PRIVACY AND SECURITY SOLUTIONS FOR INTEROPERABLE HEALTH INFORMATION EXCHANGE
Health Information Security and Privacy Collaboration
Subcontract to RTI

Final Outline for State Implementation Plans Report:
New Hampshire

Subcontract 21-321-0209825
Submitted to: Research Triangle Institute

April 16, 2007

Funded by: The Agency for Health Care Research and Quality, in collaboration with the National Governor’s Association

Submitted by the NH Institute for Health Policy and Practice at the University of New Hampshire

Robert J. McGrath, PhD, Principle Investigator

Amy Schwartz, MPH, Project Director
Background

The HISPC team has definitively established that New Hampshire has few legal barriers which prevent HIT/HIE exchange activities. An extensive review of health care systems and providers across the state revealed consistent and standard business practices for retaining privacy and security for health care data. Hospital networks have developed working committees to establish cross-institutional business policies and procedures. Most hospitals have a designated privacy officer, and rigorous training for employees with regard to the handling and sharing of patient information.

Furthermore, the historical and cultural context of New Hampshire to protect and regard privacy with the utmost care is not to be underestimated. In fact, the law in New Hampshire specifically states that the information within the patient medical record is considered the property of the patient and falls under property law.

New Hampshire is also a state that has embraced the idea of health information exchange in a pragmatic way. While there has been large investment in HIT in the state, HIE has been all but non-existent between non affiliated providers. This is not to say that there is not interest in such activities. Beginning in the fall of 2005, the New Hampshire Connects for Health Project began a statewide assessment of the interest in HIE, interviewing and convening most of the state’s health care stakeholders. This process has generated consensus that any sharing should be based on federally determined standards of interoperability, security, and privacy. It also should be based on existing (and future) and sustainable organizational level investments in technology, as determined by the organizations. To this end, a slow but purposeful process is now underway to strategically develop a set of principals from with to base future exchange. The implications of this to the HISPC project has been that specific security ‘barriers’ beyond those of the organizationally based policies collected and analyzed were not identified as this capacity does not yet exist. What this process did allow for was the development of further consensus and agreement through state-wide input and through an understanding

2
of other states that have undertaken more detailed HIE planning and implementation, on what components and standards any HIE activities should be based around.

The focus of the project team, after multiple interviews and forums with key experts and provider groups, became the consumer and provider engagement phase of the project. Therefore, much of the project effort and focus became centered on one major component: determining how HIE activities can most effectively engage providers and consumers in the pursuit of a seamless HIE environment which benefits patient care and clinical practice. Perception of privacy and security, and the care and protection of such, as well as in-depth understanding of the benefits of HIT and HIE in the patient care context is the real barrier to wider adoption of this technology. Also, while no real legal barriers currently exist, there is the potential that legislation and legal action could be developed which would hinder HIT and HIE in New Hampshire if consumers and providers are not deeply involved in the assessment and development of solutions and strategic plans.

II. Summary of the Analysis of Solutions Report

A survey of HIT penetration in New Hampshire indicates that as of September 2006 more than 40% of providers have some form of electronic medical record technology available in their practice (see Attachment A, Interim analysis of solutions report). The challenge remaining for wider implementation of health information exchange between these providers and others is engaging the wider consumer audience in a “layperson” dialogue to understand its benefits and importance. Also important will be educating providers on the definition and nature of consumer ownership of medical information and the standards for its security specific to each exchange activity.

Consumer
As previously indicated, State and federal laws do not provide insurmountable barriers, but addressing consumer perception of the balance between protection of privacy of medical information and the potential benefits of the technology is essential to the long term support and success of the HIT and HIE. The project team reviewed the Assessment
of Variations report using consumer focus groups to determine the best methods of obtaining consumer confidence relative to the security and privacy of personal health information and its exchange. The focus groups approached the issues from the perspective of ‘consumer driven adoption’ of the technology, which explores consumer perceptions and motivations regarding this technology and their medical information, taking both the potential risks and rewards into account. The solutions working group addressed the issues and concerns of the consumer in all work products to strengthen the recommendations presented. The solutions working group was comprised of members from the legal, variations, and consumer working groups in addition to interested stakeholders. In order to foster public confidence, consumer input was gathered prior to the development of the solutions and consumers will review all drafts of the solutions.

