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Consumer Engagement in Health IT: Distinguishing Rhetoric from Reality

Marsha Gold

Senior Fellow Emeritus, Mathematica Policy Research, MarshaRGold@gmail.com

Mynti Hossain

Mathematica Policy Research, MHossain@Mathematica-mpr.com

Amy Mangum

Mathematica Policy Research, AMangum@Mathematica-MPR.cm

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Conclusions and Policy Implications. There is a gap between current reality and the goals for consumer engagement. Actions that may help bridge this gap include: (1) resolving technical barriers to health information exchange (HIE); (2) developing more consumer-centric design and functionality; (3) reinforcing incentives that attract provider support by showing that consumer engagement is in their interest; and (4) building a stronger empirical case to convince decision makers that consumer engagement will lead to better care, improved health outcomes, and lower costs.

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Keywords

Health Information Technology, Patient Engagement, Health Delivery Reform, Patient Centered Health Care

Disciplines

Health Information Technology | Medicine and Health Sciences | Social and Behavioral Sciences

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Marsha Gold, ScD; Mynti Hossain, MPP; Amy Mangum, MSPH¹

ABSTRACT

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Current Reality and Barriers: Our environmental scan shows that consumer demand exists for electronic access to personal health information, but that technical and system or political barriers still limit the value of the available information and its potential benefits.

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¹Mathematica Policy Research

Introduction

In this article, we first examine how consumer engagement bears upon the overall success of the Health Information Technology for Economic and Clinical Health (HITECH) Act in the broader context of goals for health reform.¹ We then assess the current reality of consumer access and use of electronic health information, and the most significant barriers to progress. Finally, we identify strategies that may help to bridge rhetoric and reality. The paper is part of our work for the Office of the National Coordinator for Health Information Technology (ONC) in providing a global assessment of the HITECH Act.² It is based on an environmental scan using two sources of information: (1) a review of academic and gray literature, including published articles, government documents policy reports and other relevant information; and (2) interviews with 11 national leaders active in this area and discussion of relevant policies with ONC staff. Additional details on these methods are included in an Appendix.³

Background on HITECH and the Role of Consumer Engagement

The HITECH Act

HITECH is a major federal health policy initiative seeking to promote the use of electronic health information as one tool to reform the delivery of health care and improve health outcomes. HITECH provided incentives and support for providers to adopt EHRs and allow such information to be exchanged electronically to support the “meaningful use” of health information.⁴ One key provision provided up to \$27 billion in Medicare and federal Medicaid payments over 10 years to eligible providers who adopted federally certified EHR systems and attested to meeting requirements for their use. Such Meaningful Use requirements were envisioned to evolve in three stages, becoming

increasingly sophisticated over time as capacity grew.⁵ To achieve its goals, HITECH also appropriated funds for a number of grant programs designed to support providers in adopting EHRs and to help states promote health information exchange (HIE).

While HITECH preceded the Patient Protection and Affordable Care Act of 2010 (ACA), HITECH anticipated the ACA and sought to develop digitized health information regarded as important to reforming health care delivery.^{6,7} The ACA reinforced and provided resources for a broader national health strategy. It also funded new organizations with authority to reform delivery and payment through the Center for Medicare and Medicaid Innovations (CMMI) and to generate and disseminate evidence on effective health care—the Patient Centered Outcomes Research Institute (PCORI).

HITECH and Consumer Engagement

Work on health information technology (health IT) is now shifting from building digital capacity—electronic health records (EHRs)—toward facilitating better exchange and use of that capacity to achieve national health goals for “better care, smarter spending, and healthier people.”⁸ To achieve this goal, both providers and consumers need to make meaningful use of health information to improve health care (Figure 1). While many have discussed the role of payment reform and the use of performance metrics to incentivize changes in health care delivery that are viewed as critical for addressing national health goals,^{9,10,11} considerably less attention has been given to the role of consumer engagement in the process. The Federal Health IT Strategic Plan for FY 2011–2015 includes as one of its five goals “empowering individuals with health IT to improve their health and the health system”; the FY 2015–2020 plan reinforces this concept through an expanded focus that also includes families, caregivers, and communities.

