The Use of an Agile Policy Analysis Methodology in Health Information Exchange

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Abstract

Between 2010 and 2014, the Office of the National Coordinator for Health Information Technology (ONC) contracted with RTI International to administer the State Health Policy Consortium (SHPC). The project objective was to provide states with resources needed to develop solutions to challenges preventing or impeding health information exchange (HIE) across state lines.

The methods used to establish, fund, support, and manage consortiums, which we refer to as an "agile policy analysis methodology," resulted in a number of successful HIE pilot and demonstration projects. The structured yet flexible framework developed by RTI helped to identify and implement high-value projects through a grassroots approach. Challenges and opportunities within the HIE environment evolve rapidly. As solutions are implemented and HIE expands, new opportunities and tipping points emerge. The flexible SHPC model allowed ONC to take advantage of these opportunities as they emerged to make rapid progress.

This report describes the agile policy analysis methodology the SHPC developed and used to support collaboration between states regarding HIE, enumerates the benefits of this methodology and the conditions under which it succeeds, and discusses how it can be employed in the future to further support both HIE and other challenges requiring multistate collaboration design.

Background

The American Recovery and Reinvestment Act, specifically, Title XIII, the Health Information Technology for Economic and Clinical Health (HITECH) Act, established the Office of the National Coordinator for Health Information Technology (ONC) as a formal office under the US Department of Health and Human Services. Congress directed ONC 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." Recovery Act funding supported state and regional health information technology (IT) developments by financing a variety of programs such as regional extension centers, the State Health Information Exchange Cooperative Agreement Program, and the Beacon Communities Cooperative Agreement Program.

To support the development of interstate health information exchange (HIE), ONC created and funded the State Health Policy Consortium (SHPC), which RTI International administered between April 2010 and April 2014. The purpose of the SHPC was to support the development and implementation of solutions to issues preventing or impeding the interstate exchange of health information. This paper describes the agile policy analysis methodology the SHPC used to achieve this goal.

The report reviews the methods for establishing projects under the SHPC umbrella, the use of an iterative approach to testing and informing HIE policy implementation, and the support structure RTI provided. As they developed, our methods adapted a standard methodology used for software development called *agile*. As described in the Agile Manifesto (Beck et al., 2001), the four core principles of agile software development include valuing "individuals and interactions over processes and tools, working software over comprehensive documentation, customer collaboration over contract negotiation, and responding to change over following a plan" (Beck et al., 2001).

The project did not set out to employ the principles of agile development specifically. A confluence

of timing, personnel, and individual consortium project needs allowed the methodology to evolve to apply these principles. As discussed throughout this report, initial attempts to force strict adherence to predetermined schedules, processes, and timelines impeded project participation by states and organizations. Once the RTI project team chose to pursue a more flexible methodology that allowed changes in timeline and scope, the individual consortium projects began to flourish. While the need to establish a workplan and milestones remained, the consortium projects were given the opportunity to revise and replan their project work rather than to rigidly adhere to plans that would not have supported updated objectives or improved long-term outcomes.

Here, we describe how this agile policy analysis methodology was used effectively, why it was appropriate for HIE solutions, the structure developed to support each consortium project, and implications for future work in the health IT/HIE environment.

Methods

Project Identification

To identify potential projects for the SHPC, RTI developed and issued a funding opportunity in May 2010. The funding opportunity was distributed via a joint press release from RTI and ONC to state health IT coordinators and through other channels to state HIE programs. To be eligible for consideration, proposed projects had to include representatives from three or more states to enable interstate pilot testing of exchange solutions and focus on overcoming barriers to HIE as a group.

Projects were intended to support states in developing solutions to challenges preventing or impeding efforts to exchange health information across state lines. The funding opportunity suggested topic areas based on information supplied by the state HIE grantees regarding barriers they had encountered. The list of suggested topic areas was expanded in June 2010. Applicants were expected to build on current HIE work in their states and propose a project that would advance interstate exchange. All information and materials supporting the funding opportunity were posted on an RTI website dedicated to the project.

