

March 2014

ONC State Health Policy Consortium

Summary Report on the PHR Ignite Project: Advancing Consumer-Mediated Exchange

Prepared for

Office of the National Coordinator for Health Information Technology
U.S. Department of Health and Human Services
300 C Street SW
Washington, DC 20201

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1. INTRODUCTION: CONSUMER-MEDIATED EXCHANGE

The Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 provided substantial financial support for State and regional health information technology (IT) and health information exchange (HIE) activities. These funds also established the State Health Policy Consortium (SHPC) in 2010 to provide States with resources needed to develop solutions to challenges preventing or impeding HIE across State lines. ONC contracted with RTI International to administer the SHPC project. The work of the individual projects within the SHPC focused on practical solutions and regional exchange. While a careful approach to investigating issues and developing solutions was maintained in each project, the consortium consistently emphasized a singular vision to action—moving data.

One strategic goal of the Office of the National Coordinator for Health Information Technology (ONC) is to empower individuals to improve their health and the health care system through health IT. With the growth in adoption of electronic records stimulated by the various HITECH programs, data to support patient empowerment objectives are increasingly available. Applications that allow patients to use these data can enable them to more actively participate in their own health care decisions and manage conditions. With increased adoption of Direct secure messaging standards and initiatives such as BlueButton+, patients may be more likely to access their health information, and have some control over the movement of information among providers who are not yet connected through HIE services. The concept of *consumer-mediated exchange* helps overcome traditional concerns about exchange, such as consent management and state differences in disclosure laws, in addition to supporting patient engagement.

Meaningful Use Stage 2 criteria include requirements for view, download, and transmit functionality. One method for sharing data with patients is through Direct secure messaging and BlueButton+ functionalities; Direct-enabled personal health records (PHRs) may therefore be able to receive and collect information in a single location chosen by the consumer. The PHR Ignite project was initiated under the SHPC to support research on the three objectives of ONC's Consumer eHealth Program: (1) provide patients electronic access to their health information, (2) support development of tools that help patients take appropriate action with that information, and (3) support patients' attitudes and understanding about available tools and how best to use them.

The project aims to stimulate PHR use by supporting pilots that provide access to patients through Direct-enabled PHR systems, research the gap between PHR functionalities currently offered and those consumers want, and create educational materials that support a change in consumers' attitudes toward and understanding of PHRs. The project includes three components working together to support the goal of enabling consumer engagement:

1. **Objective 1 - Access:** Establish pilots at Texas Children’s Hospital in Dallas and MD Anderson Cancer Center in Texas that support the transport of structured data for consenting participants from the hospital system directly into patients’ Direct-enabled PHRs. In addition, work with the National Association for Trusted Exchange (NATE) to develop trust bundles that enable widespread Direct exchange between participating PHR systems and EHRs through participating Health Information Service Providers (HISPs).
2. **Objective 2 - Action:** Work with teams from HealthInsight in Utah and New Mexico to perform an environmental scan and assess current PHR functionalities, cross-referenced with statistics about the use of and outcomes achieved by systems. Identify functionalities that are most effective and useful to individual patients and provide recommendations about functional priorities for future development.
3. **Objective 3 - Attitudes:** Support a team led by the American Medical Informatics Association (AMIA) to develop an education framework that will increase awareness of electronic data, PHRs, and consumer-mediated exchange, especially for vulnerable populations such as rural consumers with chronic conditions.

2. SUMMARY OF KEY FINDINGS

2.1 Pilots

MD Anderson conducted data exchange from their in-house patient portal to a Microsoft HealthVault PHR. All exchange took place in a test environment. A test patient continuity of care record (CCR) was exchanged via Direct secure messaging to the test HealthVault PHR. Children’s Medical Center exchanged a continuity of care document (CCD) via Direct secure messaging to a patient’s Microsoft HealthVault PHR. The patients receiving the CCD were enrolled as part of a pilot program for sickle cell anemia patients. NATE conducted bidirectional data exchange with pilot participants in Oregon, California, and Alaska. Providers sent data to patients, and patients sent data to providers using Direct secure messaging. Data formats exchanged included CCR, CCD, and consolidated clinical document architecture (C-CDA). Table 2-1 provides a summary of the activities that each pilot site conducted to enable exchange of patient data through the use of untethered PHR systems.

