Building a Strategy to Leverage Health Information Technology to Support Patient and Family Engagement

Funded by the Gordon and Betty Moore Foundation
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Executive Summary

Health care leaders recognize that engaging patients and families as active partners in their health and health care is needed to achieve the goals of the Triple Aim: improve population health, enhance the patient experience and reduce per capita costs of health. Health care delivery models are changing in response to payment reforms that support engagement strategies and holistic management of individual and population health. There is widespread interest in leveraging health information technology (health IT) to engage patients and families in their health and health care, and a wide array of tools and technologies are becoming available. However, successful implementation of these innovative tools has yet to reach widespread adoption. This report is a step toward understanding the potential opportunities to focus innovation and creativity on a vision of technology that is consistent with the priorities of patients and their families.

To prepare this report, we conducted a targeted environmental scan, interviewed key informants and directed consumer focus-group testing. We then convened a multi-stakeholder task force to analyze and critique the draft report of the results, recommend additional considerations and provide guidance for next steps.

A variety of technology solutions (such as Web-based applications, mobile phones, remote sensing technologies, electronic health records and other devices) support patient engagement. These technologies can be used for many functions: 1) access and controlled sharing of health data and information; 2) health and lifestyle tracking; 3) management of chronic disease and outcomes; 4) shared decision making; 5) social networks and learning health systems; 6) management of behavioral healthcare. This report illustrates examples of current health IT tools and applications, and offers suggestions for how they may encourage engagement.

Our results suggest that patient engagement enabled by health IT is a major, untapped opportunity (particularly among marginalized communities) with the potential to improve inefficient communication methods and change the dynamic of the relationship between the patient and the health care system. Still, there are a number of prerequisites. Health IT design must be user-centric, starting with the needs and preferences of patients and their families. In addition to existing efforts to guide design priorities, an evidence framework to evaluate the quality and effectiveness of health IT tools specific to patient engagement will be instrumental in advancing interventions that are meaningful to patients. This framework should consider how health-IT tools improve outcomes and help consumers and health care system save time, save money and reduce stress.

Health IT tools for patient engagement are often disconnected from the health care system and in need of full integration across all opportunities for engagement. Consumer trust must be fostered to alleviate patient and provider reluctance to use these tools. Although recognition of the value of engagement is growing, leadership and collaboration are necessary for sustained impact. To advance the use of health IT in a manner that honors the priorities of patients and their families and respects the patient’s journey in health and health care, the following actions are needed:
1. Create a comprehensive statement of joint principles to advance the design, development and implementation of health IT tools that help achieve the Triple Aim.

2. Develop and implement an evaluation framework to target investment and support consumer choice.

3. Advance the development of a unified health data integration strategy that prioritizes engagement.

4. Demonstrate innovative uses of health IT for patient engagement.

How patients experience health IT, and the value they associate with their experience, have important implications for successful uptake of tools and services. Efforts to understand and set priorities would benefit from a more unified approach to creating standards that not only promote important aspects of technology, such as interoperability, but also respect user-centric principles formed with patient and care-team input. Creating a comprehensive statement of joint principles to advance the design, development and implementation of health IT tools that help achieve the Triple Aim is vital to ensuring that tools for patients and their families have the technical capability to integrate with the health care system; personalize individual needs and preferences; and have the functional capacity to optimize communication with the entire care team to promote collaborative care.

Reaching consensus will strengthen and harmonize existing efforts and provide guiding information for consumers, providers and purchasers. Widespread promotion of joint principles will be instrumental in affecting the burgeoning commercial market, but the critical measure of success will be the documented effect on implementation.

Creative innovation and technology-driven tools must be tested in order to promote their qualified use in patient engagement. Development and implementation of an evaluation framework to target investment and support consumer choice is needed to measure and understand what works best for patient engagement. Finding the technologies that provide the best value and benefits is a widely acknowledged issue, yet attempts are limited and data to guide decision making for consumers, providers and purchasers are scarce. An evaluation framework can augment existing policy efforts associated with researching meaningful use of EHRs and other related work.

The current health care environment—multiple data sources in silos, across settings—is problematic and restricts opportunity for efficient flow of information. Improving population health requires an infrastructure that supports real-time integration of health information from all sources, including patient-generated data. As data become increasingly important in the scheme of maintaining health and delivery of appropriate care, advancing the development of a unified health data integration strategy that prioritizes engagement will promote access to and use of data that are relevant and meaningful to patients.

While our scan identified promising examples of activities, we propose demonstrating innovative uses of health IT for patient engagement as a fourth strategic opportunity. In particular, demonstrations could focus
on expanding evidence; targeting activities and populations most likely to achieve the Triple Aim; and closing
the digital divide among marginalized communities.

These opportunities, and the work that informs them, are a pathway to realizing the true potential of
patient and family engagement and its impact on health and health care. Technology is poised to play a
significant role in strengthening the partnership sought by patients and providers and in expanding options
for supporting health—at home and in the community. Leadership to advance shared principles, rigorous
evaluation, seamless integration and thoughtful innovation will catalyze the field and help accomplish the
vision of the Triple Aim.
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Introduction

This report summarizes the work of Building a Strategy to Leverage Health Information Technology to Support Patient and Family Engagement, whose purpose is to develop an innovative strategy for rapid advancement of patient and family engagement by leveraging new health information technologies (health IT). The National Committee for Quality Assurance (NCQA) conducted a targeted environmental scan, sought input from key stakeholders, directed consumer focus-group testing and held a task force meeting to identify viable opportunities for leveraging the changing landscape of health IT to align with the priorities of patients and their families. This report is a synthesis of those four steps and includes a series of recommendations for advancing opportunities to use health IT to support patient engagement and progress toward the Triple Aim.
Engaging patients and families as active partners in their health and health care is considered crucial to reforming the U.S. health care system and central to achieving the Triple Aim: improve on patient experience, improve population health and reduce per capita costs of health care.\(^1\) The Institute of Medicine (IOM) lists patient engagement as essential to an effective, efficient and continuously improving health system, and recommends equipping patients with tools that deliver “reliable clinical knowledge” and asking clinicians to place a higher premium on involving patients in their own health care, to the extent that patients choose.\(^2\) Yet, as the nation’s health care system undergoes delivery system reforms, it is likely that patients and providers are not well equipped for this transformation. Only a minority of practices involve patients in their own care, and there are many barriers to successful implementation of tools for patient engagement.\(^3,4\)

Growing health IT use among patients and providers holds the promise of supporting patient engagement. Health IT includes electronic health records (EHR) and other electronic (eHealth) or mobile electronic technology (mHealth). These show potential for improving care coordination, providing provider-patient communications channels, increasing access to information and making it easier to track health and wellness goals, resulting in increased access to customized information and support for shared decision making, improved communication between providers and patients, greater adoption of active and healthy lifestyles and, ultimately, improved health outcomes.

The stimulus for the use of health IT for patient engagement stems from a variety of converging trends, including increased consumer access to IT; increased prevalence of EHRs and mobile technology use among clinicians; and implementation of a federal strategy to encourage use of consumer eHealth.

**Consumer access to IT is expanding**

Increasing use of mobile phones and social media among American consumers and clinicians provides an avenue for increasing patient engagement. A majority of adults in the U.S. now own a smartphone, and mobile technology is becoming ubiquitous in medical practice. 9 percent of American mobile phone users state they have a mobile health application (“app”) on their phone for tracking or managing their health\(^5\) and approximately 19 percent of smartphone users have downloaded at least one health app.\(^6\) It is predicted that 500 million smartphone users worldwide will have and use an mHealth app on their phone by 2015.\(^7\) The growth and development of smartphone technology is expected to continue accelerating the growth of the mHealth app industry.

