

March 2014

State Health Policy Consortium

Summary of Projects and Outcomes Final Report

Prepared for

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

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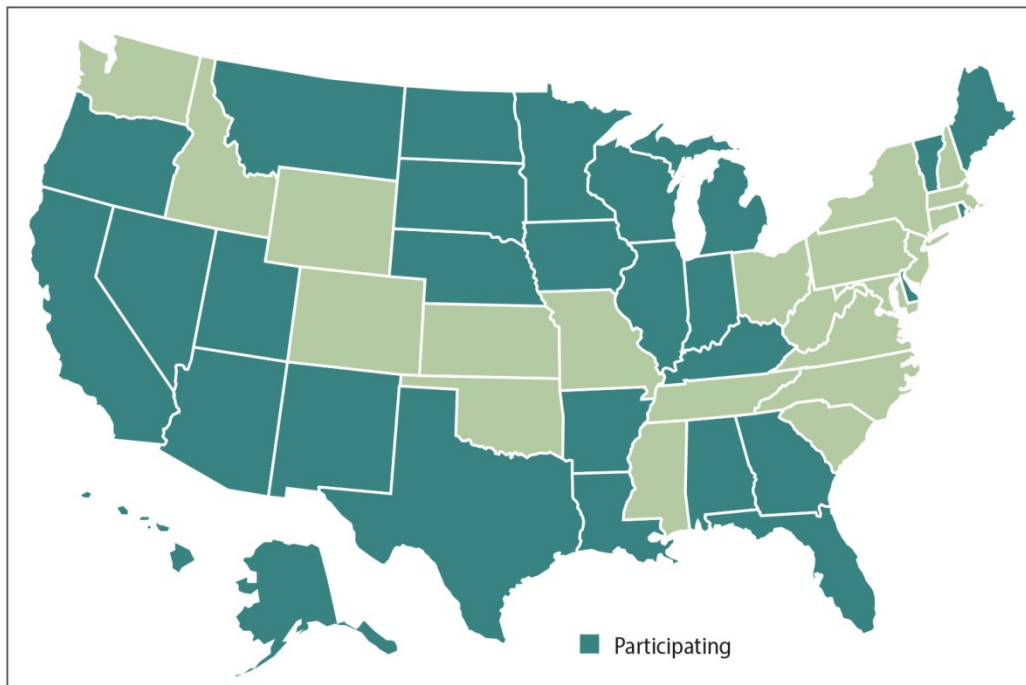
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1. EXECUTIVE SUMMARY

The State Health Policy Consortium (SHPC) convened in April 2010 under the Office of the National Coordinator for Health IT (ONC) to provide funding and management support for projects designed to advance interstate health information exchange (HIE) across the United States. Implemented alongside a suite of programs funded under the American Recovery and Reinvestment Act of 2009 (ARRA), SHPC was designed to identify challenges to the widespread adoption of HIE and develop both research and pilot demonstration projects to test solutions applicable at both regional and national levels. Over four years, SHPC supported nine official consortium projects, which included participants from 29 different States (see Figure 1).

Figure 1. State Health Policy Consortium Participants (All States)



Working with ONC, RTI International provided support to the nine consortium projects. Each project focused on furthering the understanding of how to overcome a particular issue. The projects are summarized in the following sections.

Exchange of Behavioral Health Information

The exchange of behavioral health information is usually more restricted than the exchange of other categories of health information. As such, behavioral health information is often excluded from HIE efforts even though it is an important component of health and well-being. To address this issue, the Behavioral Health Data Exchange (BHDE) Consortium

created a set of common policies and procedures that aligned with Federal regulations and the laws of the participating States. BHDE piloted these policies and procedures by connecting State-level systems to allow Direct exchange¹ of behavioral health information. This project represents progress toward the creation of an HIE system fully integrated with physical and behavioral health records.

HISP-to-HISP Connectivity

Direct secure messaging offers a simple, easy way for health care providers to exchange information. Health Information Services Providers (HISPs) enable the exchange of Direct messages, but connectivity between HISPs is required for providers to exchange Direct messages with providers using a different HISP. The Western States Consortium (WSC) was convened to address this issue. WSC developed policy solutions addressing business agreements, privacy and security protocols, identity validation, and a governance structure using a memorandum of understanding (MoU) to create an environment for trusted exchange. After successfully piloting these policies, protocols, and governance structures, WSC members established the National Association for Trusted Exchange (NATE) to continue to facilitate interstate exchange.

A Community Resource to Support Reuse of HIE Interfaces

One barrier to HIE is the cost of building interfaces between different electronic health records (EHRs) and HIEs. The Open Library of HIE (OLHIE) was convened to create a repository of HIE interfaces and other technical assets, particularly those built with State and Federal funding. The consortium developed governance policies and procedures for managing contributions to the library and sharing its resources. The library was launched in December 2013.

Consumer-Mediated Exchange

The transformative effects of health IT and HIE can only be fully realized when consumers are actively involved in their care and have access to their health information. The PHR Ignite project combined six smaller projects under one larger project to examine issues of access, actions, and attitudes affecting consumers' decisions to adopt and use personal health records (PHRs). These included two projects researching the current state of PHR functionality and creating a roadmap for future growth through technical assistance, three pilots demonstrating export of clinical data to an untethered PHR, and the production of a documentary film highlighting the transformation of health care through health information exchange to engage a wider, nationwide audience in discussion.

¹ Based on secure email protocols, Direct provides a simple, direct, point-to-point transmission of information (i.e., email) and uses widely available technology. For more information: <http://directproject.org/>

Data Exchange in a Disaster

As a result of Hurricanes Katrina and Rita in 2005, many lessons were learned about the need for health information exchange, although few practical solutions were implemented. The Southeast Regional Collaboration for Health IT and HIE (SERCH) convened to determine how HIE could improve care delivery during or following a disaster. The group examined legal, technical, and governance issues associated with such exchange, implemented MoUs across States supporting exchange in the event of future disasters, and developed five recommendations for other States who wish to address this aspect of health care delivery and information exchange.

Impact of Direct on Provider Practices

As mentioned previously, Direct secure messaging offers a simple, secure method for providers to exchange information. This consortium examined the costs and benefits of using Direct in small provider practices. Findings from the study indicate that implementing Direct requires minimal changes to workflows; and although the absolute dollar values at the individual sites are modest—ranging from \$3,000 to \$12,000—the savings associated with Direct fully implemented across all small practices could be substantial.

Interstate Consent Requirements and Management

Although the Health Information Portability and Affordability Act (HIPAA) Privacy Rule governs health information sharing at the Federal level, States are free to enact more stringent laws that further protect and restrict it. The States participating in the Upper Midwest HIE Consortium assessed the variability in consent requirements and developed a common consent form that could be used in all participating States to exchange data.

Innovative Approaches to Share Health Information with Consumers

Engaging consumers as central stakeholders in HIE is essential to foster active patient participation in medical decisionmaking and care management. The Consumer Innovation Challenge was designed to support innovations in engaging patients in their own care. Four demonstration projects were conducted under the Challenge and highlighted opportunities for supporting consumer engagement as HIE expands.

Developing a State-Level Quality Measurement, Reporting, and Feedback Infrastructure

In response to rising health care costs and uneven health care quality, the Trailblazers consortium worked to develop a State-level electronic quality measurement, reporting, and feedback infrastructure. Working with the National Academy for State Health Policy, RTI supported the work in four of the eight states chosen as Trailblazers. This work included a detailed baseline assessment and site visit in each State to identify the current information

infrastructure across many various programs and initiatives within the State and a set of tasks needed to develop a more integrated system. As a result of this process, the consortium developed extensive documentation defining a roadmap to create such a system and strengthened the level of engagement across disparate initiatives addressing common issues related to HIE.

This report summarizes the problems each consortium addressed, the solutions developed and implemented, and, to the extent known, the downstream impacts of these projects.

2. BACKGROUND ON STATE HEALTH POLICY CONSORTIUM

2.1 Project Structure and Purpose

Under the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, Title XIII of the American Recovery and Reinvestment Act (ARRA), ONC was directed by Congress to perform its duties “in a manner consistent with the development of a nationwide health information technology infrastructure that allows for the electronic use and exchange of information.”² ARRA funding has enabled substantial support of State and regional health information technology (health IT) developments by financing HIT Regional Extension Centers and the State HIE Cooperative Agreement program. The State HIE Cooperative Agreement Program funded states’ efforts to rapidly build capacity for HIE within and across States. Awardees were tasked with increasing connectivity and building on existing efforts to advance regional and State-level health information exchange (HIE) while moving toward nationwide interoperability. Key to these efforts were the evolution and advancement of necessary governance, policies, technical services, business operations, and financing mechanisms for HIE in each State.

To support the development of HIE, ONC also created and funded the State Health Policy Consortium (SHPC), which has been administered by its contractor, RTI International, since April 2010. The purpose of SHPC is to support “the development and implementation of solutions to privacy and security issues preventing or impeding the interstate exchange of health information.” This final report summarizes the projects conducted under SHPC.

The methodology used to support the consortium projects is described in detail in a companion report, *Effective Methods for Interstate Collaboration in HIE*. In summary, the RTI project team developed and circulated a request for proposals under an open and revolving funding opportunity intended to solicit projects to overcome barriers to interstate HIE. The responses required the involvement of at least three States and the written support of each State’s Health IT Coordinator to ensure coordination between the different HIE initiatives across the State. RTI staff worked with experts in the field to evaluate each submission. Successful consortium projects were supported until the designated funds were fully utilized.

2.2 Health Information Exchange and Interoperability

The landscape of HIE shifted considerably during the course of the project. When the Upper Midwest HIE (UMHIE) Consortium, was awarded support as the first SHPC project in mid-2010, many participating States were still in the process of obtaining ONC approval of their State HIE cooperative agreement strategic and operational plans. Only in 2011 did analysis

² Health Information Technology for Economic and Clinical Health Act, Pub. L. 111–5, div. A, Title XIII, § 13101, Feb. 17, 2009, 123 Stat. 230.

of these strategic plans begin to parse out various State-level HIE models, such as the capacity-builder and the public utility.

In these early stages, most States were building on widely varied HIE structures established prior to ARRA. Although the methods for coordinating HIE varied in each State, all State-level models sought the establishment of basic technical services and policies allowing for development of more robust query-based systems.

When the Direct Project gained traction in early 2011, moving HIE services forward rapidly using a system of point-to-point exchange became a practical option for exchange.³ When the second and third SHPC projects were funded in early 2011 (the Behavioral Health Data Exchange Consortium and the Southeast Regional Health IT/HIE Consortium), understanding of Direct secure messaging was limited and its integration with States' plans was uncertain. Original plans to build query-based exchange have continued to move forward in conjunction with the implementation of Direct. Query-based exchange provides a more robust set of services, such as central record locators, essential to achieving a state-of-the-art Nationwide Health Information Network. However, they are extraordinarily complex, costly to create and, therefore, slow to develop.

Direct secure messaging served as the centerpiece for many of the consortium projects funded under the SHPC because it does not require the coordination and functional build-out of complex State-level systems. Because of its simplicity, Direct quickly enabled interoperable exchange of data between States, allowing consortia to test the strength of the policies, procedures, agreements, and other materials they developed to solve interstate exchange barriers. While more sophisticated query-based systems remain largely in the future, Direct secure messaging provides HIE capabilities now.

This report groups the nine SHPC projects into three categories to facilitate discussion: HIE demonstration projects, policy and research approaches to HIE, and support for other ONC projects. The following three chapters present the projects in these categories and describe the problem addressed, the solutions developed, the demonstrations conducted, lessons learned, additional considerations, and available products. Throughout this document, references are provided to the reports prepared by the consortia. Other supplementary information is included in the appendices.

³ The Direct Project developed the technical standards and services needed to "push" content from a sender to a receiver known to each other using encrypted, secure messaging. For more information regarding the Direct Project or the specifications for implementing Direct secure messaging, visit the Direct Project website (directproject.org) or the Direct Project wiki (<http://wiki.directproject.org>).

