The Office of the National Coordinator for
Health Information Technology

Issue Brief: Using Health IT to Put the Person at the Center of Their Health and Care by 2020

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What's the Issue?

Today, in many health care settings, an individual is often more of a recipient of health care services than an active partner with their health care providers and care team. This dynamic limits the opportunities for people to manage their own health and to share in care management. Changing the paradigm to a more person-centered vision is vital to improving health and health care outcomes, particularly since the individual's actions have a great impact on health outcomes. Important developments in health policy and practice emphasize the patient as key to improving outcomes and care: patient-centered care, the patient-centered medical home, health reform programs such as pioneer Accountable Care Organizations (ACOs), and others. The emergence of health IT, including consumer eHealth tools, can enable achieving that vision.

What Has Happened So Far?

In the past year, the Office of the National Coordinator for Health Information Technology (ONC) has convened a diverse set of thought leaders across the country through a series of teleconferences and in-person workshops, resulting in a proposed vision statement based on a set of shared values.[1] ONC and other organizations are already hard at work promoting certain aspects of the vision, such as shared decision-making between patients and their care team.

Proposed Vision

ONC is offering a proposed vision of how health IT can support a paradigm shift over the next few years to facilitate effective health management by individuals, their caregivers, and their health care teams. By 2020, ONC envisions that:

> *The power of each individual is developed and unleashed to be active in managing their health and partnering in their health care, enabled by information and technology.*

Core Values

The vision is underpinned by several core values centered on the person:

- Individual self-determination and the public good are both optimized.
- People can decide whether and how much to participate in managing their health and health care.
- People can access wellness and health care services enabled by technology that reflects their individual needs, values, and choices.
- Health care is a partnership between the patient, their caregivers, the care team, and supporting services.
- Information is shared, as appropriate, between the individual and all their care partners to enable informed, participatory decision-making as desired by the individual.
- Everyone who holds information about an individual exercises responsible information stewardship.
- Easily used and useful, trusted tools are available to support the person in self- and shared-management.

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[1] http://www.healthit.gov/policy-researchers-implementers/person-center

Goals

Three overarching goals result from the proposed vision:

> Goal 1: Increased self-management and prevention
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> Goal 2: Seamless interaction with the health care system
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> Goal 3: Shared management of health care

By 2020, technology will more significantly support the goals in the following ways:

Goal 1: Increased self-management and prevention

- Empower and enable individuals to make healthier choices and to manage any health conditions.
- Make prevention part of day-to-day life.
- Motivate policymakers, employers, and other stakeholders to establish guidelines and environments that promote and support healthy behavior and self-management of conditions.

Goal 2: Seamless interaction with the health care system

- Enable smooth, easy interactions and seamless transitions as the individual moves between wellness and self-management activities, and participating in the health care system.
- Soften or erase the boundaries between what occurs inside and outside of the health care system by promoting increased information flow, and empowering people to perform on their own some of the activities that now occur only in formal health care settings.
- Allow "light touches" with the health care system when needed, e.g., interacting remotely in some situations rather than always in-person.

Goal 3: Shared management of health care

- Support more partnering of the person with his or her care team within the health care system through shared decision-making.
- Support and integrate caregivers appropriately into the care team.
- Encourage providers to value patients and their data, viewing them more holistically and longitudinally.

Related Activities

ONC and other organizations have been tackling complex problems in this area and arriving at innovative solutions. Here are some of ONC's current related efforts:

Meaningful Use Stage 2

One objective of the second stage of the Meaningful Use regulations is to provide patients the ability to view online, download and transmit (VDT) their health information within four business days of the information being available to the Eligible Provider (EP). Providing patients an electronic copy of their health information helps them and their caregivers engage more in their care and enables them to identify potential errors or omissions in their records. In addition,

when patients change providers, or even see multiple providers during the same time period, they have the ability to transfer their health information with them, providing care coordination and management.[2] The Blue Button + implementation guidelines for data holders and technology developers support providers in meeting Meaningful Use VDT requirements.

Blue Button

Through the public-private Blue Button initiative, ONC and its partners are increasing consumer access to their clinical and claims-related health information electronically from diverse sources.[3] The voluntary Blue Button Pledge program has 500 organizational members including healthcare provider systems, health insurance providers, labs, and retail pharmacies whose customers include the majority of Americans. In 2013, ONC convened focus groups, did consumer testing, and developed a set of public service announcement (PSA) videos and posters on Blue Button customized to three diverse population groups, and secured commitments from influential organizations to distribute these materials in 2014.   ONC also increased the ability of consumers to take action with their data by releasing the Blue Button + technical guidelines for data holders and developers that enable the structured sharing of data with consumers and the tools and services they designate. The Blue Button + guidelines have been piloted in six sites, and there are now 17 consumer apps that accept Blue Button + structured data, due in large part to the ONC challenges described below.