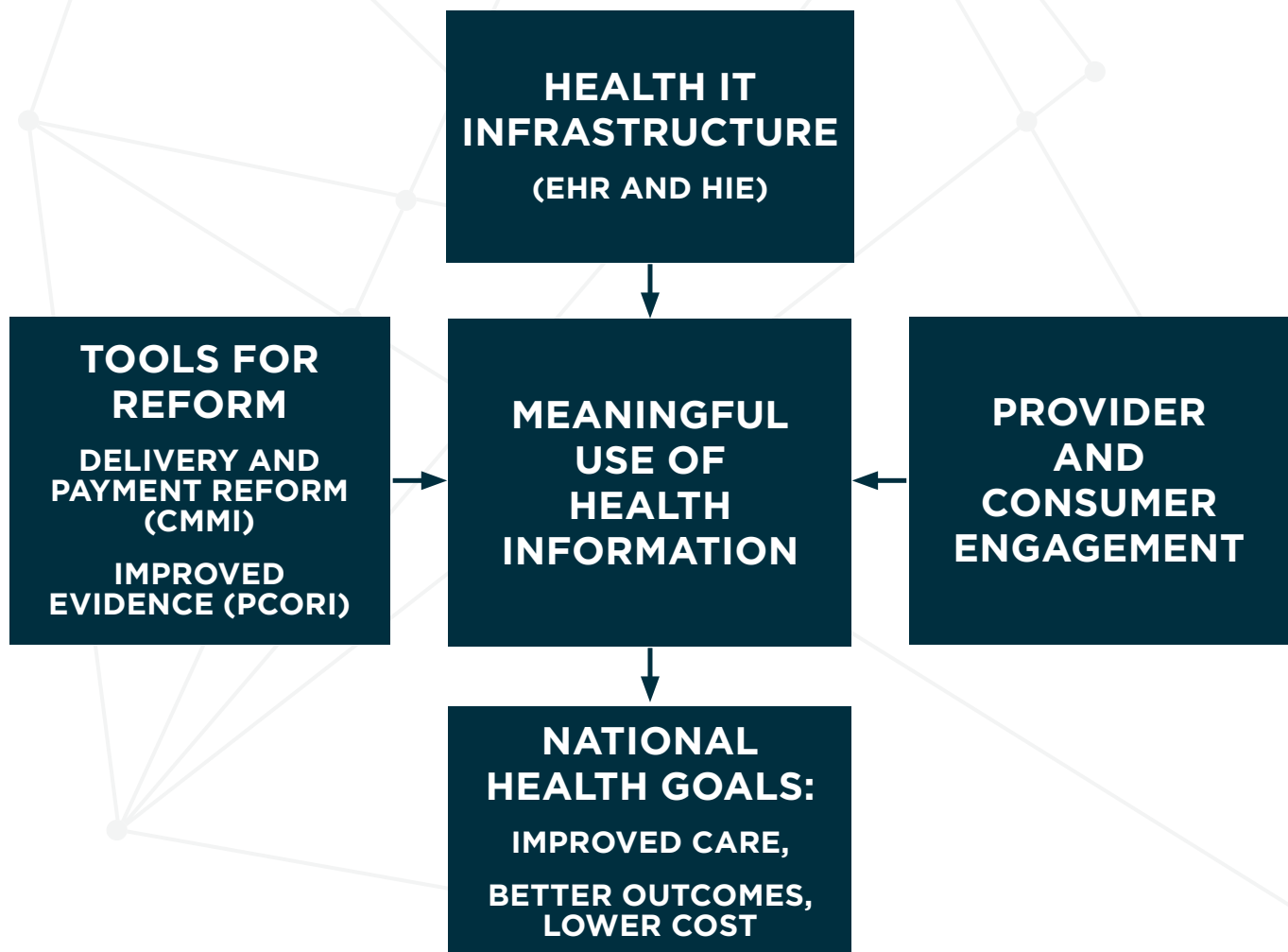


Despite years of discussion, there is no commonly agreed-upon definition of consumer engagement, or even consensus on the specific term that should be employed to describe it (Table 1). However, a core element involves greater consideration of the needs and preferences of patients in health care decisions at the individual, organizational, and policy levels.^{12,13} Ricciardi et al. (2013) have proposed a national action plan to advance consumer use of health IT as a means of increasing patient engagement and

improving individual health outcomes and health care delivery.¹⁴ Similarly, Bechtel and Ness (2010) have articulated how consumer engagement is key to a truly patient-centered care system.^{15,16}

This paper focuses on using health IT to further this type of consumer engagement. Strategies to enhance consumer engagement through health IT are intended to reinforce the process of transformation. Improved access to personal health information can enable consumers to consult with

Figure 1. Where Consumer Engagement through Through Health IT “Fits” In in Achieving National Health Goals



Notes: (1) The HITECH provisions of the American Recovery and Restoration Act of 2009 encouraged development of EHRs and HIE to support meaningful use of health information to improve health outcomes in a variety of ways.⁴ Both provider and consumer engagement is critical to this process. Consumer engagement involves access to information, action, and (changes in) attitude.¹⁴ (2) Health IT was meant to complement broader health reform later through the Patient Protection and Affordable Care Act of 2010 (ACA). The ACA reinforced and provided resources for a broader national health strategy. It also funded new organizations with authority to reform delivery and payment through the Center for Medicare and Medicaid Innovations (CMMI) and to generate and dissemination evidence on effective health care—the Patient Centered Outcomes Research Institute (PCORI).

Table 1. Selected Definitions Relevant to Consumer Engagement and Health IT

¹**Carman et al. (2013)**⁶⁴: Patients, their representatives, and health professionals work in active partnership across various levels of the health system—direct care, organizational design and governance, and policy making—to improve health and health care.

²**Center for Advancing Health (2014)**⁶⁵: Patient engagement encompasses actions people take to support their health and benefit from their health care.

³**Institute of Medicine (2012)**⁶⁶: Patient-centered care is providing care that is respectful and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all decisions.