Table 2-1. Summary of PHR Ignite Pilot Project Activities

Pilot Entity	Direction of Exchange	PHR Vendors Used	Format of Data Exchanged	Providers/HIE Entities Involved Exchanging Data in Pilot
MD Anderson Cancer Centers	Provider to patient	Microsoft HealthVault	CCR	MD Anderson Cancer Center
Children’s Medical Center	Provider to patient	Microsoft HealthVault	CCD	Children’s Medical Center
National Association for Trusted Exchange	Provider to patient and patient to provider (bidirectional)	NoMoreClipboard Humetrix My HealthVet Microsoft HealthVault	CCD, CCR, C-CDA	UCSD Medical Center; VA Alaska Healthcare System; VA San Diego Healthcare System; Santa Cruz HIE; San Diego Regional HIE; CareAccord; AeHN; LaTouche Pediatrics; Full Spectrum Pediatrics; Allergy, Asthma and Immunology Center of Alaska; Oregon Health Authority; San Diego Health Connect

2.2 Foundational Research

Both HealthInsight and AMIA focused on providing formative research for ONC to support work in consumer engagement through the use of PHR systems in the future. Each project used a similar methodology of unstructured discussions with a small but representative number of stakeholders to understand the factors that would help achieve objectives 2 and 3 of ONC’s Consumer eHealth strategy (Access and Attitudes). Although the research questions in each project were distinct, common themes emerged. Table 2-2 summarizes the common themes that these projects revealed.

Table 2-2. Summary of PHR Ignite Common Research Findings

Project	Provider Findings	Vendor Findings	Patient Findings
HealthInsight (Action)	<p>Internet access and language were important barriers with no easy solutions.</p> <p>Staff working within the health care community could be used to help those with low health or technology literacy become more comfortable with online tools to help them manage their own health care.</p>	N/A	<p>Consumers trusted their providers and felt that the information in a tethered PHR was sufficiently secure.</p> <p>Few consumers understand the distinction between HIPAA-covered PHRs and those not covered, which may contribute to a general sense of distrust consumers reported about PHR systems in general.</p>
AMIA (Attitudes)	<p>Workflows became more efficient when consumer-mediated exchange was implemented.</p> <p>Patients with complex care needs would benefit most from consumer-mediated exchange.</p> <p>Patients’ lack of access to and familiarity with technology were barriers to consumer-mediated exchange.</p>	<p>Insufficient education, training, and time devoted to how the solution is initially piloted affects consumer-mediated exchange adoption.</p> <p>Provider support and endorsement of consumer-mediated exchange, coupled with a resource that helps patients set up and gain comfort with the technology, can be the difference between broad and limited adoption.</p>	<p>Patient participants largely expressed optimism about the prospect of consumer-mediated exchange technology to improve management of chronic conditions in rural settings.</p> <p>Many patient participants said they do not have broadband access or were otherwise inadequately familiar with technology to reap its full benefit.</p>

3. REMOVING BARRIERS TO CONSUMER-MEDIATED EXCHANGE

3.1 Access: Populating Untethered PHRs; Meeting Meaningful Use Stage 2 Requirements

Under Stage 2 Meaningful Use criteria, certified electronic health records (EHRs) must support the ability to view, download, and transmit interoperable care summaries. Direct secure messaging transport protocols provide one practical approach to achieve this, and Direct-enabled PHRs can receive and collect this information in a single location, controlled by the consumer. These projects aim to stimulate PHR use by supporting projects that give patients access to Direct-enabled PHR systems, begin to fill the research gap between PHR functionalities that currently exist and those that consumers desire, and create educational materials that support a change in consumers' attitudes and understanding about PHRs.

The Children's Medical Center (Children's), University of Texas MD Anderson Cancer Center (MD Anderson), and NATE pilots all targeted enabling the exchange of information between providers and Direct-enabled PHR systems.