A team of national experts evaluated full proposals each quarter. Proposals were often 25 to 30 pages long and reflected considerable effort from their lead developers. Over time, RTI and ONC recognized the need for a simpler, more flexible application process. The revised funding opportunity released in November 2010 requested short concept summaries that described proposed activities, desired outcomes, potential collaborators, and an estimate of support required. While the original funding opportunity focused heavily on privacy and security issues, the second iteration emphasized regional approaches and technical interoperability, and the third iteration asked applicants to consider specific types of electronic transactions in their proposed projects.

The funding opportunity suggested topic areas as examples, not as a comprehensive list of the types of projects that would be considered for support. Table 1 summarizes the topics that ONC and RTI suggested in advance. The topic areas that resulted in successful proposals are marked with an asterisk; five of the nine funded projects fell under these topic areas, underscoring the rapid evolution of the health

Table 1. Summary of suggested focus areas from State Health Policy Consortium solicitations

Funding Opportunity Stage	Possible Focus Areas Suggested
1. May 2010	Agreeing on health information organization patient consent policies and designing common forms*
	Agreeing on the purposes for the exchange of information that will be enabled through the statewide exchange and the privacy policies related to those purposes
	Developing model state privacy laws to facilitate interstate exchange within a region
	Developing a governance infrastructure or dispute resolution mechanism to resolve privacy and security issues as they arise within multistate regional exchanges
	Addressing liability coverage for breaches of legal duties related to privacy and security activities of interstate exchanges
	Developing software interfaces that connect different vendor software to facilitate auditing of compliance with privacy policies
	Conducting demonstration-s to test the privacy and security features of interstate exchange
2. June 2010 (reissued with revised topics)	Working to establish regional or interoperable state-based provider registries*
	Developing policy solutions to facilitate the sharing of sensitive health information, such as mental health and substance abuse data*
	Implementing a policy framework to enable interstate exchange of health data in emergency situations, such as natural disasters*
	Addressing challenges to interstate exchange presented by the Clinical Laboratory Improvement Amendments
	Developing a governance infrastructure or dispute resolution mechanism to resolve policy issues as they arise within multistate regional exchanges*
3. November 2010 (reissued with revised topics and expedited application process)	Developing common processes/systems/requirements to track medication abuse
	Developing common procurement requirements or vehicles
	Establishing common requirements and contract language to allow for the reuse of interfaces*
	Enabling meaningful use transactions†
	E-prescribing
	Receiving structured laboratory data
	Sharing patient care summaries across unaffiliated organizations
	Integrating behavioral health into mainstream health care through health IT
	Integrating behavioral health interstate system(s) into the state's electronic health records and health information exchange
	Developing interstate provider directories*

* Indicates topic areas that received funding under State Health Policy Consortium.

† As part of the Health Information Technology for Economic and Clinical Health Act, the Centers for Medicare & Medicaid Services outlined a three-stage plan that included financial incentives for providers who demonstrate meaningful use of electronic health records.

IT/HIE environment and the benefit of using an agile methodology.

Whether applicants submitted a full proposal or a concept summary, the review and decision making process involved detailed interaction between applicants, RTI, and ONC to refine and develop proposed projects. These refinements focused on ensuring that projects (a) aligned with ONC's principles and priorities, (b) defined practical, tangible outcomes, and (c) engaged essential subject matter experts to ensure the quality, accuracy and utility of outcomes. Because of this interaction, applying for SHPC support was not a "yes or no" proposition. The SHPC process provided ONC with the flexibility to refine proposals and concepts that had anticipated value—to sharpen their focus and eliminate flaws. For some proposed projects, support for an initial phase was provided, while support for a later phase was withheld until the initial phase successfully demonstrated the feasibility and value of the later phase. For this reason, very few concept summaries submitted for consideration were ultimately rejected as outside the scope of the project. As RTI, ONC, and the proposed participants worked together, they were able to refine the initial concept and define a scope reflecting consensus on the importance of the issue and the likelihood of developing a real-world solution to overcoming the problem.