⁴**Telford et al. (2002)**⁶⁷: While the British National Health Service expects consumer involvement in the research process, there is no agreement in the literature on the use of the term. Common descriptors include the terms “patient,” “client,” “user,” “service user,” and “lay person.” Language also reflects values, with some terms reflecting a market orientation and others a link to citizenship and issues of empowerment.

⁵**Washington (2014)**⁶⁸: Patient engagement focuses on patients when they are dealing with illness or health challenges, whereas consumer engagement is a broader concept that involves engaging health care consumers while they are maintaining their own health and caring for others.

providers and take actions to improve their health, consistent with their needs and values. Goals include an increase in self-management and prevention, support for seamless interaction with the health care system, and shared management of health care.¹⁷ Some analysts believe that for this to occur, there needs to be a shift in consumers’ and providers’ attitudes toward less hierarchical, more collaborative partnerships between patients and providers, enabled by health IT.¹⁸ However, as we show below, there are considerable gaps between the rhetoric of consumer engagement and current reality.

Current Reality

Salience of Consumer Engagement

A wide variety of stakeholders agree that consumer engagement is now a salient issue. In its 2014 national survey, the National Partnership for Women and Families found that patients believe EHRs are

important; feel online access to health information can positively affect their health and make health care access more convenient; want to communicate and share information with their providers, as well as their families and caregivers; and see such information as useful in care planning (Table 2).¹⁹ In its five-year review of HITECH progress and opportunities, the Consumer Partnership for eHealth concluded that “health information is beginning to improve the health care experiences of patients and families,” affecting health care, consumer access to information, and consumer presence at the policy decision table.²⁰

Key stakeholder groups have launched initiatives to help their members respond to the interest in consumer engagement. For example, to help its member providers and vendors, the Healthcare Information and Management Systems Society (HIMSS) launched a new provider-patient



Table 2. Summary of Key Findings and Recommended Strategies: 2014 Consumer Survey on Health IT Value and Use by the National Partnership for Women and Families

AREA	KEY FINDING	KEY STRATEGY
1. Adopt and Use EHRs	Patients believe that EHRs have far greater impact and usefulness for themselves and their providers than paper record systems across a range of domains.	Providers across the continuum should continue to adopt and use EHRs to improve patient care, experience, access, and use.
2. Convenience Features	Patients find “convenience” features—such as online scheduling, medication refill requests, and avoiding repeatedly filling out forms—to be very beneficial, just as they do access to their health information.	Integrate “convenience” features as powerful tools that can enhance a patient’s comfort with and use of health IT and online access.
3. Online Access to Personal Health Data	Easy, useful electronic access to health information is a catalyst for engaging patients and families in patients’ care. Patients who use online access more frequently report a substantial increase in positive impact on knowledge of their health and desire to do something to improve it.	Strengthen initiatives to provide and increase the frequency of online access.
4. Electronic Communication and Information Sharing	Patients want to communicate and share information with their various providers electronically, as well as with family members and other caregivers.	Develop and integrate the various functionalities that allow patients to share their relevant health data with providers, and allow providers to incorporate and use patient data—such as family health history, medical device data, and data on the social and environmental determinants of health.
5. Health and Care Planning	Patients want to use health IT to help manage and plan their health and care (following treatment instructions, taking medications, tracking progress toward health goals, and so on) but they want even more advanced health IT functionality than currently is available.	Develop and integrate robust functionality to support patients’ efforts to manage their own care and health or that of a loved one.

Source: Text taken from National Partnership for Women and Families. Engaging patients and families: how consumers value and use health IT. Washington; December 2014. Findings based on Harris Poll online Survey between April 22 and May 7, 2014 of 2,045 adults who had an ongoing relationship with a physician and knew whether that physician had an electronic or paper record. The survey oversampled Latino or Hispanic, Black or African American, and Asian American adults. The report indicates that the data were weighted to reflect national adult population demographics and represent 68 percent of adults.

Table 2. Summary of Key Findings and Recommended Strategies: 2014 Consumer Survey on Health IT Value and Use by the National Partnership for Women and Families (Cont'd)

AREA	KEY FINDING	KEY STRATEGY
6. Privacy and Trust	The more that patients experience the benefits of EHRs and online access, the more they trust that the providers using these features can protect patients' privacy; in turn, the more they trust that their privacy is protected, the more they use and benefit from EHRs.	Engage and educate patients about why and how patients' health information is stored, exchanged, used, and protected.
7. Designing and Building for Diversity	The value and use of EHRs and electronic HIE are not the same for everyone, including communities of color, people with disabilities, LGBT individuals, and people who speak languages other than English.	Build and implement diverse functionalities to engage patients in a variety of ways.

Source: Text taken from National Partnership for Women and Families. Engaging patients and families: how consumers value and use health IT. Washington; December 2014. Findings based on Harris Poll online Survey between April 22 and May 7, 2014 of 2,045 adults who had an ongoing relationship with a physician and knew whether that physician had an electronic or paper record. The survey oversampled Latino or Hispanic, Black or African American, and Asian American adults. The report indicates that the data were weighted to reflect national adult population demographics and represent 68 percent of adults.

