

March 2014

Effective Methods for Interstate Collaboration in Health Information Exchange

State Health Policy Consortium

Prepared for

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

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EXECUTIVE SUMMARY

Title XIII of American Recovery and Reinvestment Act (ARRA), commonly known as the Health Information Technology for Economic and Clinical Health (HITECH) Act, codified the Office of the National Coordinator for Health IT (ONC) and provided substantial financial support for State and regional health information technology (IT) and health information exchange (HIE) activities. These funds also established the State Health Policy Consortium (SHPC) in 2010 to provide States with resources needed to develop solutions to challenges preventing or impeding HIE across State lines. ONC contracted with RTI International to administer the SHPC project.

The methods used to establish, fund, support, and manage consortiums have proven particularly effective for HIE pilot and demonstration projects and provide a structured yet flexible framework that can identify and bring high-value projects online rapidly. The HIE environment requires flexibility because the challenges and opportunities it presents evolve rapidly. As solutions are implemented and exchange 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 methods the SHPC 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 to further support HIE and other challenges requiring multistate collaboration.

Project Background and Purpose

The work of the SHPC projects focused on practical solutions and regional exchange. While a careful approach to investigating issues and developing solutions was maintained in each project, each consortium consistently emphasized a singular vision to action—moving data. The challenges and barriers to HIE consortium States identified were based on real experiences, and pilot tested to demonstrate their practicability. SHPC-supported individual projects are summarized in **Chapter 3** and described in detail in a companion report, *State Health Policy Consortium: Summary of Projects and Outcomes*.

The regional focus allowed States to work together in self-defined groups on shared barriers to interstate HIE and develop regional solutions. Solutions complied with applicable Federal laws and regulations and were effective for participating states; however, consortia members were not required to resolve all national or State-level variations. To the extent other States or regions share the same challenges or see value in their solutions, they can build on these models and successful demonstrations. The projects conducted under the SHPC were specifically designed to pursue achievable goals and tangible progress.

SHPC Methodology

Throughout the course of the SHPC project, RTI applied a flexible approach to the implementation of HIE policy which focused on iterative research, design and testing. This “agile policy investigation” methodology became a hallmark of the project. Eligibility requirements for projects included the participation of at least three States and a focus on overcoming barriers to interstate HIE. Recipients of ONC’s State HIE Cooperative Agreements or their designees were eligible to apply for support. The initial application process approved two projects and was later revised to reduce the burden on applicants, creating a faster, more flexible process. Thereafter, applicants were required to submit two-page concept summaries to initiate the process of determining the suitability of proposed projects. Under the streamlined process, 10 concept summaries were received and seven were supported.

To support each consortium, RTI retained local and national experts requested by the members. RTI assigned a consortium project manager (CPM) to draft the consortium work plan and work with the consortium members to finalize the approach. Once a project was launched, the CPM provided meeting facilitation and documentation support, coordination and management of all subject matter experts (SMEs), and support for dissemination of findings and sharable products. The CPMs provided both project management and technical expertise. Their familiarity with HIE topics enabled them to support consortia by identifying situations that required additional resources or subject matter expertise.

Conclusions

SHPC methods offer an effective strategy for encouraging multistate and regional solutions to complex problems. SHPC also supports grassroots solutions to HIE challenges and encourages a collaborative relationship between ONC and the States. Compared to a series of individually funded projects (requiring multiple procurements), this methodology allows rapid identification, funding, and startup of projects to address new challenges and take advantage of new opportunities as they emerge. It gives ONC the flexibility to keep pace with changes in the health IT and HIE environments. The SHPC has been able to address problems unknown in 2010 and has taken advantage of new opportunities as they arose. The model did not require ONC to specify the projects that would be conducted as part of the original statement of work, but empowered ONC to guide the overall direction and make mid-course corrections to achieve high value outcomes. This flexibility allowed SHPC to operate nine different projects over 4 years, each of which helped advance health IT and HIE.