3. HIE DEMONSTRATION PROJECTS

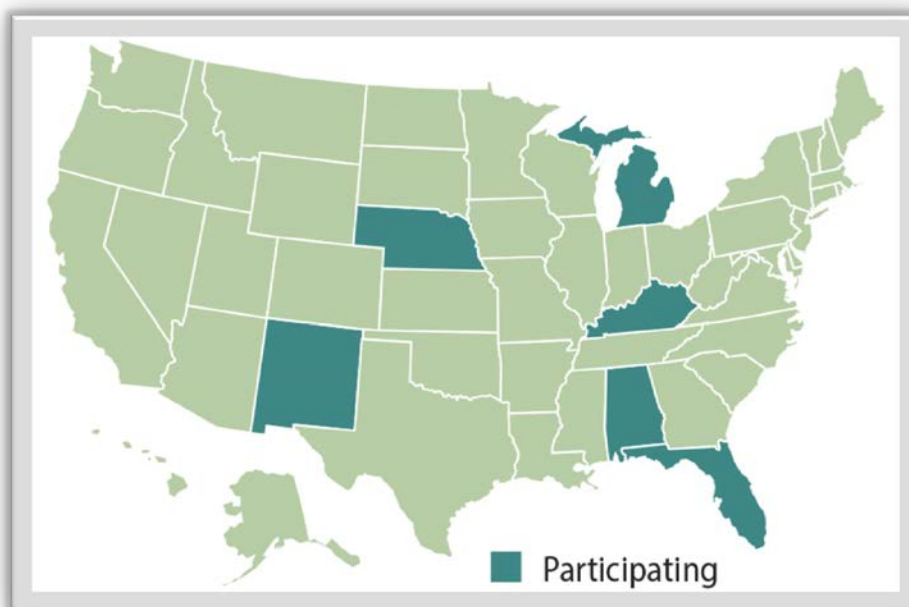
This chapter summarizes the four projects classified as pilot demonstrations or implementations. These projects were aimed at exchanging behavioral health information, addressing connectivity across HISPs, implementing a website to share HIE-related assets, and developing consumer-mediated exchange.

3.1 Exchange of Behavioral Health Information

3.1.1 Problem

Most HIE activities to date have focused on the exchange of general clinical data between providers and have excluded behavioral health data. Legal and technical complexities associated with exchanging behavioral health data pose special challenges to HIE. From a legal perspective, behavioral health data require additional protections beyond those of the Health Insurance Portability and Accountability Act (HIPAA). This includes adherence to 42 CFR Part 2, which limits the disclosure of identifiable information by a federally assisted substance abuse treatment program to any entity without signed consent from the patient to authorize the disclosure. HIPAA also restricts the redisclosure of that data by the receiving entity for any purpose without consent. Current technology has limited ability to properly distinguish and handle behavioral health data. Alabama, Florida, Kentucky, Michigan, Nebraska, and New Mexico (see Figure 2) formed the Behavioral Health Data Exchange (BHDE) Consortium to address these issues.

Figure 2. Behavioral Health Data Exchange Consortium: Alabama, Florida, Kentucky, Michigan, Nebraska, New Mexico



3.1.2 Solutions and Demonstrations

To overcome barriers to electronic exchange of behavioral health data, the BHDE Consortium participants created a set of common policies and procedures that aligned with Federal regulations and the laws of the participating States. In addition, participants put these policies and procedures into practice by enabling their State-level systems to allow Direct exchange.

The objective of the Consortium project was to execute at least one successful pilot demonstrating the ability of providers to exchange behavioral health data electronically across State lines using Direct exchange. At the end of the project, data were exchanged between providers in Florida and Alabama, and the necessary frameworks for exchange were established in three additional States.

Demonstrating the ability to exchange behavioral health data electronically is a major step forward to reduce disparities for patients with specially protected information who have been neglected by previous HIE initiatives.

3.1.3 Lessons Learned and Additional Considerations

Behavioral health data exchange is complex, but possible. This project was successful in demonstrating that specially protected information can be transmitted between States using available electronic HIE technologies. Although initial cultural and technical barriers were significant, clarification of the legal requirements for exchange reassured participants they could comply using an available technological solution.

Provider education is key to success. Educational materials and process documentation must be shared with providers to reassure them that required policies and procedures are in place for engaging in behavioral health data exchange. Although the Consortium's initial goal was to develop solutions to the policy and technical issues preventing exchange, provider education clearly emerged as a third important requirement for success.

3.1.4 Products to Share

The BHDE Final Report released in spring 2014 contains the following products:

- A comprehensive set of policies and procedures created to enable providers to exchange behavioral health information between States using Nationwide Health Information Network (NwHIN) Direct exchange protocols.
- Two checklists to outline the general mechanics and expectations for exchanging behavioral health information using Direct: one for the provider making the request and the other for the provider responding to the request.
- An educational notebook designed to guide providers through the process of exchanging behavioral health information. The notebook includes the provider checklists above and other relevant materials, including a Direct fact sheet and Direct user guides. This notebook was used and reviewed as part of the New Mexico pilot and can be customized for other entities or States.

3.2 HISP-to-HISP Connectivity

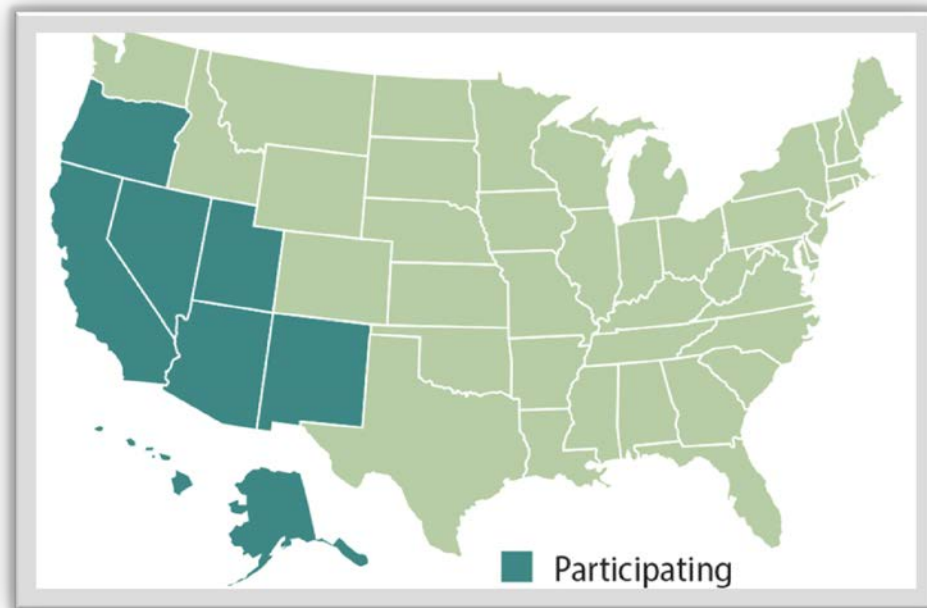
3.2.1 Problem

In early 2010, the Direct Project convened with multiple private and public stakeholders to develop a simple, standards-based method to send health information safely and securely to trusted recipients using encrypted messages. The idea for creating technical specifications to transmit health information originated because query-based or “pull” exchange was still in early development across the country, yet providers adopting electronic health record systems needed an easy method to exchange information electronically to realize greater value and potential of their systems. The resulting specifications and code were simple to implement and use, but required an entity to provide services for use of Direct such as identity verification, authentication, and encryption, among others. These entities, known as Health Information Service Providers (HISPs), developed rapidly to provide Direct secure messaging services to providers. The Direct specifications were published to allow the simplest, most straightforward exchange of information electronically and allow the highest level of interoperability between providers. However, the Direct Project developers did not anticipate the competitive market forces of the HISP entities isolating subscribers in silos of exchange. In other words, a provider using HISP A quickly found that exchange with a provider using HISP B did not work because the two HISPs could not exchange information with each other.

3.2.2 Solutions and Demonstrations

Once the problem of HISP-to-HISP connectivity became apparent, several initiatives were created to ensure common policies and governance structures were defined to enable willing HISPs to exchange information interoperably via Direct secure messages. This effort was designed to address scalability—to allow Direct implementation to expand and occur efficiently, without requiring one-to-one agreements between each pair of HISPs wanting to exchange data, through the creation of governance processes and structures. The Western States Consortium (WSC; later incorporated as the National Association of Trusted Exchange, or NATE), was one of the first groups to identify this problem and propose a solution. The WSC consisted of a core group of States: California, Oregon, Alaska, Arizona, Hawaii, Nevada, New Mexico, and Utah. Additional representatives from Colorado, Florida, Georgia, Idaho, and Washington also monitored the work and developments of the WSC throughout the project (see Figure 3). The project was convened as an SHPC consortium project to establish a set of policies and technical solutions supporting Direct exchange between HISPs and foster HIE across State borders.

Figure 3. Western States Consortium: Alaska, Arizona, California, Hawaii, Nevada, New Mexico, Oregon, Utah



The WSC developed policy solutions addressing questions about business agreements between HISPs, security and privacy protocols, acceptable interstate uses of Direct exchange, and identity validation through registration and certificate authorities. The consortium established a governance structure—a single Memorandum of Understanding (MoU) shared among all participating States—that created an environment of trust in each State encompassing all approved HISPs. Scalable interstate Direct exchange was thus enabled without requiring thousands of individual HISP-to-HISP agreements. The WSC developed a robust technical infrastructure assuring conformance to governance policy and enabling trusted exchange between unaffiliated providers and organizations, with distributed provider directory services. Specific details about these policies and procedures can be found in the full WSC Final Report.⁴

A key component of this project was to ensure it culminated in the exchange of actual data across State lines in a proof-of-concept pilot validating the governance structure created and endorsed by the States. To that end, the WSC completed two pilot demonstrations where Direct messages were successfully exchanged between California and Oregon in November 2012. Participants sent clinical messages across State lines and between different HISPs. The first pilot scenario was executed between health care provider organizations in

⁴ Banger, A.K., Rizk, S. C., Bailey, R. F., Cartland, P., Mayer, L., Sommers, R. et al. (2013, September.) *Western States Consortium ONC state health policy consortium project: Final report*. Prepared for Office of the National Coordinator for Health IT (ONC). <http://www.healthit.gov/sites/default/files/wscfinalreport.pdf>

Southern Oregon and Northern California. This pilot laid the groundwork for the WSC governance structure by testing policies and procedures outlined in a precedent-setting interstate MoU for Direct exchange. At the outset, both providers in the exchange had each other's Direct addresses and the policies in place enabled the digital "handshake" to occur between HISPs. The second pilot scenario achieved further technical progress by overcoming the challenge of providers who wanted to share protected health information (PHI) securely but did not know each other's Direct addresses. In this pilot, the providers from California and Oregon were able to connect to and search the provider directories of different HISPs and locate the Direct address for the intended recipient of a Direct message.

3.2.3 Lessons Learned and Additional Considerations

When the WSC project began in October 2011, implementation of Direct secure messaging services was just beginning. States across the country, including those participating in the consortium, were still trying to determine how to support adoption of this new exchange mechanism. It was unclear whether the Direct Project itself would create a method to enforce a governance structure. The Direct Project did release a set of trust policies entitled "Rules of the Road"⁵ but did not take any steps to enforce these rules or certify HISP adherence to the suggested policies and procedures. To fill this gap, a handful of initiatives, including WSC, stepped in to find market-based solutions to create trust communities supporting HISP-to-HISP exchange. The WSC trust community differed from some other initiatives because it did not have a formal "certification" requirement or membership cost. The WSC solution was State-based and used the State HIE program's authority to oversee exchange (including through Direct secure messaging), to establish enforcement of the policies, and to create an official governance structure.

The WSC Final Report provides additional details about the MoU for the scalable, State-based governance structure, the specific policies and procedures required for inclusion of a HISP in the community, and details about the two pilots conducted under the project.

3.2.4 Products to Share

The following products are available in the WSC Final Report:

- Links to a live demonstration of the pilot exchange provided at the Health Information and Management Systems Society annual conference in 2013, and a text-based description of the demonstration. WSC demonstrated real-world exchange between provider practices in multiple States and delivery of a structured patient record to a patient's personal health record (PHR).
- A list of the business processes (BP) the WSC defined for participation in the "trust bundle" including: BP1 – Identity registration and maintenance by organization type; BP2 – Identity provisioning and maintenance (including issuing certificate); BP3 – Verification of provider identity and secure exchange of PHI; BP4 – Assignment of

⁵ Direct Project's Implementation Group. (2013). *Direct rules of the road*. Retrieved from: <http://wiki.directproject.org/Direct+Rules+of+the+Road>

roles (for access rights); BP5 – Verification of accreditation, BP6 – Authorization to access directory services; BP7 – Authorization to exchange PHI across State lines; BP8 – Provider Directory.