The explosion of social media is contributing to the democratization of information and communication for patients. Patients are increasingly interacting through online message boards, YouTube videos, blogs and social networking sites. Social media and online tools can amplify the benefits of peer-to-peer support related to health, and provide information that can lead to a more engaged patient. For example, online
social networking sites such as PatientsLikeMe have demonstrated that participating patients experience increased understanding of their symptoms and treatment.\(^8\)

**Provider use of health IT is growing**

With implementation of federal incentives, EHR adoption among providers and hospitals has expanded rapidly. Nearly three-quarters of physicians and about one-third of hospitals use some type of EHR.\(^9,10\) Over time, federal requirements for the Meaningful Use incentives will increase expectations for patient engagement. For 2014 incentives, providers are expected to have secure e-mail and a method for allowing patients to view and download electronic clinical information.

Moreover, health care is viewed as having the highest potential in the consumer products industry, with higher rates of new growth in mobile business activities expected over the next five years.\(^11\) The use of mobile technology extends to providers: 87 percent of physicians report that they use a smartphone or a tablet in their practice.\(^12,13\) Mobile apps can help them diagnose and monitor patient conditions by gathering patient information outside the office visit.

**Federal efforts to encourage consumer engagement in health IT**

The federal Office of the National Coordinator (ONC) for Health IT is promoting consumer engagement in health care through efforts to increase consumer access to their health care data, enable consumers to use their health information, and “shift attitudes” of consumers and providers about collaborative partnership in care.\(^14\) In addition to Meaningful Use objectives related to consumer engagement, specific initiatives from ONC and others include the use of the “Blue Button” (an icon that allows patients to view, download and transmit digital information in ASCII or PDF format), adoption of common standards for data sharing among developers of consumer applications and use of a “model privacy notice” for personal health records (PHR).\(^15\)

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**Blue Button Initiatives**

- **The Blue Button Pledge**
  Launched in 2011 to promote patient access to and use of personal health data, The Blue Button Pledge provides support to organizations publicly committed to advancing Blue Button efforts—payers, providers, consumer advocacy groups, health-related associations, nonprofits. To date, more than 300 organizations participate in the Pledge Program and in educational and networking opportunities.\(^5\)

- **Blue Button Presidential Innovation Fellows**
  To extend Blue Button beyond early adopters and at the nationwide level, the White House allocated Presidential Innovation Fellows to support projects for stimulating innovation of tools that utilize data provided by Blue Button.\(^6\)

- **Blue Button Challenges**
  In 2012 the ONC catalyzed the development of tools and services to help consumers use their health care data, by issuing challenges through the ONC i2 Challenges in Health 2.0, to spur innovation and encourage development.

- **Automate Blue Button Initiative—The S&I Framework**
  The Automate Blue Button Initiative is a collaboration between the ONC, the White House and the Department of Veterans Affairs\(^7,8\) that provides a forum for teamwork with technology developers and organizations to establish industry standards and methods to allow automatic updates of health data.

- **The Future of Blue Button**
  The Blue Button Connector helps patients find providers, health plans and other organizations that offer Blue Button.
Since it began in 2010, Blue Button has been adopted by the Indian Health Service, the Defense Department, Medicare and the Social Security Administration and some private health insurers (Aetna, UnitedHealth Group). Today, more than 85 million Americans have access to Blue Button data. Medicare and U.S. veteran beneficiaries who use MyMedicare.gov and MyHealtheVet have been able to download claims, self-entered data and medical data, which can then be managed or shared through select applications. In 2012 the White House developed a program called “Blue Button for America” that seeks to extend the functionality beyond the Veterans Affairs Department.

Potential of health IT to engage marginalized populations

Medicaid enrollees and those with low income, less education or poor self-reported health have lower skills and confidence in managing their health and health care. Disadvantaged populations require a greater degree of support and targeted tools that can give them the opportunity to become engaged in their health. Through thoughtful design and implementation, health IT can offer opportunities for reducing disparities in patient engagement and health outcomes across socioeconomic and cultural groups.

The full potential of tools for promoting patient engagement has hardly been tapped, as demonstrated by the gap between consumer interest in HIT and its use. The Harris Poll indicates that there is a significant gap between consumer desire for online services to facilitate interactions with providers and consumer access to these services. According to a Markle Foundation Survey, 79 percent of Americans believe that EHRs and PHRs could improve their health, but only 2.7 percent actually use a PHR. According to the California HealthCare Foundations, the key determinant to PHR use is whether the provider uses an EHR.

Current data offer a mixed story about access to these technologies among diverse populations. Both insured and uninsured populations have demonstrated an equivalent level of interest in health IT for patient engagement such as e-mails, appointment scheduling and access to medical records and ownership of cell phones is similar across racial/ethnic groups. However, lack of resources may make it less feasible for safety-net hospitals or community health centers to incorporate health IT for patient engagement. Health care delivery organizations that serve disadvantaged patients may have few resources to take advantage of health IT, and critical access hospitals have been shown to have lower odds of receiving incentive payments for EHR adoption.

Opportunity to advance the field

Rapid advances in health IT have created the opportunity to leverage these tools for engaging patients and their families in their health and health care. Successful implementation of effective applications is crucial to improving the U.S. health care system, and central to the achievement of the Triple Aim. If designed and implemented thoughtfully, health IT may offer opportunities for reducing disparities in health outcomes across socioeconomic and cultural groups. The Gordon and Betty Moore Grant Foundation charged NCQA to identify viable opportunities for leveraging the changing landscape of health IT to align with promoting patient and family engagement across the continuum of care.
To inform a strategy for leveraging health IT to support patient and family engagement, our approach included four steps: a targeted literature and environmental scan; key informant interviews; consumer focus groups; and a multi-stakeholder task force convened to provide input, guidance and plans for operationalizing recommendations. These steps helped identify existing frameworks, initiatives and examples of tools and applications that, in turn, guided opportunities for action. The targeted scan focused on information specific to activities and trends currently underway that would influence patient engagement enabled by health IT. Exploration of the published literature, white papers, trade publications and other reports also informed this step.

We created a list of more than 70 expert stakeholders to interview, representing the perspectives of consumers, biotechnology/informatics, developers/vendors, clinicians, employers/purchasers, government officials, health care system leaders and researchers (refer to Appendix A for the list of participants). Each interview lasted a minimum of 30 minutes and addressed the role of health IT in promoting patient and family engagement. We synthesized interview results and combined them with the targeted environmental scan to develop themes and to craft recommendations. The next sections describe the results of our scan; provide examples of current health IT tools and applications for patient engagement; and integrate themes for areas of strategic action.
A variety of definitions and frameworks exist for conceptualizing patient and family engagement. Some definitions focus on the role of patients alone (e.g., Center for Advancing Health: “actions individuals must take to obtain the greatest benefit from the health care services available to them”); others refer to the role of patients and families working with health care providers (Carman et al: “patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system.”) Some definitions focus on engagement in the health care system only; others include a broader focus on health and health care (Institute for Healthcare Improvement).