Consumer eHealth Program

Through its Office of Consumer eHealth (OCeH), ONC catalyzes, coordinates, and inspires others in support of consumer engagement via eHealth by influencing policy and standards development, convening diverse stakeholders, and providing thought leadership through writing and public speaking. OCeH's efforts span its "three A's" strategy for consumer engagement via eHealth: provide *access* to information; make information *actionable* via apps and tools; and promote a change in *attitudes* regarding consumer and provider roles. OCeH works closely with several other offices at ONC (including the Office of Policy and Planning), federal partners, and members of the private sector on a variety of activities.

Federal Advisory Committee Workgroups

Two workgroups made up of volunteer subject matter experts, the Health Information Technology Policy Committee's (HITPC) Consumer Empowerment Workgroup and the Health Information Technology Standards Committee's (HITSC) Consumer Technology Workgroup, are in the process of making recommendations to ONC about how to support the use of patient-generated health data (PGHD) in the next stage of meaningful use of electronic health records (EHRs). A third workgroup, the HITPC Accountable Care Workgroup, plans to consider how to increase patient activation as a member of a defined care team, engage patients in assessments of their health, and use technology to deliver care to patients outside of traditional care settings.

Investing in Innovation ("i2") Program

ONC created the Investing in Innovation ("i2") program to award prizes competitively to stimulate innovation. The competitions offered by this program, also referred to as health IT developer contests, focus on innovations that support (1) the goals of HITECH and clearing

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[2] http://www.healthit.gov/providers-professionals/achieve-meaningful-use/core-measures-2/patient-ability-electronically-view-download-transmit-vdt-health-information

[3] Ricciardi L, Mostashari F, Murphy J, Daniel J, and Siminerio E. A National Action Plan to Support Consumer Engagement Via E-Health. Health Affairs 2013; 32:376-384.

hurdles related to the achievement of widespread health IT adoption and meaningful use, (2) ONC's and HHS' programs and programmatic goals, and (3) the achievement of a nationwide learning health system that improves quality, safety, and/or efficiency of health care.[4] A recent challenge tasked developers with creating apps that implement and use Blue Button + functionality to address one of several patient problems. ONC believes that widespread adoption of Blue Button + technology specification by app developers and providers will make patient data much more accessible on their most frequently used devices while maintaining strict privacy and security of that data.[5] Through the challenges, ONC has spurred industry innovation in consumer eHealth, including the development of apps that use Blue Button + structured data, of which there are now more than 17.

Patient Centered Outcomes Research (PCOR)

The Affordable Care Act of 2010 directs the U.S. Department of Health and Human Services (HHS) to build data capacity for patient-centered outcomes research (PCOR), and makes available a cumulative estimated total of almost $200 million between FY 2011 and FY 2019 for this purpose through the Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS PCORTF). The Office of the Assistant Secretary for Planning and Evaluation (ASPE) coordinates this effort and has partnered with the ONC as well as other HHS agencies to develop a strategy to maximize the OS PCORTF's impact. Funding from the OS PCORTF is expected to result in the development of a comprehensive, interoperable and sustainable PCOR data network infrastructure. Ultimately, a PCOR data infrastructure is expected to facilitate research that will generate knowledge for evidence-based decision making for health care and empower patients to make informed decisions related to the specific health outcomes they seek.[6]

Patient-Generated Health Data

Patient-generated health data are health-related data—including health history, symptoms, biometric data, treatment history, lifestyle choices, and other information—created, recorded, gathered, or inferred by or from patients or their designees (i.e., care partners or those who assist them) to help address a health concern. PGHD are distinct from data generated in clinical settings and through encounters with providers in two important ways. First, patients, not providers, are primarily responsible for capturing or recording these data. Second, patients direct the sharing or distributing of these data to health care providers and other stakeholders.[7] There are no widely established policies and practices to define the optimal use of PGHD, much less support it. A framework of policies and good practices can help to successfully engage physicians and patients and ensure the privacy, security, and appropriate use of PGHD. ONC has initiated several activities to advance knowledge of the field and identify policies and promising practices to support it.