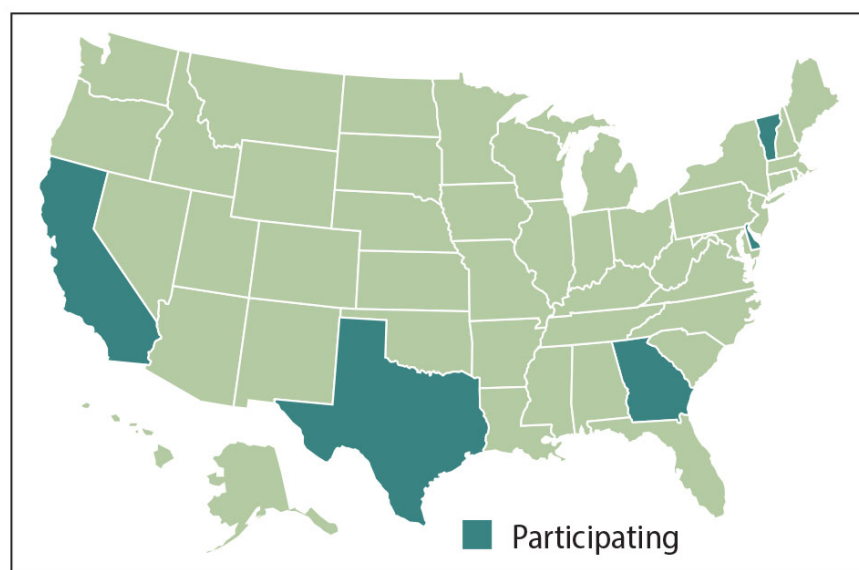
- A list of the policies and procedures to support the ability for each State to onboard HISPs⁶ into the WSC trust community and also outlining how to onboard additional States as WSC members.
- The MoU used to solidify the acceptance of States into the WSC and examples of the Statement of Authority offered by States participating in the WSC, which are used to ascertain that the entity participating on behalf of a particular State has the necessary authority to represent its geographical jurisdiction.

3.3 Creating a Community Resource to Support Reuse of HIE Interfaces

3.3.1 Problem

One of the challenges to achieving widespread HIE is the cost and time required to develop interfaces between different sources of information. There is widespread agreement across States that the cost and time required to develop interfaces create a significant barrier to HIE. The Open Library of HIE project set out to address this challenge (see Figure 4).

Figure 4. Open Library of Health Information Exchange Consortium: California, Delaware, Georgia, Texas, Vermont



⁶ Referred to as Qualified Entities (QEs) in the policy parlance of the WSC, QEs include all types of Security/Trust Agent (STAs) per the Direct applicability statement. For simplicity, the term HISP is used here.

3.3.2 Solutions and Demonstrations

The Open Library of HIE (OLHIE) Consortium project developed a repository of assets designed to reduce the time required to establish connections between health information organizations (HIOs). Reusing existing interfaces and other assets instead of purchasing or developing new ones can reduce the cost and time it takes to build HIE infrastructure, while increasing the potential for interoperability. The project team, made up of staff from open source software advocates Pronoia Health, worked with an Executive Steering Committee made up of health IT leaders in Texas, California, Georgia, and Delaware to ensure their tool would serve to fill a gap in the health information exchange landscape.

OLHIE provides an asset registry, repository, and online collaborative tools that will enable HIOs to contribute assets, identify and download other assets, and contribute modified assets back to the library. OLHIE developed mechanisms to vet the sources of contributions and resolve legal issues that would otherwise affect the use of resources in the library. The project was divided into two phases.

Phase 1 of the project involved outreach to a range of stakeholder groups, the development of a governance structure, and obtaining commitments from States in the form of Letters of Support. The outreach included State-level HIOs, the health IT vendor community, the College of Health Information Management Executives, and the National eHealth Collaborative. At the conclusion of this phase, seven States endorsed the work of the OLHIE. The governance structure was created, including establishing an executive steering committee and defining other committees required for the ongoing function and maintenance of the library. Phase 1 addressed the fundamental problem of cost by defining the guiding principle of “dollars for delta” by which HIE interfaces would be freely shared and only subsequent modifications would incur additional cost.

Phase 2 involved the creation of the repository, continuing outreach to and development of the patron community, and establishment of the committees defined in Phase 1 to advise and support the library.

3.3.3 Lessons Learned and Additional Considerations

The objective of OLHIE is to become an asset registry and interactive digital repository for HIE-related assets. Library content is being added from participants on a rolling basis and OLHIE’s technical capability to serve as a registry and repository has been confirmed. In parallel to the technical development and deployment of the library website and repository, the team has created a community of library patrons across the country. This group of State HIE organizations and other library clients has begun to download HIE-related assets into the repository, while promoting the value proposition of OLHIE.

3.3.4 Products to Share

Version 1.0 of the Open Library of HIE⁷ was released to the public in December 20, 2013. In response to the needs identified by the community, OLHIE is becoming a repository for HIE interfaces and interface specifications, plus other health IT assets including templates, data sets, technical documentation, and user documentation. The patron community also seeks example request for proposal (RFP) documents, contract language, policies, and source code for connecting to laboratories, pharmacies, and public health departments.

3.4 Consumer-Mediated Exchange

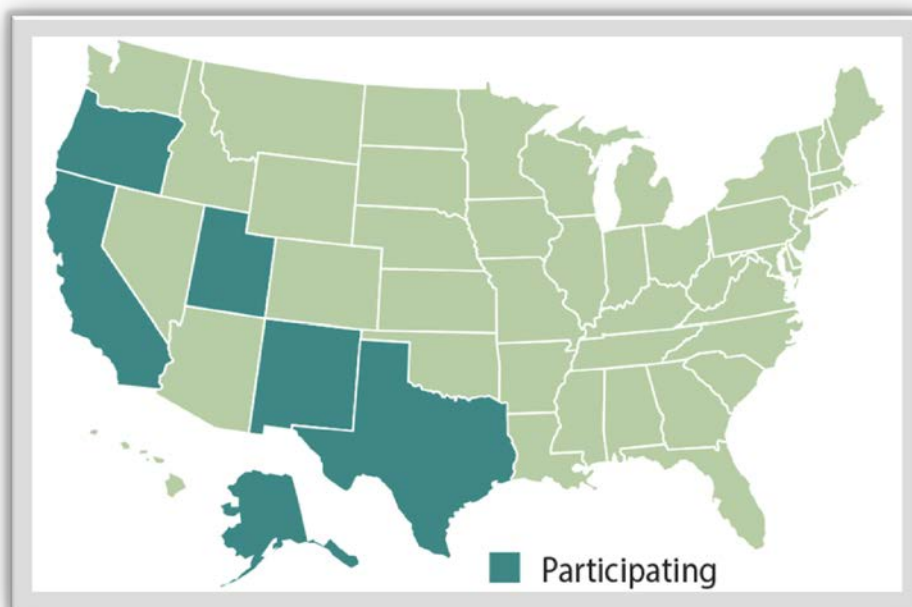
3.4.1 Problem

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 have the capacity to receive and collect this information in a single location, controlled by the consumer. These projects aim to ignite the use of PHRs 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 (see Figure 5).

⁷ The library is located at <http://www.olhie.org>

Figure 5. PHR Ignite Project Participants: Alaska, California, New Mexico, Oregon, Texas, and Utah



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.

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.

3.4.2 Solution and Demonstrations

Access

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

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.

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

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 worked with San Diego Health Connect and the VA using MyHealtheVet PHR to transmit medical data to its iBlueButton 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 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, DELPHI, and CitiSense to make environmental data, including air quality and weather information, available to asthma patients.

- Oregon Pilot—The Oregon Health Authority facilitated a pilot to electronically exchange health information between a pediatric patient-centered primary care home and parents of chronically ill children using CareAccord® and the patients' free PHR, Microsoft's HealthVault.

Action: Assessing the 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.

Attitudes: 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* video⁸ 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 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.

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.

3.4.3 Lessons Learned and Additional Considerations

Access

National Association for Trusted Exchange (NATE)

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.

⁸ ONC. *Health IT for you: Health IT for you: Giving you access to your medical records*. Video. 2012. Retrieved from: <http://www.youtube.com/watch?v=UMiPW831b1o>

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.

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.

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. The ability to export a CCR and send it directly to Microsoft HealthVault has been demonstrated, and 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 be used to inform other health systems as they make their own journey toward refining their EHRs and making more information accessible to patients.

Action: 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,⁹ 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,¹⁰ 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:

⁹ 45 C.F.R. § 160.102.

¹⁰ 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.

Attitudes: 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.

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.¹¹ 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 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

¹¹ 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.

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.

3.4.4 Products to Share

Access

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 **Appendix A** and includes information about the system architecture and technologies, details about planning the pilot such as recruitment, and testing export capabilities, and information about implementing 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 **Appendix B** and 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. Policies and procedures include:

Policies for trust profiles:

- 3.a.1 Policy that each State have a procedure for onboarding Qualified Entities to a profile
- 3.a.1.a Onboarding guidance template
- 3.a.2 Policy for multistate HISPs and HIOs
- 3.a.3 Policy for migrating profile policy changes
- 3.a.4 Policy for provider-to-provider-for-treatment trust profile
- 3.a.5 Policy for provider-to-provider-for-treatment directory search trust profile

- 3.a.6 Policy for provider-to-provider-for-treatment HISP-level cert trust profile
- 3.a.7 Policy for provider-to-PHR trust profile
- 3.a.8 Policy for PHR-to-provider trust profile

Procedures for trust profiles:

- 3.b.1 Procedure for onboarding to a trust bundle
- 3.b.2 Procedure for onboarding to provider directory¹²

Action: 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.¹³ 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.

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

The AMIA team developed a training and education framework to aid in the adoption and implementation of consumer-mediated exchange initiatives.¹⁴ 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. Each component is described in detail in the full report, along with suggestions for approaching each component tailored to patients, providers, vendors, and other stakeholders, as appropriate.

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.

¹² Bagwell, J., Rizk, S.C., Boone, E., Hall, J., Montgomery M., Cartland, P. & NATE PHR Ignite Project Team (2014, February). *PHR Ignite Pilot National Association for Trusted Exchange ONC State Health Policy project report*. Prepared for Office of the National Coordinator for Health Information Technology.

¹³ HealthInsight, Utah; HealthInsight, New Mexico; Utah Department of Health; and Utah Health Information Network. (2014, January.) *PHR Ignite—Action HealthInsight final report assessing the current environment and functionalities of PHR systems*. Prepared for Office of the National Coordinator for Health Information Technology.

¹⁴ 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.

4. POLICY AND RESEARCH APPROACHES TO HIE

This chapter summarizes the three policy-oriented projects conducted under SHPC. These included an examination of the challenges and potential solutions for exchanging health information during and following a disaster, quantifying the value of Direct for small practices, and resolving differences in consent for information sharing across State lines.

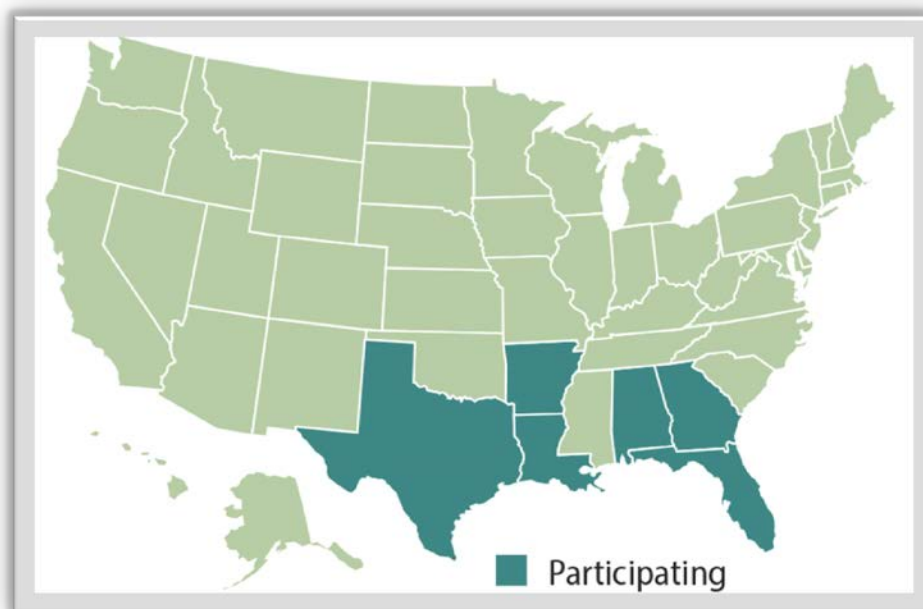
4.1 Enabling Data Exchange in a Disaster

4.1.1 Problem

The State HIE Program offered States a new and substantial pool of funding to build and improve HIE infrastructure. A group of six States from the Gulf region recognized this opportunity to build HIE infrastructure and processes supporting emergency preparedness and response, and to provide health care to displaced individuals in disasters. In November 2010, representatives from Alabama, Arkansas, Florida, Georgia, Louisiana, and Texas convened under the Southeast Regional Collaboration for Health IT and HIE (SERCH) to address these issues and begin incorporating emergency preparedness and response with HIE (see Figure 6).