Table 1. Definitions/Frameworks of Patient Engagement

<table>
<thead>
<tr>
<th>Organization</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Center for Advancing Health</td>
<td>Actions individuals must take to obtain the greatest benefit from the health care services available to them.</td>
</tr>
<tr>
<td>Institute for Healthcare Improvement</td>
<td>Actions that people take for their health and to benefit from care.</td>
</tr>
<tr>
<td>Carman et al</td>
<td>Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—to improve health and health care.</td>
</tr>
</tbody>
</table>

Several reports have expanded on these definitions to build frameworks for considering patient and family engagement. The most commonly cited patient engagement frameworks describe the opportunities for engagement activities across three discrete levels:  

- **Care** for the individual patient.
- **Organization** design and governance.
- **Policy** development and implementation.

For example, health IT can be useful in supporting patient self-management, but it can also be used in organization-level health care quality improvement initiatives or in policy-level efforts, such as gathering input for proposed rules on new payment policies or benefits coverage.

The Patient Engagement framework, published by the National eHealth Collaborative (NeHC), defines a continuum of patient-engagement steps that align with the federal EHR Meaningful Use Incentive program: informing, engaging, empowering, partnering and supporting patients in the community. The framework illustrates how each action can be addressed by tools or functionality that provide information (i.e., eTools, interactive forms, patient education, patient access to records, patient and care team-generated data, forums for community support). It is gaining traction in the health IT community and is being explored by application...
developers as a guide to understanding patients’ technology needs. The framework illuminates the pathway to patient experience that is supported by an evolving sophistication of technology.

For this report, our focus is on how health IT can support patient and family engagement in health and prevention as well as in health care, and on the patient rather than on other levels of influence. In particular, we consider opportunities to leverage health IT in ways that are connected to outpatient medical care and to home- and community-based care.
Different technology solutions support different aspects of patient and family engagement. Table 2 lists technologies and features that show promise for supporting health and health care. Health IT takes the form of Web-based and mobile tools such as EHRs, portals, social networking platforms, prerecorded videos, live video and chats, mobile phone apps and remote-sensing technologies.

Our environmental scan identified a variety of distinct types of functions that leverage health IT to support patient and family engagement. Table 3 shows how these functions address aspects of health care: 1) access and controlled sharing of health data and information; 2) health and lifestyle tracking; 3) management of chronic disease and outcomes; 4) shared decision-making; 5) social networks and learning health systems; and 6) behavioral healthcare management. For each function, we identified examples of tools and challenges that may limit their widespread adoption and impact.

Some functions are more likely to be initiated or controlled by patients and families; others by providers. Functions that are built on EHRs often lack options for tailored and meaningful connections that make it easy and relevant for patients to engage. Most consumer-facing tools offer little to no connection between patient and provider, and lack interoperability. There has been widespread implementation of only a few of these functions.

### Table 2. Technologies and Supported Features

| Web-based tools and applications | • Patient portals and EHRs  
|                                | • Social networking  
|                                | • Providing secure and controlled access to data or analytics  
|                                | • Eliciting data and information  
|                                | • Storing and integrating data  
|                                | • Supporting transactions  
|                                | • Managing and coordinating care  
|                                | • Tracking health outcomes  
|                                | • Shared decision making  
|                                | • Behavioral interventions  
| Mobile phone through SMS | • Managing care  
|                                | • Behavioral interventions  
| Mobile phone through apps | • Managing and coordinating care  
|                                | • Tracking health outcomes  
|                                | • Access to data and analytics  
|                                | • Shared decision making  
|                                | • Supporting transactions  
|                                | • Behavioral interventions  
| Telephone/IVR | • Managing care  
|                                | • Eliciting data and information  

**Access and controlled sharing of health data and information**

Today’s fractured communication system presents challenges to planning care and making decisions. Although supported by financial incentives, data sharing is limited due to concerns about who has control, the ability to edit information and sharing permissions; this is exacerbated by interoperability issues. Coordinated, easy access to health data by patients and their families is a high-value prospect. For example, the Open Notes project provides easy access to clinical-visit notes to patients via e-mail, demonstrating a simple and effective way to engage patients in enhanced communication with providers. With a market primed to respond to the needs of individual delivery systems, a more user-centric design would bridge the gaps that cause confusion and dysfunction. The foundational function of data access and its related interoperability will need to support patient and family engagement.

**Health and lifestyle tracking**

Health and fitness apps are the most prevalent type of consumer health IT and include tools such as FitBit, Jawbone and MyFitnessPal, which offer individuals wearable technology to set and analyze health goals by tracking activity and entering nutritional data throughout the day. People often use these tools with no opportunity to integrate with their EHR and without the involvement of or connection to health care providers, yet the data may be of value to their care team. Many apps focus on lifestyle activities for the healthy, but these same technologies could also support chronic disease management in partnership with a provider (e.g., tools for monitoring diabetes, chronic heart failure, asthma, blood pressure).

**Management of chronic disease and outcomes**

Technology’s focus has been primarily on the population with chronic conditions; for example, Web based tools are integrated with care delivery systems and help patients and providers identify care goals and track progress towards them. Remote sensors, telehealth, virtual medical visits and online coaching support patients at home and in the community, in an ongoing and connected manner. In addition, relevant patient-generated health data captured and communicated in a multidirectional manner will support coordinated...
care across the continuum. Innovations in this area give patients and providers the tools to improve their experience in multiple domains of care, yet few models provide full integration and their impact has yet to be fully documented and shared. There may be an untapped opportunity for gaining greater patient and family input about care by focusing on functional outcomes, in addition to—or in place of—monitoring symptoms.

**Shared decision-making**

The idea that patients should be equal partners in their health care decisions has gained traction. Shared decision making includes providing evidence-based information; eliciting patient preferences and values; and involving patients in determining a course of action that is consistent with their goals and preferences. Health IT offers an efficient approach for patient access to customized decision support. For example, clinicians can prescribe patient decision aids, supported via EHRs, as a supplement to an office visit, to help prepare patients for important decisions about tests or treatment options. As this opportunity evolves, patients will need endorsement from providers and assurance that tools are understandable, accurate and unbiased and that they offer relevant, evidence-based information on demand.

**Social networks and learning health systems**

To date, social networks such as PatientsLikeMe and SmartPatients have operated largely as informal sources of information and support. New efforts are evolving to use these networks to further research; support shared decision making and collaborative care planning; and provide opportunities for providers to connect patients and families to sources of social support. Another network, ImproveCareNow, developed as a learning health system, brings together the patient, provider and system in an effort to improve clinical outcomes and reduce the burden of illness. Exploring the success of these models will bring better understanding about what works, and how to take key ingredients of these models to a broader audience.