1. OVERVIEW OF SHPC AND PURPOSE OF THE REPORT

The American Recovery and Reinvestment Act and, specifically, Title XIII, the Health Information Technology for Economic and Clinical Health (HITECH) Act, codified the Office of the National Coordinator for Health Information Technology (ONC). 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 information¹.” ARRA funding made it possible to move ahead aggressively to support State and regional health IT developments by financing a variety of programs such as the Regional Extension Centers, the State HIE Cooperative Agreement program, and the Beacon Communities.

To support the development of health information exchange (HIE), ONC 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 report describes the 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. The support structure included a project manager dedicated to each consortium project, access to a pool of experts, and support for meeting management, documentation, report development, and dissemination. The report also discusses the conditions under which this methodology is successful and implications for future work in the health IT/HIE environment.

¹ See Title XIII of the American Recover and Reinvestment Act of 2009:
<http://www.gpo.gov/fdsys/pkg/BILLS-111hr1enr/pdf/BILLS-111hr1enr.pdf>

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2. SHPC METHODOLOGY

2.1 Project Identification

To identify potential projects for the SHPC, RTI developed and issued an opportunity to request support services (a funding opportunity) in May 2010. The funding opportunity was distributed via a joint press release from RTI and ONC directly to State Health IT Coordinators and through other channels within the State HIE program. To be eligible for consideration, proposed projects had to include representatives from three or more States and focus on overcoming barriers to HIE. Projects were to support states in developing solutions to challenges preventing or impeding efforts to exchange health information across state lines. Submitters were expected to build on current HIE work in their States and propose projects to bridge gaps in current HIE funding or work to advance interstate exchange. All information and materials supporting the funding opportunity were posted on an RTI website dedicated to the project. RFP were posted on an RTI website dedicated to the project.

The initial application process required the submission of full proposals with proposals reviewed on a rolling quarterly basis. Suggested topic areas were included with the initial funding opportunity announcement in May 2010 and expanded in June 2010. Over time, RTI and ONC recognized that a simpler process was needed. A revised funding opportunity was released in November 2010, requesting short concept summaries that described proposed activities, listed desired outcomes, named potential collaborators, and estimated support required. The original funding opportunity focused heavily on privacy and security issues, while the second iteration emphasized regional approaches and technical interoperability, and the third suggested applicants address specific types of electronic transactions.

The suggested topic areas were provided as examples of the types of projects that would be considered for support, not as a comprehensive list. In some instances, the points of conflict appeared to be known, but when States came together to collaboratively address them, they often discovered new challenges requiring additional work. Table 2-1 summarizes the topics that ONC and RTI suggested in advance. The topic areas that resulted in successful proposals are in italics and marked with an asterisk; five of the nine funded projects fell under these topic areas, underscoring the rapid evolution of the health IT/HIE environment and the benefit of an agile methodology.

Table 2-1. Summary of Suggested Focus Areas from SHPC Solicitations

Funding Opportunity Stage	Possible Focus Areas Suggested	Projects Funded (Topic)
Original funding opportunity (May 2010)	<ul style="list-style-type: none"> ▪ 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 ▪ Agreeing on health information organization patient consent policies and designing common forms* ▪ 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 demonstrations to test the privacy and security features of interstate exchange 	<p>Upper Midwest HIE Consortium <i>Interstate Consent Requirements and Management</i></p>
Funding opportunity re-issue with revised topics (June 2010)	<ul style="list-style-type: none"> ▪ Working toward agreement on health information organization patient consent policies and designing common forms* ▪ 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 (CLIA) ▪ Developing a governance infrastructure or dispute resolution mechanism to resolve policy issues as they arise within multistate regional exchanges* 	<p>The Southeast Regional Health IT and Health Information Exchange Collaboration (SERCH) <i>Enabling Data Exchange in a Disaster</i></p>

(continued)

Table 2-1. Summary of Suggested Focus Areas from SHPC Solicitations (cont.'d)

