Aligning Forces for Quality | Improving Health & Health Care in Communities Across America

Robert Wood Johnson Foundation

LESSONS LEARNED

The Value of Personal Health Records and Web Portals to Engage Consumers and Improve Quality

July 2012

Introduction

The use of **patient-facing health information technology (HIT) platforms**, such as **personal health records** (PHRs) and **web portals**, holds the promise of engaging patients in their own health care with the ultimate purpose of improving overall quality and health outcomes. Several Aligning Forces for Quality (AF4Q, a national program of the Robert Wood Johnson Foundation) Alliances indicated an interest in exploring how these tools may be implemented for specific projects within their communities. To this end, the Health Information Technology Resource Center (HITRC) for AF4Q convened the *PHR and Web Portal Workgroup* from May 2011–January 2012. This brief describes what we know about PHRs/web portals and the workgroup's lessons learned regarding the potential value that the use of these platforms can bring to patients, consumers, providers, and local AF4Q communities in enhancing patient engagement and quality improvement. While near-term opportunities exist, challenges must be overcome for these platforms to reach their full potential.

About Aligning Forces for Quality

Aligning Forces for Quality (AF4Q) is the Robert Wood Johnson Foundation's signature effort to lift the overall quality of health care in targeted communities, as well as reduce racial and ethnic disparities and provide real models for national reform. The Foundation's commitment to improve health care in 16 AF4Q communities is the largest effort of its kind ever undertaken by a U.S. philanthropy. AF4Q asks the people who get care, give care and pay for care to work together to improve the quality and value of care delivered locally. The Center for Health Care Quality in the Department of Health Policy at George Washington University School of Public Health and Health Services serves as the national program office. Learn more about AF4Q at www.forces4quality.org. Learn more about RWJF's efforts to improve quality and equality of care at www.rwjf.org/qualityequality/af4q/.

About the Author

The Health Information Technology Resource Center (HITRC) provides technical assistance to *Aligning Forces for Quality*, an initiative of the Robert Wood Johnson Foundation.

Workgroup Basics

The goals of this workgroup were:

- to inform and educate the Alliances about the evolving patient-facing HIT platforms that allow patients to access, use, and share, if desired, their own protected health information (PHI) to achieve better health outcomes;
- to examine the challenges and barriers to PHR/web portal adoption, as well as potential solutions to overcome these;
- to help the Alliances explore which current platforms may be the most feasible and acceptable within their community, especially as it relates to local Consumer Engagement (CE) or Quality Improvement/Quality-Equality (QI/QE) indicators;
- to assist Alliances in completing the *Alliance Roadmap for PHR/Web Portal Priorities and Promotion* template for uptake by local consumers and support by local health care providers; and
- to facilitate having the Alliances identify and articulate future requirements for the development of Alliance-wide patient-facing technologies for PHI use/access that more directly support the goals of AF4Q.

Glossary

Meaningful Use (MU)—the use of electronic health records (EHRs) by physicians (and hospitals) for key functions to improve the quality, safety, and outcomes of health care; incentives are given to physicians for MU from the Centers for Medicare and Medicaid Services

Patient-Facing HIT Platforms—various HIT tools and functions designed for use by consumers to support management of their own health and health care

Personal Health Record—a comprehensive health record where information within it (from EHRs, pharmacies, patient-entered data, etc.) is controlled by the patient; broadly, PHRs come in three forms:

- free-standing—wholly owned by the patient and typically hosted on an Internet-based platform, it is not officially associated with any other record
- tethered—a PHR that is hosted by one's health care provider and linked to his or her EHR
- sponsored—a PHR that is provided by a patient's employer or health insurance plan and generally populated with information based upon claims data

Web Portal—a secure website for patients, typically maintained by provider practices, that offers access to a variety of functions linked to a physician's EHR including secure messaging, protected health information (e.g., lab results, medication lists, and immunizations), appointment scheduling, and tethered PHRs; more advanced portals may offer programs for self-management or patient questionnaires

Participating Alliances included Cincinnati, Greater Boston, South Central Pennsylvania, Western New York and Wisconsin. Formal workgroup activities included two webinars, two workgroup-wide participant teleconferences, one face-to-face meeting, information dissemination via a Google group and numerous Alliance-specific consultations with the HITRC. Experts from across the country were engaged by the HITRC to provide input, advice, and information regarding the current and future outlook for the adoption of PHRs/web portals by consumers.

