

December 20, 2007

Privacy and Security Solutions for Interoperable Health Information Exchange

Impact Analysis Executive Summary

Prepared for

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EXECUTIVE SUMMARY

This Impact Analysis report is the seventh in a series of reports to be produced under RTI International's contract with the Office of the National Coordinator for Health Information Technology (ONC) and the Agency for Healthcare Research and Quality (AHRQ). During the past 18 months, participating state teams¹ have successfully completed an assessment of the variation among business practices, policies, and laws to gain a better understanding of the privacy and security landscape within their states to prepare them to develop a comprehensive plan to protect health information that is stored and exchanged electronically. The state teams also identified practices, policies, and laws that create barriers to electronic health information exchange and have worked to develop possible solutions to these barriers that both preserve and protect privacy and security and promote interoperable electronic health information exchange. The Privacy and Security Solutions project has provided the state teams with the leadership, methodology, and funding to engage and educate stakeholders within their states and build coalitions of stakeholders across diverse areas within the health care system.

The Impact Analysis report provides an analysis of the many ways that the Privacy and Security Solutions project has impacted the landscape for electronic health information exchange both within and across the participating states. To date, the project has had the greatest impact on the following areas: legislation; executive orders; leadership and governance; stakeholder education and knowledge; and, development and sustainability of health information technology (health IT)/health information exchange efforts in the states. A separate section detailing the progress of the collaborative work groups and other cross-state initiatives and interstate projects is included.

The report consists of 6 major sections:

- Introduction
- Impact Analysis
- Collaborative (Cross-State) Outcomes
- Overview of Individual States/Territories
- Conclusions
- References

Background

This report provides an analysis of the impact of the Privacy and Security Solutions project activities, both within and across the participating states. The primary emphasis of the impact analysis is necessarily state-specific: state project teams have identified outcomes

¹ Throughout this report the 33 states and 1 territory are referred to as the state project teams or as the state teams.

and impacts that are specific to their states and their unique health information exchange environments. The report also discusses impacts achieved through participation in multi- and cross-state activities. It primarily addresses the broader impacts of the project on privacy and security solutions within the states and, to a lesser degree, on larger health IT initiatives.

Methodology

To assess and analyze the impacts of the Privacy and Security Solutions project and related activities, it was necessary first to examine the states' status at the start of the project. In early 2006, states and territories applying for funding to participate in Phase I of the Privacy and Security Solutions project were asked to provide an environmental scan characterizing the health IT initiatives and projects within their states and the scope of stakeholder involvement in these efforts. These environmental scan sections of the state project proposals served as the primary source of information on the states' status at the onset of the project. These findings were then compared with the states' progress in implementing solutions to address privacy and security issues in electronic health information exchange. Impacts realized during the project were identified from reviews of the states' final implementation plans, and from participation in collaborative work groups. Additional reports from state project directors were used to verify and supplement this initial information.

Landscape Before the Project

When the Privacy and Security Solutions project began, participating states were at different stages of health information exchange development. In their project proposals, all states reported some type of existing health IT and health information exchange activity. These activities included independent, isolated health IT efforts by individual health care organizations (generally done to build or expand internal IT capabilities); implementation of 1 or more local multi-organizational health information exchange efforts, which were limited in scope and participation; and early planning of a statewide electronic health information exchange. Most of these efforts were funded by the organizations themselves or with seed or start-up monies from federal, state, or private foundation sources. Only a relatively small number of states reported a high level of maturity in their local efforts, such as the establishment of foundational components of a statewide initiative, early implementation of a statewide health information exchange effort, or an operating statewide health information exchange (HIE) program. Findings from the first and second surveys of local, regional, and state health information exchange activities conducted in 2004 and 2005 by the eHealth Initiative (eHealth Initiative, 2005) and from an independent evaluation of the evolution of state HIEs (Agency for Healthcare Research and Quality, 2006) confirm this initial assessment of the status of health information exchange development across the nation. Both studies showed that more than 100 projects related to health information

exchange existed in at least 35 states. In the remaining 15 states and territories, health information exchange projects were also likely under way but not identified because of their size, scope, or early planning stage.