3.1.1 Children's Medical Center

The specific goal of the Children's project is to test patient use of Microsoft's Direct-enabled HealthVault™ PHR with the Drop-Off and Pick-Up Application (DOPU) at Children's. Children's hosts the DOPU application that allows information to be sent to a patient's HealthVault™ PHR without requiring an additional interface between the patient and the care provider. This application allows patients to receive health information from multiple specialty and service areas in one record. Centralizing this information in patients' hands is intended to increase continuity of care, patient and provider communication, and medication management.

The PHR pilot uses mobile devices to accomplish six main objectives:

- Create a culture in which patients and families are actively involved in their care.
- Enhance the continuum of care by enabling access to the medical record to all caregivers regardless of geography.
- Provide patients' their health information in a secure manner using Direct messaging.
- Provide messaging alerts to patients and their families when the medical record is updated.
- Improve adherence to medication management via medication reminders from the patient's iPhone.
- Mitigate the effect of living in remote areas by providing ready access to clinical information.

Children's chose to pilot its PHR program with its sickle cell patients. Children with sickle cell disease have particularly complicated medical needs that can become urgent very quickly. The patient participants were enrolled during a routine doctor's appointment in Children's hematology/oncology unit, and the following steps detail the patient participation and information exchange.

- The patient or patient's caregiver receives an iPhone at a clinic visit, and the coordinator helps the individual download the iPhone application and set up the Microsoft HealthVault™ PHR account.
- The parent or guardian signs a consent form establishing that the patient becomes responsible for the use and disclosure of the medical information once it is uploaded into the PHR.
- Once the patient creates a Microsoft HealthVault™ account, Children's generates a daily report of patients identified as part of the pilot program that is cross-referenced against the EHR system to identify whether new information (clinic visit or hospital admission) has been sent since the previous transaction.
- If a change is made to the patient's medical record, the PHR coordinator generates a continuity of care document, which contains the patient's clinical information.
- The PHR coordinator accesses a secure patient drop site, enters patient identification data, and clicks SEND. The coordinator is notified of the connection via a message that reads "Success! The patient will receive an e-mail with pickup instructions."
- Whenever the PHR is updated, the patient receives an e-mail notification with a link to the PHR. To access the information, the patient must answer a security question (known only to him or her). This step is taken protect the privacy of the health data.
- If indicated, the patient receives daily medication reminders via a built-in Microsoft HealthVault™ application sent by a text message or e-mail alert. If the patient or caregiver has a question about the device or the PHR, the Children's PHR coordinator is available by phone, e-mail, or text, whichever the patient prefers. Typical questions concern missing passwords or accidental deletion of the application.

3.1.2 MD Anderson

The goal of the MD Anderson project is to pilot test a solution enabling MD Anderson patients to share medical reports and summaries in a continuity of care record (CCR) format using Direct messaging protocol from their patient portal to an unaffiliated (untethered) PHR such as Microsoft HealthVault. Since 2009, MD Anderson Cancer Center has provided patients with access to the majority of their electronic medical records through a patient portal, Clinic Station Outbound (CSO). CSO is a Web-based ASP.net application that provides a subset of the information available via ClinicStation to MD Anderson patients. Currently all files visible in the portal have a print function. Patients can choose to print a file as a PDF and export it to their PHR. The MD Anderson pilot completed the following tasks to expand the export capability of their patient portal to allow patients to become more involved in mediating the exchange of their information with providers outside the MD Anderson system:

- Added export icons to CSO
- Created the functionality to create a CCR when the user chooses to export data
- Created the functionality to send a CCR to a folder for processing to be sent to Microsoft HealthVault
- Created a test Microsoft HealthVault account for a mock PHR
- Prepared a server to set up the direct messaging to send the information to Microsoft HealthVault
- Created a process to use Direct protocol to send the CCR to Microsoft HealthVault's PHR
- Exchanged certificates for communication with Microsoft HealthVault