Initial Consumer Engagement Phase

One challenge of engaging consumers was identifying a broad cross-section of the state’s population while maintaining the internal cohesiveness of the groups. At the writing of this report, at least one focus group has yet to convene in order to get as broad a cross-section of representation as possible. A grassroots recruitment effort of cross-demographic patient groups was employed. This was accomplished using a screening form that could be completed and returned by phone, fax, mail, or on-line. The screening form, (Appendix B, Interim Implementation Report) was distributed and promoted through a variety of channels, including email lists of health care advocacy groups, print advertisement in the statewide daily paper, and through the Community Health Centers (Federally Qualified Health Centers serving low income clients) across the State.

While adhering to the fundamental strategy set forth in the earlier version of the work plan, the process was modified based on the findings of the initial phase of the project and a review of the information gleaned from other states’ experiences and findings from the consumer engagement processes. Because there were not significant structural or legal challenges identified, for which consumer reaction would need to be examined, the project focused on addressing the potential of the consumer to promote the spread of interoperable health information technology in the state. The information shared by other states provided significant insight into the basic parameters of
consumers’ desires and fears concerning the adoption of this technology. Rather than re-
visit these themes, we attempted to incorporate the information derived from these
sources with what we learned regarding the evolving implementation of the technology in
New Hampshire. Also examined was the concept of consumer ‘ownership’ of medical
information and other factors that would promote consumer-driven demand for the
potential advances that may derived from HIE.

A focus group moderator’s guide (Appendix C, Interim Implementation Report:
Focus Group Moderator Guide) was developed to structure the consumer conversations.
As noted, the questions focused on the way potential changes will be viewed and
experienced from the consumer’s perspective, with a focus on how promoting their
interests can be a key factor in facilitating adoption of the technology. Topics focused on
what degree of ownership consumers felt with respect to their medical record
information, how much control they desire, how much effort they would be willing to
expend, and how they expect they might identify the benefits (both personal and at the
broader system level) of the new technology. Consumer values were explored that
related to shared medical information and the degree to which focusing on the various
aspects of the potential changes would be perceived as positive and negative factors
influencing their health access behavior. Focus Groups began with a consumer
‘orientation’ which presented the various factors of the technological changes being
considered, such that the discussion could focus on the meaningful aspects of the project.
Themes developed from focus group dialogue were broad in scope. The facilitator then
synthesized and assessed the themes. The following list is an extrapolation of those areas
where differences in approach or concept may exist between consumers and evolving
systems. These areas include:

- Consumers desire a high degree of specificity and flexibility in terms of how
  they define what is authorized to share (diagnoses, treatments, etc.), with
  whom, when, for what purpose, and for how long. Most systems tend to be
  able to operationalize little more than 'opt in' or 'opt out' choices, which many
  consumers felt was not sufficient.
- Consumers that dislike the technology and expressed a desire to 'opt out' were
  often most afraid of 'unauthorized' access to, or use of, their information. The
  term 'opt out' does not address this, as the data would still be stored in a
  computerized system which could potentially be compromised.
Many consumers noted that the system would be of little value if it wasn't 'universal'. They noted that the providers would need to ask all the usual questions if they weren't sure that all the relevant information would be there, and they felt that emergency uses would only be effective if all emergency service providers had access (noting other states and countries). Emerging models often focus on collaboration amongst a narrower group of providers in the short term, which may be perceived as failing to provide promised value.

There was a sense that the provider interacting increasingly with the computer and not with the patient was a barrier to effective care, even if the 'relevant' information was on the computer. Many consumers felt that the system might further compromise the patient-provider relationship, while others said that the value would be more time with the provider if this truly freed up the time dedicated to taking history. This may involve a redesign of the work process in terms of when/how the computer is used.

Consumers strongly expressed the desire to access their medical record electronically, which some emerging systems could make possible. The consumers expressed this as part of a process whereby they could interact with the provider concerning the information, question items they felt to be in error or even to add personal notes or comments that would better explain their conditions. These functions are not necessarily compatible with the systems, processes, and preferences of many provider organizations. Most consumers felt that their providers did not want them to see their medical record and that it was a struggle to do so.

Many consumers strongly expressed the feeling that their insurance company should not be able to access the information in an on-line medical record system, yet many systems seem to incorporate some level of insurance company access for payment purposes.