Note: For Area 7, the findings show that all ethnic groups indicate that they find EHRs significantly more useful and helpful than paper records.

community of practice in fall 2013, the American Health Information Management Association (AHIMA) has developed best principles focused on what health information management professionals can do to support consumer and patient engagement, and the American Medical Association (AMA) has emphasized benefits to caregivers and patients as part of its rationale for improving EHR usability.^{21,22}

Many of these efforts also appear to be at an early stage, however. The National eHealth Collaborative surveyed their Learning Network members and found that, although members view consumer engagement in health IT as of "high" or "very high" importance, few said they had well-defined strategies to integrate this concept into their operations.²³

Consumer Access to Personal Health Information

HITECH did not change the fundamental right of consumers to access their health records (they already had this right), but it made that right more visible and real. Although EHR adoption and usability still remains an issue for many health professionals, HITECH has meant that more health information is digitized, making it easier for consumers to access their information.

Under HITECH, eligible providers who wish to receive Meaningful Use incentive payments must meet certain requirements, which become increasingly stringent in three stages. Though Stage 1 Meaningful Use requirements gave patients access to clinical use summaries (whether paper or electronic), our work suggests that Stage 2 requirements now being



implemented are of greater relevance to consumer engagement.²⁴ National leaders who we interviewed said Stage 2 requirements were particularly critical—providers must use secure email when communicating with patients and provide a way for them to view, download, and transmit their health information to a third party. A leader in the group health benefits purchasing community characterized the capacity to view, download, and transmit data as reinforcing “the underlying construct that everyone has a right to access their information, something that looking back 5 or 10 years was not on the radar” and is a “huge” and major change in “consciousness and functionality.” Consumer leaders interviewed said they also were looking forward to potential Stage 3 requirements that would support an increase in two-way communication, allowing consumers more ability to correct and add personal health information to their EHRs.²⁵ Proposed Stage 3 requirements, released since our interviews, strengthen metrics for assessing compliance with online access requirements for consumers; give providers an option to use two-way communication with consumers; offer more flexibility in the applications used to support download, transmit, and exchange requirements; and extend the definition of consumers to their family members and care givers.²⁶ As will be discussed however, stage 3 requirements generally, and consumer engagement requirements specifically, have proven controversial, leaving the final status of future Meaningful Use requirements uncertain.

Recent amendments to the Clinical Laboratory Improvement Amendments (CLIA) regulations and the Health Insurance Portability and Accountability Act (HIPAA) privacy rule also strengthen patients’ rights to access their information electronically and give consumers direct access to their laboratory test data, thus addressing inconsistencies in state regulatory requirements that previously served as a

barrier; most interviewees thought it was too soon to know the importance of these amendments. Federal staff noted that whereas HITECH did not change HIPAA privacy protections, it included more funding for them to conduct outreach for those requirements and to better oversee HIPAA privacy protections. Surveys have shown that consumers are concerned about privacy, though such concerns are mitigated as consumers experience benefits from receiving their health information and better understand how providers protect this information.^{27,28}

Inconsistencies exist between intent and reality, however. In 2013, only 30 percent of physicians surveyed nationally said they routinely used capabilities for secure messaging with patients, and 24 percent routinely provided patients with the ability to view online, download, or transmit their health data.²⁹ In that year (which predated Stage 2 Meaningful Use requirements), only one in three consumers nationwide said they were offered online access to their information. In addition, one-third experienced at least one of five gaps in HIE, which required them to provide a new medical history because the provider had not gotten it from another provider, bring radiology reports to the appointment, wait unreasonably long for laboratory tests, verbally repeat their medical history because the chart could not be found, or redo a test or procedure because the results could not be found.³⁰ There also are historical problems with providers not acknowledging receipt of abnormal findings or communicating them to patients in a timely fashion.³¹ The extent to which this occurs could be reduced if patients have direct access to their information, though experienced providers say this will require improving test results management systems so that they allow better tracking and visualization of test results.³²

These findings predate Stage 2 requirements, so presumably gaps will be reduced as stage 2 requirements are implemented. However, progress

is slow. The ability of patients to access their health information, especially outside of large health systems, has been limited; and attestation to Stage 2 Meaningful Use requirements, particularly among physicians, is still low.³³

Yet as many providers struggle to meet current requirements, some are moving ahead and implementing advanced functionalities proposed for Stage 3—such as support for patient-generated corrections to records—finding them operationally feasible and valuable.³⁴

Consumer Use of Personal Health Information

Whereas consumers still face barriers to having their health information easily accessible, evidence suggests they generally respond well when given the opportunity to gain such access online. National survey data show that, of those offered online access to their personal health data, 46 percent viewed them at least once; most of them thought access was either very or somewhat useful, even if they had not needed or used it.³⁵ A more recent national survey yielded similar findings across a diversity of consumer subgroups.³⁶ This survey found consumers believe access has had a positive impact, most commonly on knowledge of their health and ability to communicate with a doctor. Targeted studies of health systems that adopted online access early on found that full health record access is empowering to patients and has helped consumers become better informed, understand their health history, monitor their laboratory results, and improve their understanding of medications.^{31,32,33} Studies also show that online access is feasible and well received by patients in settings more decentralized than the large integrated health systems commonly studied.³⁷ High adoption rates also have been found in systems focused on health centers and serving largely low-income patients; racial disparities in portal access exist but are smaller than those reported elsewhere.³⁸