3.1.3 National Association for Trusted Exchange (NATE)

The NATE PHR Ignite pilot aimed to test expanding patients' ability to use PHRs to exchange data bidirectionally via Direct with their providers. The pilot PHR exchange tested operational policies for sending clinical data to receiving data from PHRs. Additionally, the project served to inform a roadmap for scalable deployment of a trusted mechanism that would enable the use of PHRs for the exchange of patient data across multiple States. The pilot considered two use cases for the bidirectional data exchange involving PHRs:

- Use case 1: Recruitment of providers to send structured data to a patient who uses a patient-subscribed NATE-qualified PHR using Direct secure messaging/BlueButton+ specifications.
- Use case 2: Patient data sent by the test patient from the PHR to a second provider using Direct secure messaging/BlueButton+ specifications.

The pilot included the following tasks:

- Develop a trust mechanism known as a "trust bundle" to facilitate the determination of trust for NATE participants interested in sending and/or receiving information to/from a PHR source.
- Identify and establish minimum technical, security, and privacy requirements for non-HIPAA PHRs participating in the pilot and trust bundle.
- Identify and support PHR vendors and providers as they provided consumers with access to their data via Direct-enabled exchange.
- Identify and resolve barriers to bidirectional patient information exchange.

The pilot established five participant groups:

- Alaska Pilot—The Alaska eHealth Network (AeHN) collaborated with Microsoft HealthVault and private providers, including two pediatric clinics and an allergy, asthma, and immunology center, to send clinical records from providers to the patient's Microsoft HealthVault account, and with the Department of Veterans' Affairs to use VA patients' Microsoft HealthVault accounts to send clinical records from

outside physicians to their VA providers who viewed the data via AeHN accounts created for the pilot.

- California Humetrix Pilot— Humetrix (<http://www.humetrix.com/>) worked with San Diego Health Connect (<http://www.sdhealthconnect.org/>) and the VA using MyHealtheVet PHR to transmit medical data to its iBlueButton (<http://www.ibluebutton.com/>) mobile application. Veterans receiving care through the VA or San Diego health care providers used their mobile phones to receive and manage health records from different providers.
- California Santa Cruz Pilot—The Santa Cruz HIE (<http://www.santacruzhie.org/>) worked with three area provider organizations to deploy the NoMoreClipboard patient portal for 500 patients so they could exchange demographic and clinical data. The pilot project built upon an infrastructure currently used for a HIE-wide patient portal.
- California UCSD Pilot—The University of California San Diego and San Diego Health Connect collaborated with Microsoft HealthVault (<http://www.healthvault.com/>), DELPHI, and CitiSense to make environmental data, including air quality and weather information, available to asthma patients.
- Oregon Pilot—The Oregon Health Authority (<http://www.oregon.gov/OHA/Pages/index.aspx>) facilitated a pilot to electronically exchange health information between a pediatric patient-centered primary care home and parents of chronically ill children using CareAccord® (<https://www.careaccord.org/>) and the patients' free PHR, Microsoft's HealthVault.

3.2 Action: Providing Patients with PHRs that Meet Functional Needs to Enable Engagement

Through the Meaningful Use program, providers are also required to share more information to help empower patients and facilitate consumer engagement in care. Both patients and providers are becoming partners in care. The emerging focus on patient engagement and care coordination has also increased focus on PHRs and related tools that may facilitate the new partnership between patients and providers.

3.2.1 Assessing Current Environment and Functionalities of PHR Systems

The HealthInsight team conducted a 9-month investigation into the technical barriers to PHR access and opportunities for broader PHR adoption in New Mexico and Utah. In the first phase of the project, the two-State team reviewed secondary resources to assess the published literature on key aspects of the PHR landscape nationally and specifically for Utah and New Mexico. The environmental scan had three major sections: a compilation of information regarding dominant payors and providers in the market, a legal review of PHR governance and the Federal privacy, security, and breach regulations, and a technical scan of the PHR offerings used most widely in within New Mexico, Utah, and across the country. The technical scan included a review of functionality and attributes, including accessibility and support, import and edit capabilities, health tracking and improvement, export and data sharing capabilities, standard information available through the PHR, mechanisms for provider contact, and information related to health care costs.