Promise and Potential

The efforts of the workgroup were driven by the belief that PHRs and web portals hold value for patients, providers, and the communities in which they live to improve health care delivery and outcomes. Organizations across the health care spectrum, including Kaiser Permanente,[1] the Office of the National Coordinator for HIT,[2] the National Partnership for Women and Families,[3] the Robert Wood Johnson Foundation's (RWJF) Project HealthDesign and others,[4,5] are touting the importance of technology-based consumer platforms in health care and, in some cases, expanding access to these tools.[6] Krist and Woolf[7] outline higher-level, advanced functions (beyond simple data repositories) that PHRs can offer to help patients take greater charge of their own health (Figure 1).

Interest in these platforms and promotion by health care providers is expected to in-

Figure 1. Advanced PHR Functions

LEVEL	FUNCTIONALITY
1	Collect patient information, such as self-reported demographic and risk factor information (health behaviors, symptoms, diagnoses, and medications)
2	Integrate patient information with clinical information through links to the electronic medical record and/or claims data
3	Interpret clinical information for the patient by translating clinical findings into lay language and delivering health information via a user-friendly interface
4	Provide individualized clinical recommendations to the patient, such as screening reminders, based on the patient's risk profile and on evidence-based guidelines
5	Facilitate informed patient action integrated with primary and specialty care through the provision of vetted health information resources, decision aids, risk calculators, personalized motivational messages, and logistical support for appointments and follow-up

crease for several reasons. The recent release of the Centers for Medicare and Medicaid Services (CMS) Stage 2 ***meaningful use*** (MU) proposed regulations[8] includes numerous physician and hospital requirements, including secure messaging platforms and patients' online access to viewing, downloading, and transmitting their PHI (including electronic hospital discharge summaries and clinical summaries after provider visits) by 2014. Once finalized, these MU requirements will most likely be met via web portals offered by physician practices and hospitals. The proposed rule also emphasizes provider accountability for patients' portal use in that at least 10 percent (which may increase in the final rule) of their patients will be required to access PHI online for the provider to achieve MU. Additionally, the accountable care movement will press organizations toward greater patient-centered HIT functionalities, as these are seen as crucial to achieving success.[9]

Consumers have, perhaps, the greatest opportunity to expand their role in their own health care with the use of web portals and PHRs, as these tools offer access to and patient-centered control of PHI in ways not previously available without HIT.

While each platform brings different specific benefits to the various users, the synergistic effects of these technologies can lead to greater communication and shared care between patients/their families and providers, a more thorough picture of a patient's overall health and medical conditions at the point of care, and increased patient involvement in self-care and decision-making. Figures 2 and 3 provide a "snapshot" view of key value elements of these tools.