**Behavioral healthcare management**

Technology-based therapeutic tools offer the potential for real-time support in behavioral healthcare, as well as in screening and telehealth, and models for care, such as avatars for psychological coaching (e.g., SmartCAT, a smartphone application that allows children with anxiety disorders to practice skills taught in cognitive behavioral therapy, and MobileMORE [My Ongoing Recovery Experience], an app that provides information, activities, tracking tools and community support resources for sober living). For the majority of the population that relies on providers and health care services to manage behavioral conditions, access to such tools can mean enhanced independence, real-time support and self-management.
<table>
<thead>
<tr>
<th>Function</th>
<th>Purpose/Goal</th>
<th>Examples</th>
<th>Challenges</th>
</tr>
</thead>
</table>
| Access and controlled sharing of health data  | • Enable patient- and family-member access to PHI and tools.  
• Provide targeted information related to services for efficient access and action.  
• Enable patient- and family-member sharing of data for care planning and decision making. | • NoMoreClipboard  
• Blue Button  
• OpenNotes  
• Kaiser MyHealth Manager  
• MS Health Vault  
• Patient Viewpoint  
• SharedCarePlan  
• AccessMyHealth  
• Custom add-ons and portals | • Integrate siloes of efforts of multiple sites with individual log-ins and limited family access.                                                                                                        |
| Health and lifestyle tracking                 | • Enable individuals to set goals and monitor progress by tracking data associated with activity (e.g., exercise, sleep, nutrition, eating, pregnancy, baby care). | • Fit Bit  
• Jawbone  
• Daily Burn  
• Calorie Tracker  
• LoseIt  
• Meal Snap  
• HotSeat  
• MyFitnessPal  
• Baby Tracker  
• kickTrack  
• Clearblue | • Lack of data integration.  
• Quality of information is not vetted.  
• Minimal mainstream use and use by those less inclined to adopt.                                                                                                                                     |
| Management of chronic disease and outcomes    | • Facilitate patient self-care and tracking of care plan and outcomes, coordination of care with providers and care plan.  
• Enable agendas and goal setting integrated into care management plans, advance care and end-of-life planning. | • Online care plan management  
• Virtual visits/coaching  
• Remote biometric sensors  
• Online nursing  
• Self-monitoring  
• Mobile condition-management tools  
• Home eHealth/Telehealth | • Lack of connectivity, sharing options and access.  
• Limited tools and options for most patients.                                                                                                                                                |
| Shared decision making                        | • Provide patients with understandable, accurate and unbiased decision-support tools at the appropriate time, to enhance decision quality and respect patient values and preferences. | • Patient decision support tools via EHRs, patient portals, tablets in waiting room, previst URL/video tool and group visits | • Lack of access to timely, high-quality tools across patient populations and decisions.                      |
| Social networks and learning health systems   | • Facilitate patient access to targeted information.  
• Connect patients and providers to share information and experiences.  
• Aggregate patient data across sites for improved care.  
• Facilitate patient self-care, symptom monitoring and outcome tracking. | • PatientsLikeMe  
• Cancerling  
• ImproveCareNow  
• SmartPatients  
• PracticeFusion  
• PatientIFusion  
• ZocDoc  
• HealthTap | • Lack of integration with health care system and care teams.  
• Available to limited patient-populations  
• Patients unaware of these resources                                                                                                                                                    |
<table>
<thead>
<tr>
<th>Function</th>
<th>Purpose/Goal</th>
<th>Examples</th>
<th>Challenges</th>
</tr>
</thead>
</table>
| Behavioral healthcare management | • Enable individuals to manage their mental health and/or substance use disorders with Web-based support interventions and management tools, including virtual reality, online support groups and mobile apps for real-time access to support strategies. | • SmartCAT  
• A-CHESS  
• Mobile MORE  
• Recovery Record  
• Wellness Recovery Action Plan  
• myStrength  
• SPARX  
• Text2Quit  
• MyPsych  
• Lifebuoy | • Expanded real-time access and better links to care team needed.  
• Lack of quality assessment of technology-delivered therapeutic programming. |
Key Informant Interviews

To inform this process and complement the targeted scan, interviews were conducted with stakeholders to gain insights and elicit recommendations. These informative sessions resulted in six core themes related to opportunities and challenges.

1. **Patient engagement is a major untapped opportunity, with the largest potential impact among marginalized communities.**
   
   For most of the stakeholders interviewed, the opportunity for patient engagement supported by health IT was promising, but virtually untouched. As one participant stated, “Bringing patients into the digital health world is an awesome yet thoroughly underutilized capability.” Several discussed the focus on the changing needs of delivery systems to manage the health of populations (particularly vulnerable subgroups), and the challenges related to those changes. Concerns about the capacity for change in a patient-centric manner were raised, with particular attention to “the abysmal state of health care communication,” as stated by one participant. Along with this assessment, the idea that engagement “changes the equation of empowerment” was an attractive benefit achieved by addressing the “need to make patients digital equals.” The shifting profile of the care team (which often includes family members) was also reflected in this theme, captured in the statement, “The intersection of health care and caregivers is miserable. It’s no one’s job and is amazingly difficult,” and, “It’s imperative that we figure out how to take patient-generated data and roll it up in a way that’s valuable for the care team.”

   Several informants stressed the opportunity for health IT to reach populations that are often marginalized in the current health care system. Public health leaders envision wide-scale use of mobile phone technology to connect and engage patients and families. The possibilities offered with remote technologies become a tangible way to bring the system to the patient and rely less on the traditional model of in-person consultations. Experts in public health speak of experience with mobile phones for emergency services and information exchange—a valuable method of reaching varied communities. Community and home health professionals view the integration of technology and care as providing an untapped opportunity to improve the health of populations challenged by the restricted, and often inaccessible, nature of the existing system of care.

2. **Health IT design must be user-centric, starting from the needs and preferences of patients and families.**
   
   Leveraging the capacity of technology to meet patient needs was of paramount importance to most interviewees. With the rapid influx of devices and apps, many expressed concern that the direction of innovation and tool development does not always match the priorities of patients and their...
families. Limits in how data are shared and the lack of alignment between commercial products and user needs were mentioned as barriers. “The state of the art for the patient to interface with electronic health information is horrible. It is an afterthought in EHR design.” Another informant noted, “Vendors need to focus on patient/consumer as customer. Standards exist but are not applied.”

Many highlighted the issue that recommendations to reshape these priorities will need to consider those less likely to adopt technologies for health and those challenged by literacy barriers. The risk that patients may not understand the health information presented via health IT tools will be reduced by thoughtful attention to literacy standards. It was also recognized that targeting marginalized communities offers enormous potential for impact when the technology becomes accessible, affordable and trustworthy.

3. **There is limited evidence to evaluate effectiveness of tools.**

“Determining what works is a high priority to move the engagement implementation agenda forward,” is how one stakeholder expressed the general idea of cataloging evidence for the benefit of all. Others noted that experience exists, but it remains localized and not widely shared and disseminated. As one interviewee stated, “Those who have implemented patient portals and other tools successfully into the workflow and have succeeded in engaging patients have a tremendous learning experience to share.”

Translational research is needed to help guide a more cohesive and multidisciplinary approach to incorporating tools for patient engagement. “Making this an expected part of the care process will require collaboration among several stakeholder groups, and understanding what works will be of great benefit.” A recent report published by the IMS Institute for Healthcare Informatics summarizes an assessment conducted on 43,000 health apps, finding that the vast majority have limited functionality or evidence of value in improving outcomes or the provision of health care, and that few are designed for those who need them most. In addition to the idea of “learning what works,” many agreed that leaders who will influence integrating technology and patient care are a key audience to include in any strategy of shared learning. This sentiment is captured here as, “We need to make the ‘aha moment’ happen or the majority of health care leaders won’t make it to the savings altar.”