RTI collaborated with ONC project officers to identify areas of shared focus across projects and between agencies. The work of one project often informed the work of others. Where necessary, ONC and RTI reached out to other agencies such as the Substance Abuse and Mental Health Services Administration, the Office of Civil Rights, and the Assistant Secretary for Preparedness and Response and other ONC offices such as the Office of the Chief Privacy Officer and the Office of Consumer e-Health. RTI's team understood the broader implications of SHPC projects and the importance of managing these critical intersections.

Projects Chosen for Funding Under SHPC

The work of each funded consortium is summarized below. A detailed description of the projects, including their history, progress toward milestones, and outcomes can be found in the companion report *State Health Policy Consortium: Summary of Projects and Outcomes Final Report* (Bailey et al., 2014).

Enabling Data Exchange in a Disaster

When the SHPC project began, there was limited practical research on how to leverage HIE to provide timely access to clinical information in response to a disaster. To build on the lessons learned from hurricanes Katrina and Rita and leverage growth in state-level HIE, the Southeast Regional HIT-HIE Collaboration (SERCH) project on health information exchange in disaster preparedness and response began in November 2010. SERCH included representatives from Alabama, Arkansas, Florida, Georgia, Louisiana, and Texas. The consortium's goal was to develop a strategic plan for sharing health information data among the Southeast and Gulf states during and following a declared natural disaster.

SERCH members carefully examined the challenges of accessing medical records and coordinating health care information for patient populations displaced due to a disaster. They developed a final report that offered a phased approach and actionable recommendations addressing key legal, technical, and governance issues to incorporate HIE into disaster planning. The work provided a roadmap for responding to HIE needs in the event of another disaster in the Gulf region.

Exchange of Behavioral Health Information

In August 2011, representatives from Florida, Michigan, Kentucky, Alabama, and New Mexico formed the Behavioral Health Data Exchange (BHDE) Consortium and were later joined by Nebraska and Iowa. The purpose of the consortium was to address legal and technical barriers to the exchange of behavioral health data between health care providers, among organizations, and across state lines and to execute successful pilot exchanges using the solutions developed.

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 with the laws of the participating states. In addition, participants put these policies and procedures into practice by following the specifications developed by the Direct Project for secure, standards-based transport of encrypted health information over the Internet, known as Direct Secure Messaging.[1] This project established a path toward the future exchange of behavioral health data. The project demonstrated that behavioral health data can be exchanged between health care providers, both within states and across state lines, and that provider education is essential for legally compliant data exchange.

Connectivity Between Health Information Service Provides (HISPs)

The Western States Consortium (WSC) was established in October 2011 by eight core states (Oregon, California, Arizona, Hawaii, Utah, Nevada, Alaska, and New Mexico) and two satellite states (Washington and Idaho) that were later joined by Colorado, Florida, Georgia, Michigan, and Ohio. The goal of the WSC was to establish a set of policies and technical solutions to support Direct Secure Messaging between HISPs and advance HIE across state borders. WSC focused on how state-level trust services and provider directories can be federated at a regional level to promote privacy and security and facilitate interstate exchange. California and Oregon participated in two proof-of-concept pilot demonstrations to show how local agreements and trust structures can be established to support interstate HIE with federated provider directory services. This pilot later expanded to include additional states in the governance body and technical implementation. At the conclusion of the WSC project, the group incorporated as the National Association for Trusted Exchange (NATE) to continue their work as an autonomous business entity.

Patient-Centered Exchange

In September 2011, the ONC Consumer eHealth initiative outlined objectives for patient engagement known as the Three A's: access, action, and attitude, which include electronic access to health information, development of tools that help patients take appropriate action with that information, and a change in attitude about the traditional role of provider and patient to one in which the patient is empowered by information and tools. The goal of the PHR Ignite project was to support work to advance all three areas of the ONC strategy for patient engagement.

First, PHR Ignite project staff conducted a series of pilots to demonstrate the value of providing patients with access to their data using Direct Secure Messaging to populate untethered PHR systems.[2] Teams from both Children's Medical Center in Dallas, Texas, and M.D. Anderson Cancer Center in Houston, Texas, exported structured data using Direct Secure Messaging protocols. Additionally, a team from NATE assembled a framework of policies and procedures for including untethered PHR systems in the NATE trust community.[3] This framework allowed information to be transmitted bidirectionally between providers using Meaningful Use Stage 2–compliant EHR systems and Direct-enabled PHR systems within the trust community; this framework was tested through the pilot exchange of data between California, Oregon, and Alaska.