The Southeast and Gulf States are particularly prone to natural disasters including hurricanes, tornadoes, and flooding which often displace patients and providers who cross State boundaries to seek safety. When SERCH convened, limited research had been conducted on how to leverage HIE to provide timely access to clinical information in response to a disaster. As the SERCH Consortium States noted in their initial proposal, “disaster planning requires preparing for your neighbor’s disaster.” While people move, their medical records do not, which creates major problems in delivering health care during times of crisis. Although many lessons were learned about providing and coordinating medical care for displaced persons following Hurricanes Katrina and Rita in 2005, few practical solutions were subsequently implemented. The SERCH States recognized that the best way to ensure health information access during an emergency is to ensure access during routine care. The work reflected the incremental progress in HIE and recognized that the various States had different HIE implementation timelines. The SERCH States agreed a phased approach would be the most appropriate strategy.

Figure 6. Southeast Regional Collaboration for Health IT and HIE (SERCH): Alabama, Arkansas, Florida, Georgia, Louisiana, and Texas



4.1.2 Solutions and Demonstrations

The SERCH project addressed barriers to HIE during and following a disaster by

- examining existing legal gaps and obstacles between the Southeast and Gulf States;
- assessing the unique technical approaches used to achieve Statewide HIE in this region; and
- identifying opportunities to create regional exchange during a declared emergency, including governance issues to be resolved prior to a disaster, such as delegation of authority, resource allocation and management, and continuity in the event of changes in State or local government leadership.

The project aimed to address these fundamental issues and provide a path forward for other States who wished to address this key aspect of health care delivery and information exchange.

The SERCH Final Report offered the following five recommendations:

- Understand the State's disaster response policies and align with the State agency designated for Emergency Support Function #8 (Public Health and Medical Services) before a disaster occurs.
- Develop standard procedures approved by relevant public and private stakeholders to share electronic health information across State lines before a disaster occurs.
- Consider enacting the Mutual Aid MoU to establish a waiver of liability for release of records when an emergency is declared and to default State privacy and security

laws to existing HIPAA rules in a disaster. States should also consider using the Data Use and Reciprocal Support Agreement to address and/or expedite patient privacy, security, and health data-sharing concerns.

- Assess the State’s availability of public and private health information sources and the ability to electronically share the data using HIEs and other health data-sharing entities.
- Consider a phased approach to establishing interstate electronic health information-sharing capabilities.

4.1.3 Lessons Learned and Additional Considerations

During the project, the consortium came to realize the importance of involving individuals working in emergency preparedness and response at State and local levels. Previously, the HIE and preparedness communities had operated largely independently without considering how combining efforts could enhance patient care during disasters. Combining these two important health care functions can help ensure that when a disaster strikes, patients and providers will have better access to information and providers will be better able to provide appropriate care.

4.1.4 Products to Share

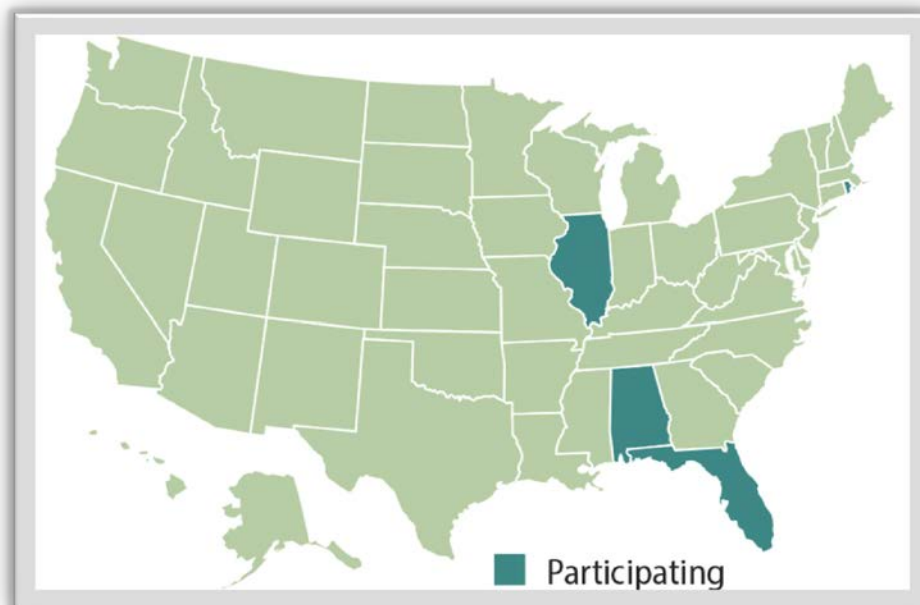
The SERCH report was published in September 2012.¹⁵ The report includes the data collection tool the consortium members used to document the laws associated with the exchange of health information and the template for a Mutual Aid MoU.

4.2 Studying the Impact of Direct on Provider Practices

4.2.1 Problem

The Direct Project came together to provide one mode of HIE by which all care partners—clinicians, hospitals, patients, public health organizations, and social-services agencies—could exchange health information (see Figure 7). From the providers’ perspective, the challenge of using Direct (and other forms of HIE) is to use these means of health information exchange without disrupting practice workflow, and with minimal financial and technical investment.

¹⁵ Banger, A.K., Rizk, S. C., Bailey, R. F., Davis-Allen, K., Arzt, N. H., Tyson, S. et al. (2012, July). *Health information exchange in disaster preparedness and response*. Prepared for Office of the National Coordinator for Health Information Technology. Available at: <http://www.healthit.gov/buzz-blog/ehr-case-studies/disaster-preparedness-health-information-exchange/>

Figure 7. Direct Use Case Study: Alabama, Florida, Illinois, and Rhode Island

4.2.2 Solutions and Demonstrations

This project, conducted by the research team from Florida International University (FIU), sought to investigate how using Direct affected practices by observing providers and their care partners in four diverse States. They examined practices that were early adopters of Direct, and other practices that were early majority adopters of Direct¹⁶. This research focused on existing Direct Project “user stories”¹⁷ and depicting these use cases with unified modeling language (UML) diagrams. Using the UML tool, the FIU team helped practices describe workflow in their offices before and after implementation of Direct. The researchers interviewed practice staff to understand and document workflow. They observed use-case dyads (i.e., both the sender and the recipient of Direct health messages), and conducted post-observation interviews to validate their observations. The team also extensively questioned the practices about the costs and benefits, both financial and otherwise, of the changes in practice that resulted from the use of Direct.

¹⁶ Rogers, E. M. (1962). *Diffusion of innovations*. New York: Free Press (Simon & Shuster). As defined in Everett Rogers’ theory, acceptance of new ideas or adoption of new technology goes through a process where a few innovators do the first groundbreaking work, followed by a somewhat larger group called the early adopters, who are followed by an even larger group he termed the early majority. Rogers labeled the lagging portions of the population as the late majority, followed last by the laggards as the final adopters of the new innovation.

¹⁷ The Direct Project User Stories can be accessed at <http://wiki.directproject.org/User+Stories>

4.2.3 Lessons Learned and Additional Considerations

The study outcomes were quite positive: all participants preferred the use of Direct to the paper-based methods of health information document delivery. The research team noted improved levels of confidence that complete documentation was received by the intended party without unintended or unauthorized access. Processes were made more efficient by reducing time spent on failed attempts to communicate by telephone and fax and reducing or minimizing hand-delivery of health documents.

Observations indicated and interviews with practices confirmed adoption and use of Direct was straightforward, with minimal change in workflow required when compared to prior methodologies for exchanging protected health information. Also, the necessary financial and technical investments needed to use Direct were minimal.

In addition, practices reported multiple benefits, especially improved coordination of care between partners in care, resulting in better care delivery. Communication of patient health information was more timely and efficient, with greater assurance that protected information was reaching the intended recipients. Also, Direct provided a mechanism to share health information electronically even with care partners who were not using an EHR.

Some practices reported an unanticipated dividend of using Direct: savings in staff time and material costs resulting from the implementation. Although these reports were preliminary and reflected only partial implementation of Direct in some practices, the results were derived from actual use and could reasonably be extrapolated to estimate what future cost savings could be achieved in a full-scale implementation. Although the absolute dollar values are modest (e.g., \$3,000 in the Alabama chronic care case management; \$12,000 for the Florida special needs children school system referral), the anticipated savings with Direct fully implemented could be meaningful, especially for small practices and social service agencies.

4.2.4 Products to Share

The following products are available in the FIU Direct Use Case report:¹⁸

- Tangible demonstration of Direct being implemented and used in a variety of practice settings, including small physician practices, surgical specialists, behavioral health clinics and social service agencies.
- Examples of actual expense reduction calculations resulting from the introduction of Direct into practice workflow.
- Concrete instances of workflow simplification illustrated using universal markup language diagrams.

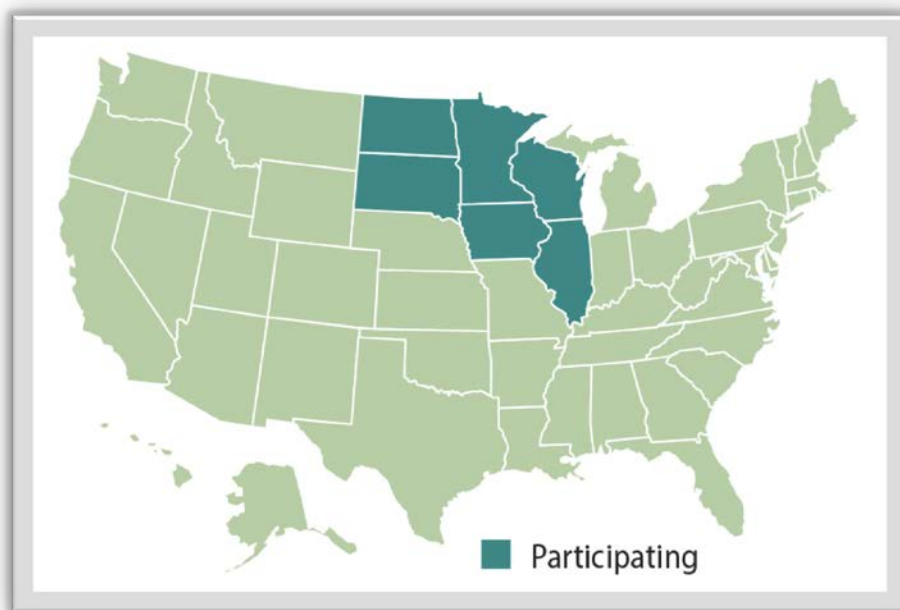
¹⁸ Tremblay, M., Deckard, G., VanderMeer, D., Shapiro, M., Rizk, S.C., & Loomis, R. (2013, December). *Use cases demonstrating the utilization of Direct in four states: Alabama, Florida, Illinois, Rhode Island*. Prepared for Office of the National Coordinator for Health Information Technology.

4.3 Interstate Consent Requirements and Management

4.3.1 Problem

The goal of the Upper Midwest Health Information Exchange (UMHIE) State Health Policy Consortium project was to develop concrete solutions to barriers affecting HIE for treatment purposes among participating States (see Figure 8). The identified barriers stem largely from the variability of State consent-to-disclose requirements, including the Minnesota Health Records Act.¹⁹ Enacted in 2007, this statute requires signed and dated consent for the release of patient records outside “related health care entities,” even for treatment purposes in many cases. Additional varying consent requirements in other UMHIE States related to special and sensitive health information were also reviewed.

Figure 8. Upper Midwest Health Information Exchange (UMHIE) Consortium: Illinois, Iowa, Minnesota, North Dakota, South Dakota, and Wisconsin



4.3.2 Solutions and Demonstrations

The project began with an environmental scan including information about State consent to disclosure law and practice. This information also revealed additional challenges to a solution for interstate consent management, including:

- technical capabilities of currently available information systems,
- disparity in provider liability risk,

¹⁹ Minnesota Health Records Act. Statute 144.291 2013.
<https://www.revisor.mn.gov/statutes/?id=144.293>

- community culture-based reticence to release information, and
- significant variation among participating States in the status of efforts to establish State HIE core functionalities.

Based on the environmental scan findings, the UMHIE Consortium created recommendations for both paper-based transactions and a transition to exchange using an electronic consent form. The UMHIE Consortium considered the degree of impact and the value of potential solutions to patients and providers, including an interstate compact, a policy alignment process, or uniform consent laws. After considering the time required to enact the various solutions, the political environment in each State, the need for stakeholder input, and the lack of technical HIE infrastructure, the group decided to focus on the policy alignment process by creating a Common Consent to Disclosure Form and instructions and policies for use by providers in paper and various electronic environments. An extended discussion about whether to include provisions designed to comply with varying State consent requirements for sensitive or special information concluded with a solution to incorporate these components into the Common Consent Form. Primary reasons for this decision included the inability for clinical sites to ensure that information subject to 42 CFR, part 2 (and other similar State-based laws) could be segmented from the information being transmitted under the request for disclosure. The consortium determined that this type of “all-or-nothing” consent form aligned with the current EHR capabilities, due to the fact that data segmentation is not in widespread use.