4. **Patient-engagement health IT tools need to be integrated with the health care system.**

“The current problem with health IT is that is has been designed to facilitate the existing medical system, which is not patient and family-centric. We are replicating the same problems with technology that we had without technology.” This quote captures a variety of concerns about patient engagement tools because of a lack of effective integration and failure to acknowledge the patient as the best integrator of data and information. Successful integration of health IT that motivates patient engagement will need to be supported by standards that advance effective interoperability, validate content and ensure usability, combined with a receptive health care setting, where workflow models align with organizational objectives and reimbursement models.
Many commented on the need for a system infrastructure that is receptive to products, tools and services that will provide value to patients and their care teams. “Health system navigation and providing the right message at the right time would bring tremendous value to patients and families,” was one comment, underscoring the need for the value proposition to be well defined and part of overall planning for implementation of technology. Many believed the current lack of emphasis on integration, interoperability and connectivity (specifically, to patient-generated data) could become major obstacles without universal understanding of their impact on engagement. Visualizing need at all levels of patient interaction with the health care system and creating roadmaps that lead to the goal of seamless integration for all health data was a frequent theme. “Change the infrastructure and the market will respond.”

Several interviewees remarked on the pace at which creative technology tools are being developed, in contrast to the pace at which the health care system is embracing and adopting them. The “execution problem,” as one interviewee stated, “is where the most help is needed, and it shouldn’t happen in a vacuum. Innovation will require both creativity and successful execution in order for all of us to learn what works and how best we forge ahead in the best interest of patients and providers.”

5. Consumer trust needs to be fostered.
Increasing public awareness of health IT has resulted in both enthusiasm and concern. Reluctance to use technology to support health and to connect with the health care system was recognized by many as an important issue to consider, in both policy development and implementation strategies. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) gives patients the right to receive copies of their health information upon request. Providers are expected to ensure that communication respects patient preferences and minimizes risk to the privacy and security of patient health information. Several surveys have identified the apprehension of consumers with regard to privacy and security of health data, often as it relates to issues of access and control. As one patient advocate commented, “Using technology to respond to and reflect the priorities of patients will strengthen this need for trust and interest.” Many stakeholders believe that by building on policy and regulatory efforts to protect consumer privacy and security of health data with enhanced public awareness campaigns and effective implementation, consumer confidence and expectations will align with the vision of health IT as a powerful facilitator of engagement.

6. Leadership and collaboration are needed to create impact.
Belief in the value of patient and family engagement is growing; initiatives are taking place across the public, private and nonprofit sectors. Our interview process included key stakeholders from ONC, NeHC, the Patient Centered Outcomes Research Institute (PCORI), the National Partnership for Women and Families, the Institute for Patient and Family Centered Care and the Beryl Institute (refer to Appendix C).
However, the need for leadership and coordinated collaboration continues. “The proliferation of activities and initiatives in patient engagement is hard to miss, but how this movement ends up and its potential for true success and real change is the story left to be told,” one individual stated. Interviewees raised concerns about the cultural hurdles and the necessity to disrupt existing paradigms of care delivery. “In the abstract, patient engagement sounds wonderful; in the trenches, it’s robbing physicians of control and it’s the opposite of what they want (compliance and adherence).” In addition to that sentiment, it was also common to hear about the disconnect between provider and patient, described by one participant as, “the need to bridge these two worlds—Provider: ‘Patients don’t do what they’re told.’ Patient: ‘Providers don’t have time for what’s important to me.’”

Although efforts are underway to advance patient engagement, many participants noted the time-limited opportunity for federal incentives and the need to nurture the seeds that were planted. The general consensus among those interviewed is that much of what currently exists in health IT and patient engagement will need an organized and catalyzing infusion of leadership and investment to allow the limited amount of implementation to take hold, achieve scale and have sustainable impact.

**Consumer Focus Group Testing**

Following the targeted literature scan and key informant interviews, recommendation areas began to take shape. Prior to the task-force meeting, we conducted two consumer focus groups to explore consumer priorities regarding health IT and to better understand how opportunities and challenges align with consumer goals and concerns.

Each focus group included nine participants with a chronic health condition (i.e., diabetes, hypertension or other condition for which they take medications and routinely see a doctor) and access to a high-speed Internet connection or smartphone. The groups were differentiated by the participant’s level of technology adoption (high or low) and categorized as “e-Embracers” or “e-Tentatives.”

The discussion guide focused on four areas:

1. The types of consumer protection standards needed to facilitate broader adoption of health IT tools for patients.
2. How health IT tools can help motivate patient engagement in health and the preferred functions of health IT.
3. How consumers view the value of health IT, compared with technologies they use in other life domains (e.g., banking, shopping).
4. Consumers’ priorities related to access, efficiency and affordability of health IT services.
In planning this step of the project, we expected to see certain differences between the e-Embracers and the e-Tentatives. Although this was the case for some issues, the e-Tentative group participants were more experienced with technology than expected and results from the two groups were fairly similar across several domains. The contrast was most evident in the areas of usability and trust, with the e-Tentative group having more concerns about ease and simplicity of use, potential misuse of data and privacy. The e-Embracers expressed an inherent trust of technology and perceived its potential benefits of convenience and efficiency as outweighing the risks and concerns about data exposure.

**Concerns**

Both groups expressed concerns associated with the use of data and health IT applications. The recent problems associated with the national rollout of [www.healthcare.gov](http://www.healthcare.gov) were mentioned, and several participants had experienced patient portals that were challenging to navigate, difficult to use and not integrated with all their providers. It was also clear that although several participants had first-hand experience with these portals, the other functions of health IT were perceived as possible but had not yet been experienced. Participants mentioned a number of examples where they felt concern about the unauthorized use of their data. Most issues were related to the potential lack of control and how their data might be used to impact employment decisions, deny insurance coverage or direct marketing efforts, as captured in the following quotes:

- “Once they find out your medical history, a life insurance company—whoever gets their hands on that data—can make your life extremely difficult.”
- “If you are applying for a job that has any kind of physical aspect and the potential employer finds out that you have knee issues and that is the reason you don’t get employed, that might be a problem.”
- “Stealing information… is my biggest fear.”

Worry about data integrity, errors and manipulation were also mentioned as potential problems associated with health IT. Most were in favor of personal access of data control (similar to the Facebook model, where permissions are granted) to counter these concerns. “If you got five doors and behind those five doors are different parts of your body, you say doctor so-and-so can look at this door for this amount of time and that door closes. Exceptions are the people (identified to) have access, but I have control over who has access,” was how one participant described it.

A second category of concern was related to the use of applications. Usability was a big issue; many participants discussed difficult and frustrating experiences with portals or related patient health IT tools. Most comments stressed the need for ease and simplicity, similar to when banking or shopping on line. Several mentioned the fear of information overload, lack of integration across providers and settings and...
disorganized data. The concept that health IT apps would be ineffective and add time and complexity was a worry illustrated by many participants’ personal examples.

**Benefit and Value**

The discussion about benefits and value was filled with concepts related to participant expectations of well-designed health IT. Given the option to rate several functions of health IT, both groups indicated that access to health records and the ability for providers to interact electronically with the patients as the priority over other functions including chronic illness support, health trackers, and social/learning portals. In addition to convenient, easy access to accurate data and to information that can be communicated and shared across patients, providers and families, patient safety and improved care were part of the vision many described, including specific examples of benefit:

- Fewer mistakes with drug interactions and miscommunications.
- More accurate and comprehensive knowledge sharing between patient and providers.
- Increased efficiency and accuracy in monitoring and managing chronic illness at home and in the community.
- More opportunities to improve individual care by pooling data on similar patients and learning from those shared data.
- Greater convenience and efficiency by providing options for virtual visits and access to a wider breadth of clinical expertise and knowledge.
- Far less repeating and remembering of health data for every clinical visit.
- Increased satisfaction and better patient experience of care.