Consumer focus groups suggest, however, that existing portals can be difficult to navigate and are not integrated across all providers, even though consumer support for these efforts remains high.³⁹ Unfortunately, literature reviews on studies of patient acceptance of health IT are dated, and they also found big gaps in knowledge available in this area; most studies focused on patient factors affecting acceptance, rather than human technology interaction, organizational factors, or environment.⁴⁰

Provider Attitudes and Response to Consumer Engagement

Solid evidence on current provider acceptance of giving patients access to their personal health information is lacking or dated, but available information suggests that provider responses vary with their experience.⁴¹ A pre-HITECH 2008–2009 survey of physician willingness to use patients' EHRs found that only a minority of physicians had such experience, though more would be willing to try.⁴² Physicians who thought such use would improve quality of care were more willing to use this information. Those who had experience with these tools were less concerned about patient access to information but also less certain that such access would empower patients.

Interviewees with experience in this area generally worked in large integrated health care systems. They said that primary care physicians in their systems showed good acceptance of such tools, though this was perhaps less true of specialists and older physicians. One physician with experience in using patient portals said:

I don't know who could be opposed to patients being more engaged. The question is how do you engage and how can health IT be used to help do that? [As a primary care physician] the portal can be incredibly valuable and useful if used well and well integrated into a physician's



work and into the patient's life...I think the challenges are related to how it's integrated into the workflow from the provider's point of view.

Unfortunately, providers have expressed dissatisfaction with the usability of current EHRs and the content and pace of Meaningful Use requirements.^{40,41,42} The backlash has lessened the physician community's support for requirements that expand patient access to their health information and has led to calls to make many consumer-oriented Meaningful Use requirements optional.^{43,44} While some studies find that enabling patient access does not necessarily increase workload,⁴⁵ it seems likely that a sizeable share of physicians remains concerned about the operational feasibility and workload demands such changes generate. Despite increased attention to consumer engagement, most stakeholders probably would agree that the health system overall, and HITECH in particular, is still focused on the needs and perspectives of providers. Thus, providers seem concerned about patient needs and preferences but may lack the commitment that signals a willingness to change and transform the way they relate to patients.

Barriers to Enhanced Consumer Engagement

The existing literature cites a wide variety of factors as impediments to enhanced consumer access to information, including the following: *patient factors* (lack of knowledge of options, variable interest, low health and IT literacy), *technology factors* (poor functionality and user-centric design, limited interoperability and use of common standards), and *system or political factors* (limited provider support, payment systems that do not incentivize such engagement, concern about return on investment).^{46,47}

From interviews, it seems that although all three factors are important, the most immediate barriers skew more toward supply (technology factors, system or political factors) than demand (patient factors). As one interviewee noted:

It's hard [for consumers] to imagine a void... If you asked me 10 years ago if I'd be happily checking my phone to see where my luggage was on Delta's app, I'd say "No way."

Surveys suggest that consumer interest in health IT exists and that, when given the option to access their health information, many consumers do so even though the available tools often are inadequate or frustrating. (see Table 2).

Our interviewees seem to agree with the merits of focusing on supply-side barriers to consumer engagement in health IT. When asked to name one policy initiative they would push in the area of consumer engagement in health IT, interviewees' suggestions all related to supply factors. Half of the national leaders interviewed cited a policy involving continued work on provider payment reform because, as one interviewee said "that powers so many other things." Of the other interviewees, all but one cited pushing for enhanced standards, interoperability, and other means of making consumer information more accessible, user friendly, and pertinent to a consumer's life.

Technical Barriers to Exchange

Interoperability is an issue for both consumers and providers. Because the formats in which data are kept or made available are not standardized across providers, consumers receiving care from providers using multiple systems (as most do) cannot easily go to a single location to access all of their health information. The federal "Blue Button" initiative attempts to address this problem by getting

organizations that have health data to commit to making it easier for patients to access it electronically and to encourage its use.^{48,49} The Departments of Veterans Affairs (VA) and Defense and Health and Human Services are among those who have committed to making information available to patients. Although many providers claim to support Blue Button, challenges still exist for patients seeking to aggregate and reconcile their health data from various sources. The individuals we interviewed perceived that most consumers treated outside of systems like the VA rely on individual provider portals to access their health information, making it challenging for consumers needing to access multiple portals to download, aggregate, and interpret their personal health information. One interviewee characterized the resulting challenges as follows:

[Considering] any provider who is offering portals, it's a messy disjointed record you are getting. There is no one place you can go to download your longitudinal health record...It's a great start and it's important and it whets the consumers' appetite for what is available, but the frustration is that people are expecting one thing when they click the button and it may or may not be what they want to see.