Once the initial research was completed, the UMHIE Consortium members set up three workgroups: (1) Common Consent Form Workgroup—to focus on finalizing, as much as possible, the Common Consent Form and related guidance, (2) Electronic Translation Workgroup—to develop an approach and recommendations for translating the Common Consent Form (and related policies) into electronic format accessible to each State, (3) Policy Alignment Workgroup—to develop policies and agreements related to the Common Consent Form (including use case scenarios).

4.3.3 Lessons Learned and Additional Considerations

When the project began in late 2010, all of the States were still planning their Statewide strategies for supporting health information exchange. No State had a functional set of HIE services operating, although some were procuring such services when the project ended in late 2011. When the project ended, specifications for the Direct secure messaging project supported under the Nationwide Health Information Network (NwHIN) program were just being released. Therefore, the Electronic Transmission Workgroup suggested participating States immediately adopt the Direct protocol to test transmission of the forms electronically across State lines. Because States were early in the implementation of their HIE strategy and introduction of Direct secure messaging was still in its infancy, pilot testing the results of the work performed in a real-world scenario was difficult. The project members achieved

their objective to outline consent management protocols that could be used in the more advanced set of HIE services being planned in each participating State, allowing the use and storage of the Common Consent Form among States.

In addition, the participating States reviewed various State and Federal statutes related to disclosure of special and sensitive health information; they agreed on how this information should be treated in the form. Although the resulting Common Consent Form was reviewed and approved by various authorities in each State and deemed appropriate for use, approval at the Federal level was not obtained due to ongoing considerations regarding consent requirements. This lack of approval did not prevent the participating States from supporting the use of the form to enable interstate exchange, but it did prevent the release of the form as an example for other States outside of the Consortium to consider.

4.3.4 Products to Share

The Common Consent Form and UMHIE report are not available through ONC; however, some participating States and clinical sites in the States published and supported the use of the form to streamline interstate exchange within the UMHIE region including:

- Minnesota Department of Health²⁰
- Access Medical & Wellness Clinic in Minneapolis, MN²¹
- North Dakota Office of Health Information Technology²²
- Wisconsin Statewide Health Information Network²³

²⁰ Upper Midwest Health Information Exchange (UMHIE) (2013, April). *State Health Policy Consortium to advance interstate exchange of patient health records*. Available at: <http://www.health.state.mn.us/divs/hpsc/ohit/umhie.html>

²¹ Upper Midwest Common Consent Form for Full Disclosure of Health Information for Treatment, Payment & Health Care Operations. (2013). Available at: <http://www.accessmedicalclinic.net/wp-content/uploads/2013/03/patientConsent.pdf>

²² Rizk, S.C., Singer, J. et al. (2011, October). *The Upper Midwest State Health Policy Consortium on Health Information Exchange: Final report on interstate consent management*. Prepared for Office of the National Coordinator for Health IT (ONC).

²³ Wisconsin Statewide Health Information Network (2011). *Interchange Exchange Workgroup deliverable*. Available at: <http://wishin.org/Portals/0/Policy/2-Interstate%20Exchange.pdf>

5. SUPPORT FOR OTHER ONC INITIATIVES

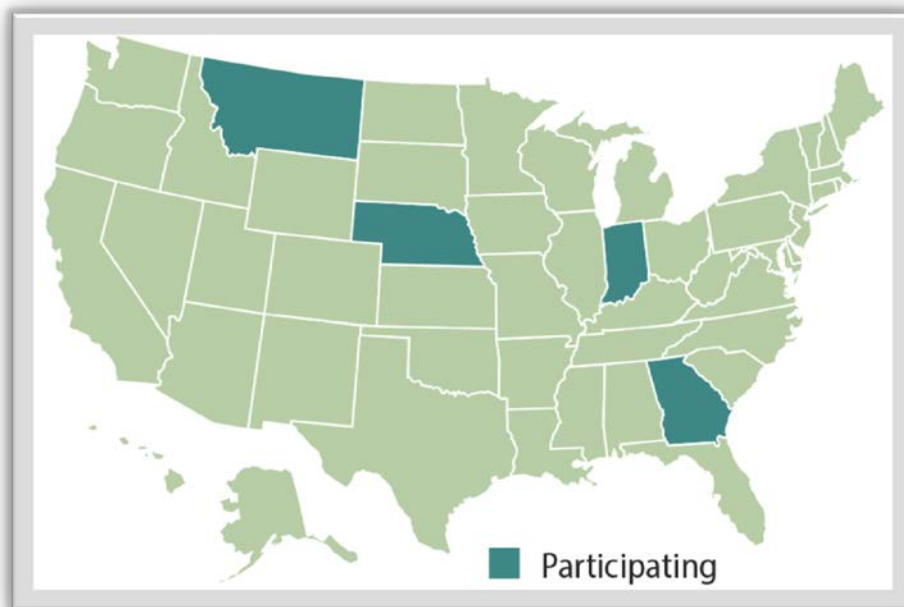
This chapter summarizes SHPC support for the Consumer Innovations Challenge and the Trailblazers project, two existing ONC initiatives.

5.1 Innovative Approaches to Sharing Health Information with Consumers

5.1.1 Problem

Health IT plays a vital role in improving consumer engagement in health care. Tools such as patient portals, PHRs, Blue Button, and secure messaging allow patients to gain access to their health information and enhance communication with their health care providers. Keeping track of health information can help patients manage their health conditions by monitoring their chronic conditions from home. Initiatives to improve consumer engagement are driven by Meaningful Use Stage 2 requirements, which contain several objectives on consumer engagement. Moving forward, providers using electronic systems must give patients the ability to view online, download, and transmit their health information and must also use functionalities such as secure messaging with at least a portion of their patients. Such capabilities have the promise of allowing patients to easily access, use, and share their health information, and may lead to improvements in overall health and long-term wellbeing (see Figure 9).

Figure 9. Consumer Innovations Challenge Participants: Georgia, Indiana, Montana, and Nebraska



5.1.2 Solutions and Demonstrations

In March 2012, ONC launched the Consumer Innovation Challenge (CIC). Its purpose was to collaborate with a vanguard group of State HIE grantees interested in enabling consumers to be partners in their care. Each participating State was asked to implement innovative approaches to sharing electronic health information with consumers and enable consumer-mediated exchange through which patients can aggregate, use, and share their own information. ONC's goals for this challenge included spurring innovation and action as well as helping States implement their consumer-targeted initiatives by providing best practices and technical assistance to ensure success. States participating in this challenge included Georgia, Indiana, Montana, and Nebraska.

To officially kick off the CIC, representatives from participating States attended an in-person meeting supported by the SHPC project. During this meeting participants discussed various components of their approaches with subject matter experts to optimize and finalize their plans. The following section summarizes each State's project and outcomes.

Georgia

ChathamHealthLink, a local HIE serving the uninsured and indigent population of southeast Georgia, continues to pursue plans to partner with the Georgia State Health Information Exchange Direct project to provide patient access to lab results via PHRs.

Indiana

The Indiana State Health information Exchange and the Indiana State Department of Health developed a portal to allow patient access to vaccine history records for individuals or their dependents.

Montana

HealthShare Montana, through a PHR, made personal health information more readily available to patients to improve consumer engagement and self-management.

Nebraska

The Nebraska Health Information Initiative (NeHII) is working to allow patients to access their health information electronically from NeHII and download it to a PHR, enabling a myriad of innovative uses and applications for consumers.

5.1.3 Lessons Learned and Additional Considerations

The following lessons and considerations were provided during a review of the CIC projects in each State:

- The growth of EHRs and HIE has created new opportunities for consumers to take a more active role in their health care and the management of their health data. Each

State participating in the CIC was strongly motivated to empower patients by providing them with new ways to access their health information.

- Work related to consumer engagement is an essential component to the long-term sustainability of the State HIE program. These projects provided important insight about the types of services consumers are willing to pay for to better monitor their health. Using Direct secure messaging to enable communication from the HIE to patients provides a general framework on which a number of valuable services can be built to meet the needs of both consumers and their providers.
- Successful consumer-focused applications can serve as a tool to encourage physicians to participate more actively in HIE. When consumers became aware of the ability to get access to their information, they asked their physicians to participate—proving that consumers have the power to drive adoption when they are presented with an application of value.

5.1.4 Products to Share

The following product is available: Best Practices for Planning Consumer Initiatives Checklist (see final report), including specific recommendations related to policy, infrastructure and technical requirements, patient engagement, and operations and metrics.²⁴

5.2 Developing a State-Level Quality Measurement, Reporting, and Feedback Infrastructure

5.2.1 Problem

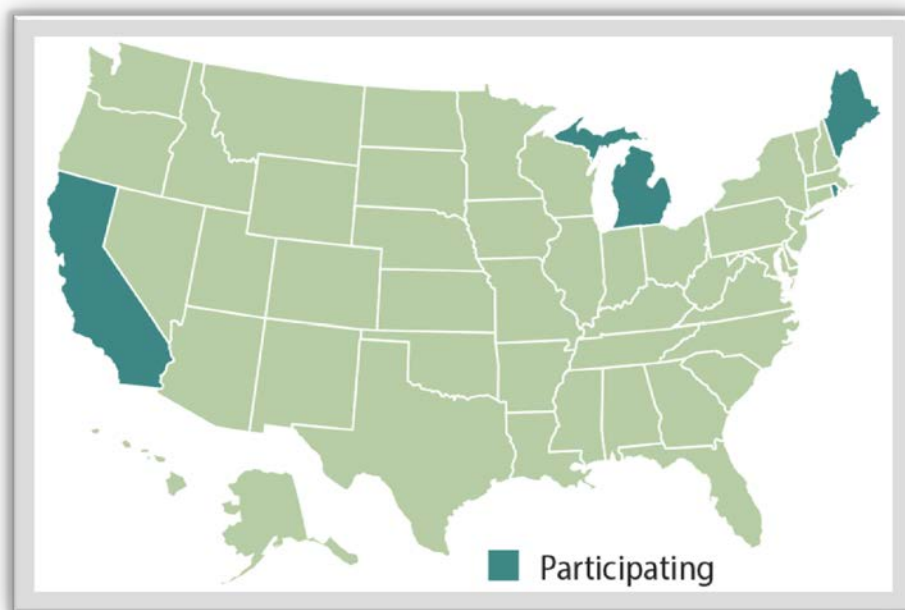
In response to the increasing cost of health care, Federal, State, and private agencies are exploring different ways of providing and paying for health care. The goal of this work is to achieve what CMS refers to as the “Triple Aim,” namely better care for patients, better health for communities, and lower costs through improvement for the health care system. Several factors must be addressed to accomplish this goal, such as:

- Comprehensive and reliable data need to be available.
- Quality measures need to be aligned to reduce provider burden.
- Data are currently being captured, stored, and shared in a multitude of systems and formats and need to be integrated.

To move toward the Triple Aim goal and address these factors, the Trailblazers project worked to develop a State-level electronic quality measurement, reporting, and feedback infrastructure that combines data from multiple sources into one effective system. Working with the National Academy for State Health Policy (NASHP), RTI supported the work in four of the eight states chosen as Trailblazers: California, Maine, Michigan, and Rhode Island (see Figure 10).

²⁴ Rizk, S. C., Bailey, R. F., Webb, J. Reynolds, P., Weston, C., Gonzalez, K. et al. (2013, February). *Consumer Innovation Challenge: Final report*. Prepared for Office of the National Coordinator for Health IT (ONC). Available at: <http://www.healthit.gov/sites/default/files/cic-paper-final.pdf>

Figure 10. Trailblazers Consortium (SHPC-funded): California, Maine, Michigan, and Rhode Island



5.2.2 Solutions and Demonstrations

Trailblazer States worked to develop a State-level quality measurement reporting and feedback infrastructure through information gathering, discussions with stakeholders and subject matter experts, analysis, and creating action plans. Key tasks and issues were identified and explored throughout the project, helping States to move further down the path to developing such an infrastructure.

The first key task was conducting a baseline assessment to identify and describe the relevant current programs and infrastructure related to data measurement and reporting in each State. A Baseline Assessment Template, developed by the NASHP, was used. This assessment was composed of the following sections:

- Health IT Architecture and Infrastructure
- Provider/Practice-Level Support Capacity
- Current Payment Reform or Quality Improvement Initiatives
- Quality Measure Data Collection/ Reporting Programs or Initiatives
- State Innovation Model (SIM) initiative

The second key task was conducting a site visit. Site visits included the following components and were grounded in materials tailored to each State:

- review of the baseline assessment, which identified and described relevant programs and infrastructure related to data measurement and reporting,
- ONC presentation of and discussion about the various Federal quality measurement initiatives underway, focusing on those most relevant to the State,
- identification and discussion of short-term goals and steps, and
- discussion of how best to include the Trailblazer work into the SIM initiative (during site visits that took place after the SIM awards were announced).

