

# State and Regional Demonstration in Health Information Technology: Rhode Island



## ***Final Contract Report***

---

# **State and Regional Demonstration in Health Information Technology: Rhode Island**

**Prepared for:**

Agency for Healthcare Research and Quality  
Department of Health and Human Services  
5600 Fishers Lane  
Rockville, MD 20857  
[www.ahrq.gov](http://www.ahrq.gov)

**Contract No. HHS-290-04-0007**

**Prepared by:**

Rhode Island Department of Health  
Providence, RI

**AHRQ Publication No. 15-0074-EF  
December 2015**

The content of this document may be used and reprinted without permission except for the following: Federal Government logos, items noted with specific restrictions, and those copyrighted materials that are clearly noted in the document. Further reproduction of those copyrighted materials is prohibited without the specific permission of copyright holders.

**Suggested Citation:**

Rhode Island Department of Health. State and Regional Demonstration in Health Information Technology: Rhode Island Final Report. (Prepared under Contract No. HHS 290-04-0007). AHRQ Publication No.15-0074-EF. Rockville, MD: Agency for Healthcare Research and Quality. December 2015.

**None of the investigators has any affiliations or financial involvement that conflicts with the material presented in this report.**

This project was funded by the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services. The opinions expressed in this report are those of the authors and do not reflect the official position of AHRQ or the Department of Health and Human Services.

## Preface

This project was one of six State and Regional Demonstrations in Health Information Technology (IT) contracts funded by the AHRQ Health IT Portfolio. The goals of the projects were to identify and support data sharing and interoperability activities aimed at improving health care for patients and populations on a discrete State or regional level. These States and their respective health information organizations (HIOs) are as follows:

- Colorado: Colorado Regional Health Information Organization (CORHIO)
- Delaware: Delaware Health Information Network (DHIN)
- Indiana: Indiana Network for Patient Care (INPC)
- Rhode Island: *currentcare*
- Tennessee: Mid-South e-Health Alliance (MSeHA)
- Utah: Utah Health Information Network (UHIN)

For more information about these projects, including a cross-project summary of lessons learned, please visit <http://healthit.ahrq.gov/stateandregionalhie>.

# Contents

- Executive Summary ..... ES-1
  - Background and Purpose ..... ES-1
    - Results..... ES-2
    - Governance ..... ES-2
    - Finance..... ES-3
    - Technical Infrastructure ..... ES-3
    - Business and Technical Operations ..... ES-4
    - Legal/Policy ..... ES-5
    - Evaluation ..... ES-5
  - Recommendations for Future Research ..... ES-7
- Background and Purpose ..... 1
  - Purpose and Scope of the Final Report..... 1
  - Background on the Project and Local Environment ..... 1
    - Project’s Primary Goal..... 2
  - Formation of the Project: Rhode Island Health IT Project Chronicle of Events (September 2004 – June 2011)..... 2
    - Project Goals and Objectives ..... 6
- Results..... 16
  - Governance ..... 16
    - Identifying Partners and Other Stakeholders ..... 16
    - Governance Structure..... 16
    - Formation, Usefulness and Evolution of the Steering Committee (a.k.a., Technical Advisory Panel) ..... 18
    - Lessons Learned About Governance ..... 18
    - Conclusions..... 20
  - Finance..... 21
    - Initial Sources of Funding..... 21
    - Developing and Implementing the Sustainability Plan..... 21
    - Lessons Learned About Finance and Sustainability ..... 22
    - Conclusions..... 22
  - Technical Infrastructure ..... 22
    - Selecting Technical Infrastructure Design..... 22
    - Overview of Key Issues that Informed the Technical Solution ..... 22
    - Selecting a Vendor ..... 23
    - Deployment of Technical Infrastructure Design..... 23
    - Security Policy and Practices..... 29
    - Lessons Learned about Technical Infrastructure ..... 32
    - Conclusions..... 33
  - Business and Technical Operations ..... 33
    - Developing Partnerships and Programmatic Linkages ..... 33

Role of Stakeholder Preferences / Opinions on Business and Technical Operations .....	34
Identifying Data Elements for Sharing .....	35
Implementing Data Sharing .....	36
Maintenance of Technical Infrastructure .....	37
Impact on Sustainability Plan .....	37
Lessons Learned About Business and Technical Operations .....	37
Conclusions.....	38
Legal/Policy .....	38
Policy Development and Implementation.....	38
Role of Legal Counsel .....	38
Specific Legal/Policy Discussions (including role of stakeholder preferences / opinions)..	39
Lessons Learned about Legal/Policy Development.....	43
Conclusions.....	43
Evaluation .....	43
Developing the Evaluation Plan.....	43
Implementing the Evaluation Plan.....	45
Results.....	46
Recommendations for Future Research .....	49

## Tables

Table 1. <i>currentcare</i> --RI Health Information Exchange: Description of policies and procedures.....	40
---	----

## Figures

Figure 1. Initial Rhode Island Health IT system strawman model (December 2005) .....	10
Figure 2. RI HIE System “Release 1” Services Model (December 2005).....	13
Figure 3. Initial RIQI / RI Health IT project governance structure (2005-2010) .....	17
Figure 4. Current RIQI / Rhode Island RHIO governance structure (2011) .....	19
Figure 5. HIE system funding.....	21
Figure 6. <i>currentcare</i> high-level application architecture for initial deployment.....	25
Figure 7. <i>currentcare</i> information architecture for initial deployment.....	26
Figure 8. <i>currentcare</i> network infrastructure .....	27
Figure 9. High level overview of ri hie system with 2-part consent model.....	30
Figure 10. Detailed information flow of RI HIE system’s 2-part consent model.....	31

## Appendix

Appendix A: Select Project Artifacts.....	50
---	----

# Executive Summary

## Background and Purpose

This report provides a full account of the process and results of over 6 years of work in Rhode Island intended to improve the State's health care system by implementing new approaches to health information exchange (HIE). This work was performed from August 2004–June 2011 by the Rhode Island Department of Health (HEALTH) as the prime contractor to the Agency for Healthcare Research and Quality (AHRQ) accountable for specific deliverables under the State and Regional Demonstration (SRD) Project. The AHRQ SRD initiative was a bold exploration of the use of health information technology (IT) to support data sharing and interoperability activities aimed at improving health care for patients and populations on a discrete State and regional level. Rhode Island was one of six States that participated; others were Colorado, Delaware, Indiana, Tennessee, and Utah. What sets the SRD project apart from many other health IT initiatives that have followed is the foresight by AHRQ to dedicate at least 5 years to discover, document, and share lessons learned. Today in Rhode Island, the SRD effort has facilitated development of the capability to deploy health information infrastructure at a statewide scale. The physical infrastructure along with the policy, legal, and operational framework derived from the project is just beginning to be used to augment the practice of medicine in Rhode Island. It is anticipated that over time, these foundational efforts will demonstrate improved individual and population health by enabling better decisionmaking by authorized health care providers and public health agencies as a result of having timely access to full, accurate health information.

The Rhode Island experience demonstrates how a rich spectrum of events unfolded when a State government set out to engage a broad community of stakeholders to implement and sustain a statewide HIE system. The resulting Rhode Island (RI) SRD Project and the deployment of *currentcare*, Rhode Island's HIE System, was a journey through uncharted territory across a business, technical, and political landscape that was continually shifting. While the story in Rhode Island is still being written, this report gives the reader an appreciation of the scope of issues and the intensity and complexity inherent in developing solutions in the State-level HIE domain.

The RI SRD Project was designed and conducted as a collaborative effort from the outset with HEALTH working in tandem with the Rhode Island Quality Institute (RIQI). RIQI was initially a one-person quality improvement collaborative that ultimately grew to become the State-designated Health Information Organization (HIO). Its initial role in the project was to ensure that the statewide community took the lead to establish the project vision and goals and participate in key decisions and results. While RIQI's initial role focused on governance and HEALTH took on project management responsibility for building and deploying the statewide HIE, there was general agreement that the statewide HIE, once operational, would be managed and maintained outside of State government. Both entities brought unique attributes, history, perspectives, and challenges that played out in different ways over the course of the project. For the State, areas of strength include its ability to act as a convener, foster transparency, enforce the oversight of data use and confidentiality policy, promulgate regulations, set standards, require measurement and accountability, and ensure fairness. State challenges include

contracting and purchasing (these tend to be lengthy and involved processes in government) and operations.

For RIQI, areas of strength include leveraging a Board of Directors that includes a powerful cross-section of Rhode Island executives from business, health, consumer groups, and academia that can individually and collectively bring political visibility and influence to the effort. This has resulted in fostering the collaboration required for this project. As for challenges, in the early years RIQI lacked any real capacity to support the project at a meaningful level and, due to its leadership composition, has been subject to the influence of large, dominant players in the Rhode Island market. Thus the public-private partnership between HEALTH and RIQI that was established at the beginning of the project reflected a highly interdependent relationship acted out through a collaborative model to achieve a shared vision for statewide HIE. The results of the project were not entirely as expected; the length of time required to develop and deploy the first phase of a statewide HIE system took much longer than anticipated and has affected the ability of the HIE to generate value and achieve sustainability; yet other areas, such as policy development, passage of HIE legal protections, and consumer engagement, have become RI's hallmarks of success both locally and nationally and exceeded community expectations.

## **Results**

The RI SRD Project was subject to several unanticipated and significant schedule delays and, as such, did not deliver a fully functioning HIE solution in time to measure and report the impact on health outcomes. However, the project did deliver a collection of notable results including development of a comprehensive HIE policy framework, the passage of State law and promulgation of regulations to ensure patient privacy safeguards, demonstration of a consumer-driven consent model with implementation of a Participation Service to broker consented data sharing, and a "leveraged infrastructure" model that dovetails into current HIE trends. The report organizes the details of these results across governance, finance, technical infrastructure, business and technical operations, legal/policy, and evaluation domains. A summary of results follows.

## **Governance**

HEALTH contracted with the RIQI to assume responsibility for project governance. Under the auspices of RIQI, the RI SRD Project Steering Committee was constituted in March 2005 as the primary decisionmaking entity for the initiative. Supported in its governance role by the RIQI Board of Directors, the Steering Committee skillfully established the structure and process to engage the broader community in the HIE dialogue. The Steering Committee commissioned a Technical Solutions Group (TSG) with representation from technology leaders in the State and organizations interested in becoming Data Submitting Partners (DSPs) in the HIE System. This group was charged with developing informed recommendations for functional requirements, technical architecture and infrastructure, implementation plans and related policies.

The TSG worked in concert with three other committees, the Consumer Advisory Committee, the Policy and Legal Committee (both standing RIQI groups) and the Professional Advisory Panel, a group of providers initially established for the project yet eventually merged with RIQI's Clinical IT Leadership group. Issues and/or the need for decisions were identified and debated within the committees and recommendations were circulated between the groups and refined to the point of consensus. The business of the Steering Committee included reviewing, discussing, and refining community-informed recommendations and bringing them to

a vote by a quorum of its members. The effectiveness of this process was a topic in the project evaluation and, by all accounts, Rhode Island stakeholders believed the community decisionmaking process served them well.

Stakeholders also believed that “the public-private partnership experiment in leadership carries with it the benefit of shared responsibility and the threat of competing interests.” This dynamic was clearly a factor in the project as *currentcare* moved closer to deployment; as the stakes got higher, competitive interests impacted the project pace and direction and risk aversion became a stronger force in determining partners’ “readiness” to share health data. Amidst these dynamics, the Steering Committee led stakeholders through several critical decision points:

- A change in the assumed consent model for *currentcare* and re-definition of the technical requirements to support it;
- A commitment to pursue State legislation and the promulgation of regulations by HEALTH to ensure safeguards for consumer privacy and confidentiality;
- The development of a technical and contractual model that was realigned after the Health Information Technology for Economic and Clinical Health (HITECH) Act to eventually become acceptable to DSPs to enable their participation in the HIE system; and
- Restructuring the *currentcare* deployment approach after a 100-year flood destroyed the hosting data center and all HIE system hardware and software beyond restoration during final user acceptance testing.

The project governance model was integrated into the permanent RIQI structure after the full transition of governance and operations from HEALTH to RIQI in June 2010. The RI SRD Project Steering Committee was sunset in September 2010, approximately 6 months prior to deployment of the first live data feed through *currentcare* on April 5, 2011.

## Finance

The RI SRD Project received \$5 million from AHRQ over the course of the project. In addition, HEALTH and RIQI were able to obtain an additional \$1.2 million for HIE system development. Once HITECH funding became available, RIQI was able to successfully obtain approximately \$27 million in Federal grant funding for health IT expansion activities, including some growth of the HIE infrastructure, electronic health record (EHR) adoption efforts through the creation of a regional extension center and a number of practice redesign and quality improvement efforts, which are dependent on EHR adoption and/or utilizing the HIE system. These funds are not intended for sustainability of the HIE system, and they will be largely expended by 2014. In mid-2011, RIQI was unsuccessful in its efforts to secure the required community and political support for a funding stream to be derived from an assessment on commercial insurance claims. Thus, a long-term funding model to sustain Rhode Island’s statewide HIE infrastructure has not yet been determined. At the time of this report, sustaining the HIE infrastructure is a major priority for RIQI.

## Technical Infrastructure

Rhode Island selected its technology partners through a competitive procurement conducted according to State purchasing requirements. Hewlett Packard (HP, formerly EDS) was selected as the primary systems integrator in partnership with InterSystems Corporation, the software vendor that provided the solution now known in Rhode Island as *currentcare*. *currentcare* is an integrated HIE application based on a customized instance of InterSystems’ Healthshare solution. The technical architecture for *currentcare* is a hybrid model (with both federated and

centralized data storage) intended to allow DSPs to participate in HIE at a level that properly aligns with their business, legal and technical requirements. Each nonfederated DSP has its own edge cache repository securely housed within the *currentcare* system.