The findings from the environmental scan were then supplemented with additional details drawn from discussions with key stakeholders, including payers, health systems, providers, and consumers in these two States. Two unstructured consumer discussions were conducted by team members in Utah, followed by four discussions with key consumers. An additional unstructured discussion was held with key consumers in New Mexico. During the discussions, project staff described concepts related to PHRs and asked those in the group to provide their perceptions. Similarly for providers, discussions were conducted with representatives from various types of provider organizations in Utah and New Mexico. Members of the Utah Health Information Network (UHN) Clinician Community advisory group also provided feedback.

3.3 Attitudes: Increasing Awareness and Supporting Educational Opportunities to Strengthen Electronic Communication between Patients and Providers

Realizing the full potential of PHRs requires understanding the attitudes of patients, providers, and vendors toward PHR use and consumer-mediated exchange. Consumer-mediated exchange has the potential to facilitate the partnership between patients and providers and improve care for patients with complex medical histories and patients in rural areas who may not have access to care. However, merely building or offering a PHR is insufficient for increasing consumer engagement.

3.3.1 Development of Technical Assistance and Educational Materials to Support Consumer-Mediated Exchange

In this project, the American Medical Informatics Association (AMIA) conducted a 9-month assessment of stakeholder attitudes toward consumer-mediated exchange, both in its present state and in its potential future state. The team held stakeholder roundtable discussions throughout the country both in-person and remotely, targeting stakeholders who provided care for rural and/or cancer care patients and also speaking with patients from rural regions who were seeking care.

The roundtable discussions were framed by two hypothetical scenarios, one designed to convey how care coordination for a patient with chronic illness works in today's health care environment (the *Today Story*), and the other imagining how a similar series of events might unfold differently two years from now, when consumer-mediated exchange is being used to facilitate communication among patients, caregivers, and providers (the *Future Story*). These stories, along with the ONC's *Health IT for You* video¹ used during the consumer sessions, provided a framework for open discussions among participants about the current conditions of chronic care management in rural settings and the potential for consumer-mediated exchange to improve care management. No questionnaires or forms

¹ ONC (2012). *Health IT for you: Health IT for you: Giving you access to your medical records*. Video. Retrieved from: <http://www.youtube.com/watch?v=UMiPW831b1o>

were used to guide these discussions. Themes were identified after each discussion. A total of 104 stakeholders participated in 11 roundtable discussions during a period of four months.

3.3.2 No Matter Where—HIE Documentary

Stone Castle Pictures partnered with Vanderbilt University to complete a documentary that portrays the activities and people associated with the transformative effect of HIE systems. The documentary describes the challenges of health care delivery for many common situations related to emergency care, disaster planning, and coordination across multiple care settings. The film seeks to educate a national audience of consumers interested in learning about HIE, including current challenges to timely information access, concerns about privacy, and the needs of providers caring for transient populations or for people challenged by access to primary care. Filmmakers traveled to New Orleans and also visited the site of the Moore, Oklahoma tornado to capture narratives demonstrating the importance of accessible records during disasters. Additionally, patients and providers through the State of Tennessee provided their stories and perceptions of HIE. Finally, policymakers in ONC provided a national perspective on the importance of HIE.

4. OUTCOMES AND IMPACT

4.1 Access

4.1.1 National Association for Trusted Exchange (NATE)

Products to Share

Children's

A technical summary served as the final product provided by the team at Children's, in addition to the successful completion of live patient data exchange. The summary can be found in the **SHPC Final Project Outcomes Report** and includes information about the system architecture and technologies, details about planning the pilot such as recruitment and testing export capabilities, and information about implementation and supporting the live exchange of data to participating patients.

MD Anderson

A technical summary served as the final product provided by the team at MD Anderson as well. Portions of this summary can be found in the **SHPC Final Project Outcomes Report**, which includes information about the system architecture and technological capabilities, details about working with HealthVault as the test PHR system, and technical preparations for completing a proof-of-concept exchange in a test environment.

NATE

A final report served as the final product for the NATE project. In addition to the final report, products of the project include a list of the policies and procedures to support the ability for each entity to onboard HISPs and PHRs into the NATE trust community.