In addition, site visits provided an opportunity to bring together stakeholders and subject matter experts to discuss challenges and next steps. The baseline assessment and site visit identified key elements needed for the development of a State-level electronic quality measurement reporting and feedback infrastructure. The final period of the project focused on exploring some of these elements by engaging relevant subject matter experts in discussions, analysis, and report writing. During this last period, States also worked on short-term and long-term action plans.

5.2.3 Lessons Learned and Additional Considerations

As described in NASHP's Vision Brief,²⁵ the Trailblazers project identified key elements of a successful infrastructure, namely:

- a core set of quality measures in payment reform programs aligned to priority goals shared by private and public payers and providers,
- data that flow efficiently and securely to meet appropriate needs,
- architecture that maintains patient privacy and enables secure data collection, reporting, and feedback,
- access to timely and actionable data, and
- providers who are motivated to improve care through the use of health IT.

Because of the complexity of these elements, the project team explored them further and categorized them into several sub-elements.

- A core set of quality measures must be meaningful, valid, parsimonious, and tied to mutual priorities.
- Data that flow efficiently and securely to meet appropriate needs must be governed, private, secure, and include identity management.
- Architecture (infrastructure) that maintains patient privacy and enables secure data collection and reporting must include:
 - EHRs that support providers in capturing, calculating, and reporting quality measures;

²⁵ Miller C, Arons A (2013). A vision for quality data infrastructure to support health system transformation. Portland, ME: National Academy for State Health Policy.
http://www.nashp.org/sites/default/files/Trailblazers_Brf6-13.pdf

- technology that can accept and create standardized formats for quality measures, and can transform and aggregate data into at local, State, and national levels;
 - tools to analyze data and produce actionable feedback for various stakeholders; and
 - security systems that meet Federal and State requirements to maintain patient privacy and protect identifiable patient information from breaches or other unauthorized use or disclosure.
- Access to timely and actionable data is crucial. There is a potential role for data intermediaries in collecting, processing, and sharing data at the local level.
 - Providers can be motivated to improve care through the use of health IT. Provider engagement and education is critical.

5.2.4 Products to Share

The following products resulted from the Trailblazers work. Links are provided to publicly available copies of documents and resources.

- Baseline Assessment Template
- Rhode Island Unified Provider Directory Assessment and Recommendation Report (created by Audacious Inquiry)
- The Health and Human Services' (HHS) Measure Policy Council (MPC) Measures Spreadsheet, which includes detailed information about the measures.
- Action Plan Templates and Action Plan Examples
- January 30th 2013 Trailblazer meeting e-book; this link includes meeting presentations and resources from States and presenters.
<http://www.nashpcloud.org/HIT.Trailblazers.January.30th.meeting.ebook.updated.pdf>

6. PROJECT OUTCOMES

6.1 Project Outcomes

SHPC supported nine projects over four years with participation from 29 States and more than 40 subcontractors and consultants who served as subject matter experts.

The outcomes of these consortium projects include

- addressing legal and technical barriers to the exchange of behavioral health data between health care providers, among organizations, and across State lines, including a pilot exchange to test solutions;
- establishing a set of policies and technical solutions to support Direct exchange between HISPs, advance HIE across State borders, and demonstrate how local agreements and trust structures can be established to support interstate HIE with federated provider directory services;
- creating a repository of HIE-related assets to facilitate their discovery and reuse;
- conducting a series of pilots to demonstrate the value of enabling patients to access their data using Direct secure messaging by populating untethered PHRs;
- completing an environmental scan of prevalent PHR functionalities and develop an assessment framework for determining high-impact PHR functionalities;
- developing a roadmap of technical assistance and educational materials to support consumer-mediated exchange;
- developing a full-length documentary that educates the general population about HIE;
- developing a strategic plan for sharing health information during and following a declared natural disaster, featuring a phased approach and actionable recommendations addressing key legal, technical and governance issues;
- observing the use of Direct exchange by diverse health and social service provider organizations in multiple states, demonstrating the value of Direct to small practices;
- developing a standard, shared consent form that meets the requirements of participating States, solutions for exchanging consent data electronically, and a framework for developing an interstate consent management solution;
- supporting four State projects designed to increase consumers' ability to obtain, view, and manage their own clinical information including vaccination records and claims data and to use Blue Button technology to enhance PHR functionality; and
- supporting a multistate project designed to support State Innovation Model grantees and consider how to best capture or combine data, create or refine performance measures across providers, and generate reports or provide feedback in ways that promote health care quality improvement.

6.2 Downstream Outcomes

The individual projects were, by necessity, contained in scope, but many continue to have effects in both SHPC participant States as well as in States that did not participate. This chapter summarizes some of the downstream effects of selected SHPC consortium projects available at the time of this writing.

6.2.1 Behavioral Health Data Exchange Consortium

The work performed during the scope of this project serves as a catalyst for additional work. Nebraska continues to work on a data exchange pilot based on the preliminary work completed during the project with a pilot expected in March 2014. Florida and Alabama are building on the technical and organizational connections established during the pilot. Following completion of the Consortium work, they expanded their HISP-to-HISP network (to enable the exchange of Direct messages) to include State programs in Georgia, Louisiana, South Carolina, Michigan, West Virginia, and Wisconsin. Providers in this network can be confident that participating providers are all adhering to the same policies and standards for ensuring the confidentiality of behavioral health information. Providers can now send Direct messages using these services at any time to facilitate care coordination interstate for patients. Perhaps most importantly, this project represents a significant contribution to the HIE environment because it specifically includes patients and records that were previously excluded from HIE due to regulatory complexity.

6.2.2 Western States Consortium and NATE

After completion of the project, the Western States Consortium became the National Association for Trusted Exchange (NATE), an independent entity operating without support from ONC or RTI. States continue to join the group and as of January 2014, 10 States had officially signed the MoU and were actively participating in HISP-to-HISP exchange across State lines: Alaska, California, Arkansas, Florida, Hawaii, Michigan, Nevada, Oregon, North Dakota, and Utah.

NATE continues to function as a participant in various projects that are newly emerging as part of the HIE landscape. In addition to the PHR Ignite pilot project, they also support various groups assembled as part of the National Governance forum, and are involved in piloting work related to federated provider directories.

6.2.3 Southeast Regional Collaboration for Health IT and HIE

The SERCH project helped participating states understand potential linkages between HIE and disaster preparedness and to develop connections with the State entities responsible for providing those response services. In addition, members of the SERCH Consortium selected Direct secure messaging as the preferred mechanism for exchanging data. Florida and Arkansas have both become formal members of the National Association for Trusted

Exchange (NATE), and other SERCH States have considered joining to support the use of Direct in a widespread disaster.

The participating States have also established MoUs to enable data exchange in a disaster. Future steps for the group include establishing a provider directory and HISP-to-HISP agreements to enable providers to search shared provider directories. In addition, the members of the SERCH Consortium have presented their work at a variety of public health, preparedness, and health IT conferences while continuing to engage with State and local preparedness agencies. Recent experiences, such as the tornado in Joplin, Missouri and Superstorm Sandy along the east coast, have further demonstrated the value of HIE in disasters and validate the work conducted under SERCH.

6.2.4 Consumer Innovations Challenge

The CIC projects highlight the ability to harness the power that can be provided by an engaged consumer. The team from Georgia, including Chatham HealthLink and the Georgia Department of Community health, continue to work on integration and rollout of a patient health record that contains information from multiple providers within Chatham County. The use of GeorgiaDirect to transmit clinical information to the patient from the provider in the pilot helped influence providers associated with Chatham HealthLink to enroll in the service and eventually facilitated their connection to the Statewide health information network, GaHIN. In Indiana, the MyVaxIndiana site continues to grow at a steady pace. Since going live, over 40,000 personal identification numbers to log in have been requested. The team has continues to market the availability of the tool, working with providers to sign up their patients at the point of care. The MyVaxIndiana tool is now available on mobile devices.

6.2.5 Trailblazers

Maine

The Trailblazers project was helpful in determining Maine's rationale for data collection and reporting as well as the policies in the clinical data realm. Maine is pursuing the use of PHI in a public all-payer claims database. The Trailblazers consultation was instrumental in shaping discussions with key stakeholders. In addition, the HIE in Maine opened their governance process to State representation, and the State health data organization engaged a multistakeholder process to examine the use of PHI to support emerging delivery system reform models.

Michigan

The project provided an opportunity to break down silos and bring stakeholders together to discuss how to move toward a data-driven quality improvement infrastructure. With initiatives already occurring in the State, the project served as the starting point for stakeholder planning on how to leverage current work, including alignment of three State-

level health IT initiatives in Michigan: the Medicaid Behavioral and Physical Health Data Analytics Program; the Integrated Care for Persons Dually Eligible for Medicare and Medicaid demonstration project; and the State Innovation Model Design Stage.

Rhode Island

The Rhode Island team has used the provider directory recommendations to guide development of a Statewide provider directory. The Trailblazers work, including the provider directory recommendations, the quality measures grid, and the action plan, fed into an interagency data and analytics workgroup assembled by the Lieutenant Governor's office. In addition, the Trailblazers action plan was used as the basis for recommendations from the Health Information Technology and Measurement community workgroup to the SIM design State process. The Trailblazers project encouraged Rhode Island team members to come together as a convening force to work on the upcoming SIM work.

7. LESSONS LEARNED

7.1 Value of HIE Pilot and Demonstration Projects

The work of the SHPC projects focused on practical solutions to achieving health information exchange across State borders. Consortium States identified challenges and barriers based on real experiences, not hypothetical scenarios, and the solutions were often pilot tested to demonstrate their practicality. Projects conducted under the SHPC were specifically designed for manageable scope, achievable goals, and tangible progress to pilot test emerging HIE solutions.

The SHPC methodology²⁶ provides a framework for taking thoughtful, deliberate steps forward in a rapidly evolving environment. Health information exchange requires extensive collaboration among individual providers, regional health systems, and State and Federal policymakers to achieve progress. Because the stakeholder base is so large, it is often impossible to identify barriers and anticipate resistance until they are encountered. SHPC achieved success by focusing on collaboration and shared solutions to overcome complex HIE barriers.

7.2 Flexibility Supports Innovation

The methods used to establish, fund, support, and manage each consortium were particularly effective for pilot and demonstration HIE projects. SHPC methods provided a structured yet flexible framework seeking to identify and bring high-value projects online rapidly. HIE projects must remain flexible to accommodate frequent evolution of challenges and opportunities. As solutions are implemented and exchange expands, new opportunities and tipping points emerge. While the goals and objectives for the projects were always defined in advance, in many instances the exact method by which they would be achieved was unknown. A number of SHPC projects employed a phased design. The initial phases were exploratory, collecting information and reviewing possible solutions. Later phases were defined only after feasible solutions were identified. In short, the outcome of many of the SHPC projects was truly unknown because the participants were charting new ground with their work.

The flexibility the SHPC model provided allowed ONC to take advantage of these opportunities as they emerged and make rapid progress. In addition to the commitment to identify and resolve barriers, the flexible model of SHPC supports grassroots initiatives, providing “bottom-up” solutions that balance States’ needs to meet “top-down” Federal

²⁶ For more detail regarding the methodology used to select and manage the SHPC projects, please see the companion report [Banger, A.K., Bailey, R. F., Rizk, S. C. (2014, March). *Effective methods for interstate collaboration in health information exchange*. Prepared for Office of the National Coordinator for Health IT].

requirements. The successes the SHPC projects achieved show that, with direction and management, tackling the unknown can yield substantial progress.

7.3 Conflict Can Produce Powerful Results

ONC and RTI encouraged the consortia to “push toward conflict.” Identifying practical barriers to exchange became a goal in itself, allowing States to address those barriers collaboratively. There is value in convening the individuals working on HIE, asking them to define the challenges that must be addressed for exchange to expand, and giving them the support they need to succeed. Moving forward with plans that are inflexible or fail to account for rapid change and unexpected barriers to implementing HIE could easily lead to missed opportunities, resentment, and a loss of interest in achieving the collective goal. The project members often engaged in active debates about policies, procedures, and implementation, which resulted in stronger, more practical, and more widely applicable solutions.