The agreed upon technical infrastructure for *currentcare* is comprised of two elements: an integration framework based on a service-oriented architecture and integration standards, and a suite of functional components that provide the required services. *currentcare* includes an Enterprise Master Patient Index combined with data/user registries and data repositories to create a longitudinal EHR for each registered patient. The software solution also includes two modules customized for the Rhode Island implementation: (1) Consumer registration / consent management and (2) distributed user administration accessible by authorized users in participating provider organizations.

The technical approach leverages existing State infrastructure with the use of the Ocean State Higher Education Economic Development and Administrative Network to provide connectivity to *currentcare* via a dedicated circuit to a secure data center where the system is hosted. A pre-production security audit was performed and, after minor remediation, the system and data center passed all security requirements prior to the transmission of DSP data into the production environment. Today, after the full transition of the technical solution from the State, RIQI is accountable for all system administration and support with assistance from its vendor partners.

At the time of this report, 17 percent (172,000) of the Rhode Island population is registered in *currentcare*, the consumer-directed consent capability is in place in the system and the repository model has been deployed beginning with laboratory data from multiple lab partners and Admission/Discharge/Transfer (ADT) from one hospital and continuity of care document data from one practice. Additional Lab ADT and continuity of care document data are scheduled to go live before the end of the month. Mutual performance requirements for data submission to *currentcare* are contractually defined in DSP Agreements developed through the project.

In spite of a series of delays in *currentcare* deployment, RIQI sought opportunities to leverage the *currentcare* infrastructure through interoperability with emerging technology models, namely Direct, a program of the Nationwide Health Information Network. This was a well-placed tactic that may help preserve the technical viability of the statewide model in Rhode Island amidst a Federal HIE culture where creating large scale exchange utilities is no longer the dominant thinking.

## **Business and Technical Operations**

HEALTH had clear foresight regarding the limitations of its role in the business and technical operations of the HIE system. In mid-2008, after RIQI won a competitive solicitation to receive the State's designation as Rhode Island's HIO, HEALTH and RIQI finalized contractual agreements stipulating performance parameters and capacity building requirements to enable RIQI to take over *currentcare* management and operations. The full transition was completed in June 2010, 1 year prior to the end of HEALTH's contract with AHRQ. Today, RIQI has grown its staffing resources to nearly 40 employees that operate according to many policies defined by Rhode Island stakeholders.

Consumer enrollment in Rhode Island's HIE system is a unique requirement and was among the first HIE functions that RIQI assumed full responsibility for. With help from the State in testing enrollment strategies, to date RIQI has pre-registered 172,000 consumers in *currentcare* which has enabled health data for consented patients to flow into the system and accumulate

prior to “go live” with provider users. Enrolling Medicaid patients in *currentcare* has been a focus area and the State has provided leadership and funding through a Medicaid Transformation Grant to direct enrollment efforts toward long-term care facilities and community health centers where Medicaid beneficiaries receive care.

In addition to enrollment, RIQI has established provider outreach and relations capacity to ensure that patient participation in *currentcare* is endorsed and supported by the provider organizations that will ultimately be using the system. Mutual performance requirements by RIQI and participating providers are contractually defined in *currentcare* user agreements. User go live is slated for early 2012.

Many lessons were learned about what it takes to establish a statewide HIE system. Among the most important was the need to deeply test policy decisions for operational feasibility and business sustainability. The jury is still out on the Rhode Island consent policy and whether the large operational burden posed by the consumer enrollment and consent management process can be financially sustained.

Another important lesson is the recognition that there is a delicate balance to be maintained between dependence on stakeholder resources and organizational self-reliance. During the transition of responsibility for technical operations from HEALTH to RIQI, there was some lag in building RIQI’s capacity to independently manage and operate the technical solution. As a result, there was continued reliance on stakeholder direction which came very slowly during a time when schedule delays were costly to the achievement of project goals and deliverables.

## **Legal/Policy**

The legal/policy domain is where the Rhode Island experience is set apart from other large HIE initiatives. Engaging stakeholders in direct discussion and formulation of HIE policies was a guiding principle of the project. As a result of the deliberate, open community dialogue, Rhode Island consumers, policymakers, business leaders, providers, and technical experts developed 19 policies and 2 contractual agreements that are now the backbone of a fully operational HIO. In addition, Rhode Island lawmakers passed the HIE Act of 2008 and HEALTH promulgated regulations specifically applicable to *currentcare* and RIQI as the State-designated HIO. Despite its full participation in the policy development process, after two public hearings and finalization of HIE regulations, the Rhode Island Chapter of the ACLU sued HEALTH on grounds that it violated the Administrative Procedures Act. This litigation remains in process and as such, no further details or analysis of this case can be discussed.

## **Evaluation**

The project evaluation included two parts: (1) a focus group analysis of the HIE System policy development process and (2) an analysis of the patient enrollment experience in long-term care facilities where the value and need for the HIE System is perceived to be high. A summary of results for each part follows:

### **A) Policy Analysis: Focus Groups**

- The community decisionmaking process:
  - Trust in the process was perceived as strong.
  - Transparency of meetings and the decisionmaking process was maintained.
  - Patience and consensus-building contributed to most decisions.
  - Praise was expressed for strong leadership and staff support.

- Community involvement was considered imperative in key policy decisions.
- Leadership and the public private partnership:
  - The value of the public private partnership was asserted.
  - HEALTH was perceived as the appropriate agency to lead the HIE initially.
  - HEALTH has valuable experience, but has additional priorities and moves slowly.
  - RIQI was perceived as able to maintain key players in the HIE process.
  - RIQI was praised for attracting large grants to continue implementation.
  - There was concern about RIQI board members' competing private interests.
  - Guarded optimism was expressed about the HIE's long-term viability.
- The opt-in enrollment decision:
  - Community consensus process leading to the opt-in decision was praised.
  - The opt-in decision was described as a national model of privacy rights.
  - The HIE Act of 2008 was seen as a triumph.
  - The opt-in model was seen as causing higher costs and slower enrollment.
  - Technological challenges from opt-in enrollment were perceived as complex.

## **B) Enrollment Analysis: Long-Term Care Facilities**

After 6 months of effort to integrate enrollment procedures into the intake process at eight Rhode Island nursing homes, the proportion of residents with signed consents for current *care* ranged between 10 percent and 100 percent and, in five of the eight nursing homes, less than 50 percent of the residents enrolled.

Nursing homes with higher enrollment rates, compared to those with lower rates, had lower proportions of short-stay residents, greater success in other enrollment efforts (i.e., obtaining advance directives), and devoted more (initial) time to the enrollment effort. Residents and nursing home staff believed the HIE system was less relevant for rehabilitation and/or short-stay residents. This thinking probably contributed in part to the lower rates of enrollment observed in facilities with higher proportions of therapy residents.

High enrollment facilities had enrollment processes reflecting more active (e.g., picked up phone, other) rather than passive (e.g., mail, other) processes. Successful enrollment processes were described as active engagement with residents and families by staff members familiar with the residents and families (or surrogate decisionmakers).

In conclusion, leaders for the Rhode Island project made the decision to directly engage the broader community to formulate policies and design technical infrastructure that had a direct impact on the HIE System planning and implementation process. Over the course of the project, there were delays in system development related to administrative, technical, and policy complexities and the challenges of consensus building. However, the community firmly stands behind the rationale for Rhode Island's chosen approach, the resulting policy decisions, how policies were implemented, and the implications for the process and results. It is hoped that the project's contribution to the HIE body of knowledge can be used to emphasize how actively pursuing and managing the direction of change in social and health systems can be tools for progress in a given community.

## Recommendations for Future Research

The following recommendations are derived from the Rhode Island experience and further research would provide beneficial insights for continued and positive change in the statewide health care system. These questions could include:

- Research Question 1. How might an HIO achieve long-term financial sustainability under an opt-in authorization model which requires affirmative consent prior to patient data flow to the HIE and additional authorization to permit disclosure to participating, authorized users?
- Research Question 2. What is the financial impact and level of customer satisfaction among various opt-in authorization models that have been fully implemented?
- Research Question 3. What is the range of variability in the legal definition of “disclosure” of health information in an electronic HIE system?
- Research Question 4. What is the optimal role of the State in regional / statewide health information initiatives? How does this impact health information infrastructure maintenance and operations? Strategic IT planning? Regulatory oversight? New program development?
- Research Question 5. What opportunities exist to leverage regional / statewide health information infrastructure to support Medicaid administration and care coordination?
- Research Question 6. What is the ideal technical infrastructure to support broad HIE goals in environments where dominant stakeholders have deployed mature HIE technology solutions?
- Research Question 7. What entities do the public trust the most to maintain and operate a HIE network, community based organizations and/or other private or quasi-public entities versus government? Who and how are HIOs held accountable; what is the role of State government in the accountability of HIOs and HIE systems?

# **Background and Purpose**

## **Purpose and Scope of the Final Report**

As per guidance from the Agency for Healthcare Research and Quality (AHRQ), the purpose of this final impact report is to document progress made during the course of the Rhode Island State and Regional Demonstration (RI SRD) project, specifically the methods used to accomplish the project goals and objectives, key deliverables, findings, and lessons learned. The report articulates the details and dynamics that characterize the experience of developing a statewide health information exchange (HIE) system in Rhode Island and the related governance, policy, legal, technical infrastructure, and business operations over a period of 6 years. In addition, this report will describe past and present funding sources, the evolving value proposition of the Rhode Island statewide HIE system and the prospects for long-term sustainability.

## **Background on the Project and Local Environment**

Rhode Island is a coastal community (1,214 square miles) with just over one million residents—1,050,000 (U.S. Census Bureau). Rhode Island's size presents a tremendous advantage in enabling face-to-face outreach across the State and helps establish the basis for a highly dynamic laboratory-like environment for testing and deploying new ideas. Given the culture of community engagement as a backdrop, one of the going-in principles of the RI SRD Project was to support open dialogue among all stakeholders in order to achieve consensus on the project vision, objectives and related policy and legal provisions that would shape the initiative.

The Rhode Island Department of Health (HEALTH) received funding from AHRQ in 2004 to conduct the SRD project. The project was conducted through a community-driven framework established by the Rhode Island Quality Institute (RIQI), a nonprofit collaborative organization comprised of leaders in the Rhode Island community including CEOs of hospitals, health insurers, and businesses, along with leaders of consumer groups, academia, and government. This group intends to significantly improve the health care system in the State by building on the availability and advantages of health information technology. While HEALTH was the recipient of the contract award and was responsible for leading efforts to build a statewide HIE system, in July 2010, RIQI accepted full management and operational responsibility for administering the HIE system, including completion of the initial build and system deployment and expansion. The transition from HEALTH to RIQI, as the State's designated Health Information Organization (HIO), was an initial objective of the overall SRD project and was intended to align with the end of the AHRQ contract.

There have been some clear benefits of Rhode Island's chosen approach including HEALTH's ability to use governmental authority as needed, its ability to be trusted as a neutral convener working in the community's interest, and its experience in and provision of existing infrastructure and processes to support the development of an HIE system. There have also been some challenges inherent in the procedural and time requirements for government to perform procurement and other business functions required to deploy the HIE system. Further, as per the original governance model and based on the HIE Act of 2008, which was enacted into law as a result of project outcomes, HEALTH was required to transition from being a collaborator with public and private sector entities to becoming a regulator of the HIE system.

The benefits and challenges of this approach, as well as Rhode Island's decisions relating to community involvement and privacy protections, have been studied and their impact on Rhode Island's progress has been analyzed as a core part of the project evaluation. This final report characterizes these dynamics in conjunction with a technical development path and various approaches to long-term sustainability that clearly demonstrates a range of challenges from which other emerging HIE initiatives can learn.

## **Project's Primary Goal**

The project established a shared vision among stakeholders in Rhode Island and set goals that aligned with the momentum behind a new era of health information technology coupled with emerging models to support the electronic exchange of health information. The stated goal of the RI SRD Project was to design, implement, and evaluate the foundation for statewide comprehensive electronic HIE, using affordable technologies and leveraging technologies already in place. Specifically, the Rhode Island Department of Health and its partners (including consumers, health care practitioners, stewards of health data, and industry stakeholders) will develop the capacity to connect a core set of personal health data from various health care providers, and, with an individual's consent, make the information easily available and accessible to providers for use in that individual's care.

As one of six SRD contract recipients, Rhode Island set out to determine how best to establish a statewide HIE system in a social and business environment characterized by Rhode Island's history of independent thinking. Given the goal of creating statewide HIE capability, *currentcare* was established to create an opportunity for every Rhode Island provider to participate. This includes all 6,531 practicing providers in the State (licensed M.D.s, D.O.s, midwives, N.P.s, P.A.s, and podiatrists in all provider practices and all provider facilities) including small and large practices, community health centers (the safety net providers and Health Center Controlled Network), home health agencies, behavioral health clinics, school based health centers, long-term care facilities, and primary and tertiary hospitals. It was known that *currentcare*'s value proposition would vary among providers depending on their use of health information technology such as electronic health records (EHRs), their need for the types of information accessible through *currentcare*, and what alternative means were available to access patient health information, among other factors.

The evolution of achievement of project goals is ongoing in Rhode Island. The history of the HIE initiative can be described in a chronicle of events that presented both challenges and opportunities, all with some bearing on the ultimate outcomes of the project.

## **Formation of the Project: RI SRD Chronicle of Events (September 2004 – June 2011)**

### **YEARS 1-2: Initiate and Organize Project, Select Vendors, Explore Requirements**

- September 2004–March 2005: Organized project; developed and submitted initial project deliverables; constituted a community-based governance structure and process through the RI SRD Project Steering Committee (equivalent to the AHRQ-specified Technical Advisory Panel).
- April 2005–April 2006: Established project management and full committee structure; selected contractors; developed, issued and evaluated responses to a Request for Proposals for a technical solution; built support for the Governor's IT Capital Budget Request Hearing

before the Rhode Island General Assembly to seek long-term (conditional) funding for the RI HIE.