Second, researchers from HealthInsight spoke with stakeholders in New Mexico and Utah to complete an environmental scan of prevalent PHR functionalities and to develop an assessment framework for determining high-impact PHR functionality. The purpose of this research was to better understand the types of PHR functionalities that might be most useful for patients as they encounter increasing opportunities to send and receive their data electronically.

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[1] Based on secure e-mail protocols, Direct Secure Messaging provides a simple, direct, point-to-point transmission of encrypted information (i.e., e-mail) and uses widely available technology. For more information visit http://directproject.org/.

[2] The term *untethered* refers to a PHR system that is not directly tied to a single provider's or vendor's EHR system. Although a PHR system tethered to an EHR system can often prepopulate the PHR with clinical data, it typically does not send or receive data that may be included in other providers' EHR systems. Therefore, it may not provide a complete record for the individual patient.

[3] Trust communities are defined by NATE as a collection of organizations electing to follow a common set of policies and processes related to health information exchange.

Third, the American Medical Informatics Association helped develop a roadmap of technical assistance and educational materials to support patient-mediated exchange. Patients' access to their electronic health information is expected to significantly change the traditional relationship between patients and their providers. The roadmap outlined salient points of discussion and education to enable providers and their patients to talk more effectively about patient-generated data and to begin the shift in attitudes needed to take full advantage of this data revolution in routine health care. In addition, RTI worked with Vanderbilt University and StoneCastle Productions to develop a full-length documentary film entitled *No Matter Where*. The film, which was under review at ONC (as of September 2014), follows the progression of successes and failures in HIE and how they have affected real patients and providers. It seeks to educate the general population about the recent history of HIE.

Studying the Impact of Direct on Provider Practices

The Direct Project established a simple, secure, scalable, standards-based mechanism for sending authenticated, encrypted health information directly to known, trusted recipients via the Internet. Researchers from Florida International University observed diverse health and social service provider organizations from Alabama, Florida, Illinois, and Rhode Island in varying stages of the adoption and implementation of Direct Secure Messaging to enable exchange in 10 use-case scenarios. The results of these observations demonstrated to small practices the value of using Direct Secure Messaging, including improvement in coordination and delivery of care, more timely and efficient transmission of health data, assurance that the information was received by the intended party, and the ability to electronically exchange information with other providers who do not have an EHR.

Creating a Community Resource to Support Reuse of HIE Interfaces

Achieving widespread HIE requires time and funding to develop and implement interfaces between different sources of information. Since the time and cost required to develop interfaces are a significant barrier

to HIE, using existing interfaces and other assets instead of purchasing or developing new ones can reduce resources needed to build HIE infrastructure while increasing the potential for interoperability. The Open Library of HIE (OLHIE) created a repository to facilitate the discovery and reuse of HIE-related assets, especially those developed with federal or state funding. Representatives from five states (California, Delaware, Hawaii, Texas, and Vermont) were involved in beta-testing or committee leadership (or both) to support the library/repository OHLIE, which went live in December 2013.

Innovative Approaches to Sharing Health Information with Consumers

In March 2012, ONC launched the Consumer Innovation Challenge. Its purpose was to collaborate with a vanguard group of state HIE grantees interested in enabling consumers to be partners in their care. ONC asked the state HIE grantees 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. Georgia, Indiana, Montana, and Nebraska participated in this consortium and completed four 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, a consumer-facing version of Direct Secure Messaging to enhance PHR functionality.

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

In conjunction with the National Academy of State Health Policy, the Trailblazers project worked to advance state efforts in aligning health IT activities and in transforming delivery systems. This effort included intensive work with a selected group of states to develop a streamlined electronic quality measurement reporting and feedback infrastructure to support their state innovation model initiatives. The Trailblazers project helped participating states create action plans for developing the data infrastructure needed to support their state innovation model work. Each state developed a unique plan driven by a comprehensive review of various disparate data sources to consider

how best to capture or combine data, create or refine performance measures across providers, and produce reports or provide feedback to promote health care quality improvement.