The goal of the NATE PHR pilot project was to enable the wider use of PHRs as a vehicle for patients to bidirectionally exchange data with their providers and inform privacy and security policies as well as operational policies in order to scale the growth of trusted exchange with patients across the nation. NATE member States support and look forward to continuing their multistate governance approach to increase interoperability, decrease the cost and complexity of Direct exchange, increase trust among participants, facilitate consumer-mediated exchange, and mobilize exchange to support patient care. Significant work remains to be done to reinforce and build on the work that NATE has accomplished. Member States will benefit from repeated testing and deployment as more HISPs become engaged in PHR-to-EHR exchange and more providers begin to use Direct exchange services executed in a flexible way across different State environments.

The NATE Final Report provides additional details about the governance structure, the specific policies and procedures required for inclusion of a HISP and a PHR in the community, and details about the pilots conducted under the project.

4.1.2 Children's Medical Center

Children's implemented a brief survey using their own resources to measure patients' satisfaction and experience managing their health care data. From the survey, the Medical Center learned that having access to updated health information via Microsoft HealthVault™ makes patients and their

caregivers feel more empowered in managing their health care. The next steps include establishing direct messaging with Epic to eliminate the process of manually exporting the CCD and automate sending directly from Epic to Microsoft HealthVault. Positive results from the initial pilot have buoyed Children's resolve to expand offerings. The goal is to partner with marketing arm of their organization to develop a campaign to increase knowledge of PHRs' potential. Children's plans to target individuals via e-mail addresses in Children's next expansion of this project.

4.1.3 MD Anderson Cancer Centers

This project gave MD Anderson staff experience working with a PHR, enabling them to gain familiarity with the formatting requirements and other changes necessary to create a CCR that could be easily imported into a PHR. Having demonstrated the ability to export a CCR and send it directly to Microsoft HealthVault, future patients who use Microsoft HealthVault should be able to import MD Anderson information. Additionally, MD Anderson technical experts were able to create servers and folders to hold and send CCRs, although they acknowledge that they might need to expand these capabilities in the future.

MD Anderson expects to leverage the knowledge gained through this project to inform its export initiatives for future EHR systems as well as its coordination with other PHR-related systems, including Blue Button and Blue Button+. This knowledge and experience could also

Products to Share

Assessing the Current Environment and Functionalities of PHR Systems

The HealthInsight team developed a final report that includes recommendations addressing the key themes they identified in their research. Included as an appendix to the final report, the team also developed implementation guides to aid in the rollout of PHRs in the providers' workflow.

be used to inform other health systems as they make their own journey toward refining their EHRs and making more information accessible to patients.

4.2 Action

4.2.1 Assessing the Current Environment and Functionalities of PHR Systems

The environmental scan and stakeholder discussions highlighted barriers to PHR adoption that centered on consumer protection, functionality, and implementation. The environmental scan identified key gaps in the understanding of legal issues, technical barriers

to wider PHR adoption, questions about security of the information, techniques for importing and editing data, the ability of applications to support patient health tracking or improvement, and the ability to make contact with providers.

The review of the PHR legal landscape documented a number of important findings. The HealthInsight team highlighted some nuances between tethered and untethered PHRs.

Although all PHRs store health information, only PHRs that have a relationship with HIPAA-covered entities through a business associate agreement (BAA) are obligated to meet the requirements of the HIPAA Privacy Rule. HIPAA applies to covered entities, defined as health plans, health care clearinghouses, or health care providers that transmit health information in electronic form in connection with health care transactions,² and their business associates. HIPAA-covered entities and their business associates are required by law to protect individually identifiable health information. Although Federal Trade Commission (FTC) regulation (16 CFR Part 318) provides requirements for PHRs not otherwise governed by HIPAA, the regulation only defines the action that PHR vendors must take in the event of a security breach. The FTC Health Breach Notification Rule,³ issued on August 17, 2009, applies broadly to non-HIPAA-covered entities that are vendors and custodians of PHRs, defined as electronic records of health information identified with a particular individual. Additionally, the FTC regulation does not require standards for privacy and security of consumer health information. The patient is left to decipher the nuance between tethered and untethered PHRs by reading potentially lengthy user agreements. While some untethered PHRs offer more stringent privacy protections than others, this distinction is not always evident to consumers.