- May 2006: Steering Committee approved a motion to limit the initial scope of RI HIE data use for clinical and project evaluation purposes only; conducted consumer focus groups to understand the public's perspective on the HIE system concept; policy and legal debate on consent and authorization for the HIE system was fully underway; Legislature passes revenue bond bill that authorizes State funds for HIE development contingent upon all other insurers contributing a fair share allocation to a State designated HIO.
- July 2006: Selected EDS (now Hewlett Packard) as the HIE systems integrator with InterSystems as the subcontractor for the software platform; initiated contract negotiations.
- August–November 2006: A stakeholder-driven Technical Solutions Group (TSG) continues its work to refine the technical architecture and system design with a particular focus on infrastructure and consent management requirements.

### **YEAR 3: Achieve Community Consensus on Consent Model**

- November 2006–January 2007: Developed and submitted a draft Project Evaluation Plan using a structure-process-outcome framework; focused on defining the consent management model for the HIE system; convened a panel of health care attorneys to review the State mental health law which identified differing interpretations regarding “disclosure,” resulting in agreement on a conservative approach to information disclosure and consent requirements for the HIE; State CIO (an HIE advocate) resigned.
- February 2007: Conducted Joint (All) Committee meeting to ratify a proposed consent model for the HIE system; this pivotal meeting resulted in a change to the initial RI HIE authorization policy which now requires two levels of consumer consent prior to provider access; stakeholders demanded legislative safeguards for consumer privacy protection.
- July–August 2007: Executed contract with EDS for technical solution; initiated RI HIE system requirements definition and worked to refine architecture to support authorization (consent) model; Joint Committee formally approved two-part consent model; State issues a Request for Proposals for Rhode Island Health Information Organization (RHIO) designation.

### **YEAR 4: Align Technical Solution with Consent Policy; Pass HIE Law; Enroll Consumers**

- October 2007: Steering Committee approved RI HIE Authorization (consent) Policy; TSG worked with EDS to develop/finalize technical requirements for consent management; established an Enrollment Work Group to define operational implications of voluntary enrollment in the RI HIE.
- November – December 2007: Rhode Island Quality Institute received State's designation as the RHIO through a competitive process; RIQI Board approves draft privacy legislation; initial prototype of basic HIE functionality demonstrated to stakeholders (without consent management module); policy development accelerates; technical project plan falls behind schedule by 30 days.
- January – March 2008: Technical requirements (including consent management) nearing finalization; seeking vendor options to develop RI HIE Participation Solution (consent checker); conducted second round of consumer focus groups on RI HIE and authorization concept; Steering Committee approved consumer enrollment policy.
- April – June 2008: RI HIE system is named *currentcare*; RI HIE Act of 2008 passes into law; finalized RIQI performance contract for State designated RHIO and finalized RIQI

capacity building contract for transitioning HIE operations; finalized functional requirements for RI HIE with approval of EDS/InterSystems Corp (ISC) proposal to develop Participation Solution (consent management)—contract modification required; revisions to Authorization Forms and educational brochures underway; ISC, the HIE software vendor, certified for Surescripts connection; conducted second HIE system prototype; launched first *currentcare* enrollment strategy: Direct mailing to Medicaid beneficiaries; began working with nursing homes to identify enrollment sites.

- July – September 2008: Project schedule “rebaselined” due to technical and contractual delays; all *currentcare* policies under development; RIQI aggressively building enrollment capacity; completed second Medicaid enrollment mailing and began onsite enrollment in a large community health center.

#### **YEAR 5: Build RHIO Capacity; Address Technical Challenges**

- October – December 2008: Executed vendor contract for consent management solution; persistent technical delays due to inadequate identity management solution; actively testing consumer enrollment strategies; conducted first community review of HIE regulations; RIQI restructures Board committees for RI HIE oversight; RIQI identifies lack of support for revenue bond strategy, RIQI engaged Boston Consulting Group to develop business case for *currentcare*.
- January – March 2009: EDS finalizes recommendations for identity management solution; installed/configured all required software and hardware for production environment; planning/procurement underway for preproduction security audit although a major cause for schedule slippage; HEALTH conducted a second community review and formal public hearing on proposed HIE regulations; *currentcare* enrollment approaches 1,500; Federal American Recovery and Reinvestment Act (ARRA) incentives bolster interest in EHRs.
- April – June 2009: HEALTH promulgated final HIE regulations; Completed first round of HIE system testing after delays due to configuration issues with identity management solution; deployed regional enrollment strategy (Warwick, Rhode Island); experiencing delays in Surescripts negotiations for medication data exchange; actively reviewed data sharing agreement with partners; updated policies to comply with Federal HITECH Act; enrolled 4,500 consumers through 87 partner sites; RIQI initiated new Board-level discussions on a viable long-term funding strategy for the HIE system.
- July – October 2009: User acceptance testing (UAT) delayed due to inadequacy of proposed user authentication product (OpenSSO) requiring EDS to develop custom solution; RIQI initiates planning for Limited EHR Aggregation Project to bolster data exchange with EHRs; continued contract negotiations for security audit; *currentcare* enrollment reaches 24,000; deployed online enrollment capability.

#### **YEAR 6: Pursue RHIO Funding; Test HIE Solution; Disaster Recovery; Transition; *currentcare* Go Live; SRD project comes to a close**

- November–December 2009: HP acquires EDS; initiated UAT, HP actively addressing priority issues; RIQI pursues Federal HIE, Regional Extension Center and Beacon Community grants; *currentcare* enrollment exceeds 30,000; RIQI gathering support for a budget article that would institute an assessment on health care claims to support long-term funding for the HIE system.
- January–March 2010: Data Submitting Partners (DSPs) identify new mandatory audit log requirements for *currentcare* which will require customization, specs approved by DSPs,

awaiting pricing from HP; “go live” redefined as data flow from DSPs to *currentcare*, access by providers to be delayed; completed second round of UAT with outstanding issues; completed negotiations for pre-production security audit; *currentcare* long-term funding strategy excluded from Governor’s budget; RIQI awarded \$11 million in HIE/ Regional Extension Center grants; *currentcare* enrollment at 45,400.

- April–May 2010: HP corporate offices and data center destroyed in record-breaking flood, resulting in a total loss of hardware and protracted delays in restoration of software; intensified efforts to transition *currentcare* operations to RIQI as planned; RIQI awarded \$15.9 million Beacon grant; *currentcare* enrollment approaches 62,000.
- June–August 2010: HEALTH requests and is granted a 9 month SRD contract extension to complete HIE deliverables; HP development/hosting contract with HEALTH expires; HEALTH transfers responsibility for all HIE development and operations activity to RIQI and contract development to support transfer is in process; deferred security audit until new production environment is established under RIQI management; RIQI continues working with ISC (HIE software provider); Limited EHR Aggregation Project initiative goes live; Rhode Island Chapter of the ACLU files a complaint against HEALTH on grounds that it violated the Administrative Procedures Act by using policies not subject to “public vetting” to supplement the promulgated rules regulating the HIE; ACLU representative ceases participation in RIQI Policy and Legal Committee, the community forum for HIE policy deliberation.
- September 2010: RI SRD Project Steering Committee approves final *currentcare* policy and the group is “sunset” after 5.5 years as the project governance structure is transitioned according to RIQI’s HIE Strategic Plan; RIQI signs contract for *currentcare* hosting services with new vendor (not HP); RIQI orders replacement hardware; *currentcare* enrollment reaches 89,000 consumers.
- October 2010: HEALTH executes contract with RIQI to complete initial HIE development as defined in the SRD contract, work anticipated to be completed by April 2011
- November 2010–February 2011: Lincoln Chaffee becomes the first independent candidate to be elected as Governor of Rhode Island. Governor Chaffee appoints RIQI Board member Lt. Governor Elizabeth Roberts as the Chair of the newly formed RI Healthcare Reform Commission. Lt. Governor tendered her resignation from the RIQI Board effective January 26, 2011 to assure that there were no conflicts of interest. RIQI receives additional \$404,775 in funding for RI Regional Extension Center; intensifies outreach efforts to the business sector, elected officials, and legislative and gubernatorial staff to build support for its long-term funding strategy. Final testing of the *currentcare* technical platform began in mid-January; *currentcare* enrollment reaches 122,000 persons. On February 2, the Office of the National Coordinator for Health IT (ONC) celebrated the first beneficial use of the Direct secure message technology and recognized Rhode Island’s and RIQI’s achievement of the first exchange of personal health information (PHI) via Direct between health care providers.
- March 2011–April 2011: DSP agreements are executed with a large regional laboratory, an independent hospital and one of the State’s largest integrated delivery networks. Live laboratory data began flowing into *currentcare* on April 5, 2011. RIQI also began advancing the use of Direct in Rhode Island. In addition to exchanging PHI between providers, RIQI developed a way to use Direct to transport consented PHI between HER systems and *currentcare*. RIQI discontinues the LEAP pilot project in favor of the Direct

solution. All Beacon Community partners have signed Letters of Agreement for currentcare and over 90 percent have begun enrolling their patients into currentcare. New DSPs are recruited and agreements are being negotiated.

- June 2011: currentcare enrollment exceeds 150,000 consumers; approximately 15 percent of the State's population (17 percent, 172,000, at the time this report was drafted). Efforts to execute RIQI's long-term funding strategy are in full force yet despite major outreach, the health information infrastructure funding proposal was not included in the Governor's budget. RIQI contemplates other options for long-term sustainability. While the currentcare consent management solution and repositories are in production to receive health information from laboratories, hospitals and providers, the full end user model for information retrieval from currentcare is expected to go live to providers in early 2012. The final extension of the SRD contract with AHRQ expired June 30, 2011.

## Project Goals and Objectives

The RI SRD Project developed and approved a vision statement in November 2005. (See [Appendix A-4](#)). This vision drove the project's high-level goals: To design, develop, test, deploy, and evaluate an initial health information network to support the secure and reliable exchange of health information, beginning with laboratory results and medication history information. The system was envisioned to link longitudinal, patient-level information from source data systems using a master patient index (MPI); provide a Web-accessible viewer to authorized users in any setting; and to enable HIE with EHR systems. Initially, establishing the MPI was a major focal point of the project, however, it was quickly understood that an anticipated core technology solution could not be allowed to drive the project direction. The HIE landscape was changing rapidly and considerations beyond technology were increasingly important.

The details below describe additional project goals and related objectives, where applicable, in terms of the five elements deemed to be integral to HIE system development, deployment, and sustainability.

### Governance

As described, HEALTH contracted with RIQI to provide a working governance structure. Through this structure, project decisions and direction were based on a collaborative, community-led governance model. A Steering Committee comprised of public and private sector leaders was constituted in March 2005 and convened monthly through September 2010. From project inception, a private, community-based collaborative organization was expected to take over management of the contract with the State's technical vendor for the HIE and accept assignment of the applicable terms of the contract. In August 2007, as a result of a competitive procurement process, RIQI was designated as Rhode Island's RHIO and in addition to governance responsibilities, RIQI must develop a sustainability plan for financing the HIE to ensure that its management, technical operations and development of RHIO policies expand appropriately to serve the entire State.

Governance focused on providing a decisionmaking mechanism intended to ensure achievement of high-level goals. The following decisionmaking objectives were set forth by the RI SRD Project Steering Committee:

- To adopt guidelines that support achievement of consensus on all decisions put forth for a vote by the RI SRD Project Steering Committee where consensus is defined as "*no single voting member present or by proxy being in opposition of a group decision.*"

- To implement a decisionmaking process that accommodates and considers differences in Steering Committee member positions.

The complete list of Steering Committee Decision-Making Guidelines may be found in [Appendix A-1](#). These decisionmaking objectives were intended to support leadership of a public-private partnership during the initial HIE development and deployment. This partnership took its ultimate form when RIQI was awarded a contract as the State-designated RHIO and assumed full operating responsibility of the HIE with the State transitioning to a regulatory role. RIQI's RHIO objectives were as follows:

- Advance the use of the HIE in order to improve the quality, safety, and value of health care;
- Keep health information secure and confidential; and
- Use the HIE to contribute to progress towards meeting public health goals.

The RI SRD Project governance structure was integrated with management and implementation components, largely staffed by subcontractors operating under the authority of HEALTH. Key subcontracts included the following:

- **Project Management (Prime Contractor) – Rhode Island Department of Health** – Provide overall project leadership and management in building a statewide health data exchange.
- **HIE Governance & Coordination with Statewide Health IT efforts – Rhode Island Quality Institute (RIQI)** —Provide governance structure by administering the Governing Council (Board of Directors), Steering Committee and ad-hoc workgroups including DSPs, Consumer Advisory Committee; Assure strong coordination between RI SRD Project and other statewide health IT efforts; develop strategies for sustainability.
- **Health Care Provider Engagement: Quality Partners of Rhode Island (QPRI/QIO)** – Create a professional users group of providers, to obtain input on design, enroll providers in the system, train on system use. Expand these activities to other providers over time and as more data sources are linked to the system.
- **Consumer education and engagement: Clarendon Group** – Obtain consumer input and incorporate into Health IT System design, educate consumers on System value, establish an enrollment process, develop materials and marketing, obtain feedback.
- **Well-defined evaluation: Brown University** – Evaluate usage and satisfaction by providers and consumers as well as identify outcome measures to the extent feasible.
- **Technical design and development of the HIE system: HP, formerly EDS/InterSystems Corporation** – Design, build, test, and implement the initial releases of the Health IT System and its connectivity.

## Finance

While AHRQ provided core funding for the Rhode Island HIE initiative and additional sources of financial support were leveraged during the project period (Medicaid Transformation Grant funds, insurer contributions, Federal appropriation), the issue of long-term sustainability was a known challenge. A broad goal of the initiative was to establish a solid value proposition through demonstrable HIE upon which a sustainable funding model could be launched. However, there were business dynamics and other factors that bounded the range of potential sustainability models:

- Electronic results delivery was already in place among some major providers in Rhode Island, thus limiting options to deploy this service as a source of revenue;
- There were a variety of potential models that might be considered for the HIE system, however, in the early years, none of these models had yet been proven;
- The current *care* consent model was technically complex and its acceptance/value and true operating cost were largely unknown; In addition, the length of time to acquire enough data in current *care* to make the business case for its use was a barrier to achieving support; and
- It was known that funding options would need to be thoroughly vetted by stakeholders to ensure equity and mitigation of unintended consequences resulting from economic/value reallocation caused by any given sustainability model.