Figure 2. Value of Personal Health Records

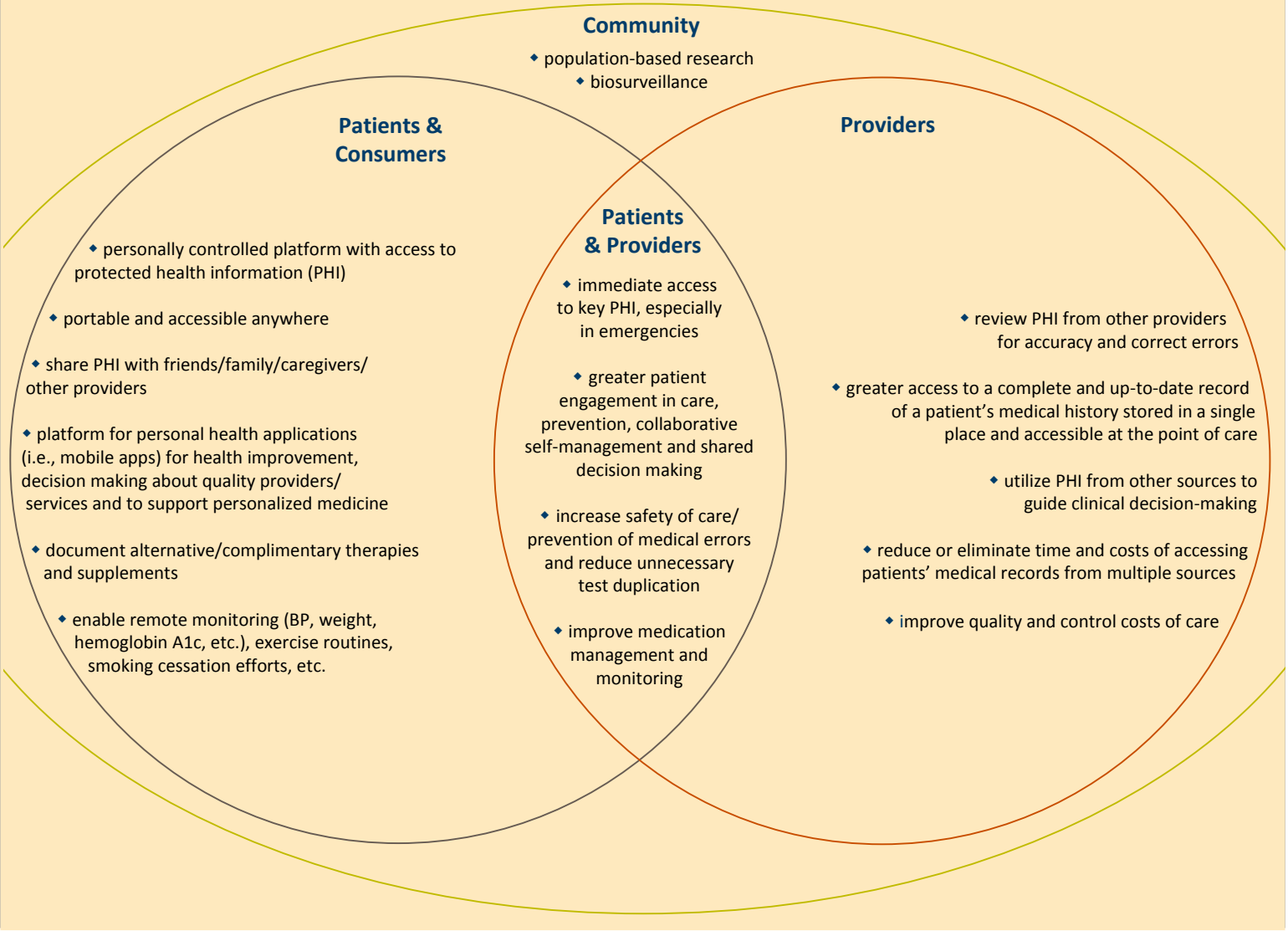
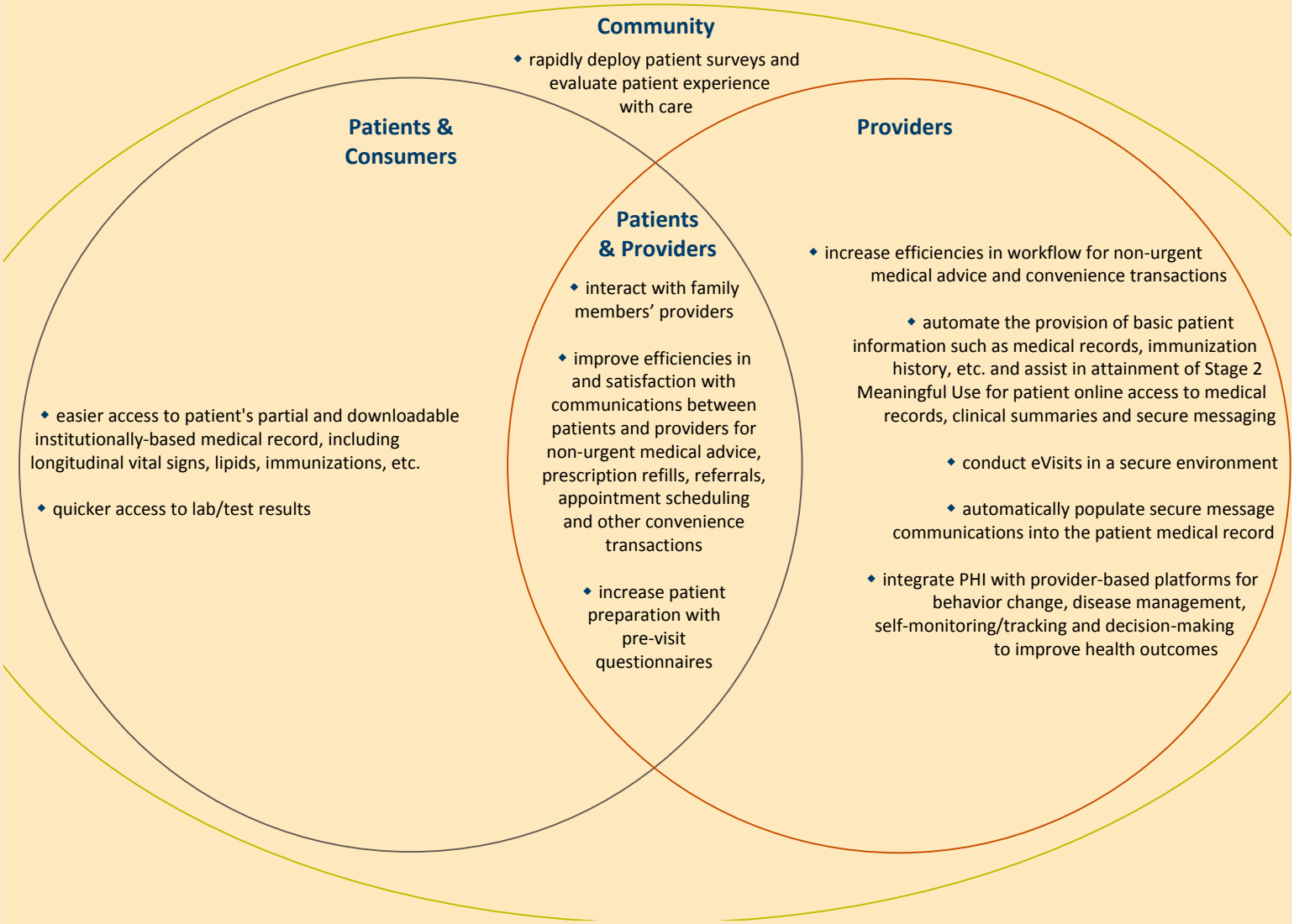