These studies reveal 2 important points about the early stage of health information exchange development (before the start of the Privacy and Security Solutions project):

- A relatively small number of states had a defined entity or program that was recognized as the “state HIE effort” (ie, both a defined state HIE effort and an identified independent entity or government agency that had taken the formal role of facilitating, coordinating, convening, or operating this state effort).
- No state “anchor” or multistakeholder body (whether a state committee, commission, board, or other) had been given responsibility for addressing health information privacy and security issues.

Other important factors were evident in these early stages of development:

- The underlying state infrastructure for health IT and health information exchange was lacking.
- Few states had started statewide health information exchange planning efforts, including assessments of needs and capabilities (ie, surveying state providers to assess the level of penetration of foundational health information technologies, such as electronic health records (EHRs)) or development of a framework and road map for moving forward.
- Organization and governance for a state health information exchange effort were evolving.
- The key roles of state government as a participant, convener, and coordinator were emerging.
- Ensuring consumer participation in the process was a major challenge.
- Financial models for initial development and sustainable operations were being developed.

Evolution of the Landscape During the Project

The period between 2005 and 2007 was instrumental in moving the nation closer to a transformation in health IT and health information exchange. This process has been fueled by the significant investment and national leadership that the federal government provided for these issues through the efforts of the Office of the National Coordinator for Health Information Technology, the Agency for Healthcare Research and Quality, the Centers for Medicare & Medicaid Services, the Health Resources and Services Administration, the National Library of Medicine, the Centers for Disease Control and Prevention, the Substance Abuse and Mental Health Services Administration, the Department of Veterans Affairs, the Department of Defense, and many others.

During this period state policy makers (both state governors and legislatures) and the private sector have become highly interested in health IT and health information exchange

issues and have recognized their significance. Over the past 2 years alone, more than 300 state legislative initiatives related to health IT and health information exchange have been introduced across the country. A number of state governors have issued executive orders identifying, assigning, or creating state bodies to guide the development of state health information exchange efforts. Findings from the third annual survey of health information exchanges conducted by eHealth Initiative (2006), the State Level Health Information Exchange project implemented by the Foundation of Research and Education of the American Health Information Management Association (FORE/AHIMA; 2007a,b), and the National Governors Association (NGA) State Alliance for e-Health (NGA, 2007)² provide evidence of this impressive body of state policy making initiatives in support of local, regional, and state health IT and health information exchange. As documented by the National Conference of State Legislatures' (NCSL's) Health Information Technology Champions (HITCh) initiative (NCSL, 2007),³ legislation adopted and enacted in 2007 alone covered 5 major areas:

- increasing state funding to support the adoption of health information technologies (such as EHRs by state providers);
- creating and supporting local and regional health information organizations and providing core funding for the implementation of a statewide HIE;
- establishing governance structures to guide and coordinate the planning and development of a statewide HIE;
- addressing privacy and security issues, such as consent approaches, and creating a state privacy and security board; and
- supporting the participation of public health and Medicaid in state HIE pilot projects and initiatives.

From 2004 (before the Privacy and Security Solutions project) to 2007, state partners made significant progress in implementing statewide health information exchange. According to reports from state project directors (supplied for the Assessment of Variation and Analysis of Solutions Report), a shift has been noted from the stages of early planning to more mature efforts establishing foundational components, early implementation, and establishing an operating statewide implementation.

Impact Analysis

The impact of the Privacy and Security Solutions project can be observed in 5 major domains: legislation, executive orders, leadership and governance, stakeholder education and knowledge, and support for health information exchanges. The information analyzed in

² Information on the NGA State Alliance for e-Health is available at the website (NGA, 2007).

³ NCSL's HITCh initiative is a partnership aimed at strengthening the capacity of state legislators to respond to issues related to the use of technology to improve access, quality, and effectiveness in health care. HITCh maintains a list of all introduced and enacted health IT and health information exchange state legislation. More information is available at the website (NCSL, 2007).

this section was drawn from the individual state reports of progress that occurred from the beginning of the project through the conclusion of Phase II (see Section 1.2 for additional discussion of methodology). The process of the Privacy and Security Solutions project played a critical role in state teams' success. In identifying variations, developing solutions, and implementing foundational privacy and security solutions, the teams were able to build awareness of health IT and health information exchange issues across their respective states and generate momentum toward interoperability. This section addresses key areas in which states have made substantial progress as a result of the project.

Legislation

States are in different stages of progress regarding legislation: some states have already passed new legislation, others have bills under active consideration, and still others are drafting legislation to be introduced in future legislative sessions in 2008 or 2009.