As part of the functionality and attributes review performed as part of the overall environmental scan, the HealthInsight team found tethered and untethered PHRs also have distinct functionality differences. Because untethered PHRs are typically not linked to a single provider, patients have greater flexibility to collect data from multiple providers in one convenient location, but must manually enter data. In contrast, tethered PHRs are often auto-populated by the sponsoring health system, but data are not portable to providers outside the health system.

These findings were supported through the stakeholder review task. Patients expressed the desire to share health information in their PHR with multiple providers, a key functionality of untethered PHRs, but also expressed a general sense of mistrust for untethered PHRs that were not directly connected to their providers. This tension between desired functionality and security concerns poses a considerable limitation to the increased use of PHR systems. All stakeholders noted the need for PHRs to support, rather than detract from, the patient-provider relationship, and both providers and patients view the PHR as a way to be more efficient in communications by reducing phone calls, phone wait time, and unnecessary appointments. The information gathered during both the environmental scan task and the stakeholder review task culminated in a final report that provided an assessment of the PHR environment and PHR functionalities and included recommendations for actions that could increase PHR use and adoption. The final recommendations from HealthInsight included:

² 45 C.F.R. § 160.102.

³ Federal Trade Commission. *Health Breach Notification Rule.*, 74 Fed. Reg. 42962. 2009, August 25. <http://www.gpo.gov/fdsys/pkg/FR-2009-08-25/pdf/E9-20142.pdf>. Accessed 2013.

- Privacy and security: A Notice of Privacy Practices, such as that required under HIPAA, is needed as a standard for all PHRs so that both tethered and untethered systems may be independently rated.
- Standards: For PHRs to seamlessly integrate with other data sources, vendors need to work toward standardized messaging and exchanges. Developing interface connections between tethered PHRs and outside sources of clinical data could create more complete patient records and speed adoption of consumer-mediated exchange.
- Consumer adoption: The majority of consumers will need support to adopt and use PHR systems, and features that have clear utility for consumers such as secure messaging, appointment scheduling, and the ability to view laboratory results must be included to begin gaining momentum with earlier adopters.
- Bidirectional data flow: Research is needed that explores the value of bidirectional information exchange from the perspectives of providers and patients. Establishing rules and guidelines for the provenance of patient-generated or patient-entered data will be important to ease provider concerns about data accuracy and liability issues.
- Implementation: Successful implementation and use of PHR systems requires provider workflow changes, office staff training, the inclusion of features that meet the needs of patients, and a concerted effort to educate and enroll patients.
- Cost and incentives: Providers and patients must see clear value for the sustained use of PHR technology to continue after incentive programs end. Understanding and sharing the benefits for providers will be essential if PHR use and adoption are to occur beyond the scope of these incentive and penalty programs.

4.3 Attitudes

4.3.1 Development of Technical Assistance and Educational Materials to Support Consumer-Mediated Exchange

The stakeholder discussions of consumer-mediated exchange conducted by AMIA highlighted the concerns and attitudes of providers, patients, and vendors. Concerns centered on the lack of technology, uncertain effect on workflow, and payment reform.

The consumer-mediated exchange-enabled benefits most likely to improve care coordination include improved information access and sharing; more accurate records; improved patient visit utilization; improved provider workflow; the potential to be more effectively linked to available social infrastructure services; increased patient engagement; increased control in one's own medical care; increased ability to care for patients between visits and to more effectively support homebound patients; and secure communications between the patient/caregiver and the medical team.

As a result of these findings, the following guiding principles for consumer-mediated exchange technical assistance and training framework design were established:

For patients:

- Focus on improving patient and family caregiver consumer-mediated exchange technology familiarity, communication skills, and health literacy.