In 2008, RIQI engaged Boston Consulting Group to develop a business case for the statewide HIE. At the time, a total investment of \$25M was projected through 2014, with \$3M in annual funding required thereafter. While HITECH funds did contribute significantly to the advancement of the HIE, most of that funding supports HIE expansion and in some cases redirects priorities for new HIE functionality. These funds do not support ongoing maintenance and operations of the foundational system. Thus long-term funding remains a challenge.

Considering the near-term expiration of grant funded sources, RIQI has and continues to seek investment funding from Rhode Island stakeholders while also working to define a strategy for long-term sustainability.

### **Technical Infrastructure**

Technical infrastructure for the HIE system was always a topic of stakeholder discussion and the earliest models depicted cost and technology “in the center”. In early 2005, a multi-stakeholder TSG was commissioned by the RI SRD Project Steering Committee. Its initial charge was to provide a scope document illustrating the boundaries of the overall technical vision and approach with the potential to identify specific components that will be delivered through the project.

The TSG defined its work along three development paths: (1) technical, (2) data prioritization, and (3) HIE System policies.

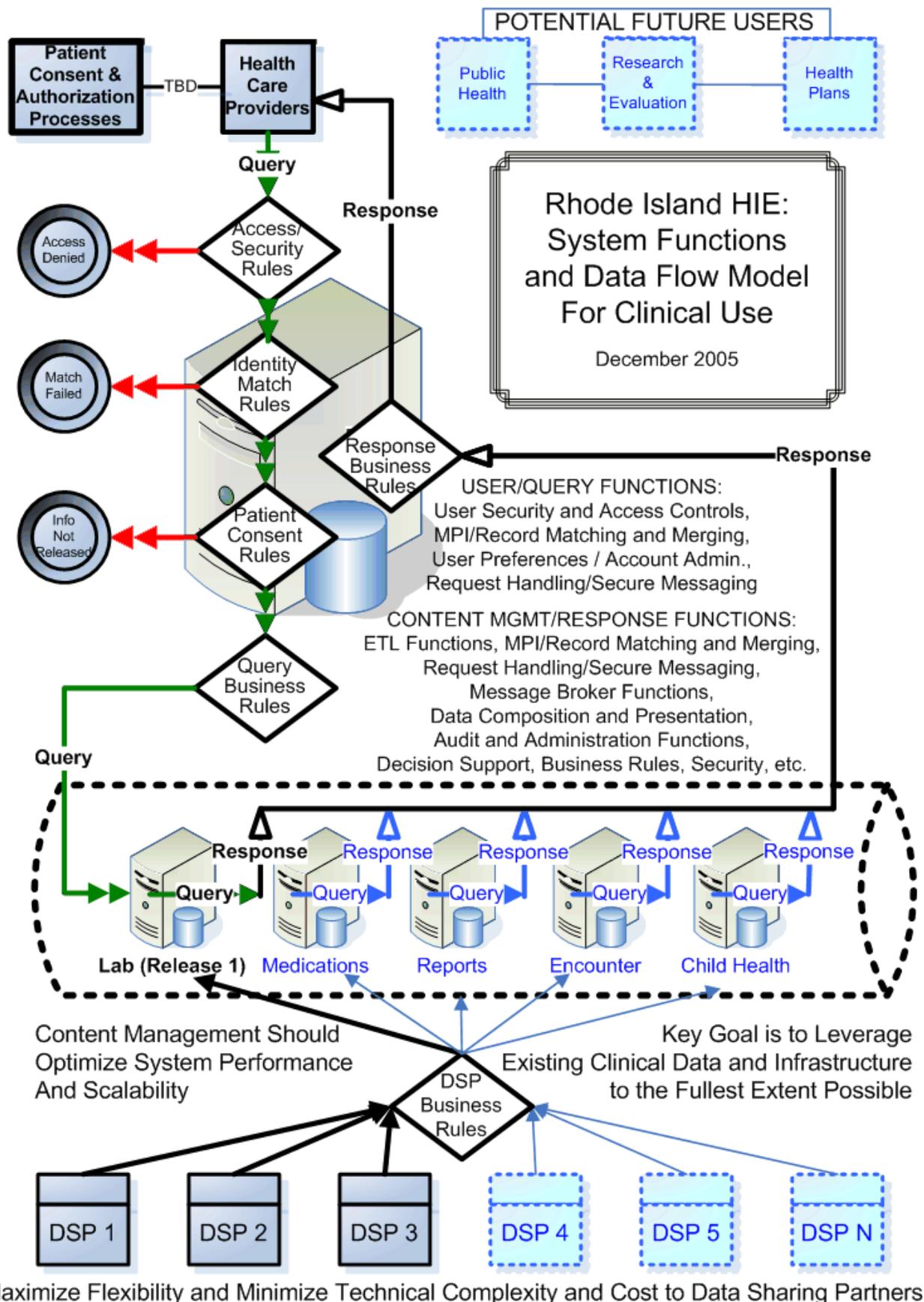
**Technical Development.** The technical development path was initially described in a high-level architecture that reflected key functions and attributes of the envisioned HIE infrastructure:

- Establish a “user portal”
  - key functions:
    - Users sign up
    - Set data “flags” to manage access
    - User security (authentication)
    - Information requests returned
    - Audit function
    - Other functions, TBD
  - infrastructure objectives / attributes:
    - Ensure consumer control of access to information
    - Support many user types; deploy a flexible interface
    - Use a hosted service model
    - Support participation of all willing DSPs (i.e., transport data through the HIE system)
- Include an Aggregation Layer in HIE design
  - key functions:

- Information requests handled
- Security maintained
- User preferences applied
- Master Patient Index (MPI) links/“placeholder”
- Decision support
- Messaging agent
- Audit function
- infrastructure objectives / attributes:
  - Supports defined Privacy, Confidentiality, Security policies & laws
  - Intelligent routing
  - The most complex tier
  - Conducive to cost-sharing
  - Unlimited deployment model, ASP, in-house, combo in-source/outsource
- Incorporate a data clearinghouse
  - key functions:
    - “Centralized data gatherer of decentralized same-type data”
    - Manages database categories; Narrow and deep data
    - Information requests handled
    - MPI links-“placeholder”
    - Audit function
  - infrastructure objectives / attributes:
    - Preserve performance/speed
    - Highly scalable-add data types as defined
    - Provide security/availability-use of distributed databases
    - Preserve flexibility of data governance/management
- Engage DSPs
  - key functions:
    - Multiple databases, locally controlled
    - Information requests handled
    - MPI links-“placeholder”
  - infrastructure objectives / attributes:
    - “Ease of entry”--no complex, expensive infrastructure requirements (message based) at the Data Submitting Partner (DSP) level
    - Flexible participation options for large and small DSPs
    - Minimizes impact on DSP daily operations

Figure 1 illustrates the initial “strawman” technical model, a four-tiered architecture designed to protect consumer privacy, preserve performance and to keep the “cost in the middle” to encourage adoption and use of the system by all providers, large and small.

Figure 1. Initial Rhode Island Health IT system strawman model (December 2005)



The proposed strawman technical architecture included using a highly flexible, scalable service-oriented architecture that was component-based (a collection of “packaged” applications) to allow for incremental addition of services. These components would be loosely coupled with a preference for Web services interfaces. The service “stack” would be standards-based to the fullest extent possible while also allowing for flexibility in the specific implementation. The strawman was unique in the use of a highly scalable data staging area that would be functionally organized by data type such that content management would not degrade system performance. A key goal was to leverage existing clinical data and infrastructure to the fullest extent possible. Initial data management and exchange priorities include core demographic information and laboratory data followed by medication information and reports (e.g., procedures, diagnostic interpretations, discharge summaries).

In October 2005, HEALTH sought external review and validation by the AHRQ National Resource Center of the proposed HIE system architecture, technical infrastructure and consent model. The opinions that were returned were considered, debated and allowed to challenge current thinking to support refinements to a Request for Proposal intended to procure the services of a vendor to design, develop and deploy the HIE system. It should be noted that the proposed Rhode Island model differed from what was being advanced by the “thinking of the day,” which was primarily dominated by Markle’s Connecting for Health initiative and the Record Locator Service (RLS) design, thus Rhode Island was innovating. Stakeholders were not daunted by the differences, in fact, a different way of thinking was understood and embraced considering what was necessary to meet Rhode Island’s requirements for consumers’ control of their information and inclusion of providers both large and small.

In November 2005, the RI TSG responded to the external review with the following recommendations:

The RI SRD Project TSG and Data Submitting Partners offer the following recommendations for consideration by Project stakeholders:

1. Support efforts to ‘. . . ensure that what you believe to be most important is not designed out of the system at its inception.’ (from AHRQ Resource Center Review)
2. Preserve Rhode Island’s commitment to the pursuit of a technical infrastructure for statewide HIE that is patient-centric, will enable improvements in clinical care and public health, and is inclusive of the health services stakeholder composition unique to Rhode Island. This commitment is supported by the following points:
  - a. Reviewers agree that the proposed Rhode Island model is consistent with stated national goals. However, Rhode Island proposes an approach that is more closely aligned with prevailing clinical information system design than a record locator service or a results delivery utility. Therefore, there is a recognized difference in RI’s approach from those popularized by the RHIO movement and an appreciation that all of these models are unproven.
  - b. The RI solution will explicitly support patient control over disclosure of their protected health information. While the technical solution will evolve, considerations for this capability must be included in the initial design. It is recognized that this is a deliberate departure from other popular approaches.

- c. The RI solution is intended to support the needs of both public and private sector data sharing partners and end-users regardless of organizational size, technical sophistication or financial status. It is recognized that an inclusive approach to statewide HIE requires special architectural considerations not yet reflected in other popular models.
3. Develop additional clarifying details and diagrams describing functional requirements and data flow with special attention to the following areas:
    - a. Regional Master Person Index – Methods to support management of patient identity and related health information across multiple data sources.
    - b. ETL –The “extract, transform and load” processes that enable the system to move data from multiple sources, reformat and cleanse it, and load it into another database, or on another operational system to support a business (clinical) process.
    - c. Aggregate, De-identified Reporting – Methods to support broad analyses for public health, research and other approved purposes.
  4. Take early action to identify an equitable, feasible business model and the community support required to sustain the envisioned HIE system, recognizing that consumers and health plans are primary beneficiaries.

Continued technical development efforts produced a detailed set of functional requirements resulting in issuance of a competitive Request for Proposals (RFP) in January 2006. Both State and community evaluation committees reached the same conclusion that the proposal submitted by EDS/InterSystems was the best choice given the envisioned technical model and the need for flexibility to support continued technical and policy evolution.

Figure 2 below depicts the Release 1 Services Model that appeared in the RFP. It describes the scope of services for lab information exchange to be deployed in the initial architecture.

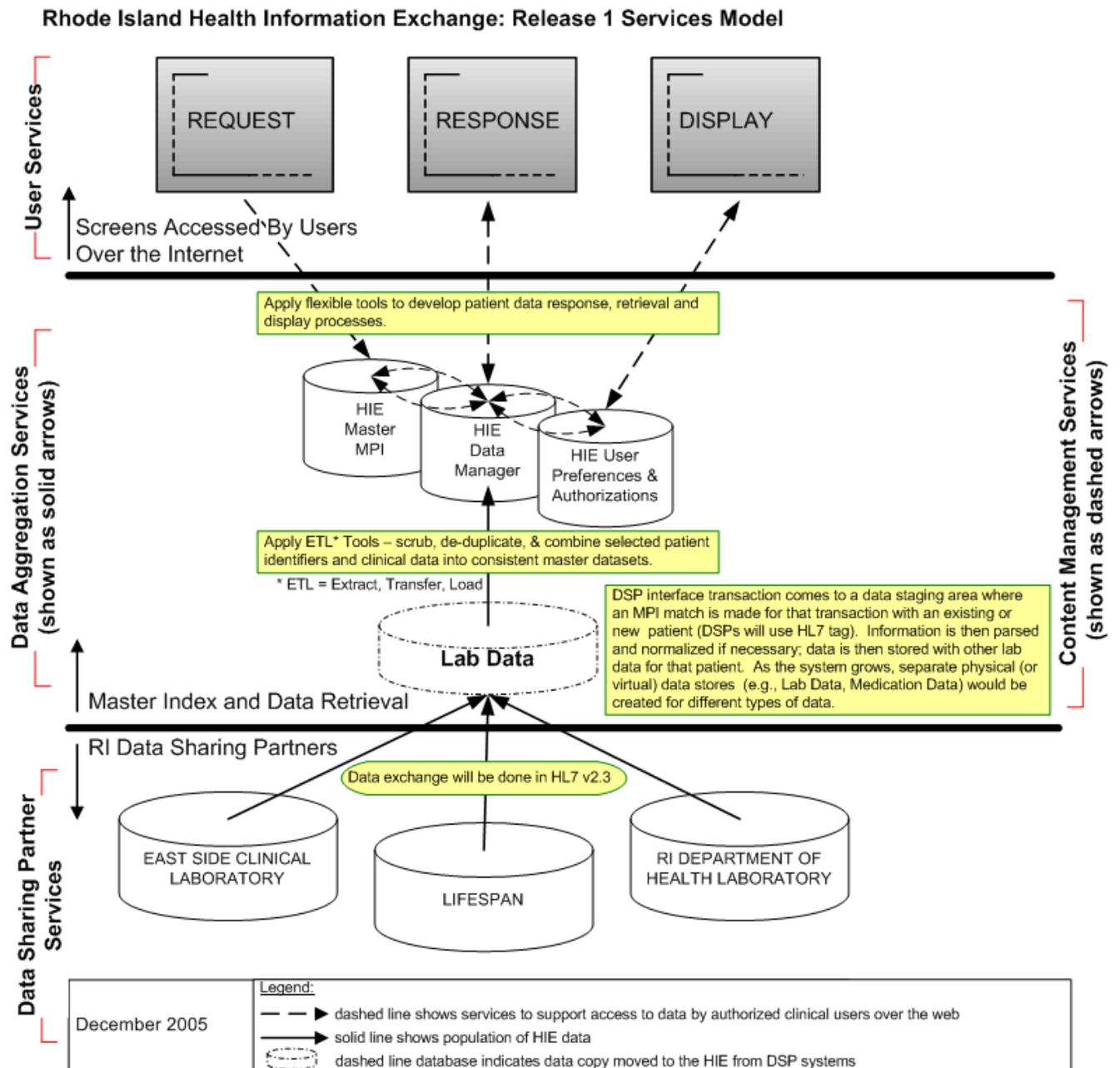
### **Data Prioritization**

The Data Prioritization effort called upon a broad set of technical as well as provider users and DSP stakeholders to identify a priority data set, based on “feasibility and desirability of use”, to be exchanged in the statewide Health IT System during proof of concept, prototyping and initial system deployment in the Rhode Island health care community. Specific objectives of this data prioritization plan included:

- 1) Support achievement of AHRQ contractual requirements for clinical data exchange; and
- 2) Promote broad adoption and use of the Health IT System.