Consent Requirements and Management

Policies and laws governing patient consent to disclose health information vary from state to state. In an interstate transaction, the sending (releasing) state must comply with the local law regardless of policies and laws in the receiving state. To address this issue, participants from Illinois, Minnesota, North Dakota, South Dakota, and Wisconsin formed the Upper Midwest HIE Consortium. The Upper Midwest HIE Consortium developed a standard, shared consent form that meets the requirements of all the participating states as well as policies and procedures for using the form. In addition, they developed

solutions for exchanging consent data electronically and a framework for developing an interstate consent management solution in the future. Finally, they considered the market and regulatory levers that could be used to implement such solutions.

Most of the consortium projects described in this paper produced project reports or other work products that were publicly released. The specific project details—including the project processes, difficulties encountered, and how they were overcome—are described in many of these final products. Links to the final reports and products developed by each consortium are provided below in Table 2.[4]

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[4] The final product of the Upper Midwest HIE Consortium was a report that is available through individual participating states but it was not approved for final release by the client and is therefore not included in Table 2.

Table 2. Final consortium products and project descriptions

Project Focus	Consortium Name	Available Products
Enabling Data Exchange in a Disaster	Southeast Regional HIT-HIE Collaboration (SERCH)	Final Report: ONC State Health Policy Consortium Project: Health Information Exchange in Disaster Preparedness and Response (RTI International, July 2012) http://rti.org/pubs/SERCH-White-Paper.pdf
Exchange of Behavioral Health Information	Behavioral Health Data Exchange (BHDE) Consortium	Final Report: Behavioral Health Data Exchange Consortium: ONC State Health Policy Consortium project (RTI International, June 2014) http://rti.org/pubs/bhdeconsortiumfinalreport_06182014_508_compliant.pdf
Connectivity Between Health Information Service Provides (HISPs)	Western States Consortium (WSC)	Final Report: Western States Consortium ONC State Health Policy Consortium Project http://rti.org/pubs/wscfinalreport.pdf
Patient-Centered Exchange	PHR Ignite	Video: Technology with a Human Touch https://www.youtube.com/watch?v=S6agwVCVlIU&feature=youtube_gdata
		Final Report: National Association for Trusted Exchange, ONC State Health Policy Project (RTI International, March 2014a) http://rti.org/pubs/nate_phr_pilot_final.pdf
		Final Report: AMIA Final Report on the Development of Technical Assistance and Educational Materials to Support Consumer-Mediated Exchange (RTI International, March 2014b) http://rti.org/pubs/amia_phr_ignite_final_report.pdf
		Final Report: HealthInsight Final Report Assessing the Current Environment and Functionalities of PHR Systems (HealthInsight, March 2014) http://rti.org/pubs/phr_ignite_comp_final_rpt.pdf
Studying the Impact of Direct on Provider Practices	Direct Use Cases	Final Report: Use Cases Demonstrating the Utilization of Direct in Four States: Alabama, Florida, Illinois, Rhode Island (Tremblay et al., December 2013) http://rti.org/pubs/Report-Direct-Use-Cases.pdf

(continued)

Table 2. Final consortium products and project descriptions *(continued)*

Project Focus	Consortium Name	Available Products
Creating a Community Resource to Support Reuse HIE Interfaces	Open Library of HIE (OLHIE)	Repository site: http://olhie.org/
Innovative Approaches to Sharing Health Information with Consumers	Consumer Innovation Challenge	Final Report: Consumer Innovation Challenge (RTI International, February 2013) http://www.healthit.gov/sites/default/files/cic-paper-final.pdf
Developing a State-Level Quality Measurement, Reporting, and Feedback Infrastructure	Trailblazers	Project description and outcomes on the National Academy for State Health Policy site: http://www.nashp.org/about-hit-trailblazers-project

Project Management Approach

RTI assigned a consortium project manager (CPM) to build and refine the scope of work described in each successful application for SHPC support. The CPM developed a project work plan that described tasks, defined schedules, assigned responsibility, and identified required resources. The work plan established a shared understanding of the tasks to be completed and was used to create the statement of work for each participating entity. Although work plans clearly defined the challenges or barriers each consortium was formed to address, they were tolerant of unknowns in project process and outcomes.