The Third Annual Survey of Health Information Exchange Activities at the State, Regional and Local Levels, conducted by the eHealth Initiative and summarized in the report *Improving the Quality of Healthcare Through Health Information Exchange* (eHealth Initiative, 2006), and a summary from the National Council of State Legislatures provides an extensive overview of legislation passed between 2005 and 2007. This includes many bills that fall under the broad umbrella of health IT. With respect to legislation, this section of the report considers a narrower set of bills, namely those where the Privacy and Security Solutions project participants directly contributed to the legislation's drafting or passage. Discussions with project directors in each of the states participating in the Privacy and Security Solutions project led to identification of additional project-related legislative activities in 11 states.

The intent of state legislation was to update and align statutes with the electronic health information environment and address legal barriers to electronic exchange. States worked diligently to mitigate the risk of codifying existing variations in business practices related to health information exchange by involving multiple stakeholders and getting feedback from a broad audience before passage. The positive impact these legislative efforts have on electronic health information exchange and how well they reduce privacy and security variations in their application among organizations who engage in electronic health information exchange will be an important measure of success.

Executive Orders

Executive orders issued by state governors are another indicator of the Privacy and Security Solutions project's impact. Some of the executive orders predate the project, and when this is the case, state teams often cited the executive order as an impetus for applying for funding under the Privacy and Security Solutions project. As a direct result of this project, executive orders have been issued in Kansas, Mississippi, and Ohio. Several states reported

that executive orders are under consideration by their respective governors. The executive orders offer formal support for the project and help to sustain efforts towards interoperable exchange.

Leadership and Governance

As state teams moved through the process of identifying variations, creating solutions, and beginning implementation, many identified a need for specific privacy and security leaders to take ownership of the implementation process and oversee future steps. The Privacy and Security Solutions project was designed to support sustainable solutions for interoperable health information exchange—for example, by having state teams work closely with stakeholders and by requiring teams to secure a letter of support from their governor. The project has built on the existing leadership at the state level, allowing states to identify champions and accelerate progress toward interoperable exchange.

Before the launch of the Privacy and Security Solutions project, state-level leadership and support for health IT and health information exchange varied widely, with most states lacking well-defined, coordinated leadership. As a result of the Privacy and Security Solutions project, state teams generally reported the formation of 3 types of leadership structures: government-supported boards, commissions, or task forces (15 states); leadership structures of HIE entities (3 states); and convenor organizations (4 states). The leadership of HIEs and convenor organizations has continued, and state teams have built from the existing expertise and commitment, even though the work of the government-supported initiatives was often limited by time or task objectives.

The Privacy and Security Solutions project has also proved significant in its reach. Many state teams reported much higher levels of interest from governors, legislators, and state agencies than existed before the project. This reported increase in interest is supported by the increased number of introduced bills and executive orders related to health IT and health information exchange that occurred during the contract span. State teams also received support in other ways, such as the endorsement of the Privacy and Security Solutions state project teams and the establishment of steering committees by their legislative and executive branches.

Stakeholder Education and Knowledge

A key goal of the Privacy and Security Solutions project was for state teams to create a broad base of support among stakeholders in their states to develop consensus solutions and sustainability that would extend beyond the contract period. The Privacy and Security Solutions project provided state teams with the resources to engage a broader range of stakeholders than would have been possible otherwise. Similarly, it afforded states the resources to engage on a broader array of issues.

One of the key developments in this area is the understanding that privacy and security are essential components of exchange. Similarly, state teams have also realized that the technology to support exchange exists, and that policies, workflow considerations, and broad stakeholder buy-in must be established for successful exchange. Using the resources and tools provided through participation in the project, state project teams were able to examine the business practices for the exchange of health information not only in direct patient care, but also within a broader context. The 18 specific scenarios that were developed and used in the examination of business practices covered the following areas: treatment; payment; regional health information organizations (RHIOs); research data use; law enforcement; prescription drug use/benefit; health care operations/marketing; bioterrorism; employee health; public health; and state government oversight. A broad representation of stakeholder groups ensured that the project's review of variations and legal drivers would be comprehensive, and that a coalition of support would form and be sustained within the states to ensure that solutions developed and implementation plans would be carried forward successfully.