To illustrate some of these themes, here are some compelling comments from focus groups:

- “I am so tired of giving my history and telling my story. I don’t remember my history and dosage—I don’t have space in my head and I probably get it wrong”
- “I recently had an appointment with a dermatologist, but it was a video. She was out in San Diego somewhere. I was at the VA and she wrote my prescription and I went down to the pharmacy to get it. It tripped me out at first because I thought she was maybe upstairs, but she was in San Diego and that’s wonderful.”
- “The patient will benefit ultimately, but the doctor will, too, as it minimizes his risk because he is more informed too.”
“I see the body as a system and I want every doctor to know everything; I think everything is connected. I would worry to not let my optometrist know that the spot on my eye is a symptom of something else that we might not even know because we have not been able to compile all the data from hundreds and thousands of people who had that spot on their eye.”

Participants were asked to suggest features of health IT that would make them more likely to use the tools; the most commonly cited was “ease of use”: familiar, customized, intuitive functions operating on universal platforms that integrate all relevant data. Participants also discussed important security characteristics, including message/data encryption and sources of information that are trustworthy and endorsed by providers.

Efficiency of technology was mentioned repeatedly as a significant driver of uptake and included remote monitoring of biometric data, virtual clinical visits, symptom tracking and connection to knowledge sources, including patients with similar conditions, clinical trials and disease-specific information.

The issue of trust was explored and similar responses were discussed in both groups. Brand familiarity and a seal of approval from a trustworthy entity were important, as reflected in this quote, “Isn’t there some kind of organization that provides certification for certain companies’ security? I feel that when I see a sign [indicating the site is secure], it gives me a level of security that I may not have otherwise.”

Several participants mentioned provider endorsement. “I trust technology because I think it is what we are coming to—that doesn’t worry me—I trust my doctors, I trust where my information is going.” The groups also agreed that insurance companies were not a trusted source; the e-Embracer group suggested the endorsement of institutions such as the National Institutes of Health (NIH) or the Centers for Disease Control and Prevention (CDC) to serve in this role.

Consumer focus-group testing was important for evaluating how core themes that evolved from key informant interviews correlated with consumer goals, concerns and preferences. Much of what we learned from this process underscored these themes and provided greater specificity to understanding the consumer perception of the value equation. The next step involved participation of a group of experts serving as a task force.

**Task Force Meeting**

A 14-member multistakeholder task force, representing consumers, health IT, delivery systems, employer/purchasers, health care providers, health informatics, public health and research (refer to Appendix B for the list of members), was convened in Washington, DC, in November 2013. The meeting had three objectives:

1. Review and critique the analysis and strategic opportunities recommended in the preliminary report.
2. Develop a framework for evaluating how health IT for patient engagement can support achievement of the Triple Aim.
3. Develop a plan for next steps in policy, research and implementation.
The task force was given a preliminary version of this report prior to the meeting and had the opportunity to critique it and reshape priorities. Consumer focus-group testing results were shared at the meeting, with video clips highlighting testing segments. The meeting format consisted of brief presentations summarizing key points from the work to date; the majority of the meeting was spent eliciting answers to project staff questions through moderated discussions and written and posted notes. Discussion results were summarized and analyzed by staff and incorporated into this report.

A significant result of the meeting was the group’s recommendation to simplify the most relevant aspects of successful health IT-enabled patient engagement. Task force members agreed that technology tools to support engagement and improve outcomes should save money, save time and reduce stress. These core principles were recognized as important issues for patients, providers and policy makers, and provide an overarching context for design, development, implementation and evaluation.
Recommendations

A cohesive strategy is needed to harness the interest and enthusiasm for using health IT to support patient and family engagement. The following section defines the four interrelated recommendations resulting from this work:

1. Create a comprehensive statement of joint principles to advance the design, development and implementation of health IT tools that help achieve the Triple Aim.

Empowering patients and families through health IT that is secure and tailored to meet their needs and preferences is critical. This goal is challenged by current priorities in design, development and implementation of health IT, which lack adherence to principles that place end-user priorities at the forefront. Exploring current initiatives and support for a multistakeholder approach to development, widespread dissemination and implementation of user-centric principles would offer significant benefit to patients, developers, policy makers, purchasers and providers. This recommendation includes steps to consider the content of such principles, as well as methods to establish them as widely recognized and influential.

In addition to information security and safeguards, other areas need standards and quality oversight to provide comprehensive assurance that information shared and received is always high quality, is accessible at appropriate literacy levels, is managed by the individual and is meaningful to patients and their care teams. Leadership by organizations—for example, ONC and its health IT standards committee, the National eHealth Collaborative, the National Partnership for Women and Families and Continua Alliance—is paving the way for standards development, but implementation; expansion of concepts and principles; and harmonization are needed.

Although pledges to Blue Button are growing, it is unclear if data made available by providers are consistent. Lack of consistency will limit the usefulness of applications and the opportunity for bidirectional data sharing. Making data useful to patients is what will turn “just another app” into a tool that can be relied on. Incorporating patient-generated health data that can be accessed by the entire care team builds a partnership toward successful care planning. A methodology for educating consumers on tools that are reliable because they meet a set of criteria will guide patients and providers around choices that might otherwise dissuade them from using the technology, or subject them to unnecessary harm or worry.
Suggested Topics for Consumer Principles (table format)

| Usability                                  | • Easy to use, with instructions and examples.  
|                                          | • Understandable, accurate and unbiased information.  
|                                          | • Attention to issues of literacy and limited English proficiency.  
|                                          | • Usability for common impairment (i.e., hearing loss, vision impairments, physical limitations).  
| Personalization and control               | • Methods for tailoring and customizing data.  
|                                          | • Permit patients to manage all data and information pertinent to their health and health care.  
| Integration                               | • Ability to communicate with the entire care team.  
|                                          | • Support decisions made at home and in the community.  
|                                          | • Follow patient journey over time (not provider by provider).  

Next steps to establishing joint principles

- Explore current initiatives and opportunities for developing standards or principles specific to health IT and engagement.

- Consider lessons learned from other initiatives, such as Choosing Wisely and the Patient Centered Primary Care Collaborative, and building on the newly released Consumer Principles for Health and Care Planning in an Electronic Environment, published by the Consumer Partnership for eHealth and coordinated by the National Partnership for Women and Families.

- Convene a multistakeholder effort to develop and articulate principles for user-centric design of health IT.

- Provide access in multiple languages.

- Include broad group representation from all consumer areas of expertise, including anthropology, community-based organizations, academia, marketing, product design, ethnography and agencies involved in social determinants of health.

- Promote widespread awareness among all health care stakeholders, and in conjunction with the Blue Button campaign, of technologies that allow consumers to view, download and transmit data.

- Identify and engage in opportunities to develop and leverage policies to support these joint principles.

2. Develop and implement an evaluation framework to target investment and support consumer choice.

Policy and innovation are moving forward, with the expectation that implementation will follow, yet questions about the value of health IT for patient engagement remain unanswered. Defining an evaluation framework is critical to understanding the benefit and value of health IT-enabled patient engagement and
would be an important step in creating a national certification program to recognize high-quality products and services. A national certification program would advance the pace of implementation that is currently challenged by a lack of comparative data for selection and integration of tools.

The table below is based on task force discussion and contains a preliminary set of topics that consider the perspectives of consumers, providers and the health care system.