Personalized Health Care

While the concept of personalized health care (PHC) is not new, genomic, proteomic, and other discoveries are accelerating the tailoring of patient treatments, risk assessment, and diagnostic reasoning. The 2008 publication of the Priorities for Personalized Medicine report to the

[4] http://www.healthit.gov/policy-researchers-implementers/health-it-prizes-challenges
[5] http://www.healthit.gov/buzz-blog/health-innovation/onc-announces-winners-blue-button-challenge
[6] Request for Proposals #13-233-SOL-00295 for HHS Office of the Secretary Patient-Centered Outcomes Research Trust Fund: Strategic Opportunities for Building a Patient-Centered Outcomes Research Data Infrastructure. March 2013.
[7] Shapiro M, Johnston D, Wald J and Mon D. Patient-Generated Health Data: White Paper Prepared for the Office of the National Coordinator for Health IT by RTI International. April 2012. Available at http://www.rti.org/pubs/patientgeneratedhealthdata.pdf.

President's Council of Advisors on Science and Technology (PCAST) described personalized medicine as "the tailoring of medical treatment to the specific characteristics of each patient… [involving]… the ability to classify individuals into subpopulations that are uniquely or disproportionately susceptible to a particular disease or responsive to a specific treatment."[8] The use of health IT can support shared decision-making and increased communication in clinical practice, helping providers and patients to manage and use patient-specific information. In 2012, ONC conducted some initial research on PHC to better understand the current landscape and the definition of the topic. As a result, challenges were identified and health IT-related policy areas are under consideration.

What Are the Opportunities?

As public sector agencies develop their strategic plans and health reform begins to change how providers and patients interact, there are opportunities for a more person-centered paradigm to take hold. As stated above, new innovative applications (apps), advances in personalized health care, and increased use of patient-generated health data are enabling more health and care management activities to take place outside traditional care settings. The government can help coordinate and provide a platform to call attention to these efforts while stimulating innovation that leads to a brighter, more inclusive future.

Through ONC's discussions with experts, several strategic policy areas have emerged where progress can be made in both the public and private sectors in the coming years. While comprehensive, the following list of potential activities by policy area is not all-inclusive.

Access

- Make up to date, comprehensive, accurate, and actionable information about a patient easily accessible and usable by the patient (including designated caregivers) and providers. This may include access to data from traditional clinical sources in addition to data from new sources, such as retail pharmacies and state immunization registries.
- Make information, informed advice, testing and care available to individuals, caregivers, and health professionals when they need it through diverse channels.
- Customize practices to address a patient's desired level of privacy.

Use of Data

- Promote technology that shows trends in diverse health status measures, including deviations from normal for the given individual.
- Facilitate the aggregation of health and health care information for individuals and populations from diverse sources, including non-clinical information if desired.
- Promote policies and technologies that enable the inclusion of patient-generated health data in the medical record while meeting HIPAA requirements and identifying data provenance, and addressing related concerns (e.g., provider liability).

Integration with Life

- Promote easy-to-use technologies that integrate individuals' health activities and treatment into the rest of their lives, where and how they already live, work, and play.

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[8] PCAST. Priorities for Personalized Medicine. President's Council of Advisors on Science and Technology; 2008.

- Develop and/or accommodate diverse locations and mechanisms for delivering preventive services.
- Enable individuals to make light touches with the health care system as needed, rather than interacting only during formal encounters for episodic care. For example, a patient or caregiver could communicate electronically with their provider to obtain advice about side effects the patient is experiencing from a prescribed medication.

Communication

- Enable easy communication between individuals and providers with appropriate triage and documentation of health conditions.
- Clarify roles and responsibilities for individuals (and their caregivers) for their interactions with the health care system that reflect their desires, abilities, and needs; mutually set expectations with health care providers.
- Encourage interaction in online communities via social media.

Learning

- Promote technology that supports healthy choices and behavior in ways that have been proven effective.
- Empower individuals to understand their options and to act on their preferences and values as they make choices about their health and health care. Conduct research on self-management and caregiving to guide efforts to support and strengthen these activities.
- Promote the development and use of trusted, curated health content that can be accessed electronically by individuals and caregivers.
- Build appreciation for and competence in technology-enabled self- and shared management of health and health care, by both providers and individuals.

Partnering with Care Team

- Encourage shared decision-making and partnering between the individual, their caregiver, and their care team.
- Enable sharing of data as desired by the individual.

What Are the Challenges?

Achieving the vision of enabling individuals to be active in managing their health and partnering in their health care is a complex undertaking that will occur over a long period of time. Yet it is crucial to realizing the full benefits of health reform efforts. Changes in payment models and acceptance of technological advances will alter existing models of care. It is unknown if consumers and providers will fully embrace the resulting cultural shift. ONC is optimistic that stakeholders will rise to these challenges and will realize the vision for improved health outcomes.

What's Next?

Planning is underway for future activities to further develop the health IT policy framework outlined in the white paper, enhance the visibility of this topic, promote nationwide dialog, and catalyze change among stakeholders involved in the health of the U.S. population.