8. GLOSSARY

Acronym	Description
ACO	Accountable Care Organization
AHRQ	Agency for Healthcare Research and Quality
ARRA	American Recovery and Reinvestment Act of 2009
BHDE	Behavioral Health Data Exchange Consortium
BP	Business process
CIC	Consumer Innovation Challenge Consortium
CMS	Centers for Medicare & Medicaid Services
DOPU	Drop off and pick up application
EHR	Electronic health record
Health IT	Health information technology
HHS	U.S. Department of Health and Human Services
HIE	Health information exchange
HIO	Health information organization
HIPAA	Health Insurance Portability and Accountability Act
HISP	Health Information Service Provider
HITECH	Health Information Technology for Economic and Clinical Health Act of 2009
IHE	Integrating the Healthcare Enterprise
MoU	Memorandum of Understanding
MU	Meaningful Use
NATE	National Association for Trusted Exchange
NwHIN	Nationwide Health Information Network (formerly NHIN)
NPI	National Provider Identifier
OCR	Office for Civil Rights
OLHIE	Open Library of Health Information Exchange
ONC	Office of the National Coordinator for Health Information Technology
PCMH	Patient Centered Medical Home
PHI	Personal health information
PHR	Personal health record
RFP	Request for Proposals
SAMHSA	Substance Abuse and Mental Health Services Administration
SERCH	Southeast Regional Collaboration for Health IT and HIE
SHPC	State Health Policy Consortium
SIM	State Innovation Model
UMHIE	Upper Midwest Health Information Exchange Consortium
UML	Unified modeling language
WSC	Western States Consortium

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Appendix A:
Children's Medical Center Technical Summary

A.1 Summary

The specific goal of this project is to test the patient use of Microsoft's Direct-enabled Health Vault PHR with the Drop Off and Pick Up Application (DOPU) by Children's. Children's will host the DOPU application that allows information to be sent to a patient's Health Vault PHR without requiring an additional interface between the patient and the care provider.

A.1.1 Current Architecture

A.1.1.1 Services Primary Technologies

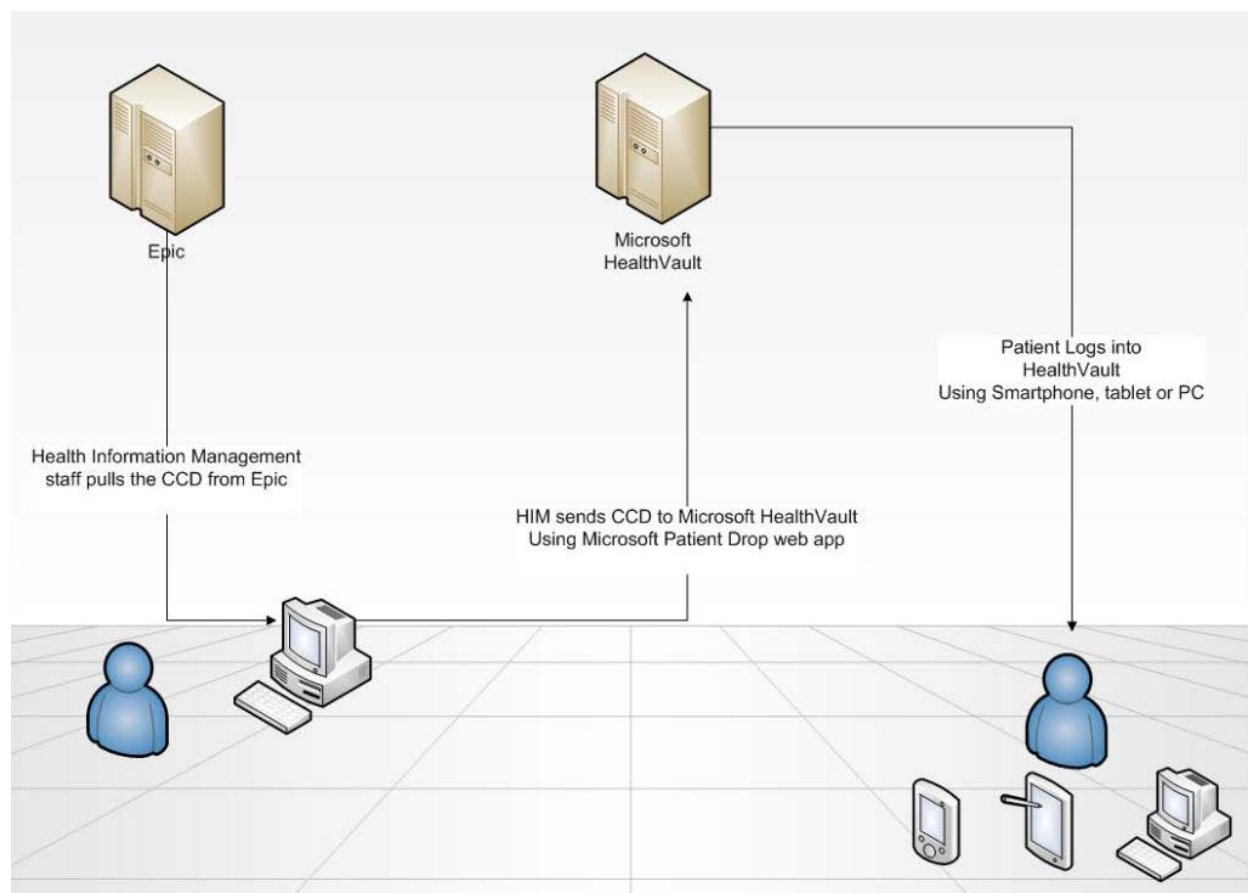
The Epic Release of Information (ROI) module is used to download the patient's CCD, which required no additional build for this project. The ability to send the CCD to Microsoft HealthVault™ via Direct Messaging was accomplished by installing a small Web service called Patient Drop onto an existing server. Microsoft provided the Software Development Kit (SDK) for the patient drop Web application. Children's IT staff installed the Web application on a server and configured it to send CCDs to Microsoft HealthVault.™

A.1.1.2 Client Primary Technologies

Children's Health Information Management (HIM) users access an internal Web page to access Patient Drop to send the CCD to HealthVault™. The Web interface only requires five fields to be completed and the CCD to be attached to send the patient's Children's CCD to Microsoft HealthVault™.

A.1.1.3 Current Export Capabilities

The Epic ROI provides manual extraction of the patient's CCD utilizing native Epic functionality.

Figure A-1. EMR Conceptual Architecture

A.2 Pilot Planning

A.2.1 Choosing Partners

The group analyzed more than 40 PHR applications and determined that Microsoft's HealthVault™ was the best solution. HealthVault™ is free to patients and is Direct enabled to receive secure messages from providers. It is available on the iPhone via a downloaded application and through the Internet on any device. Sean Nolan, chief architect of the system, is able and willing to lend his input and expertise to Children's during this project.

When individuals sign up for a HealthVault account, they get a Direct address to use for importing files from external sources. Another approach to importing is using a feature that includes using newuser@direct.healthvault.com. An EHR can send a standard Direct message containing the clinical content to that address and set the subject of the message to the patient's personal e-mail address. When HealthVault receives the message, it stores it and then forwards the patient a pickup message in an e-mail to his/her personal address that includes a special code and instructions for setting up a HealthVault account and

claiming their information. Alternatively, if the user receives a pickup message but already has a HealthVault account, he/she can log in and add the information to the existing PHR.

With technical support from Microsoft, the Children's team was able to use the Microsoft Software Development Kit (SDK) to develop a drop-off and pick-up (DOPU) connection, or "drop site", which allowed messages to be sent from the EMR to the patient's HealthVault™ account. With efficiencies and MU Stage 2 requirements in mind, the CCD was chosen as the data source for patients to receive.

A.2.2 Testing Export Capabilities

Both Epic and HealthVault™ provide nonproduction environments. No additional setup was required in Epic or Microsoft HealthVault.™ An additional test instance of the Patient Drop Web application and exchanging of test certificates were required to send the test patient's CCD from the Epic test environment to the HealthVault™ test environment.

A.2.3 Testing Approach

A test patient was created in Epic TST and an office visit was documented to give the patient clinical data. A Microsoft Hotmail account was created for the test patient; then the CCD was extracted from Epic TST and sent to Microsoft HealthVault™ Test using a test copy of Patient Drop, which directs the messaging to the test environment of HealthVault™. An e-mail is sent to the test patient's e-mail Hotmail account. The analyst logs into the Hotmail account and clicks the link to access HealthVault.

A.3 Pilot Implementation

A.3.1 Technical Preparations and Adjustments

This project required no new hardware and little technical setup. The Web application was placed on an existing IIS server and configured to send CCDs to Microsoft HealthVault. An SSL Certificate from Children's' IIS server was sent to Murphy and Associates, which was acting as a third-party vendor for Microsoft. The vendor incorporated our SSL information into a certificate containing Children's and Microsoft SSL information and provided a certificate for Children's to enter in our IIS server.

A.3.2 Proof-of-Concept Demonstration

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. They also experience physical pain that must be closely monitored and treated. From shortly after birth and throughout their entire lives, patients require daily medication, including antibiotics, preventive drugs, and various pain medications. This hereditary condition alters the shape and functions of red blood cells, and can damage organs and systems throughout

the body. Frequent medical and emergency department (ED) visits are the norm, generating enormous volumes of medical records with critical information that the next health care provider needs to know before making a treatment decision. Being many miles away from a specialist makes the situation even more difficult. Relying on a patient's or family member's memory or taking the time to cull through stacks of papers can be unreliable and sap valuable minutes or hours when a child is in respiratory distress, has a high fever, or is in extreme pain. Many providers outside of major medical centers simply do not know the signs of a crisis in children with this condition and may not be swayed to act immediately by a parent's pleas in crowded ED. The families at Children's sickle cell clinic in Tyler, Texas, 100 miles away from Dallas, were the first patients approached.

A.3.3 Patient Enrollment and Live Exchange

The process of actually getting the patient to use the iPhone application begins during a routine doctor's appointment in Children's Medical Center's hematology/oncology unit. There, while the patient sleeps or meets with the physician, the PHR coordinator from the Medical Center engages the caregiver and/or patient in a conversation about the pilot and how it works. If the patient or caregiver agrees to participate, the 30-minute implementation process begins.

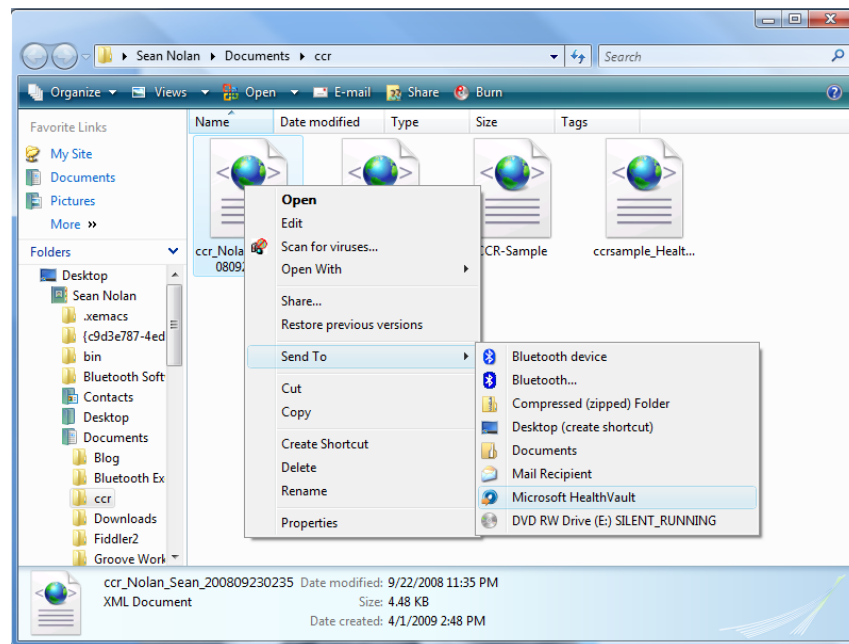
A.3.4 Live Exchange

1. PHR Coordinator assists patients / families in registering for PHR.
2. Report generated daily to identify changes/updates to patients participating in pilot PHR.
3. If a change is identified:
 - a. PHR Coordinator generates a CCD document from Epic.
 - b. PHR Coordinator accesses Microsoft HealthVault patient drop site and enters patient information.
 - c. Clicks "Send to HealthVault."
 - d. Patient receives an e-mail notifying him/her of new clinical information with link to HealthVault.
 - e. Patient accesses information.

A.3.4.1 Sending the CCD to HealthVault

Any document can be sent to HealthVault with a simple "right-click" menu option or by saving it to a special "pickup" folder on the workstation's hard drive. Once the file is selected, a dialog is used to request the patient's e-mail address and other necessary information. CCD, CCR or Consolidated CDA documents are sent as structured information and can be "unpacked" upon arrival at HealthVault. Figures A-2 through A-4 provide screenshots of the process of using the Microsoft HealthVault drop site to send the structure documents to a patient's account.

Figure A-2. First Screenshot: Utilizing Microsoft HealthVault DropSite



A.3.4.2 Addressing/Security Dialog

When the file is selected, a dialog appears requesting information about this document:

- The patient's name.
- The patient's e-mail address. An e-mail with a special "Pickup URL" will be sent to patient.
- A security question and answer that the patient will remember. This is used to provide extra assurance that information is not improperly disclosed.
- An optional note from the provider.