Figure 3. Value of Web Portals



Conceptually, PHRs may hold greater empowerment for consumers than web portals, given they are at the center of control for this platform. However, significant benefits can be brought to providers in their patients' PHR use, especially where the value points intersect.

Though web portals might appear to offer greater advantages for providers, patients can use the many convenience services these platforms have to offer, including access to vetted health information, secure messaging, and appointment scheduling. Those web portals that have a tethered PHR or the capacity to upload PHI to a free-standing PHR provide added patient benefits.

Current Interest and Uptake

Because of the fairly nascent nature of PHR and web portal platforms, surveys, studies, and reports have focused primarily on the challenges and design requirements of implementing them[10,11] or on consumer and provider interest in their use rather than the health outcomes of employing these tools. Findings have included:

- the deployment of an updated personal health management system (i.e., a PHR) saw a 30 percent increase in unique users and a 42 percent increase in sharing of records with family members;[12]

- 36 percent of consumers would like to use mobile health tools to engage with their health care providers, and 33 percent want to manage their health records online;[13]
- 430,000 US veterans used the Veterans Affairs (VA) "Blue Button" tool, which allows vets to download their claims information, when projected use was only 25,000 patients;[14]
- 79 percent of My Health*e*Vet (the VA's PHR) users wished to share record access with a friend, family member, or non-VA health care provider;[15] and
- patient enthusiasm and belief about the potential for increased involvement in their own care when provided access to their physicians' clinical notes.[16]

Despite these positive results, there is also commentary that challenges the potential benefits of these tools. Regarding PHRs:

- 51 percent of consumers have never been exposed to the notion of using a PHR, and only 7 percent have used one;[17]
- many PHR products currently on the market do not provide value to patients[18] and often serve only as digital storage for PHI rather than platforms for engagement;[19] and
- a review of PHR studies noted that most of these were created from the perspective of physicians, with little patient input into the design of this platform.[20]

As for web portals:

- while 56 million US consumers have viewed their PHIs via a web portal, another 140 million have not done so and are not interested in doing it;[21] and
- of those patients who did have access to a web portal, 44 percent said it had either no impact or a negative impact on their desire to improve their health.[22]