### Potential Topics for Evaluating Health Information Technology for Engaging Consumers

<table>
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<tr>
<th>Consumers</th>
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<tbody>
<tr>
<td>• Initial use; frequency, type and longevity of use.</td>
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<tr>
<td>• Usability (easy to use, simple, customizable).</td>
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<tr>
<td>• Efficiency (saves time and money, integrates all relevant data).</td>
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<td>• Benefits (reduces distress, enhances communication, improves health).</td>
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<td>• Decision making (provides transparent and trustworthy information, supports better decision making).</td>
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<th>Providers</th>
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<tbody>
<tr>
<td>• Initial use; frequency, type and longevity of use.</td>
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<tr>
<td>• Usability (easy to use, customizable, aligned with workflow).</td>
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<tr>
<td>• Efficiency (saves time, reduces waste or unnecessary care, aligns with quality measures and other requirements).</td>
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<tr>
<td>• Benefits (improves cohesion of communication, includes all pertinent data, maximizes patient/family preparation, tracks mutually agreed outcomes).</td>
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<tr>
<td>• Quality (accurate, consistent, trustworthy, reliable).</td>
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<tr>
<th>System</th>
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<tr>
<td>• Population health outcomes.</td>
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<tr>
<td>• Patient experience.</td>
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<td>• Provider experience.</td>
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<tr>
<td>• Costs of care.</td>
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<tr>
<td>• Safety and reduction of harm.</td>
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<tr>
<td>• Productivity and efficiency.</td>
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### Next steps to developing an evaluation framework

- Conduct a comprehensive scan to document evidence on existing tools and models for engaging patients using health IT, and assess strategies for evaluating key outcomes (i.e., improved population health, enhanced patient experience, reduced per capita health costs).

- Create metrics to allow and encourage comparative analysis of factors (i.e., access, motivational tactics, affordability, matching capacity with need, participation level, literacy, numeracy, usability and feasibility) that will increase adoption across all patient communities.

- Explore and define outcomes that address both health and engagement as distinct targets for measurement to support sustainable business models for health IT tools and services.

- Integrate metrics into policy and regulations to support alignment and harmonization of evaluation efforts and universal standards of assessment.
Identify methods for public reporting that will promote quality improvement and provide valuable consumer information.

Develop a highly recognized national program to certify patient engagement applications that would incorporate the evaluation framework and address privacy, security, usability, integration, connectivity and interoperability.

3. Advance development of a unified health data integration strategy that prioritizes engagement.

Optimizing population health, improving patient experience and promoting cost efficiency requires an infrastructure that provides real-time integration of data from different health care settings with data generated by patients. Today, health data sit in silos, which are often closed and proprietary systems with diverse formats that limit interoperability. Approaches for integrating data in a manner that is meaningful and relevant to patients should involve providers, payers and plans, and include not only information specific to clinical conditions and administrative functions, but also information that impacts a patient’s day-to-day life. Caregiver support, transportation; access to meals; daily functions; impairments that affect communication and literacy; and personal goals are examples of what should be reflected in a strategy that makes patients the priority.

As data sets grow in complexity and data sources become more diverse, integration will be even more of a challenge. Successful integration and engagement require the standards to support effective use of tools and a receptive care setting where providers endorse the tools. Standards are taking shape across the health IT industry, with coordination in select circles. Unified efforts to support these standards, as well as content validation and ways to ensure effective usability, will increase the likelihood that innovation of products and services recognizes the need for consumer motivation and incentives to drive use.

As health care settings devise health IT implementation strategies specific to patient engagement, strategies must align with the overall objectives of the institution and its provider reimbursement models, and support a delivery workflow that prioritizes health IT-enabled engagement. In addition, policies and incentives designed to advance data access and sharing between patients, providers and the system will need to consider not only EHRs and patient portals, but the myriad of data being generated by patients and the growing number of products being used by providers across the health care spectrum.

Next steps to advance data integration that prioritizes engagement

- Identify regulatory and policy mechanisms for influencing or setting standards for data integration and interoperability.

- Identify stakeholders key to alignment around integration—including alliances, developers and standards organizations/efforts (e.g., ONC, Markle Connecting for Health Common Framework, Health Privacy Project at Center for Democracy and Technology).
Assess the current state of the problem (e.g., system data blocks, disparate data silos, vendor requirements, vendor understanding of related standards and legislation, data ownership, formatting standards, proprietary issues) and identify opportunities within current efforts to advance integration.

Define a role for development of conceptual models, principles, guidelines, IT metrics, methods or infrastructural support to promote open-sourced data integration that enables data flow to fit multiple purposes.

Identify opportunities for integration with existing efforts and frameworks that seek to harmonize and incorporate patient-reported data and influence standards for eHealth.

4. Demonstrate innovative uses of health IT for patient engagement.

There is a need for integrated health IT solutions focusing on outcomes that are relevant and important to patients. The ability for individuals to collect, track and use data to guide health management decisions is growing rapidly, yet it is disconnected from the health IT infrastructure evolving in the health care system. Efforts to create this connection would benefit from resources focused on bridging the gap between the data and information that patients want and their providers and systems of care.

Demonstrations that consider the needs and functions most valued by patients will offer the data, experience and information necessary to build knowledge and set priorities for innovation. Existing models of practical-use cases are limited, and although some offer great promise, most are challenged by barriers to long-term sustainability, lack of opportunity for test replication and competing priorities. A broad initiative that builds on lessons learned among successful-use cases would promote prospects for patient engagement via health IT and be an influential driver of advancement.

Table 3 illustrates promising IT functions for supporting patient and family engagement.

### Opportunities for Developing and Testing New Health IT

#### Patient Engagement Tools

1. Integrate patient-generated data, including patient-reported outcomes and goal setting, into care management, chronic disease management, self-care management and overall health, to assess the impact of patient-reported outcomes and agreed-on agendas for health and disease management.

   **Potential targets:** People with multiple chronic conditions and behavioral healthcare needs.

2. Expand the role of analytics, evidence and outcomes data to guide choices and support tailored care that incorporates individual preferences for decision making and leads to higher engagement and decision quality.

   **Potential targets:** Orthopedic surgeries, prostate cancer treatment, cancer screening, breast cancer treatment, cardiac interventions.

3. Support patients, families and caregivers through access to shared care plans for enhanced communication, progress tracking and transparency of care decisions.

   **Potential targets:** Frail elderly, long-term care patients, chronic disease management.


   **Potential targets:** Neurological conditions, asthma, cardiovascular disease, diabetes, depression, heart failure, chronic pain.
**Next steps to increasing demonstrations of health IT-enabled patient engagement**

- Identify areas that are most likely to succeed and explore opportunities for further learning, expansion and replication.

- Identify existing efforts that have potential for:
  - Achieving the Triple Aim.
  - Further developing and learning to achieve purpose/goals.
  - Collaboration across communities and stakeholders (e.g., geographic, professional, patients, payers).
  - Reaching marginalized populations.
  - Demonstrating best practices for widespread implementation.
  - Replicating in broader populations.

- Establish protocols and priorities to maximize the impact of demonstrations that will inform understanding of what works, guide development of empowering principles and feed a shared-learning community.

**Next Steps**

The opportunities outlined in this report represent an interdependent list of catalyzing actions toward technology-enabled patient engagement. They recognize that tools do not automatically equate to improved patient experience or engagement without policy changes that support widespread implementation, aligning reimbursement structures and provider endorsement.

To move these initiatives forward, we propose the following steps for consideration:

- Establish a coordinated funding effort to move the recommendations in this report forward.