Products to Share

Development of Technical Assistance and Educational Materials to Support Consumer-Mediated Exchange

The AMIA team developed a framework for the development of training and education materials to aid in the adoption and implementation of consumer-mediated exchange initiatives. This framework provides practical suggestions for implementing education targeted to providers and patients on the benefits of consumer-mediated exchange and provides detailed implementation considerations. In addition, the final report included one appendix providing the user stories that facilitated discussions about CMx and another appendix that defined 20 archetypes identified during the analysis phase to describe existing or potential representative roles in the future development of CMx.

No Matter Where—HIE Documentary

After receiving approval from ONC, Stone Castle Pictures and Vanderbilt will seek to widely distribute the film through film festivals and TV networks. Using these distribution channels, the film can potentially reach a wide audience, particularly those who may not be familiar with HIE policy. Upon completion, the film will give ONC an engaging tool to educate and inform the public on the intricacies of HIE that will persist long after the completion of the project.

For providers:

- Focus on improving provider consumer-mediated exchange technology familiarity, a collaborative culture of care, and patient engagement communication skills. Provide opportunities for first-hand observation of consumer-mediated exchange in practice. Provide professional assistance when needed during consumer-mediated exchange implementations.

For consumer-mediated exchange vendors:

- Focus on improving vendor awareness of the latest consumer-mediated exchange policy, emerging employer/payer consumer-mediated exchange use mandates and best practices associated with consumer-mediated exchange adoption and implementation.

The AMIA team developed a training and education framework to aid in adoption and implementation of consumer-mediated exchange initiatives.⁴ This framework provides practical suggestions for implementing education targeted to providers and patients on the benefits of consumer-mediated exchange and provides detailed implementation considerations. Five core technical assistance framework components were recommended.

1. **Planning and organizational support:** Provider organizations should receive technical assistance to support organizational planning that includes consumer-mediated exchange considerations. The technical assistance should stress the importance of creating a consumer-mediated

⁴ Martin, R. D., Koss, S., Barsch, K., Cunningham, S., Rizk, S.C., Bailey, R. F. (2014, March). *AMIA final report on the development of technical assistance and educational materials to support consumer-mediated exchange*. Prepared for Office of the National Coordinator for Health Information Technology.

exchange plan that is consistent with the shared perspectives of providers, patients, and commitment from leadership to achieve buy-in.

2. **Readiness assessment:** Provider organizations should seek to understand what barriers they may face in pursuing adoption of consumer-mediated exchange, including an assessment that reviews policies, processes, technology, and culture to help determine how best to approach the adoption of consumer-mediated exchange and what fundamental organizational or structural changes may be needed prior to adoption.
3. **Design and implementation alternative guidance:** Roundtable and interview participants identified the need for varied design and implementation models for consumer-mediated exchange initiatives based on significant organizational and community differences. Provider and vendor organizations need technical assistance to understand the value in providing multiple types of consumer-mediated exchange platforms and customizable programs. Technical assistance should guide project plans and show how consumer-mediated exchange models and implementation can be tailored to the needs of an organization or community.
4. **Education and awareness:** All stakeholder groups agreed that using consumer-mediated exchange could be beneficial. Case studies and lessons learned relevant to a stakeholder's local setting should be available to communicate the value of consumer-mediated exchange and local user feedback. Technical assistance begins by supporting early education and awareness building and then transitioning to assistance for consumer-mediated exchange use.
5. **Training:** Technical assistance should support the targeted piloting and full implementation of consumer-mediated exchange by training and supporting both provider and patient participants. Training should be tailored to the needs of the individuals and be designed to fit within the constraints of their work and lives. Because consumer-mediated exchange implementations must be tailored to local settings, training should be customized to the local consumer-mediated exchange solution

5. CONCLUSION

The PHR Ignite projects provide a foundation for stimulating patient engagement through the use of PHR systems by supporting consumer-mediated exchange. This foundational and pilot demonstration work provides a basis for executing real-world implementations of consumer-mediated exchange and provides guidance for the developers of PHR systems to promote functionalities that support communication between patients and their providers. Lessons learned from these projects will inform future work to support and implement consumer-mediated exchange on a larger scale.

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