The approved recommendations of the initial Data Prioritization effort were to pursue a Two-Track Data Prioritization Plan. This entailed evaluation and implementation of a top clinical priority data set (which initially included laboratory and medication information) and pursue feasibility of an administrative track (including insurance eligibility information) with Rhode Island Quality Institute Board-level action. The administrative track was not pursued largely because it did not align with the clinical focus of the AHRQ-funded contract requirements. The final, approved Data Prioritization decision appears as Appendix A-2. This plan was later augmented by a position on the Prioritization of Initial Data Uses; see Appendix A-5 for details.

Figure 2. RI HIE System “Release 1” Services Model (December 2005)



## Policy Development

As the technology discussion evolved, the need for a policy framework became increasingly evident. As such, the TSG and RIQI's Policy and Legal Committee began a concurrent technical and policy development effort. The overarching goal of the HIE policy track was to ensure that stakeholders defined policy and that these priorities prevailed in the technical solution development. A set of Information Technology Principles was developed by the TSG and approved by the Steering Committee. These principles served as a consistent reference point during policy and technical solution development. The principles can be found in [Appendix A-3](#).

In Rhode Island, the patient authorization (a.k.a., consent) policy was a tremendous driver of technical architecture. (The consumer version of the RI HIE Patient Authorization Policy Statement can be found in [Appendix A-6](#).) The community discussion to define HIE consent policy took nearly 2 years and the resultant model was found not to be technically feasible using the purchased solution. As such, additional functional requirements were defined and, after confirming the absence of commercially available solutions that satisfied the requirements, EDS/ InterSystems set out to build a custom consent management solution for *currentcare*. In parallel, a full range of additional policies were slated for development; some of them being highly dependent on technical capabilities. Thus the technical and policy development paths of the RI HIE System were linked from the outset. Additional details of the objectives and scope of HIE System policies are included in the Legal/Policy section below.

## Business and Technical Operations

A key principle of the Rhode Island experience is that technical infrastructure must support policy even if it means retrofitting existing technology solutions. In concert with technical and policy alignment, the value proposition for a proposed or emerging system must be clear, credible and supportable by stakeholders. In Rhode Island, data look-up and retrieve were the functional focus for the HIE system. A results delivery model was rejected as a value proposition early on so as not to duplicate current capacity and create undue interference with regional business dynamics.

Initial business objectives focused on making longitudinal health records available to participating providers anywhere, anytime. User adoption was promoted by including priority clinical data and ensuring confidentiality protections for consumers.

Specific objectives for business and technical operations could only be contemplated after the State transferred full responsibility for *currentcare* management and operations to RIQI. These objectives are now set in the context of the statewide HIE Strategic and Operational Plan submitted to the Office of the National Coordinator for Health IT in July 2010 and further revised in November 2010. These objectives are forward looking from 2010 – 2014 and include the following:

- Achieving an enrollment target of 50 percent of the population of the State of Rhode Island in the HIE.
- Facilitating options that allow providers to receive structured laboratory results.
- Integrating discharge summaries, administrative, patient-generated measures, medications, radiology, cardiology, pathology, immunizations, and behavioral health, Medicare/Medicaid data, problem lists, allergies, ADT/registration, medication, clinical care summaries, and advance directives data sources into the HIE (supports clinical summaries and e-prescribing).

- Implementing statewide EHR aggregator(s) as part of the HIE system that gathers data from a myriad of individual sites operating EHRs.
- Building an analytics warehouse that is used to promote improved health and health care in accordance with State and Federal laws.
- Enabling a connection to the Nationwide Health Information Network and Direct.

## **Legal / Policy**

A key goal for legal and policy considerations was to engage all stakeholders in the policy debate. In addition to technical, provider and consumer stakeholders, the RIQI Policy & Legal Committee was charged to consider the scope and impact of policy options across a full spectrum of issues. As noted in the Business / Operations section above, the Rhode Island Health IT Project directly addressed the policy implications of deploying a statewide HIE System.

The scope of policy and legal considerations was broadly inclusive of patient/consumer rights and confidentiality considerations as well as risk management, technology, contractual, and operational considerations. At the outset, approximately 20 policies were identified for development.

A policy framework and development process was established. The policy development approach involved identifying policy topics at the Steering Committee level or capturing them as the need became apparent in other venues such as the Policy and Legal Committee. Once identified, policy work was sequenced according to a logical development path and an appropriate “flow” through the committee review process was scheduled. Once all committees had completed their review and comment, final refinements were made and the policy was included on a Steering Committee meeting agenda for initial consideration. After thorough discussion and resolution of any outstanding issues, the policy was slated for a formal vote of acceptance in a subsequent Steering Committee meeting.

It should be noted that the RI SRD Project evaluation included a deep exploration of the community-based approach used by Rhode Island to establish the patient consent policy and, ultimately, pass the RI HIE Act of 2008 to enact privacy legislation, and promulgate regulations specifically for *currentcare*. Although not an initial objective of the RI SRD Project, it has become a critical endeavor to determine if the policy basis for *currentcare* can now be technically implemented and fully scaled to operate statewide in a financially sustainable model. See Results immediately following for details.

# Results

## Governance

With RIQI serving as the governing entity for the RI SRD Project, adopting a collaborative, community-led approach was a certainty. Thus, the RI SRD Project Steering Committee was initially constituted in March 2005 to enable a broad set of stakeholders to participate in project-level decisionmaking. This Steering Committee was conducted as a committee of RIQI in accordance with the RIQI Committee Membership Policy; see Appendix A-7 for the full policy narrative. As the contract closed and RIQI became fully responsible for the HIE system in September 2010, the initial governance body was retired and reconstituted as the currentcare Advisory Committee. (The final special communication to the Steering Committee is included in Appendix A-8.) This restructuring was intended to rebalance the need for broad representation with the need for timely action as required to expand and enhance the production HIE system in a market-driven environment.

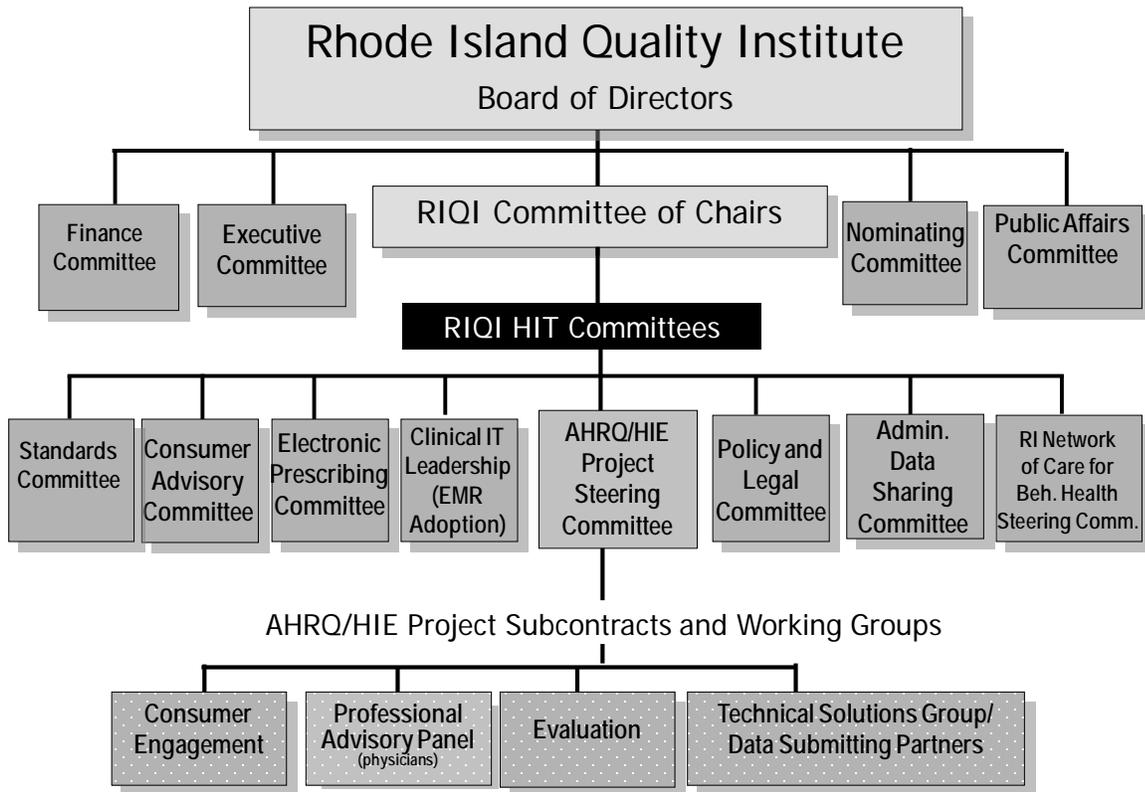
## Identifying Partners and Other Stakeholders

Initial stakeholders for the project were defined in an AHRQ-required deliverable submitted in November 2004. This list was very broad and representative of most organizations in the Rhode Island health care market. Included among stakeholders were all Rhode Island hospitals and integrated delivery networks, professional associations, community health centers, State government, physicians/medical groups, insurers, laboratories and various other health services organizations.

## Governance Structure

Figure 3 illustrates the initial governance and management structure in RIQI that supported the project. Within this structure the RI SRD [HIE] Project Steering Committee, the designated governance body, was focused on project decisionmaking and formulating strategic recommendations to the RIQI Board of Directors. It served in this capacity for 5 ½ years.

Figure 3. Initial RIQI / RI SRD project governance structure (2005-2010)



January 2007

## **Formation, Usefulness and Evolution of the Steering Committee (a.k.a., Technical Advisory Panel)**

Throughout its tenure, the RI SRD Project Steering Committee proved to be invaluable in several important ways. First, it became the mechanism by which public-private sector representation and collaboration could be explicitly expressed in terms of decisions that established the direction and impact of the project. The Steering Committee created a direct channel for advancing the community's recommendations to the RIQI Board of Directors and the Department of Health.

As the project evolved, Steering Committee membership was periodically reevaluated and realigned to ensure that stakeholders with relevant perspectives were among the voting members. Thus, the project took on a community-led identity and Steering Committee members took ownership for project outcomes to the extent that they could control them. Within their own organizations, Steering Committee members provided essential support in terms of advocacy and participation to achieve the goal of operationalizing a statewide HIE system.

In addition to setting project direction, the Steering Committee allowed RIQI and the Department of Health to gain insights into the organizational and political dynamics that must be addressed in a permanent governance structure. Using this experience, RIQI recast the initial governance and management organization to enable it to act more decisively while preserving access to community perspective through other committees and working groups.

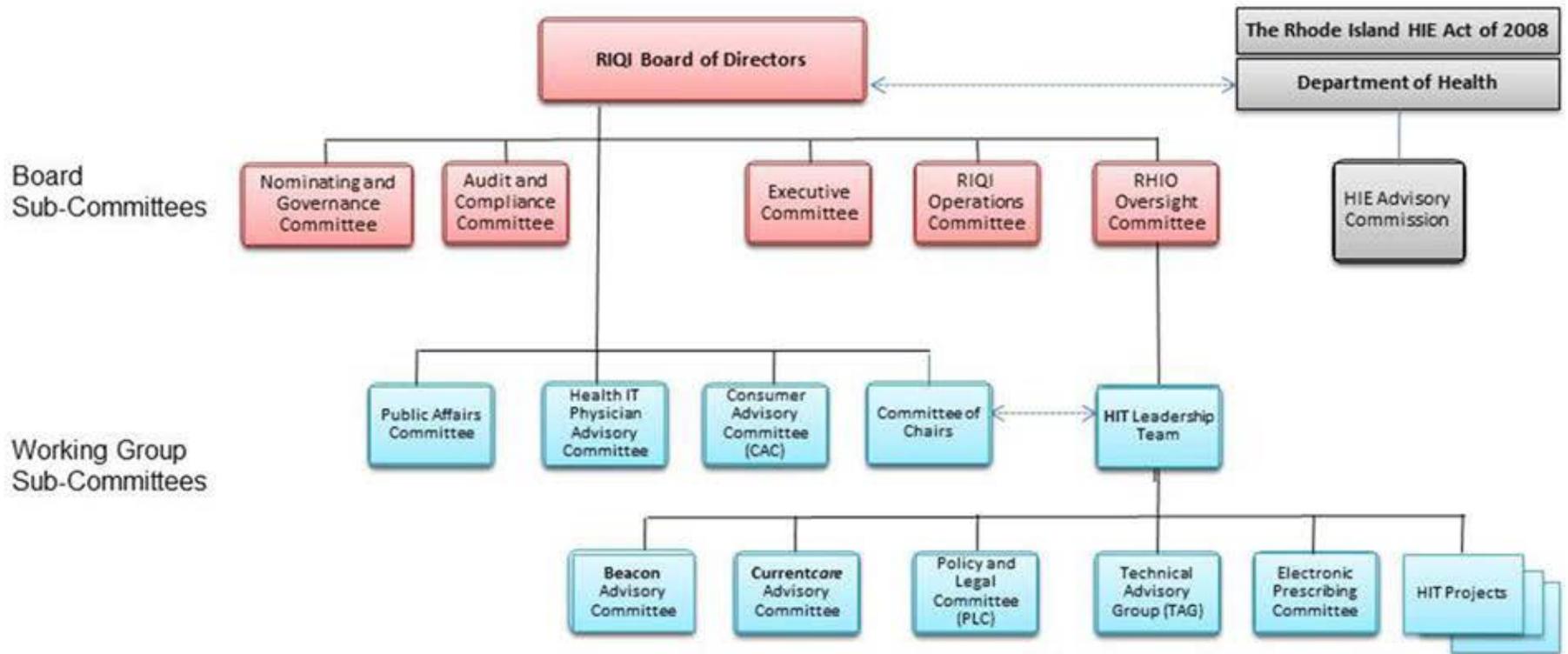
Figure 4 represents the current governance structure of RIQI including newly established RIQI operations and RHIO oversight functions. Note the addition of the Rhode Island Department of Health in its regulatory capacity is in part implemented through the required creation of an HIE Advisory Commission. In addition to the reformulated *currentcare* Advisory Committee, new committees have been established by RIQI to provide coordinated guidance for numerous health IT/HIE initiatives such as grant funded programs like ONC's Beacon Communities.