An interviewee from an advanced system agreed, saying:

Our ability to have a portal is limited because of our legacy system and the use by beneficiaries is low because the user interface isn't so good [but] as we give additional access, demand continues to grow. For example, we can provide a historical record but it's a giant PDF. We can give them the data but it's not user friendly.

Although interviewees backed Blue Button conceptually as part of their overall support for the view, download, and transmit functionality, they said the data included are limited and cumbersome

to access. Some questioned the appropriate paradigm to achieve interoperability. They feared that traditional patient portals and personal health records rely on "old technology" and lack the ease or functionality possible with application program interface (API) technology; health IT developers lacking host program technologies can find this easily and use it at no charge. Proposed rules for Stage 3 Meaningful Use payments begin to address this concern.

Although consumer and provider interests in interoperability converge, these two groups do not necessarily have the same needs and functionality requirements, and their workflow requirements differ. Pressure could build to deal first with providers' immediate concerns for strengthening functionalities important to them before investing in consumer priorities. However, interoperability built around providers' needs may not necessarily be structured to easily support the functionalities consumers perceive as important, like the ability to download all of their personal health information from one site in a form that is useable to them.

Weaknesses in Consumer-Centric Design and Usability

Interviewees stressed the distinction between data and information. Although not ignoring barriers created by variation across population subgroups' health and IT literacy, several interviewees suggested it was incumbent on developers of health IT products to address these barriers with user-centric designs that allow use to be more intuitive, as in some other consumer technology (e.g., smartphones). While there are many issues with lab testing reporting (such as lack of uniformity in reference codes), such reporting also provides one example of how interpretation of technical results can be improved by putting findings in a context that allows consumers to understand their meaning



and any desirable follow-up. As one interviewee noted, “If we share medical records with people, we need to figure out a way to put them in terms so that they’re accessible to people across the range of health literacy”—arguing, as another termed it, for “plain language” and simplicity of writing that patients find accessible.

The diversity of consumers’ needs, information preferences, and personal characteristics that influence health and health IT literacy makes the issue of consumer-centric design and usability particularly challenging.⁵⁰ Interviewees provided a number of suggestions as to how to address this diversity, including presenting information in ways accessible to the least sophisticated consumer or asking users to choose whether they wanted to obtain information in a basic, intermediate, or advanced form. They also noted that health needs vary, making information more salient to certain consumers or at particular points in time. For example, those with complex conditions or an immediate need to make a decision on treatment could be priorities for outreach. As one interviewee experienced in shared decision-making noted “Most people don’t want to be medicalized when they’re not facing something [specific].”

Making health IT usable for consumers also means incorporating interfaces with at least some mobile apps. As one interviewee explained, a segment of the consumer population is interacting with the Internet through mobile technologies, which ease access to information. Even though apps vary in quality, it would be valuable to allow the best of them to connect with EHRs.

Uneven Provider Support for Consumer Engagement

Interviewees differed in their views about the importance of provider support for consumer engagement. Generally, most acknowledged that without provider support, some tools for consumer

engagement (like consumer portals) might not exist and others may go unused (such as those enabled by patient-generated health data). Interviewees differed on the importance of provider support in motivating consumers to use such information when it was available, noting that this support might be more relevant to some consumers’ actions than to those of other consumers. For example, interviewees said older patients may be more likely to look to physicians for direction compared with younger people who grew up in a mobile environment and are used to initiating their own searches for information.

One consumer-focused interviewee noted, “We’re trying to create a partnership where we keep asking patients to be more engaged and empowered, but if we don’t welcome them into that role, that won’t work.” As this person viewed the situation:

Providers today are a mixed bag, with some perceiving consumer engagement [as] valuable in improving their office workflow and generating huge benefits from giving patients access to health information, and others saying they implemented a portal because the government told them to and they are checking a box and don’t care what patients want.

A number of interviewees commented on the value of reinforcing the gains to providers from consumer engagement. One who had experience in establishing a provider-based patient portal agreed that aligning interests was very important. This person said that providers reacted very negatively to the portal at first because they were angry about the enormous growth in patient calls in response to posting lab requests. After the IT team modified the portal to better educate patients on interpreting results, call volume decreased substantially; providers then viewed the portal as invaluable in reducing the costs associated with

patient communication. Tools that integrate well into both provider workflow and patient needs seem particularly well positioned to create gains for both.

Conclusions and Policy Implications

The combined efforts of HITECH and the ACA have created an environment that has greatly expanded interest in consumer engagement and the tools available to consumers seeking to become more knowledgeable and involved in their health care. Consumer engagement is more rhetoric than reality in many dimensions, however. Future progress is likely to depend on addressing barriers that limit the supply of health information to consumers. Thus, if consumer engagement is truly valued, it is critical to address technical shortcomings that limit interoperability and functionality and to create the incentives and knowledge needed to make consumer engagement more a priority for providers as well as consumers. The analysis in this article suggests potential areas that could make a difference in whether consumer engagement can be leveraged to achieve national health care goals.