A. Summarize Solutions to be implemented: Analysis of Proposed State Solutions

Health information exchange activities in New Hampshire are only now entering the planning phases. This has been purposeful as stakeholders expressed a desire to develop a firm concept of what HIE would be and a vision and set of principals for participation. This project was especially important in assessing those related to privacy and security. Given consumer input, it is clear that consumers need to be engaged on two levels. One is that there needs to be clarity and synthesis of what patient consent means, primarily in the form of a uniform consent document. Second, any specific solutions should be directed at tangible exchange scenarios yet to be developed. Thus, the project team will be integrating the HISPC reporting outcomes and implementation phase with the HIE
priorities of the NH Citizen’s Health Initiative to implement several electronic health
technology initiatives. The Citizen’s Initiative, at the direction of the governor’s office,
has requested that the New Hampshire Institute of Health Policy and Practice at the
University of New Hampshire develop a statewide HIT/HIE strategic plan. The Citizen’s
Initiative and the HISPC project have worked closely to integrate outcomes and process
in order to align strategic solutions.

The following are the mission and priority of the planning team:

- To develop an HIE Strategic plan which incorporates the key elements of
  shared vision statement, a consensus-based set of principals to guide HIT and
  HIE development, the adaptation of national standards for HIT participation
  across NH and long-term sustainability.

- To develop and implement a pilot exchange project involving at least 3
distinct stakeholders in the NH health care community (such as health center,
hospital, lab, pharmacy, etc). The project team will review areas of the state
where key developments in HIT/HIE have already begun, building on existing
momentum. This project will allow participating providers the ability to
access electronic medical records, ePrescribing, personal health records and
health information exchange.

- Development of a unified consent form and process using regional
partnerships and national standards to guide the development and
implementation of uniform consent practices. Consent should be consumer-
driven, easily understood, universally applied and able to be administered with
minimal operational disruption.

- To develop a marketing and education approach for providers and public
consumers around HIE which integrates consumer driven principals in all
aspects of HIT strategic planning and project development. We envision this
process to be parallel to the planning and pilot project; consumer input will be
sought and integrated into program development.
Within this context and specific to the HISPC component, the solutions report identified the need to both understand in more detail the nature of consumer and provider understanding and support around HIT/HIE and to integrate this with the creation of a standardized and simplified consent form. Such a form would need to be developed with the participation of consumers, providers, employers, legal professionals, and legislators. It would also need to be aligned with the medical record property rights of consumers.

B. Describe the success measurements or other benefits to be derived from these solutions.

◊ **Benefit of the HIT/HIE Strategic Plan:** Development of a set of working principles to guide further development of HIT/HIE. Rather than develop specific technological requirements or demands for provider organizations, this plan should establish common working goals for technological adaptation, the use of IT as related to improved health quality and the governance and sustainability of a state wide exchange system. The success measurement would be the production of a foundational document for all participating strategic partners.

◊ **Benefit of pilot exchange project:** The pilot exchange project will create a micro-environment to test and address the barriers to HIT/HIE before more wide-scale implementation and to refine solutions to technical and community barriers including provider and consumer concerns. The success measurement is the beginning of provider to provider exchange within one year of initiating the project. The project team will work with providers to determine further measures of evaluation.

◊ **Benefit of Uniform Consent form:** It is without dispute that the patient consent form and process needs to be addressed to make consent meaningful, easily understood, transferable and able to be operated in the administrative systems. The success measurement is the development of a working team to develop a single standard form, using regional and national models.
Benefit of Marketing and Education Program: No HIE/HIT program will be implemented successfully without the widespread understanding of providers and consumers with regard to the benefits and enhancement to service delivery that HIE provides. Quite simply, policy, practice and procedures cannot be developed separate from consumer and provider engagement; providers and patients are the main “customers” of any HIT efforts and as such, need to be engaged as key stakeholders. The success measurement is tight and documented integration of consumer and provider input in all levels and stages of HIT strategic planning and project implementation.

III. Review of State Planning Process

Implementation planning in New Hampshire over the period May 2007 through May 2008 (12 months) will focus primarily on three of these areas.

1) It will integrate with the NH Connects for Health project which is developing a statewide strategic plan for HIE, as well as promoting the proliferation and use of both electronic medical records and electronic prescribing technology statewide, and is coordinating exchange efforts regionally with Vermont and Maine. This will also include the development of a pilot HIE project described below.

2) It will develop specific consumer education and marketing plans for the developing HIE pilot.

3) It will examine the creation of a unified consent form for statewide health information exchange, but also regional health information exchange, as well as adhere to national consent standards that are developed.