Overall, when proxy patients were involved in testing off-the-shelf HIT patient-centric platforms, 122 challenges to their use were found, 32 percent of which were considered at least moderately severe.[23] Despite patient/physician enthusiasm regarding the use of these platforms, physicians are more skeptical about the benefits,[16] expressed concerns about the impact of PHRs on data and practice management,[24] and are worried about the integrity of incorporating patient-generated electronic data, especially as they relate to physician accountability for maintaining an accurate patient record.[25]

The Cincinnati AF4Q Alliance conducted consumer and physician focus groups in October 2011, with similar findings and conclusions as above (quoted verbatim from the Alliance's report[26]):

- *PHRs have the potential to increase consumers' engagement in their health care by promoting increased accountability to themselves and their physicians.* Once consumers see and understand a PHR, they view it as an enabling product with meaningful benefits such as strengthening communication with their physician(s).

Pilot Project: Greater Boston

The Greater Boston AF4Q Alliance and MA Health Quality Partners are working with a physician organization to capture patient experiences in ambulatory care through a web portal. Using the CAHPS Patient-Centered Medical Home survey tool, they are testing this method of surveying as a way to increase consumer engagement and provide timely feedback to practitioners to improve quality of care.

Methods:

- contacting patients through email and inviting them to participate in the survey through a web portal
- evaluating the feasibility of using this approach to collecting patient experience data based on the survey response rates

Benefits:

- survey is accessible via a variety of electronic platforms, including handheld devices
- data collection through the Internet will simplify analytic processes and facilitate the creation of provider reports
- offers providers more frequent patient experience information to support quality improvement
- is significantly more cost effective than current survey modes

However, current awareness of MyChart (Epic's EHR web portal)/PHRs and their capability and benefits was low among participants.

- *Adoption and leveraging MyChart/PHRs requires health systems/practices to actively promote the benefits of PHRs to patients, physicians, and staff.* Patients are more likely to use MyChart/PHRs if they have a clear understanding of these products and how they would uniquely benefit from their use.
- *A significant barrier to patient adoption is resistance from physicians to add one more item to talk about in an office visit.* Physicians would need to be convinced of the value and trained on the PHR system. It would then be imperative for physicians to advocate and promote the usage of a PHR as a tool for better health of their patients.
- *Unanimously, participants strongly prefer a PHR sponsored by their physician rather than their health insurance company.* Consumers trust their physician to have access to their medical records more than their insurance company. The groups felt that their physicians cared about them and their insurance company "cares about the money." Additionally, participants said they would be more likely to use a PHR provided by a physician because their employer may change insurance providers, but patients are more likely to be with a physician for a long time.

One notable example of a successful, community-wide, patient-facing HIT platform implementation is the Shared Care Plan.[27] As part of the Pursuing Perfection national program of RWJF, the St. Joseph Hospital Foundation team used a multi-faceted approach to improving health care performance and patient outcomes. It used a web portal containing patient-generated data that enabled sharing of electronic health record information with patients and multiple providers to support collaborative care and improved self-management.

Evidence Base

There is a limited but growing body of research and empirical evidence regarding the impact of PHR and web portal use on process and clinical measures related to improved health outcomes. Recent findings include better blood glucose control amongst low-income people with diabetes who used a PHR,[28] increased mammography and flu vaccinations for patients who received electronic prompts through an eJournal embedded within a PHR,[29] and improved blood pressure (BP) control in patients who remotely monitor their BP in the context of a patient-centered medical home (PCMH).[30] However, there was a lack of web portal use by women targeted for colorectal cancer screening.[31]

Overall, though, the jury is still "out." Hibbard and Greene observed that highly activated patients are more likely to be referred to web portals and are also more likely to use them.[32] Additionally, systematic literature reviews note the need for more research on PHR/web portal use and their links to health outcomes, efficiency, cost and value.[4,33,34]

Pilot Project: Western New York

The Western New York AF4Q Alliance (P^2) will be engaging providers and their patients with diabetes by giving physicians the option of a free, community web portal not tethered to an EHR system and empowering patients to begin using this portal to manage their health status. The community web portal will extract data from the local Regional Health Information Organization (RHIO) and import it, upon physician consent, into the patient's Microsoft HealthVault PHR account.