Use Public Policy Levers to Reinforce the Value of Consumer Engagement to Meeting National Health Goals

While there are limits to the ability of public policy to generate change, especially when such change is controversial or potentially burdensome, at least in the short run, the evidence reviewed here clearly illustrates the ability of public policy to increase the visibility and salience—across a wide variety of stakeholders—of changing the way medicine is practiced so that it better supports consumer engagement and delivery reform. One such area of public policy involves the scope and speed of introducing Meaningful Use requirements to support consumer engagement. While aspects of the proposed stage 3 Meaningful Use requirements (originally due to take effect in the years 2017–2018)

have been praised, some groups—particularly those representing providers—have raised serious objections to the requirements, asking for delays in timing and revisions in scope.^{51,52} While the perceived burden of meeting consumer engagement requirements dealing with online access and care coordination are not the only or even necessarily the major focus of concern, Congress has held hearings on Stage 3 requirements and introduced legislation to delay federal rule making.⁵³ Recently, the Centers for Medicaid & Medicare Services (CMS) also proposed changing stage 2 requirements for consumer engagement as part of its draft regulations modifying Meaningful Use rules for 2015–2017.⁵⁴ The way the federal government responds to these issues is likely to influence provider perspectives on the importance of consumer engagement to policymakers.

Another area of policy interest involves the priorities set for HIE infrastructure. There is widespread recognition that there are critical gaps in the available infrastructure to support interoperability and exchange of health information.^{55,56} While federal advisory panels agree, they also have concluded that a comprehensive plan cannot be mandated at the national level without broad-based, voluntary multi-stakeholder buy-in. The ONC and its stakeholders are developing the Interoperability Roadmap, with the goal of broad-based interoperability by 2024, preceded by what they call “short-term wins.”⁵⁷ While consumer engagement is recognized in the plan, it remains to be seen how initial goals will be translated into action in a multi-stakeholder environment.

Prioritize Exchange Development on Means that Create a “Win-Win” for Providers and Consumers

Consistent with a recommendations in a report by the National Commission for Quality Assurance for the Gordon and Betty Moore Foundation, one way to



align consumer and provider interests in consumer engagement is to focus on “win-win” business cases that save time and reduce stress for all involved—patients, providers, and policymakers.⁵⁸ Provider support for consumer engagement could also be increased if the former view such engagement as critical to improving both quality and the quality metrics upon which their payment depends. While beyond the scope of this paper, the success of emerging efforts by Medicare to better align quality metrics and payments to encourage use of EHRs and consumer engagement, such as by paying providers to collect and use patient-generated data in their practices, are important in aligning incentives to promote consumer engagement.

Operationally, such policies are more likely to be effective when relevant products and implementation efforts integrate with provider workflow and recognize the value of provider communication that addresses the benefits to providers of consumer engagement. Such operational concerns are responsibilities of IT vendors, delivery system leaders, and management and administrative staff.

Generate Better Evidence for Decision Makers

To some extent, support for consumer engagement is less a philosophy than a pragmatic judgment that fostering such engagement is a route to more fundamental goals, such as improved patient care, lower costs, or greater practice efficiency. Because consumer engagement efforts related to health IT are relatively new, there is limited evidence on this question.⁵⁹ However, while one reviewer of five older controlled studies on the impact of patient portals found evidence that patients considered them helpful but did not find measureable impact on outcomes,⁶⁰ more recent evidence from an organized delivery system found more positive results.^{61,62}

Currently, CMS is investing considerable funds in evaluating innovative ways to change payment and delivery models. According to the CMS, only a few payment reforms that the CMMI is testing (such as the Comprehensive Primary Care Initiative) explicitly reward providers for consumer engagement.⁶³ However, in many other initiatives, consumer engagement is either a key element (such as in medical home initiatives) or an implicit factor influencing certain desired outcomes (such as in reduced hospital readmissions). Making such linkages explicit may increase provider support for consumer engagement. It is important that evaluations of the effects of these models identify clearly how consumer engagement factors (or not) into the design, logic, and success of the models.

In sum, despite knowledge gaps and technical challenges in moving forward, there are concrete steps that existing experience suggests will be valuable in making consumer engagement more of a reality than it is today. As discussed, these include making effective use of public policy levers to reinforce the importance of consumer engagement, emphasizing exchange activities that jointly benefit providers and consumers, and developing better empirical evidence on the value of consumer engagement in achieving national health goals. But taking these steps is likely to require strong commitment from policymakers toward the goal of consumer engagement and thoughtful development of strategies to promote it in a multi-stakeholder context.

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APPENDIX A: ADDITIONAL DETAIL ON ENVIRONMENTAL SCAN, SOURCES OF INFORMATION, AND METHODS

Literature Review

We first identified relevant literature by asking staff at the ONC for their suggestions, using the Google search engine to review sources—by topic and selected organizations—and reviewing quarterly monitoring reports developed as part of this project for references relevant to consumer engagement. This review was particularly useful at identifying sources in the “gray literature” relevant to the topic.