The planning process to date has focused primarily on objectives (2) and (3). Towards objective (2), the Governor through the Citizen’s Health Initiative has conveyed the importance of developing a strategic plan for HIE and HIT in the
state. To this end, a strategic planning workgroup is being convened on May 23rd that will act as the initial implementation planning workgroup.

A. Describe the organization of the State Implementation Planning Workgroup, including its charge, leadership, membership and stakeholder representation. If necessary, note any additions to workgroup membership or stakeholders engaged through outreach in vetting implementation plans by updating the Stakeholder Participation table that was submitted as an attachment to the final variations and solutions report.

See appendix A for a list of participants, titles, and affiliations

In addition to these activities, the HISPC project will continue to engage with the Community Health Institute to develop consumer marketing and education plans and also the Franklin Pierce Law Center to monitor legislative activity and needs.

B. Briefly describe how the group assessed the feasibility of implementation plans

The planning group will be convened later in May of 2007. Guided by facilitators from the NH Health Information Center at UNH and also former HISPC team leaders, attendees will address the following:

1. To develop a consensus-based set of principles to guide health information technology (HIT) and health information exchange (HIE) spending in New Hampshire to meet the needs of our medical providers, patients, and insurers. To use this set of principles as a set of guideposts for individual health care organizations to follow, while allowing for flexibility in their own HIT/HIE activities. These principles are not meant to dictate in any way what a particular organization does, but instead is to provide a framework for ensuring future connectivity and exchange between all health care organizations.

   **Deliverable:** In May 2007, convene New Hampshire health care information technology leaders to outline the principles and develop a consensus process, with the anticipation of reaching consensus on a set of HIT/HIE principles by mid-summer 2007.

2. To secure and implement at least one pilot project, to begin in 2007, that will promote health information technology and health information exchange in New Hampshire and can serve as a model for future work in the state.

   **Deliverable:** Conduct a needs assessment and develop a request for proposal for a health information exchange pilot project in the North Country to include electronic medical records, personal health records, ePrescribing, health
information exchange engine, and a process for securing implementation funding. Begin a pilot project by the end of 2007 that has the foundation to create the underlying infrastructure for long term health information exchange throughout the state.

3. To be open to the possibility of collaborations with Maine, Massachusetts, or Vermont entities pursuing similar goals. There are Regional Health Information Organizations (RHIOs) in our neighboring states. New Hampshire has not pursued this model to date, but we believe that the knowledge and experience gained by our neighbors may be useful in helping us to frame our next steps in New Hampshire.

We will be joined at our meeting by Devore Culver, Executive Director, Maine HealthInfoNet, who will share their experiences, lessons learned, and future plans for furthering HIT and HIE in the State of Maine.

C. Describe how implementation plans are organized, prioritized, and presented in this report

See above

D. Discuss any specific implementation planning methods and/or tools used

See above and work break-down structure, Appendix B

IV. State-level implementation Plan

A. Statewide strategy and coordination:

The Final Assessment of Variation and the Analysis of Solutions Report will identify a number of solutions for possible implementation, some of which are likely to be unrelated in terms of resources required and implementation approach. Describe the strategy for overseeing the implementation of a variety of disparate solutions; identify responsible persons, organizations or agencies, staffing and other resources, and timelines

Solution 1: Development of an HIE Strategic Plan:

Strategy: Convene Implementation Working Group to define the HIE principals stated above.

Timeframe: May 2007 through July 2007
Solution 2: Development of a pilot project for HIE:

Strategy: The rationale is to bring the following capabilities to any provider (hospital, clinic, home health agency, physician, etc.) who wishes to be a part of the effort:

- Electronic medical records
- ePrescribing
- Personal health records
- Health information exchange engine.

Funding for this activity has not been identified. Doing so will be an early deliverable.

Timeframe: TBD dependent on funding

Persons: Project Staff, collaborators. Coordination with other states where applicable (see section V.)

Solution 3: Development of a Unified Consent form

Strategy: Unified Consent form:

- Assess current consent form landscape.
- Identify NH Standards and consumer-identified principles.
- Convene legal, advocacy, and privacy experts.
- Develop uniform consent form and coordinate efforts with surrounding states, ONC, the e Health Initiative and others.

Timeframe: Ongoing

Persons: Project Staff, Community Health Institute

Solution 4: Development of Consumer Education and Marketing Plan:

Strategy: Curriculum Development developed based on: Specific set of proposed exchange activities defined by the pilot and based on the agreed upon core principals as well as any defined consent form standards. Review other state activities and coordinate where appropriate.