## **Lessons Learned About Governance**

As determined through the project evaluation's analyses of focus group responses to questions about governance and project decisionmaking, prominent themes suggest four key lessons learned:

- (1) The community decisionmaking process can be slow and requires a large time commitment, but the outcomes of the process are worth the time and effort invested;
- (2) All parties invested in or affected by the HIE system should participate in the community dialogue;
- (3) Community members' concerns with privacy protections and autonomy over personal health data must be respected;
- (4) The public-private partnership experiment in leadership carries with it the benefit of shared responsibility and the threat of competing interests; and
- (5) The role of State government in governance needs to be carefully considered and will likely change and evolve over time.

Figure 4. Current RIQI / Rhode Island RHIO governance structure (2011)



There has been a significant evolution of the governance structure from the inception of the RI SRD Project to the current state of current*care* operation as a statewide HIE system. The project was initiated as a public-private partnership with a number of State officials serving on RIQI's Board of Directors. Over time, as considerations related to State funding contributions were being vetted and the official designation of a State RHIO through an open bid process was required, the nature of the relationship between RIQI and State government needed to change. The potential for conflicts of interest became an important consideration which resulted in numerous State officials resigning from RIQI's Board. While still working collaboratively to complete initial development of the HIE system, the nature of the relationship between the State and RIQI as the RHIO, shifted from a public-private partnership to one of a regulated entity and regulator.

With the changes in governance, many lessons have been learned. RIQI, as the State's designated entity and RHIO, now responsible for administering and maintaining current*care*, has put into practice key lessons learned about governance. RIQI's perspective on governance includes these takeaways:

- Community involvement is crucial in order to modernize health information infrastructure, address the complexities of medicine and patient privacy, and avoid multiple parties working at cross-purposes with each other.
- Establish a communication approach intended to guide discussion, investigation, and experimentation in meetings that are open to the public with participation encouraged.
- Ensure that the organization's Board of Directors is ultimately responsible for HIE activities. Responsibility requires that the Board actively monitor performance. To that end, RIQI created a RHIO Oversight Committee to monitor performance in conjunction with the Audit and Compliance Committee of the RIQI Board. In addition, the Health IT Leadership Team was created to facilitate the need for increased accountability and coordination of daily activities given the expanded responsibilities under three new Federal grants. This leadership team includes RIQI's CEO and COO/CIO and is accountable to the RHIO Oversight Committee. Relevant Work Group subcommittees provide advice and guidance to the Health IT Leadership Team.<sup>1</sup>

## Conclusions

Rhode Island's decision to contract with a collaborative, community-driven entity for governance has received broad support by stakeholders. The lessons learned shed light on the challenges of building consensus around a technical and policy model that can be perceived to, and may in fact, conflict and compete with local business objectives. Transparency and accountability are critical principles to support and must be operationalized early in the governance and organizational development process so that both stakeholder support and resistance can be identified and addressed in a timely and productive manner. The role of State government needs to be carefully considered and may evolve over time but ultimately needs to protect the interests of its tax payers and citizens.

---

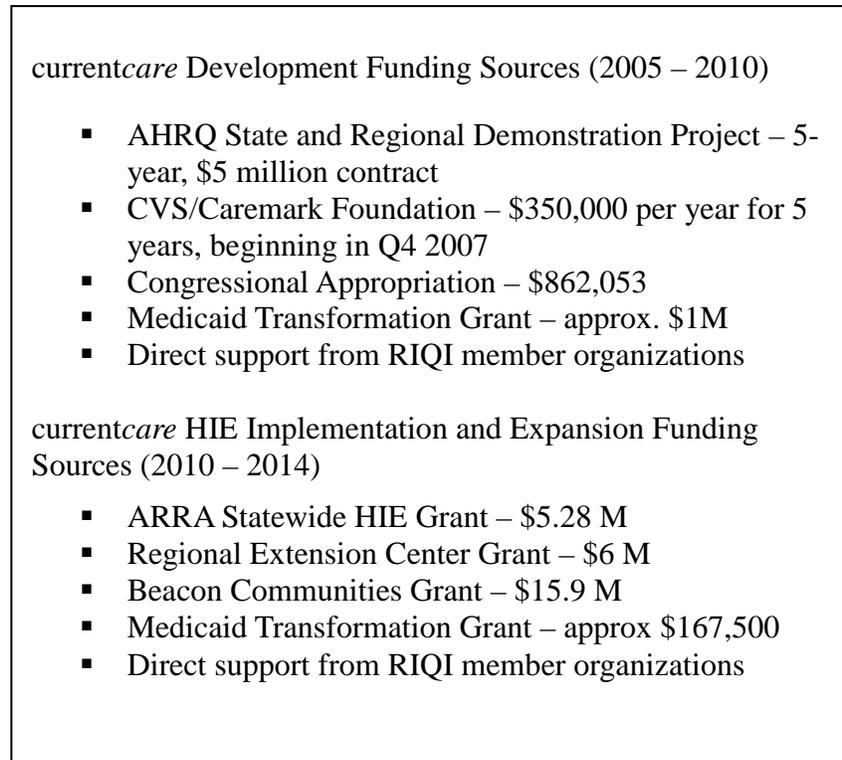
<sup>1</sup> Rhode Island Quality Institute. "Rhode Island Strategic and Operating Plans", November 2010.

# Finance

## Initial Sources of Funding

In addition to the AHRQ contract, RIQI has pursued ONC-sponsored grants as bridge funding until a long-term funding plan can be implemented. Figure 5 lists initial and current sources of funding for the project.

**Figure 5. HIE system funding**



## Developing and Implementing the Sustainability Plan

Under existing agreements as the State-designated RHIO, RIQI is responsible for ensuring currentcare's business viability. As such, a long-term sustainability plan was an important RIQI deliverable that was of great interest to the RIQI Board of Directors and its stakeholders, including AHRQ. A sustainability plan was submitted to AHRQ on September 29, 2008. This plan was largely focused on an analysis of value accrual and potential models for long-term funding. Long-term costs and an infrastructure development path were not yet known. Thus, the plan offered an initial view of possible approaches.

There are a variety of potential models that have been considered for sustaining currentcare and the overall HIE infrastructure, for example, a per claim tax, bed tax, and look-up fees. A key assumption has been that once the HIE System begins to get traction and produces demonstrable results, additional options might be explored, e.g., building services around the use of aggregated de-identified data to support quality improvement or health care research. To date, there has not been sufficient support for any given model to enable RIQI, the State, or any party working on their behalf, to execute a long-term funding plan.

## **Lessons Learned About Finance and Sustainability**

- The first and most important lesson learned about sustaining a large scale HIE system is that the business case must be clear, broadly understood and supportable. Establishing credible estimates for return on investment (ROI) is a major challenge, especially in the absence of a comparable operational system with proven results.
- A health information organization must seek to gain a firm understanding of the level of key stakeholder support for the value proposition, their agreement with the technical solution and their commitment to participate in both the development and success of the HIE system offering.
- Duplicative and/or overly complex and expensive technical infrastructure or low value/high risk HIE solutions are not generally supportable by stakeholders, especially in the presence of competing business objectives.

Stakeholders will not generally support the “greater good” principle over the long-term without a positive ROI and strategic IT alignment with their own HIE solution development path.

## **Conclusions**

Addressing the long-term sustainability of current *care* is the most pressing challenge for the Rhode Island initiative today. Numerous long-term funding models have been advanced and have failed to generate enough support by a critical mass of public and private sector stakeholders. Solid financial analyses, transparency and early, open communication are required for an HIO to gain traction for either a market-based (private sector) or tax-based (public sector) sustainability model designed to support HIE system operations and growth over time. In either case, early and continuous efforts must be made to demonstrate ROI, ensure strategic IT alignment, garner political and business support and ensure consumer and provider buy-in and participation.

## **Technical Infrastructure**

### **Selecting Technical Infrastructure Design**

The Technical Solutions Group (TSG), which included key technical personnel from stakeholder organizations and Data Submitting Partners, were charged with evaluating and recommending a technical architecture and functional solution for the statewide HIE system. A methodical, systematic approach was taken to establish a clear vision of key functions and attributes of the ultimate solution, define requirements, and design, build and test a solution. Because the TSG was a stakeholder-led group, the role of stakeholder preferences was completely dominant, i.e., recommendations made by the TSG consistently reflected stakeholder opinions and many times the most informed and/or most influential stakeholders were the opinion leaders. The final architecture and technical solution was described in written deliverables titled “Technical Architecture Design” and “Infrastructure Requirements.” To follow is an overview of key issues that informed the technical solution.

### **Overview of Key Issues that Informed the Technical Solution**

Led by the TSG and debated among the project Steering Committee, decisions pertaining to the HIE system technical solution were of utmost importance to ensure that policy direction and intent were preserved. Early discussion of HIE and system design included detailed deliberations over issues such as—

- The model for patient consent to authorize access to personal health information;
- The degree of consumer control over access to specific health information;
- Options for HIE system users to view and use electronic data relative to local systems—portal versus integration;
- System infrastructure options and DSP requirements to support shared data (centralized/decentralized/brokered services);
- The level of stakeholder technology and financial investment required to operate and sustain the HIE system (cost in the middle versus cost at the edges); and
- The degree of DSP (local) control over the impact of HIE system participation on their business operations (real time data transfer versus store and forward).

The basis for the final authorization (consent) policy was determined in February 2007 after a joint meeting of all RI SRD Project committees. From the community guidance generated out of this meeting, the TSG developed a revised technical model to address the privacy policy requirements articulated by stakeholders. The technical solution called for a two-part consent process that: 1) supports movement of data to *currentcare* only after explicit, active patient consent has been declared; and 2) enables the patient to control disclosure of their health information to authorized users. Additional privacy and confidentiality safeguards were enacted into law through the HIE Act of 2008.

In addition to a customized enrollment and consent management solution, the agreed upon technical infrastructure for *currentcare* would be comprised of two elements: an integration framework using products based on a service-oriented architecture and integration standards and a suite of functional components that provide the required services. The architecture of the HIE system would include an Enterprise Master Patient Index combined with Data Registries and Data Repositories to create a longitudinal EHR for each patient. It was believed that this architecture would provide the platform that is capable of supporting a broad range of available clinical data about a patient from a variety of source systems.

## Selecting a Vendor

The TSG was instrumental in informing a formal Request for Proposals (RFP) issued by the State to evaluate and select the technical vendors to provide the HIE system solution. The evaluation and selection process was conducted under the auspices of the Rhode Island Department of Health and the Rhode Island Department of Administration, Division of Information Technology with strict adherence to State procurement rules. The State allowed the use of external reviewers in an advisory capacity yet the stakeholder-led team was not permitted to participate in the official vote for any vendor. Staff supported rigorous analyses and an objective scoring process. In the end, the final recommendations of the community advisory group were in complete alignment with the independent decision of the State-led selection committee. Rhode Island awarded a 3-year \$1.7 million contract to EDS in partnership with InterSystems Corporation to design, build, and deploy the initial RI HIE system. Contract negotiations took longer than expected and led to a request by HEALTH for a 1-year extension of the AHRQ SRD contract and applicable deliverables.