For example, the work plan for WSC included a pilot phase but left definition of that task as the goal of the project's initial phase. This approach reflects the overall SHPC goal of leveraging an agile policy analysis methodology to uncover new challenges to interstate HIE and develop appropriate solutions. The level of detail included in work plans ensured accountability while allowing flexibility in reaching consortium project goals. The work plans served as a reference point throughout the project and provided a timeline for deliverables. In addition, work plans specified the level of effort expected of each state staff member, experts, and the CPM.

RTI identified a pool of technical experts at the outset of the SHPC project. These individuals were selected for the depth and breadth of their expertise and knowledge of specific subject areas, such as privacy law and technical standards. Each consortium was invited to identify experts from the existing pool or propose others if needed to retain specific areas of

expertise. In addition to serving in advisory roles for the consortia, the initial pool of experts reviewed and commented on proposal submissions, consortium work plans, and consortium products.

After establishing a consortium project's scope, schedule, and budget, and retaining needed expertise, the CPM held the project kickoff meeting and conducted biweekly or monthly check-in meetings thereafter. The RTI CPM and the experts served as a small, informal technical expert panel for the group. The CPMs frequently worked offline with experts and RTI project leadership to refine strategies, identify key gaps, troubleshoot issues, and identify points of intersection across projects and initiatives.

The CPMs maintained familiarity with federal health IT and HIE initiatives and a wide range of subject matter experts while providing project management expertise. CPMs were thus able to identify and bridge gaps by introducing additional experts and resources to projects when needed. Project management expertise was essential to guiding the collaborative process, ensuring timely completion of deliverables, and managing the logistics of geographically dispersed staff. In addition, CPMs also coordinated production of final reports and postings to appropriate websites and scheduled webinars or other venues to showcase the work.

In many cases CPMs were essential in ensuring the group got the support it needed. For example, RTI connected the SERCH group with individuals who had emergency preparedness expertise. This expanded the group's perspective beyond legal and technology issues to include outreach with state and

federal emergency preparedness staff and agencies. As another example, the CPM of the Behavioral Health Data Exchange (BHDE) consortium convened the resources needed to move the group from a theoretical and policy-oriented approach toward the technical expertise needed to conduct a successful pilot demonstration involving the exchange of mental health data. CPMs frequently noted gaps in the group's expertise and suggested additional subject matter expertise, identified the appropriate experts, and integrated them into the group to help overcome barriers and ensure valuable outcomes.

Results

Research projects often encounter unanticipated challenges. Project directors and government project officers learn to manage them carefully and tend to view them negatively, as potential threats to project scope, schedule or budget. Under SHPC, consortiums were actively encouraged by ONC and RTI to "push toward conflict" and explore such challenges, to uncover and identify new barriers to exchange and develop practical solutions. From this perspective, conflicts are embraced rather than viewed as inconvenient setbacks or threats. Identifying barriers to exchange, expected or unexpected, complex or simple, allowed states to develop solutions collaboratively. The SHPC method placed value in convening individuals working on HIE to identify common challenges, propose solutions, and obtain needed support to develop solutions.

In addition to uncovering barriers, the flexible model of SHPC enabled the recognition of incremental progress. For example, ONC supported a planning phase for OLHIE prior to providing support to build the interface library. Throughout each project, the CPMs met regularly with the SHPC project leadership and ONC sponsors to review progress, identify and troubleshoot potential issues, determine channels of communication and dissemination, and ensure that the project remained focused on advancing interoperability. This layered management approach allowed ONC to pursue high-value outcomes and achievements and removed the burden from states to contract with one another or locate subject matter expertise.

A total of 30 states and territories, along with 45 subcontractors and consultants, worked on nine different SHPC projects over 4 years. Most of the nine projects prepared detailed final reports outlining their process, solutions, barriers, and lessons learned. Several products, including the SERCH report, the WSC report, and the PHR Ignite project updates, were publicized on the ONC Buzz Blog and other venues.