Funding Opportunity Stage	Possible Focus Areas Suggested	Projects Funded (Topic)
<p>Funding opportunity re-issue with revised topics and expedited application process (November 2010)</p>	<ul style="list-style-type: none"> ▪ 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 lab 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 (EHRs)/HIE ▪ Developing interstate provider directories* 	<p>Western States Consortium <i>HISP-to-HISP Connectivity</i></p> <p>Behavioral Health Data Exchange Consortium <i>Exchange of Behavioral Health Information</i></p> <p>Open Library of HIE (OLHIE) <i>Creating a Community Resource to Support Reuse of HIE Interfaces</i></p> <p>Trailblazers <i>Developing a State-Level Quality Measurement, Reporting, and Feedback Infrastructure</i></p> <p>Direct Case Studies <i>Studying the Impact of Direct on Provider Practices</i></p> <p>Consumer Innovations Challenge <i>Innovative Approaches to Sharing Health Information with Consumers</i></p> <p>Patient-centered Exchange: Personal Health Record (PHR) Ignite Projects</p> <p>Access: <i>Populating Untethered PHRs; Meeting Meaningful Use Stage 2 Requirements and Beyond (Children’s Hospital Dallas/MD Anderson)</i> <i>Developing a trust framework for PHRs using Direct (National Association of Trusted Exchange (NATE))</i></p>

(continued)

Table 2-1. Summary of Suggested Focus Areas from SHPC Solicitations (cont.'d)

Funding Opportunity Stage	Possible Focus Areas Suggested	Projects Funded (Topic)
		<p>Action: <i>Environmental Scan and Assessment Framework for Determining High Impact PHR Functionality (HealthInsight)</i></p> <p>Attitudes <i>Development of Technical Assistance and Educational Materials to Support Patient-Mediated Exchange (AMIA)</i> <i>Development of a Documentary to Increase Awareness of HIE (StoneCastle Productions)</i></p>

**Indicates topic areas that received funding under SHPC*

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 projects aligned with ONC’s principles and priorities, defined practical, tangible outcomes, and engaged essential subject matter experts (SMEs) to ensure the quality and accuracy 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 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 value of conducting the later phase.

Close collaboration between ONC project officers and RTI enabled the identification of intersections 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 & 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.

The work of each funded consortium is summarized below. The projects are described in detail in the companion report *State Health Policy Consortium: Summary of Projects and Outcomes*.

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 as well as the laws of the participating States. In addition, participants put these policies and procedures into practice by connecting their State-level systems to allow Direct exchange². As a result of this project, a path towards future behavioral health data exchange has been established. 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.

HISP-to-HISP Connectivity

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 WSC was created to establish a set of policies and technical solutions to support Direct exchange between Health Information Service Providers (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.

Creating a Community Resource to Support Reuse of HIE Interfaces

Achieving widespread HIE requires time and funding to develop interfaces that must be set up between different sources of information. States agree that the cost and time required to develop interfaces create a significant

² 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/>

barrier to HIE. 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 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 six States (Vermont, California, Delaware, Texas, and Hawaii) were involved in either beta-testing and/or committee leadership to support the library/repository, OHLIE went live December 2013.

Patient-centered Exchange: Personal Health Record (PHR) Ignite Projects

The ONC Consumer eHealth initiative outlines objectives for patient engagement known as the “Three A’s”: Access, Action, and Attitudes, which include electronic access to health information, development of tools that help patients take appropriate action with that information, and a change in attitudes about the traditional role of a provider and patient empowered by the new 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 access to their data using Direct secure messaging to populate untethered PHR systems.³ Teams from both Children’s Medical Center in Dallas, TX and M.D. Anderson Cancer Center in Houston, TX worked to export structured data using Direct messaging protocols. Additionally, a team from NATE assembled a framework of policies and procedures for including untethered PHR systems into the NATE trust community. This framework allowed information to be transmitted bi-directionally between providers using Meaningful Use stage 2 compliant EHR systems and Direct-enabled PHR systems within the trust community, a framework that was tested through the pilot exchange of data in California, Oregon, and Alaska.

Second, researchers from HealthInsight spoke to 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.