Timeframe: Ongoing, determinant on HIE strategic plan, pilot development and funding, and development of a standard unified consent form.
B. Implementation plans for identified solutions:
The Initiative will begin steps towards the formulation of a strategic plan for health information exchange in New Hampshire. Work will address each of the solutions identified above.

1. Identify and convene a stakeholder steering committee
2. Identify a mission and vision for HIT/HIE in New Hampshire.
3. Form subgroups to examine priorities and standards relative to clinical application of information technology (IT); the use of IT for reimbursement and the promotion of quality; the use of IT for patient-shared care decision making; the use of IT relative to public health needs; the governance and sustainability of HIE efforts in New Hampshire.
4. Pilot Project Rationale
The rationale is to bring the following capabilities to any provider (hospital, clinic, home health agency, physician, etc.) who wishes to be a part of the effort:
- Electronic medical records
- ePrescribing
- Personal health records
- Health information exchange engine.

These capabilities would be delivered in an application service provider (ASP) model in order to be able to provide the services in a cost-effective manner and to
promote active cooperation between the providers involved.

The diagram on the right is a depiction of the “front end application interfaces” and “back end data sources” that would be delivered under this ASP arrangement.

It is anticipated that the exchange engine purchased for this project could also be used to interface with existing electronic medical record installations throughout the state. While not explicitly committing to the development of a Regional Health Information Organization (RHIO), this project would certainly provide the foundation for a RHIO should the State wish to move in this direction.

Ultimately, we are trying to create healthy populations and effective systems of care. A critical component to ensuring this occurs is to develop and implement health information technology and health information exchange capacity within the state, and across our borders. The benefits of such technology include better outcomes for patients, reduced transactional costs, research databases, public health surveillance systems, and many others. This project is a critical step to advancing these goals. A vendor RFP will be developed to sustain this effort.

5. Analyze models of sustainability
   a. Develop vendor RFP

6. Develop Education/Marketing Plan (see Development of Consumer Education and Marketing Plan below)

**Phase II: Implementation**

1) Secure implementation dollars

2) Develop detailed work plan

3) Identify implementation inputs

4) Implement Education/Marketing Plan – Align with HIE activities (see Development of Consumer Education and Marketing Plan below)

**Development of Consumer Education and Marketing Plan**
As stated, these activities will focus on the defined exchange activities developed by the Implementation working group for the pilot project. The rationale for doing so is that consumer education and marketing materials differ for different exchange mechanisms. For example, the education provided for disease management exchange is different than for e-prescribing or than for utilizing a personal health record. This phase will utilize specific tools created by the eHealth Initiative. They have developed a Communications and Outreach toolkit to raise awareness of health information exchange among consumers, providers and employers. The materials contained in the module were developed by several working groups and advisory boards. This project intends to utilize this resource throughout this phase where applicable. The activities for this phase are:

1) Review consumer findings against provider/structural findings to identify areas of commonality and areas of difference. See pages 3&4 above for themes.

2) Develop presentations for providers on consumer themes and concerns

3) Conduct focus group (or similar process) with providers around what the consumers said
   - What can/can't they do
   - What would they do to make it more palatable (and drive adoption)
   - What can the state / CHI do to make it work better

4) Develop plans for a system (solution) that facilitates various aspects of consumer preference and authorization across the range of providers.

5) Develop materials to raise awareness regarding health information exchange for consumers and providers
   - Craft messages from survey research and e Health Initiative Toolkit
   - Target messages to each group

6) Create Communication Partnerships
   - Work with Consumer Advocacy Groups
   - Work with Providers Groups, Professional Societies
   - e Health Initiative Toolkit

V. Multi-state Implementation Plans

As mentioned throughout, all efforts described above will be done with consideration of activities being conducted in neighboring states. New Hampshire conducted the HISPC project in close consultation with Vermont. Since that time, the NH Connects for Health Project as had conversations with Maine as well. New Hampshire has not pursued this
model to date, but we believe that the knowledge and experience gained by our neighbors may be useful in helping us to frame our next steps in New Hampshire. Specific activities have yet to be determined; however Devore Culver from Maine will be addressing the implementation planning workgroup in May 2007. Some initial conversations have also occurred with Vermont on potential project sharing capacity, and similar conversations could be created for Massachusetts.