Many projects that started under SHPC have continued in different forms. The work of the SERCH consortium has been expanded to include other states in the Southeast, to test information exchanges, and to include other stakeholders in both the HIE and preparedness communities. The SERCH members believe that the relationships forged during this project will support the participating states in responding more effectively to disasters in the future.

As noted earlier, the WSC members formed NATE, which continues to support a robust governance model for HIE and supports the work of ONC's Exemplar HIE Governance Entities Program. As part of the PHR Ignite consortium, they continued to expand the scope of their framework to include direct-enabled PHRs in the trust community, opening up a more streamlined and efficient method of communication between patients and providers.

The team from Children's Hospital in Dallas became the first hospital in the country to export structured data from the hospital's EMR system directly into a patient's untethered PHR. This pilot allowed children with sickle cell disease in Tyler, Texas, and their parents to sign up for medication reminders driven by prepopulated clinical data and to share real-time data from their clinical record at Children's with local emergency room physicians who otherwise might not have immediate electronic access to that information.

Practical barriers to HIE start at the individual provider office. The Direct Use Cases project demonstrated that practice staff could use Direct Secure Messaging to provide better care more quickly and efficiently without disrupting existing clinical workflows.

These project successes are highlights of a larger body of work under the State Health Policy Consortium with immediate positive impact on the implementation of interstate HIE. The framework of the project led to tangible steps forward from the policy level to the individual patient level.

Discussion

The agile policy analysis methodology offers a framework for other initiatives operating in a rapidly evolving environment that requires extensive collaboration to make progress, and where barriers and constraining factors may not be known until they are encountered. The layered management approach, incorporating federal sponsorship and guidance, state-level activity, and project management support from RTI, allowed ONC to pursue high-value outcomes and achievements. It also removed from the states the burden of contracting with one another and retaining required expertise. Several factors have contributed to the success of the collaborative model—thought leadership at the state level, collaboration across states, successful placement within the overall HIE environment (determined by federal sponsorship and by limiting applications to HIE grantees or appropriate designees), the leveraging of established relationships, and flexible and adaptable leadership within the consortia, the RTI team, and the ONC sponsors.

Using the agile policy analysis methodology described here has enabled consortium projects to accomplish the following project outcomes:

- address legal and technical barriers to the exchange of behavioral health data between health care providers, among organizations, and across state lines and pilot HIE using these solutions

- establish a set of policies and technical solutions to support Direct Secure Messaging exchange between health information service providers (HISPs), advance HIE across state borders, and demonstrate how local agreements and trust structures can be established to support interstate HIE

- create a repository of HIE-related assets to facilitate their discoverability and reuse

- conduct a series of pilot studies to demonstrate the value of enabling patients to access their data using Direct Secure Messaging to populate untethered PHRs

- complete an environmental scan of prevalent PHR functionalities and develop an assessment framework for determining high-impact PHR functionalities

- develop a roadmap of technical assistance and educational materials to support patient-mediated exchange

- develop a full-length documentary film to educate the general population about HIE

- develop 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

- observe the use of exchanging information using Direct Secure Messaging by diverse health providers and social service providers in multiple states, demonstrating the value of Direct to small practices

- develop 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

- support 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

- support a multistate project designed to support state innovation model grantees and consider how to best capture and combine data, create or refine performance measures across providers, and generate reports and provide feedback in ways that promote health care quality improvement.

The number and diversity of these achievements demonstrates the usefulness of the SHPC team's agile approach to implementing policy solutions. This method proved flexible enough to support grassroots initiatives, providing innovative solutions

from people using the exchanges that also balance state needs to comply with federal requirements. The push toward conflict allowed consortium participants to recognize conflicts as opportunities to develop solutions collaboratively. In a time-limited project where transformation and innovation are the goals, identifying problems and finding solutions rapidly is critical. While a thoughtful and methodical approach has been followed throughout, these projects have been guided by a singular vision: to identify barriers to HIE and develop practical solutions that allow health information to be exchanged where and when needed. The projects completed under SHPC reflect this vision and offer additional insights into the work necessary to achieve interoperable health information exchange.

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