Third, the American Medical Informatics Association helped develop a roadmap of technical assistance and educational materials to support patient-mediated exchange, as the availability of data to patients 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 fluidly about patient-generated data and to begin the shift in attitudes needed to take full

³ 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 also typically does not send or receive data that may be included in other provider’s EHR systems. Therefore, it may not provide a complete record for the individual patient.

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 follows the progression of successes and failures in HIE and how they have affected real patients and providers, educates the general population about HIE and may affect their attitudes.

Enabling Data Exchange in a Disaster

When the SHPC project began, there was limited research on how HIE could be leveraged 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 and 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.

Studying the Impact of Direct on Provider Practices

The Direct Project established a simple, secure, scalable, standards-based way of 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 Direct exchange adoption and implementation in ten use-case scenarios. The results of these observations demonstrated the value of Direct to small practices, 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.

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 Minnesota, Illinois, North Dakota, South Dakota, and Wisconsin formed the Upper Midwest HIE (UMHIE) Consortium. The UMHIE 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.

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. They were 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. 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 to enhance PHR functionality.

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

In conjunction with the National Academy of State Health Policy, this project worked to advance State efforts in aligning health IT activities and delivery system transformation, including intensive work with a selected group of States to develop an electronic, streamlined quality measurement reporting and feedback infrastructure to support their State Innovation Model (SIM) initiatives. The Trailblazers project helped develop action plans for the data infrastructure to support the SIM work, and considered how to best capture or combine data, create or refine performance measures across providers, and report or provide feedback in ways that promote health care quality improvement.

2.2 Project Management Approach

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. Work plans 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 project's initial goal. This approach reflects the overall project goal of leveraging a flexible methodology to uncover new challenges and develop appropriate solutions. The level of detail included in work plans ensured accountability while allowing flexibility in reaching project goals. They served as a reference point throughout the project and provided a timeline for deliverable production. 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 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 "mini" 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 leverage 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, postings to appropriate Web sites, 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 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 SME resources, identified the appropriate resources, and integrated them into the group to help overcome barriers and ensure high value outcomes.

2.3 Project Implementation

Consortiums were encouraged by ONC and RTI to "push toward conflict." Pushing toward conflict acknowledges that uncovering and identifying new barriers to exchange creates new opportunities to develop solutions. From this perspective, conflicts are embraced rather than viewed as inconvenient setbacks. Identifying practical 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 of States contracting with one another and locating 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 and WSC reports, and 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 complete testing of 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 States in responding more effectively to disasters in the future. The initial build-out of OLHIE begun under SHPC is being sustained by state supporters and funders as they recognize the value of an open source library of interfaces.

As noted above, 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 Activities. As part of the PHR Ignite consortium, they continued to expand the scope of their framework to include Direct-enabled PHRs into 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 their EMR system directly into a patient's untethered PHR system. This pilot allowed children with sickle cell disease in Tyler, Texas and their parents to sign up for medication reminders driven by pre-populated clinical data, and to share real-time data from their clinical record at Children's with local ER 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 Case project demonstrated that practice staff could use Direct 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.

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3. CONCLUSIONS

The SHPC methodology offers a framework for other initiatives operating in a rapidly evolving environment that requires extensive collaboration to make progress, but 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 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 investigation methodology described here has enabled consortium projects to:

- address legal and technical barriers to the exchange of behavioral health data between health care providers, among organizations, and across State lines and pilot exchange using these solutions.
- establish a set of policies and technical solutions to support Direct 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 with federated provider directory services.
- create a repository of HIE-related assets, to facilitate their discovery and reuse.
- conduct a series of pilots to demonstrate the value of enabling patients to access their data using Direct secure messaging by populating 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 which educates 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 Direct exchange by diverse health and social service provider organizations 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 SIM 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

The number and diversity of these achievements demonstrates the efficacy of the SHPC agile policy investigation methodology. This method supports grassroots initiatives, providing "bottom-up" solutions that balance States' needs to meet "top-down" 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, rapidly identifying problems and finding solutions 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.