- Identify nationally recognized partner organizations to take leadership roles in each initiative area and form a collaborative approach to achieving impact.

- Establish effective and efficient ways to capitalize on existing organized efforts that relate to the initiative objectives.

- Create an ongoing communication strategy to elicit broad support for initiatives and disseminate outcomes of the work.

- Organize a structure of continual feedback via the task force to maintain oversight of initiatives.
Summary

Opportunities to shape the expanding field of patient and family engagement are being considered across several sectors of the health care system. This report reflects a comprehensive assessment of these opportunities, with a focus on the role of health IT. The four steps to inform results provided perspectives from all relevant stakeholders and offered an opportunity to reach cohesive themes and accurate recommendations. Shared principles, rigorous evaluation, seamless integration and thoughtful innovation are all necessary to accomplish the vision of genuine patient and family engagement in a receptive and high-functioning system of care. The next step is leadership and collaboration to support an approach to learning and advancement that underscores the goal of achieving the Triple Aim.

Appendix A. Key Informants

<table>
<thead>
<tr>
<th>First Name</th>
<th>Last Name</th>
<th>Perspective</th>
<th>Title</th>
<th>Affiliation</th>
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<tbody>
<tr>
<td>Marie</td>
<td>Abraham</td>
<td>Consumer</td>
<td>Senior Program and Policy Specialist</td>
<td>Institute for Family and Patient Centered Care</td>
</tr>
<tr>
<td>Jerry</td>
<td>Avorn</td>
<td>Clinician + Research</td>
<td>Chief, Division of Pharmacoepidemiology and Pharmacoeconomics</td>
<td>Brigham and Women’s Hospital</td>
</tr>
<tr>
<td>Bruce</td>
<td>Bagley</td>
<td>Clinician</td>
<td>Interim President and CEO</td>
<td>TransforMED</td>
</tr>
<tr>
<td>Christine</td>
<td>Bechtel</td>
<td>Consumer + HIT</td>
<td>Advisor</td>
<td>National Partnership for Women and Families</td>
</tr>
<tr>
<td>Kate</td>
<td>Berry</td>
<td>Vendor + HIT</td>
<td>Chief Executive Officer</td>
<td>National eHealth Collaborative</td>
</tr>
<tr>
<td>Clarence</td>
<td>Braddock</td>
<td>Research</td>
<td>Professor of Medicine and Director</td>
<td>Stanford School of Medicine/Center for Medical Education Research and Innovation</td>
</tr>
<tr>
<td>Philip</td>
<td>Brosterhous</td>
<td>System</td>
<td>Chief Medical Officer</td>
<td>Palo Alto Medical Foundation</td>
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<td>Janet</td>
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<td>Software Developer</td>
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<td>Cipriano</td>
<td>Vendor + HIT</td>
<td>Senior Director</td>
<td>Galloway Consulting</td>
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<tr>
<td>Dave</td>
<td>Clifford</td>
<td>Vendor</td>
<td>Public Health and Government Affairs</td>
<td>PatientsLikeMe</td>
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<tr>
<td>Richard</td>
<td>Colletti</td>
<td>Clinician</td>
<td>Professor</td>
<td>University of Vermont ImproveCareNow project</td>
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<tr>
<td>Helen</td>
<td>Darling</td>
<td>Employer + Purchaser</td>
<td>President and Chief Operating Officer</td>
<td>National Business Group on Health</td>
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<td>Tom</td>
<td>Delbanco</td>
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<td>Co-Director</td>
<td>Beth Israel Deaconess Medical Center OpenNotes</td>
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<td>Karen</td>
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<td>Health Commissioner</td>
<td>City of New Orleans</td>
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<td>Peter</td>
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### Appendix B. List of Task Force Members

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Appendix C. Organizations and Initiatives in Health IT and Patient Engagement

Several policy initiatives have paved the way for improvements in health care delivery that respect the need for greater participation of patients and families. As part of the 2009 High Information Technology for Economic and Clinical Health (HITECH) Act, the Meaningful Use incentive program was created to provide incentives for health care providers to illustrate “meaningful use” of a certified EHR. Multiple organized efforts have evolved from this and other funding associated with these incentives. Connection and collaboration with these initiatives will benefit the efforts of the Moore Foundation; for example:

- **Office of the National Coordinator for Health Information Technology (ONC):** The principal federal entity charged with coordinating nationwide efforts to implement and use the most advanced health IT and the electronic exchange of health information. The ONC Consumer eHealth Program supports ONC efforts to fulfill a core strategy: empower individuals to improve their health and health care through health IT. The collective aims of this eHealth program are best summarized by the objectives known within ONC as the “Three A’s”: Access, Action and Attitudes.
  
  • Increase **ACCESS** to health information: Consumers and patients are active participants in the secure, easy and electronic flow of information pertinent to their health and health care.
  
  • Enable consumers to take **ACTION** based on their health information by encouraging development of tools and services that help make electronic health information useful and meaningful for them.
  
  • Shift **ATTITUDES**: Consumers think and act as partners in their care with the support of eHealth tools.

- **Agency for Healthcare Research and Quality (AHRQ) Health IT Portfolio:** Develops and disseminates evidence and evidence-based tools about the impact of health IT on health care quality. To accomplish this, the Portfolio:
  
  • Anticipates the future needs of the health care system and supports development of innovative health IT solutions.
  
  • Identifies and fills current gaps in knowledge about health IT
  
  • Leverages the capability of health IT to improve the quality, safety, efficiency and effectiveness of health care.

- **Patient-Centered Outcomes Research Institute (PCORI):** Authorized by Congress to research the best evidence available to help patients and their health care providers make informed decisions. PCORI research is intended to give patients a better understanding of available prevention, treatment and care options, and of the science that supports those options.
- **National eHealth Collaborative (NeHC):** A public-private partnership that accelerates effective use of health IT to create a more patient- and family-centered health care system, with better outcomes and greater value.

- **HiMSS:** A global, cause-based, not-for-profit organization focused on better health through IT. HIMSS leads efforts to optimize health engagements and care outcomes using information technology.

- **National Partnership for Women and Families Consumer Partnership for eHealth (CPeH):** A nonpartisan coalition working to ensure that efforts to drive health IT adoption meet the needs of patients and their families. CPeH includes members from nearly 50 consumer, patient and labor organizations working on both the national and local levels, and remains the only coalition composed solely of consumer and patient advocates.

- **The Beryl Institute.** A global community of practice and premier thought leaders for improving the patient experience in health care, defining the patient experience as the sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care.

- **Institute for Patient- and Family-Centered Care.** Essential leadership to advance the understanding and practice of patient- and family-centered care by promoting collaborative, empowering relationships among patients, families and health care professionals.

Interest has grown in the private foundation world and with initiatives that include the Commonwealth Fund, the California Health Care Foundation, the Macy Foundation, Grantmakers in Health, the Pew Research Center and the Robert Wood Johnson Foundation. At a recent meeting co-hosted by ONC and the Commonwealth Fund, several funders (private and public) discussed how best to align efforts in research and implementation for consumer eHealth. The Commonwealth Fund is synthesizing results from these discussions.

In addition to these government, private foundation and nonprofit entities, the cadre of expertise in the consulting sphere is also expanding in the area of health IT and patient engagement. Firms such as Premier, Accenture and The Advisory Group are playing significant roles in shaping priorities and investment in health IT for hospitals and health care systems.
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