## Deployment of Technical Infrastructure Design

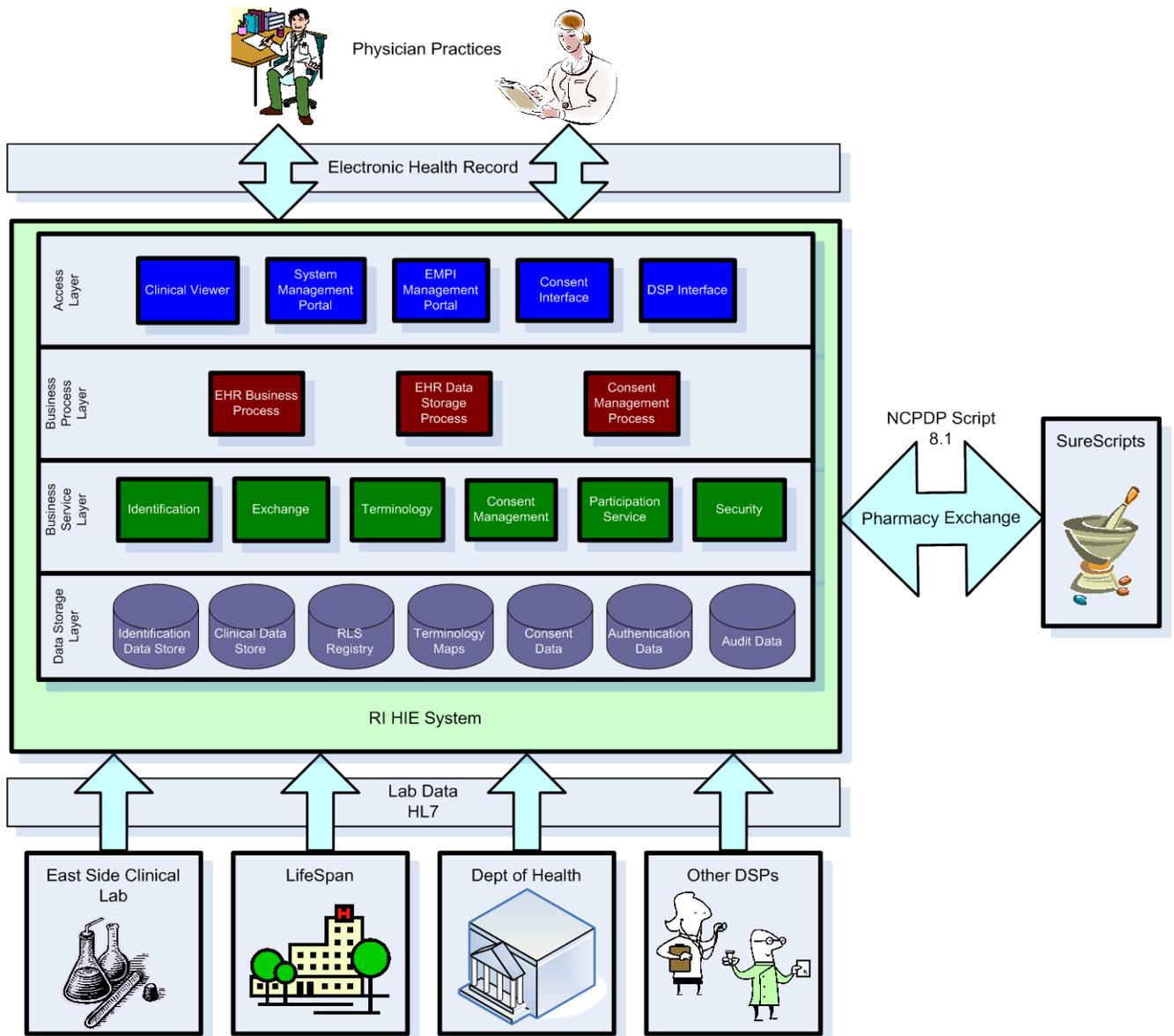
The EDS (now HP)/InterSystems team worked diligently with Rhode Island stakeholders through a comprehensive design, development and testing effort required to produce a highly customized instance of InterSystems' HealthShare HIE product. The solution currently deployed

includes the addition of a patient enrollment/registration module and all related consent management functions as required to implement the 2-part authorization model defined by policy and stipulated under Rhode Island law. There was much deliberation and effort by HP and DSPs to ensure proper technical deployment and mutual contractual protections pertaining to the Participation Gateway (consent checker) servers that reside behind DSP firewalls to support the opt-in consent model. Also, with the advent of HITECH provisions being made law as part of ARRA in 2009, DSP audit logs at the Participation Gateway were added to the list of required customizations.

In the initial stages of deployment, the TSG directed the project to focus on the design, development, testing and implementation of Release 1 of *currentcare*. Release 1 was defined as the implementation of data exchange between laboratory and medication DSPs with a small number of providers. The technical approach would leverage existing State infrastructure with the use of the Ocean State Higher Education Economic Development and Administrative Network to provide connectivity to *currentcare* via the addition of a new TLS line to HPs Data Center where *currentcare* would be initially hosted. Network infrastructure is depicted in Figure 8.

The application architecture detailed in Figure 6 relates to initial system requirements and illustrates two views into the HIE system. The first view includes front end presentation services that users will see while interacting with the system. The second view includes back end DSP services used to support system-to-system interoperability. Using InterSystems' flexible Ensemble platform, new components to the architecture can be added and new orchestrations created to utilize those components.

Figure 6. currentcare high-level application architecture for initial deployment



After much debate, in the final information architecture, each DSP has their own data repository. Figure 7 shows the location of the data stores used within *currentcare*. The data is normalized at both a terminology and transaction level prior to retrieval. Clinical transactions are stored using the native format of InterSystems' HealthShare, the core application upon which *currentcare* is based. The multi-dimensional array is then transformed into HealthShare's Simple Document Architecture (SDA) for communication between the services in *currentcare*. The SDA format is loosely based on the HL7 Clinical Document Architecture, but contains proprietary fields required by the application.

The clinical data stores are detailed as the Edge Cache Repositories managed by the Edge Gateways which can reside either remotely at the DSP, or locally within the hardware domain where the Hub resides. In the instance of a remote (federated) data provider, for example SureScripts, the data will be held by the remote system and selected by *currentcare* in an "on request" mode. The information will be transformed to the SDA data format once the data is received from the remote source.

**Figure 7. *currentcare* information architecture for initial deployment**

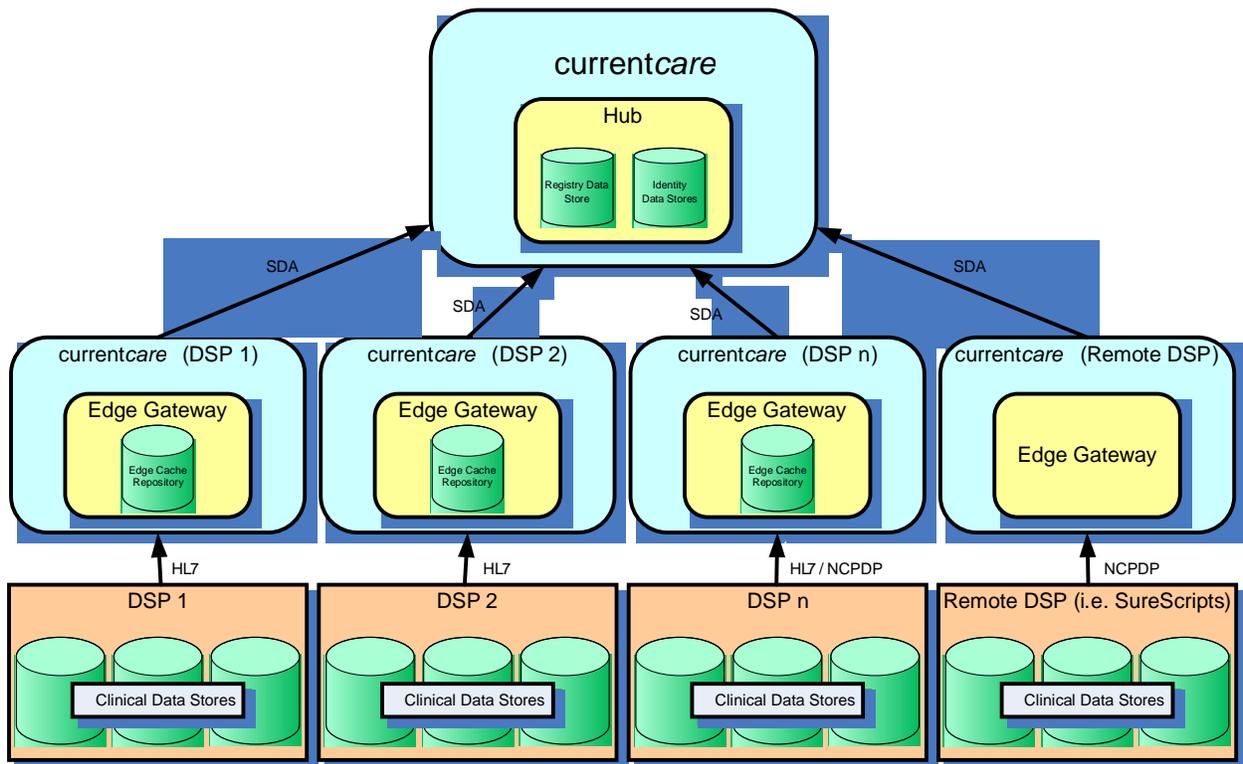
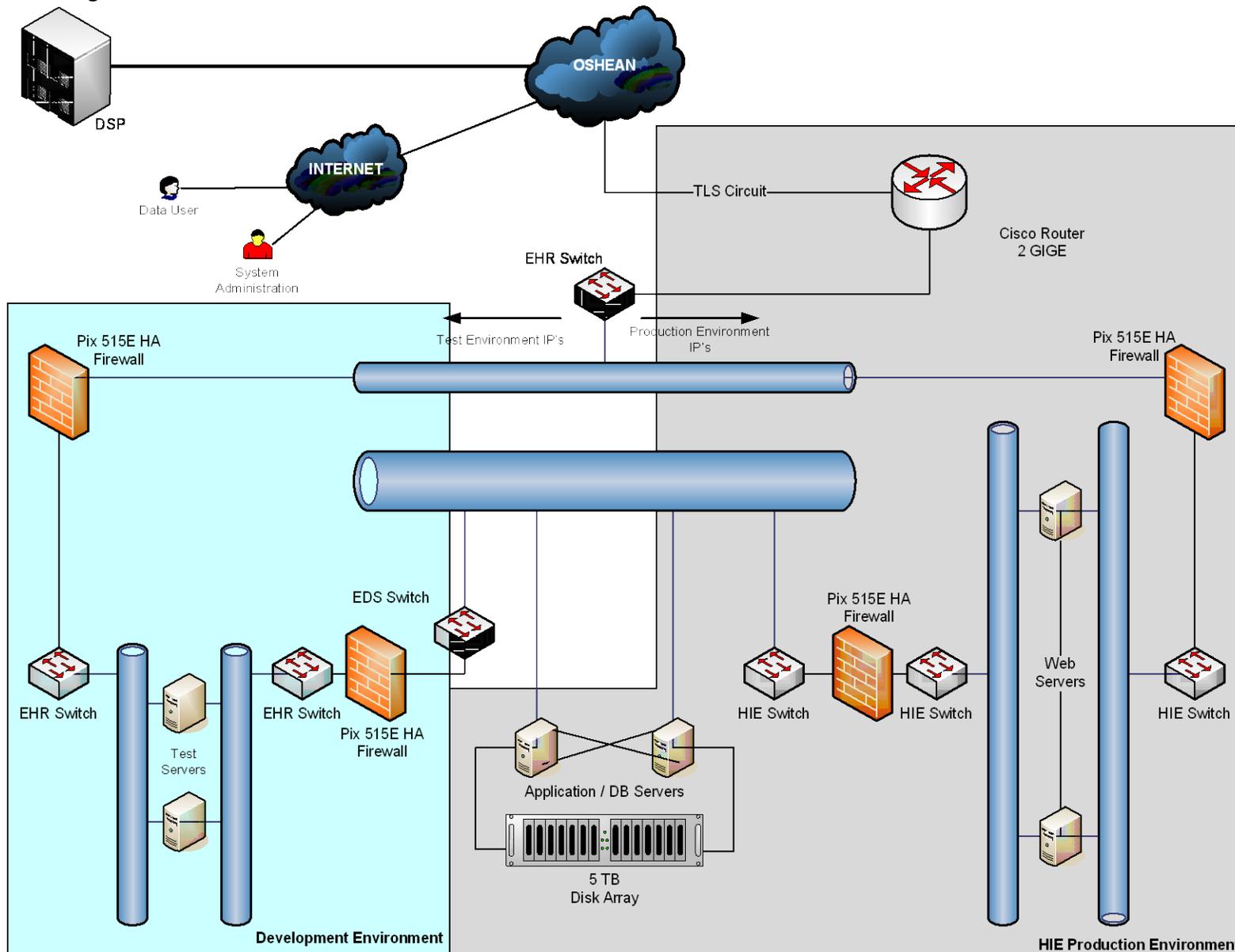


Figure 8. currentcare network infrastructure



Throughout the course of *currentcare* development, additional customization was required to create a satisfactory identity management solution with delegated (distributed) user administration and monitoring capability which allows provider organizations to authenticate and manage access controls and permissions for their organizations' authorized users. After a failed implementation of Sun Microsystems' (now Oracle) Open SSO, custom development of the required consent management and identity management capability created significant delays in the project schedule.

In August 2009, after 2 years of development, slow but steady progress was being made on all fronts, system testing was largely complete for core functionality, and HEALTH and RIQI conducted the first round of a pretesting effort for user acceptance. Formal user acceptance testing began in December 2009 and was proceeding along an iterative path with some fixes required.

In late March 2010, Rhode Island experienced the worst flooding in 100 years. When the Pawtuxet River crested well beyond major flood levels, HP, the HIE system integrator (and also the State's Medicaid fiscal intermediary) lost its Data Center at 171 Service Lane in Warwick, Rhode Island. The entire data center was located on the first floor of a building that was flooded up to the ceiling tiles. The Medicaid and HIE programs were affected as was the RI SRD Project timeline.

In the flood, HP experienced a total loss of all hardware, software, and data stored on the premises. The event triggered full disaster recovery procedures that ultimately restored Rhode Island's Medicaid operations in a secondary hosting site. However, the *currentcare* development environment was not replicated nor was a disaster recovery site immediately available. Implementation of full failover and disaster recovery capability was reserved for the *currentcare* production environment which had not yet been implemented. This was a deliberate decision made early on in the project for budgetary reasons. Thus while full software backups were assumed, *currentcare* hardware was not subject to HP's disaster recovery plan.