Methods:

- participating physicians will be primarily responsible for encouraging their patients to register and access the portal
- the P^2 team, collaborating with RHIO staff, created targeted promotional materials and a physician operations manual
- P^2 Consumer Engagement Associates (CEAs) will support recruiting and training

Benefits:

- the free portal will bring this functionality to physicians and patients who would otherwise not have access to one
- portal use will have the capacity to enhance consumer engagement and improve patient-provider communication
- will offer provider groups a low-cost HIT solution to maintain their competitive edge

Lessons Learned

Are there near-term opportunities for the use of PHRs and web portals within the AF4Q Alliances? *Some*.

Do these platforms offer enough value and demonstrable functionality to justify their promotion? *Almost*.

Despite the promise that these tools offer, the workgroup Alliances encountered many of the same challenges noted above when considering these platforms as a means to improve quality and engage consumers. These are outlined below.

- *Many platforms are not fully interoperable with EHRs and consequently not quite ready for widespread adoption.* Not unexpectedly, the workgroup Alliances were eager to do more with PHRs and web portals than what most of these platforms have the capacity to do today. As in other areas, AF4Q Alliances hold a cutting-edge vision of using HIT in transformative ways. Challenges such as lack of interoperability and interactivity, the likelihood of a platform's survival (i.e., Google Health's demise), undefined outcome measures of quality, and a limited evidence base as to how these tools actually impact health outcomes will need to be overcome for PHRs/web portals to achieve their full potential.

- *You can't use what you don't know about.* Lack of consumer awareness to the information about PHRs and web portals is a major barrier, as demonstrated in the research done by the Cincinnati Alliance. As mentioned above, the Office of the National Coordinator for HIT recently has launched a nationwide effort amongst various health care constituencies to encourage consumer education about and involvement in their health care, especially by taking advantage of patient-facing HIT tools.[2] This area may be ripe for Alliance investment as these platforms move beyond digital repositories of data. Additionally, informed consumers may help to drive the build-out of more sophisticated, interactive platforms.

- *Access does not equal interest.* Simply providing patients or providers with a connection to use these tools will not be enough to get them engaged. All stakeholders need to perceive the value those PHRs and web portals hold for them, as well as how the technologies' initial disruptive use (especially for providers) offers a long-term opportunity to improve quality of care. A point of intervention for AF4Q Alliances may be to promote these platforms among patients with chronic conditions, given the greater need for regular interfaces with the health care system. As accountable care and Stage 2 meaningful use approaches, increased incentives for physicians will help to push adoption of these platforms.

- *Interest does not equal activation.* Despite stated consumer desire in using these platforms, even those who are interested may not engage with PHRs and web portals for myriad reasons. Current market products may be cumbersome, limited in scope and content, not interoperable with other HIT platforms, or have limited personalization for language, culture, and health literacy differences. Much as incentives were necessary for physicians to adopt EHRs on a large scale, similarly consumers will likely need incentives to stimulate engagement and increase adoption of these tools. Employers are using a range of incentives for the use of PHRs to get employees more engaged in their health.[35]

- *Physician and community champions are needed.* Health care providers are under increasing pressure to attend to and participate in a vast array of programs (PCMH, accountable care, meaningful use, etc.), straining workflow, patient and data management, and HIPAA privacy and security monitoring, among others. For these and other reasons mentioned above, provider resistance to networking with patient-facing HIT platforms can be significant and hinder or halt community-wide efforts to encourage patient adoption of these tools. AF4Q Alliances should seek out early-adopter physician and organizational leaders in their communities who will work collectively to champion the need for evidence-based HIT adoption and interoperability, especially those platforms designed to engage patients, as a means to achieving greater health outcomes.

Future Implications

The rapid growth of EHR adoption by physicians will accelerate deployment of web portals and PHRs as PCMHs, Stage 2 meaningful use, and accountable care organizational structures take root. The business case for these tools becomes much more compelling when reimbursement is predicated on quality and population health, which these tools are likely to promote and enable.

Although not yet realized, PHRs and web portals will assume a major role in the evolving health care system and will become instrumental to engage consumers and aid in improving their health and achieving the goal of true patient-centered care.

Finally, as future web portal and PHR platforms are developed to deliver deeply tailored (i.e., personalized to the specific patient),[36] highly interactive and "just-in-time" (i.e., on the spot feedback) functionalities, their value to consumers will increase, boosting consumer adoption.

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