At this point the document will be automatically queued for sending to the patient at the specified e-mail address. No further clinical action is required.

Figure A-3. Second Screenshot: Utilizing Microsoft HealthVault DropSite

Send To Microsoft HealthVault

Sandbox for Microsoft® HealthVault™

Full page photo.xps

This document is for:

Name

EmailAddress

Security Question

Must be at least 8 characters long.

Security Answer

Must be at least 8 characters long.

Notes (Optional)

Figure A-4. Third Screenshot: Utilizing Microsoft HealthVault DropSite

Send patient information via HealthVault

Success! The patient will receive an email with pickup instructions.

Clinical User Name:

Patient Name:

Patient Email:

Patient Verification Question:

Patient Verification Answer:

Continuity of Care Document:

Patient receives e-mail, clicks on the "Pickup URL":

1. Web page details steps to follow.
2. User provides secret code; this is included on the e-mail notification.
3. User is asked secret question and provides answer.
4. User confirms which record should receive the information.

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Appendix B:
MD Anderson Cancer Centers Technical Summary

B.1 Summary

The specific goal of this project is to pilot a testing solution that would enable MD Anderson patients to share medical reports and summaries in a CCR format using Direct messaging protocol from CSO to HealthVault. CSO is a Web-based ASP.net application that provides a subset of the information available via ClinicStation to MD Anderson patients, and as such, it is the best resource for patients to have access to their health information. This report outlines the testing procedures used that will inform future information exchange.

B.2 Background

B.2.1 Current ClinicStation Architecture

ClinicStation is an n-tier application with a layered architecture pattern used by the clinicians. The middle tier is a Web services tier that provides SOAP-based Web services consumed by 12 other applications.

ClinicStation Outbound (myMDAnderson) is a Web-based ASP.net application that provides a subset of the information available via ClinicStation to the patients and referring physicians.

The data in ClinicStation is primarily stored in relational SQL database, but integrates data from over 65 data sources, including Oracle, mainframe, Sybase, MySQL, PDF's files, DICOM data, HL7 v2.x, CCD/CCR, JPEG, TIFF, and Web services.

B.2.1.1 Services Primary Technologies

This layer is a service-oriented architecture endpoint providing access to over 65 back-end systems. This uses .NET 3.5 Web services with simple object access protocol (WSDL endpoints). Several common capabilities are accessed using the common access framework (CAF) providing security, governance, auditing/logging/exception handling and instrumentation/monitoring. Web Services Enhancement 3.0 implements WS-trust and WS-policy and all SOAP transactions digitally signed using WI Framework. ClinicStation Outbound is one of the applications that consumes the Web services and presents information to patients and referring physicians.

B.2.1.2 Client Primary Technologies

The client application is a .NET 3.5 Windows Client that uses WPF and Windows forms. All ClinicStation "folders" are implemented as plug-in modules. Folders can be added and removed via app configuration. It is designed to contain third-party applications and be contained by third-party applications and has an auto-update capability built in that allows all the desktops to be updated without any downtime.

ClinicStation Outbound (myMDAnderson) is a .NET 3.5 ASP.net application that consumes the Web services exposed by the ClinicStation SOA. The main entry point for this application is via the myMDAnderson website, which is developed in ColdFusion. There is a hand-off between the two applications in which the credentials are passed to ClinicStation Outbound.

B.2.1.3 Current Export Capabilities

Currently through ClinicStation Outbound (myMDAnderson), users can print to PDF any report they wish as well as save or download materials to their desktops. This is the only current export capability.

B.3 Pilot Planning

B.3.1 HealthVault as a Test PHR

Microsoft's HealthVault was chosen as an export target for this project in part because it is a widely available and free to patients. Additionally, Sean Nolan, chief architect of the system, is able and willing to lend his input and expertise to MD Anderson during this project.

HealthVault, started in 2007, is a Web-based PHR that lets individuals gather, store, use, and share various health information. In addition to providing a place to organize and store health records online, it lets individuals manage records for other family members (such as children), as well as use various mobile applications, other software, websites and devices to connect to other information, such as tracking numbers from monitors for blood pressure or glucose levels and accessing records on smartphones.

When individuals sign up for a HealthVault account, they get a Direct address to use for importing files from external sources. Another approach to importing is using a feature that includes using newuser@direct.healthvault.com. An EHR can send a standard Direct message containing the clinical content to that address and set the subject of the message to the patient's personal e-mail address. When HealthVault receives the message, it stores it and then forwards the patient a pickup message in an e-mail to a personal address that includes a special code and instructions for setting up a HealthVault account and claiming their information. Alternatively, if the user receives a pickup message but already has a HealthVault account, he/she can log in and add the information to the existing PHR.

B.3.2 Testing Export Capabilities

MD Anderson would enable patients using ClinicStation Outbound (myMDAnderson) to share their medical report/summary in CCD format using the Direct messaging protocol to HealthVault. All the changes will be made in test environment.

To enable this exchange to occur, the following high-level steps need to be taken:

1. Changes to myMDAnderson/CSO Web server

- Create a separate test branch of the CSO code base.
 - Make changes to the patient summary view of the CSO code base to put in user interface elements to allow patient to export medical record via Direct.
 - Based on the user input, create the CCD and send it to the MD Anderson Direct Server for further processing.
2. Set up MD Anderson Direct Server
- Stand up a VM of windows server 2008 with SMTP, IIS 7.x.
 - Ensure large message hot fix has been applied (Fix354919).
 - .Net Framework 3.5+ with SP1 with WCF.
 - SQL Server 2008/2012.
 - Install the .net C# Direct Reference application and configure it.
 - <http://wiki.Directproject.org/CSharp+Reference+Implementation>
 - Obtain/install the trust certificates.
 - Ensure network ports are set up correctly.
3. Anchor certificates
- Use the HealthVault organizational public certificate for encryption that can be obtained from <https://apps.healthvault-ppe.com/messagecenter/certs/certs.zip>.
 - Create/obtain a copy of MD Anderson's public certificate and use it to sign the Outbound messages with the private key. Provide a copy of the public certificate to HealthVault for them to set up MD Anderson as a valid source of Direct messages.
4. Provide patient directions
- Provide consent on the use of Direct for sharing their information.
 - Provide a HealthVault Direct e-mail address, e.g.:
your_name@direct.healthvault.com
 - If user does not have a HealthVault Direct e-mail address, then HealthVault allows providers to sign up users by sending an e-mail using the Direct protocol to newuser@direct.healthvault.com with a subject line containing the patient's existing e-mail account. The patient will be sent instructions to set up an account and receive a secure health message.

B.3.3 Testing Approach

- MD Anderson team will use mydev.mdanderson.org and the test account for patient 0282273 for testing.
- MD Anderson team will configure mydev.mdanderson.org to point to the CSO test environment setup for Direct messaging.
- MD Anderson team will provision HealthVault test accounts and Direct addresses at <https://apps.healthvault-ppe.com/messagecenter/>, which connects to HealthVault.

- MD Anderson team will work with Sean Nolan of HealthVault on obtaining particulars for ensuring proper connectivity to the HealthVault test environment.

B.4 Pilot Implementation

The pilot took place in a secure, test environment using mock accounts for both CSO and HealthVault. Early discussions regarding this project revealed two primary obstacles to creating a live test with patients. First, MD Anderson is in the process of planning its switch to another electronic medical record system, moving away from the proprietary ClinicStation to a system from Epic. Second, using any real patient information or patient actions would require a study proposal and approval by the MD Anderson Institutional Review Board, which is intended to safeguard patients and their information but is also a prohibitively long process for the timeline laid out for this project.

B.4.1 Technical Preparations

The technical preparations, and which tasks (1-7) each correlates with, were as follows:

- Creating What a Patient Needs (aligned with tasks 1 and 4)
 - Provide consent on the use of Direct for sharing their information.
 - Provide a HealthVault Direct e-mail address, e.g.:
your_name@Direct.healthvault.com
 - If user does not have one, then HealthVault allows providers to sign up users who do not yet have a HealthVault account by sending an e-mail using the Direct protocol to newuser@Direct.healthvault.com with a subject line containing the patient's existing e-mail account. The patient will be sent instructions to set up an account and receive their secure health message.
- Changing the CSO Web Server (aligned with tasks 2, 3, 5 and 6)
 - Create a separate test branch of the CSO code base.
 - Make changes to the patient summary view of the CSO code base to put in UI elements to allow patient to export the medical record via Direct.
 - Based on the user input, create the CCR and send it to the MD Anderson Direct server for further processing.
- Set up MD Anderson Direct server (aligned with tasks 5 and 6)
 - Set up a VM of windows server 2008 with SMTP, IIS 7.x.
 - Ensure large message hot fix has been applied (Fix354919).
 - .Net Framework 3.5+ with SP1 with WCF.
 - SQL Server 2008/2012.
 - Install the .net C# Direct Reference application and configure it.
 - <http://wiki.Directproject.org/CSharp+Reference+Implementation>
 - Obtain/install the trust certificates.
 - Ensure network ports are setup correctly.

- Establish anchor certificates (aligned with task 7)
 - Use the HealthVault organizational public certificate for encryption, which can be obtained from <https://apps.healthvault-ppe.com/messagecenter/certs/certs.zip>.
 - Create MD Anderson direct server's certificate and use it to sign and encrypt the outbound messages with the private key. Provide a copy of the public certificate to HealthVault for them to setup MD Anderson as a valid source of Direct messages

B.4.2 Proof-of-Concept Demonstration

All actions took place in a test environment using mock accounts for both CSO and HealthVault. For CSO, this means mydev.mdanderson.org and test patient 0282273 were used in testing and were configured to point to the CSO test environment setup for Direct messaging. The technology experts at MD Anderson used a HealthVault test accounts and Direct addresses at <https://apps.healthvault-ppe.com/messagecenter/>, which connects to HealthVault, and Sean Nolan from HealthVault worked with the experts to get particulars for ensuring proper connectivity to the HealthVault test environment.

The testing was done in a modular fashion. The first component was communication between the MD Anderson direct server and the HealthVault server. A manually created message was sent to HealthVault via the MD Anderson direct server to verify that certificate and mail delivery were working. Some problems arose during this component (detailed in the Obstacles section of this report), but the certificate problems were resolved with help from Sean Nolan and others at HealthVault. The network team helped to resolved mail and DNS problems.

Once communication functionality was verified, a human readable form of the mock patient's CCR (for CSO "patient" 0282273) was printed and used to compare with data in HealthVault. Several iterations were performed to ensure that missing values were corrected and present in HealthVault's data. The CCR schema was changed to match HealthVault's schema.

The next step was the test CSO's send function. The output of e-mail was compared against verified e-mail with a third-party tool, and errors in message headers are corrected.

Finally, an end-to-end test was performed. A more complete overview of the entire end-to-end test, demonstrating proof of concept, is detailed below.

- A test account was created on HealthVault-ppe.com.
- The user logged into CSO.
- The user navigated in CSO to the Patient Demographics page, which is under the Patient Information page.
- During technical preparations, CSO was enhanced with direct messaging capability.

- By clicking “Send,” a direct message is sent to HealthVault-ppe.com, and the user gets a confirmation message in CSO showing the action, The CCR, or sent information, becomes a message that is encrypted and signed by the MD Anderson direct server.
- When the CCR is received and processed by HealthVault-ppe.com, the user receives a receipt e-mail in his or her e-mail address as well as a receipt message in his or her HealthVault Message Center.
- The receipt e-mail sent to the user’s e-mail address contains a link for the user to review and add information to his or her HealthVault account. By using that link, the user is taken to HealthVault.
- Once within HealthVault, the user can review new information (in this case, from the CCR from CSO) and choose to make changes by adding the information to the PHR before saving the records,
- Once the changes have been added to HealthVault, the HealthVault summary page will update with the new health information. New allergies and an updated list of current medications are also a part of the HealthVault summary page.
- By navigating through HealthVault to individual sites, a user can see more details about information that was imported from CSO.

B.5 Adjustments

Some adjustments to the CSO and HealthVault test accounts were made during this final phase, and the efficacy of the export was also demonstrated to leaders with the MD Anderson system during an Institute for Cancer Care Innovation leadership meeting, held Monday, Nov. 9, 2013.

The adjustments made to the CSO and HealthVault test accounts were purely aesthetic, serving only to align the account names and demographics to more closely mimic the parallels that would be seen if an actual patient were looking at his/her CSO information and HealthVault account. The adjustments are detailed below.

Now that the test HealthVault account matches that of the CSO test account, the direct messaging capability within CSO reflects an e-mail address that matches. Once the CCR is received and processed by HealthVault-ppe.com, the receipt message in the HealthVault Message Center shows that there is an available CCR from MRN 0900289, again reflecting the same “patient. And, finally, the “patient” can choose to review and add new information from the correlating CSO account.