Development and Sustainability of Health IT/HIE Efforts in the States

The Privacy and Security Solutions project has helped states establish a privacy and security foundation with which to develop new health IT efforts. Moreover, state teams have reported increased engagement of stakeholders in the development and continuation of health IT efforts. As the state teams develop privacy and security solutions and implement them, they decrease barriers for other health IT and health information exchange efforts. This work is supported by the progress of existing projects to higher levels of development, and has fostered the development of new HIEs.

Collaborative (Cross-State) Outcomes

Almost unanimously, states reported that working with 33 other states and territories on the Privacy and Security Solutions project proved extremely valuable in understanding their state-specific challenges for health IT and health information exchange within a larger nationwide framework.

The relationships that the states have forged, or are planning to pursue, reflect a variety of cross-state interests. A number of states have established better communications with states in their geographical area. Many states, however, have developed relationships that are based on shared interests, not on geographical proximity. Some states need to share health information with distant states because their citizens often travel between them for vacations or health care. Other states have formed relationships to share information about common approaches to health information exchange architecture, issues, or projects.

Collaborative Work Groups

To increase the focus on cross-state collaboration, RTI was tasked with coordinating and overseeing the formulation of multistate, collaborative work groups during the extension period (June through December 2007) of the Privacy and Security Solutions project. Seven collaborative work groups have been focused on the following areas:

- consumer education and engagement
- provider education
- standards policy adoption
- harmonizing state privacy law
- consent options, outcomes, and best practices
- consent data elements required for data transfer
- interorganizational agreements

Other Cross-State Initiatives and Interstate Projects

In addition to the formal multistate collaborative groups formed under the Privacy and Security Solutions project, a number of states have reported laying foundations for or undertaking cross-state projects as part of the Privacy and Security Solutions project work. Some of these cross-state interactions resulted from networking opportunities provided by the project. Many states were able to point to distinct instances in which discussions with other states served as a significant resource informing their own projects. The potential for multistate and cross-collaborative work between the states is exceptionally strong, especially given the foundation that has been provided by the Privacy and Security Solutions project.

Overview of Individual States/Territories

Section 4 in this report summarizes the impact of the Privacy and Security Solutions project on the individual states participating in the project. Participating states are presented in alphabetical order. Each state's report includes 3 sections. The first section, Health IT/HIE Privacy and Security Landscape Before the Privacy and Security Solutions Project, describes the status of electronic health information exchange that existed before the project began. These descriptions have been drawn primarily from the proposals submitted by each state to be part of the project. The intent of this section is to provide the context for understanding the impact of the project and describe the particular challenges faced in each state related to factors such as geography, population, and the health care delivery system. The second section, Current Health IT/HIE Landscape, captures changes that have occurred since those proposals were submitted, drawn from project reports on activities in each state, review of websites and other available material, and verified in discussions with key project staff in each state. The section describes progress made toward exchanging health

information, such as the development of RHIOs or similar entities, or efforts to expand the exchange of health information. The third section for each state, Current Privacy and Security Landscape, focuses on privacy and security impacts within each state and also draws primarily from project reports and discussions with key project staff. This section is intended to provide detail about the heightened awareness of privacy and security issues in each state and the actions state teams have taken as a result of their participation in the Privacy and Security Solutions project.

Conclusions

This report provides a comprehensive review of the work conducted under the Privacy and Security Solutions project. It is clear that the 34 state teams have made substantial progress toward the reaching the goals stated at the outset of the project, which include:

- Assess variations in organization-level business policies and state laws that affect health information exchange;
- Identify and propose practical solutions, while preserving the privacy and security requirements in applicable federal and state laws, and;
- Develop detailed plans to implement solutions.

This report describes the progress that state teams have made during the past 18 months toward meeting these goals. The teams have identified the sources of variation that must be reduced to arrive at a common set of policies that will permit private and secure nationwide health information exchange. They have worked to educate and engage the stakeholders within their individual states, laying the groundwork for an enduring statewide constituency through which they can work to achieve consensus on the implementation of solutions. The state teams now have an infrastructure in place that positions them to work toward harmonizing privacy practices, policies, and laws both within their individual states and across states. They are also leaving behind in states and communities a knowledge base about privacy and security issues in electronic health information exchange that endures to inform future health information exchange activities. The next steps for the state teams include accelerating the implementation of solutions by working in multistate collaboratives, developing dissemination pathways to achieve widespread adoption, and coordinating with the other national initiatives.