and Quality.

Mostashari is the founder and past chair of the International Society for Disease Surveillance. He earned a master’s degree in population sciences from Harvard University and a medical degree from Yale University.

Judy Murphy

Judy Murphy is deputy national coordinator for programs and policy at the ONC. She coordinates federal efforts to assist health care providers and organizations in adopting health information technology to improve care. Murphy also works to promote consumers’ greater understanding and use of health information technology for their own health.

Shelby with more than twenty-five years of health informatics experience at Aurora Health Care in Wisconsin, where she led its electronic health record program for more than fifteen years. Murphy earned her bachelor’s degree in nursing from Alverno College.
Jodi Daniel is the director of the Office of Policy and Planning in the ONC, where she leads efforts to inform, develop, and execute health information technology policies to support adoption of electronic health records and to advance electronic health information exchange. Her efforts include overseeing the development of regulations for adoption of standards and criteria for electronic health records, establishment of a health information technology certification program, and governance for a nationwide health information network. Daniel also leads the ONC’s legislative policy efforts and provides health information technology-related technical assistance to Congress. She received a master’s degree in public health from the Johns Hopkins University and a law degree from Georgetown University.

Erin Siminerio is a policy analyst in the Office of Consumer eHealth in the ONC. She plays a key role in the development, articulation, and execution of a strategy for the office’s newly created Consumer eHealth Program. Siminerio is working toward publication of an online, interactive strategic plan for the Office of Consumer eHealth and previously coordinated efforts to update and publish the Federal Health IT Strategic Plan: 2011–2015, a strategy for working with the private and public sectors to improve health and health care for all Americans through the use of information and technology. She also helped lead the development, launch, and ongoing maintenance of the Blue Button Pledge Program, a voluntary initiative that has recruited more than 450 organizations to expand access to and use of electronic health records, and the development of the animated video. Siminerio earned a master’s degree in public health, with a health policy concentration, from the George Washington University.