We then conducted a more formal search of the published literature. The search was limited to studies published after the HITECH Act was enacted in 2009. We searched on relevant key words in a range of research databases: Scopus, Academic Search Premier, CINAHL, and Health Policy Reference Center.

Key words used in the search include the following:

- Consumer engagement
- Consumer participation
- Consumer satisfaction
- Electronic health records
- Health literacy
- Health information technology
- HITECH
- Medical informatics
- Patient activation
- Patient engagement
- Patient participation
- Patient satisfaction
- Patient portals
- Privacy

We screened titles and abstracts identified through this formal search, screening out articles that did not involve patients or consumers, were focused on a very narrow or specific part of consumer

engagement, were not in English, and were not (in general) pertaining to the United States. Through this process we identified about 15 articles, mainly empirical or analytical work from journals, that were relevant to the topic.

Interviews

We conducted interviews with 11 national leaders, 2 of whom were federal officials associated with federal health programs (Medicare, Department of Defense). The other 9 officials included 3 with long experience working with consumer groups active in patient engagement, 3 were leaders in health IT coming from a clinical, private purchaser, or information technology perspective, and 3 were involved in various ways in supporting or studying consumer engagement in shared decision-making.

The interviews were meant to complement the literature, identifying critical emerging issues and perspectives and helping to put what the literature said into some context. We were limited to nine interviews with nonfederal officials because of federal Office of Management and Budget requirements, as well as budget limitations. Potential interviewees were selected in collaboration with ONC staff. By design, they also were focused heavily on those with some national perspective on these issues and involvement in consumer concerns. That meant many (though not all) of those interviewed were familiar with ONC’s work and many served on the advisory committees to ONC. The interviews are not necessarily representative of the all individual stakeholder concerns or experience at the local level.

Interviews were conducted from late December 2014 through February 2015 by telephone. They lasted

about 45–60 minutes. Our senior author conducted them and followed a protocol list of questions (see below). An analyst took detailed notes that were reviewed by the two person interview team and finalized soon thereafter. Because the interviews were conceived of as context rather than research, we did not use formal coding, instead we relied on notes for analysis in two forms: by interviewee, and by question.

ONC and Related Staff Discussions

To help inform the interviews and our review of the literature, we also held seven telephone discussions with federal staff responsible for implementing HITECH and particularly its consumer and privacy provisions. Most of those interviewed worked at ONC but a few worked elsewhere, such as in the Office of Civil Rights. While the interview process was generally the same, the nature of the questions was flexible and geared toward the particular responsibilities of individual staff. While some of the topics were the same as those for the national leaders, the emphasis of these discussions was on background about relevant policies and programs, the way ONC engaged with consumers, and their interests in this study. Most of these conversations took place in late 2014.

LIST OF QUESTIONS FOR DISCUSSION WITH INTERVIEWEES

General Questions

1. How important do you see what is variously called consumer/patient and family engagement to the effectiveness of change in health care delivery and national quality goals? Why?
2. Where do you see HITECH and Health IT contributing to achieving these goals and why?
3. How important is health IT/ehealth, etc. to achieving goals for consumer and patient focused care?
4. To what extent do you think the “average health care consumer or patient” would agree with you? What are their views in this area?
5. If you are based in an organization that delivers health care or supports consumers: Have you attempted to engage consumers, patients and their caregivers in accessing and using information from their electronic health records to support patient centered care? What did you do and what was your experience? What did you learn?
6. Focusing specifically on HITECH, what do you see as the most important accomplishments in terms of leveraging health IT to engage consumers in their care?
7. What do you see as the most critical challenges or barriers to progress in this area?
8. To what extent does the ability to promote consumer engagement with health IT depend on a supportive provider community? Where do you see providers today and what opportunities do you see for consumer engagement within that context?

Questions On Specific Topics

9. To what extent do you see privacy/security concerns as a barrier to greater use of health IT , why, and what do you think needs to be done beyond what already is in place?
10. How well do you perceive ONC and the policy process took into account the interests, concerns and priorities of consumers in implementing HITECH? Are there ways to strengthen decision-making so that consumer interests are better accommodated?
11. “Blue Button” is a major federal initiative to allow consumers to better access their health data. How important do you view this initiative and what do you believe it has accomplished to date? Are there things that need to happen in the future to enhance its success?



12. What effect do you see of the new Clinical Laboratory Improvement Amendments (CLIA) that give consumers access to information from their laboratory tests? Are there actions that can be taken to enhance the benefit of this capacity?
13. Health literacy has been an issue that has limited the ability of consumers to access information, become activated, and engaged in their health care. What, if anything, do you think ONC/HITECH can do on this issue? What actions do you see as valuable elsewhere?.
14. What CMS policies/innovations do you see as particularly central to ONC's interests in the consumer role?
15. What do you see as the role for mobile health apps in patient engagement and promoting the goals of HITECH, how important are they and why?

Wrapping Up

16. There are many changes on today's plate. What do you feel is realistic to expect in terms of consumer/patient engagement and health IT?
17. If you could have one policy initiative in this area, what would you push?
18. What do you think we've left out that is important for us to understand on this topic?