Unfortunately, post-flood recovery efforts failed to produce a fully functional backup copy of the software for the *currentcare* system, which was nearing the end of user acceptance testing and modification after nearly 3 years in development. This failure and related legal and logistical complexities forced a complete halt to *currentcare* development and delayed the system go live date by more than 9 months in order to reconstruct and test the software, replace the hardware, engage a new hosting vendor and complete a security audit of primary and secondary hosting sites prior to (re)establishing permanent processing environments.

During this recovery time, HEALTH allowed the contract with HP to expire and executed the transfer to RIQI of full operating responsibility for *currentcare*. Thus RIQI was in control of decisions pertaining to rebuilding the HIE infrastructure. Needless to say, security and disaster recovery were implementation priorities in the new environment. The significant delays caused by the flooding disaster prompted rethinking the plan for *currentcare* "go live". In an effort to maintain momentum, the Steering Committee, TSG and key Data Submitting Partners agreed to a phased approach which split *currentcare* implementation into two major parts: (1) DSP go live—the flow of consented data from DSPs (via the Participation Service) accumulating in the *currentcare* production environment with no user access to the system; and (2) User go live—access to patient health information through *currentcare* by authorized users in participating provider organizations.

Today, procedures for technical deployment of the "black box" consent solution at DSPs have been refined to follow a standard approach, however, initial testing and integration requirements were more complex and time consuming than expected. Further, DSPs participating in *currentcare* must utilize a technology solution and adhere to State consent laws

that are more stringent than those required under Federal law for their respective organizations to exchange health information without using *currentcare*. These factors are key implementation considerations and reinforce the need for a significant value proposition to compel DSPs to participate in *currentcare*.

Over time, the original infrastructure model has been adapted to increase the amount and types of health information made available through *currentcare*, and to take advantage of new HIE approaches advanced by the Office of the National Coordinator for Health IT. In June 2010, RIQI went live with its Limited EHR Aggregation Project (LEAP) as a pilot to demonstrate the feasibility of establishing connectivity between electronic health record systems. The LEAP initiative underwent an evaluation of its live data exchange and, when compared to the potential of the emerging HIE mechanism of the Office of the National Coordinator for Health IT's Direct initiative, a decision was made to sunset the LEAP initiative in favor of Direct. On February 2, 2011, the Office of the National Coordinator for Health IT celebrated the first beneficial use of the Direct secure message technology and recognized Rhode Island's and RIQI's achievement of the first exchange of protected health information (PHI) via Direct between health care providers. In addition to promoting Direct as a method to securely exchange PHI between providers, RIQI has developed a way to use Direct to transport PHI between EHR systems and *currentcare* and, through the Regional Extension Center, has begun to drive the use of Direct in Rhode Island.

Figures 9 and 10 illustrate the original scope of the technical infrastructure design of *current care* as it is deployed today which includes Figure 9, Parts A and B, and Figure 10, Steps 0 – 3. At the time of this report, 17 percent (172,000) of the Rhode Island population is registered in *currentcare*, the consumer-directed consent capability is in place in the system and the repository model has been deployed with laboratory data from multiple lab partners with Admission/Discharge/Transfer (ADT) data scheduled to go live in October 2011. As noted, the first lab DSP went live with consented data flow to *currentcare* on April 5, 2011. User go live is slated for early 2012.

## **Security Policy and Practices**

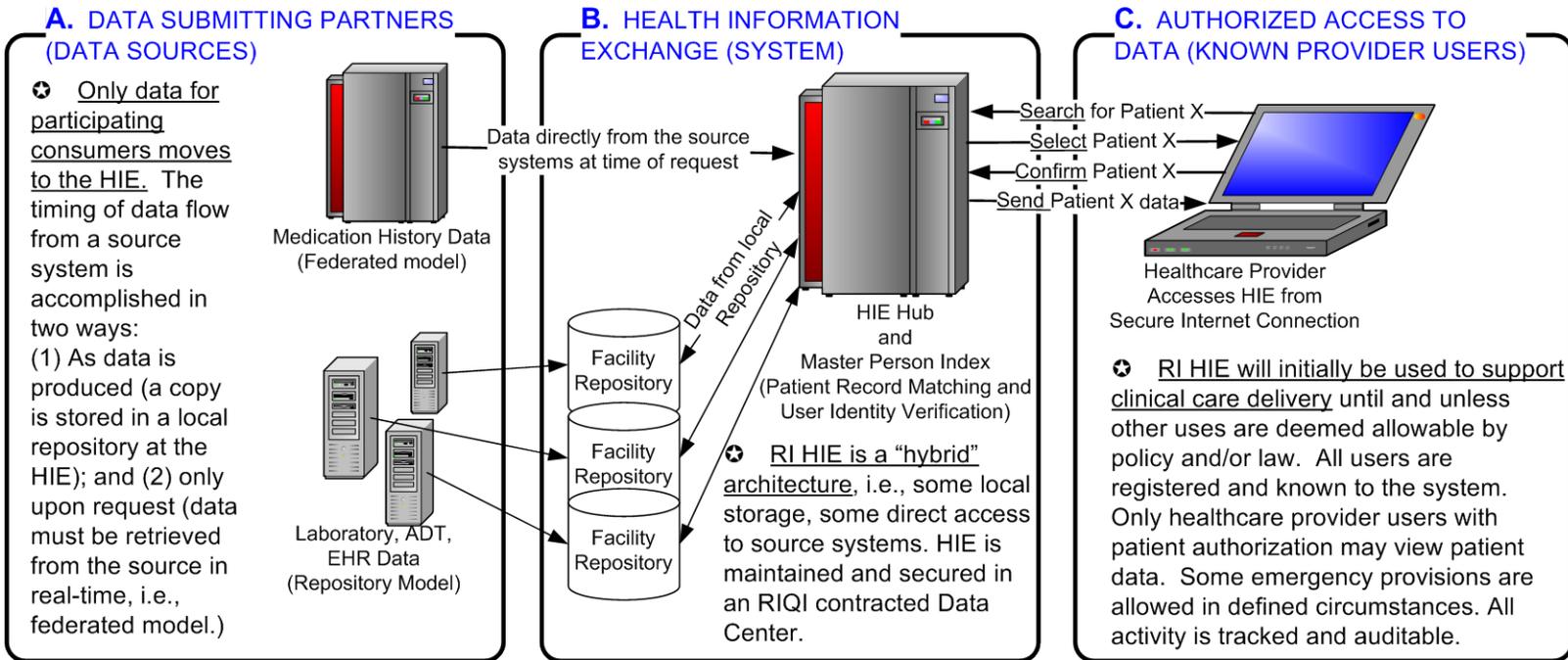
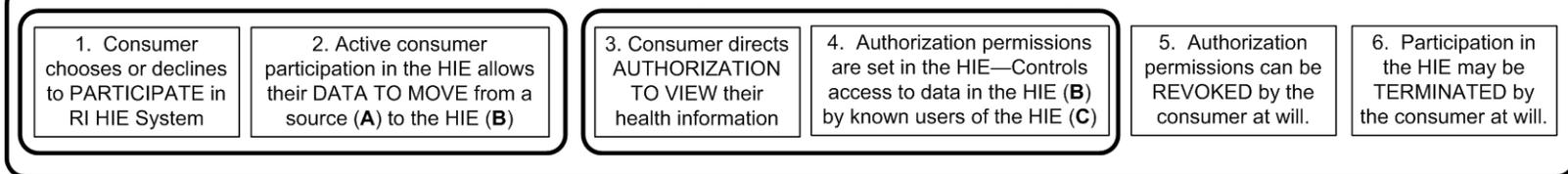
Security was and is a major technical, operational and policy priority in HIE system development. The Rhode Island stakeholders demanded assurances from HP including a written Security Plan, evidence of the intent to satisfy SAS70 Type II security compliance requirements prior to production and agreement to a preproduction security audit, including penetration testing. An IT security team, including the State's Chief Information Security Officer from the RI Division of Information Technology, was consulted to review State IT security policies relative to the HP Security Plan. In addition, security experts from key data submitting partners participated in plan review.

Addressing security requirements was a critical and intensely time consuming effort. Much time was spent negotiating non-disclosure agreements to allow data submitting partners to participate in the review of the HP Security Plan; additional time was spent trying to work through options to fund a preproduction security audit that would be in compliance with State procurement rules. In the final analysis, the flooding disaster reset the entire process. After expiration of the HEALTH - HP contract, RIQI elected not to engage HP going forward. Instead, RIQI contracted with InterSystems Corporation (the software vendor) to rebuild *currentcare* and issued an RFP to eventually select a commercial data center to host the system. A pre-production security audit was performed and after minor remediation, the system and data center passed all security requirements prior to DSP go live.

Figure 9. High level overview of RI HIE system with 2-part consent model

## Rhode Island Health Information Exchange: System Overview January 2011

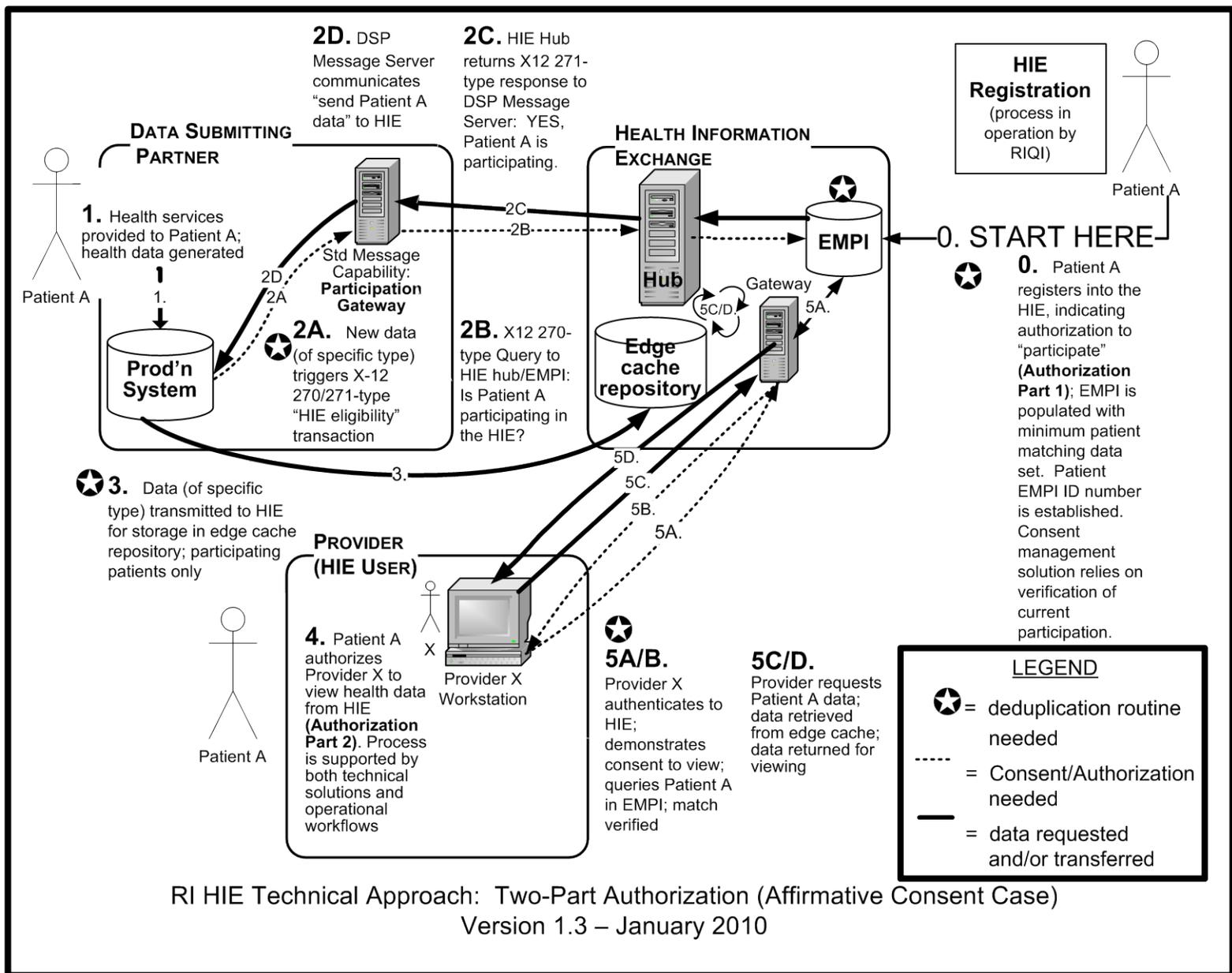
### CONSUMER-DIRECTED AUTHORIZATION (OPT-IN): RI HIE Two-Part Authorization (Consent) Model



### GOVERNANCE, LAWS, POLICIES AND PRACTICES

- ❑ Lab, ADT and EHR information are the first data types in the HIE. Medication history to follow. Live data flow in April 2011; User go live scheduled for late 2011.
- ❑ HIE is currently governed by Rhode Island Quality Institute (RIQI) a 501(c)3 public-private collaborative organization and the state designated RHIO (Regional Health Information Organization). Broad stakeholder involvement in governance, development of system policies, technical design and supporting legislation.
- ❑ RHIO designation enables entity to receive state support and subjects it to regulatory oversight.
- ❑ HIE is augmented by legislation; the RI HIE Act of 2008 addresses patient choice to participate, oversight by HIE Advisory Commission, applicable to HIE only.
- ❑ Long-term sustainability models are under consideration; system value must be proven through demonstration and adoption.

Figure 10. Detailed information flow of RI HIE system's 2-part consent model



## Lessons Learned About Technical Infrastructure

There were many lessons learned in Rhode Island pertaining to design, development, and deployment of technical infrastructure for a statewide HIE system. Key lessons learned can be summarized as follows:

- Internal technical leadership and expertise is essential to ensure progress. While the participation of community stakeholders is the hallmark of the Rhode Island experience, heavy reliance on external stakeholder organizations presents challenges due to the lack of accountability for results and the potential for introduction of bias in infrastructure design by dominant participants.
- Independent validation of architecture and infrastructure assumptions is recommended and should be tied to market-based environmental analyses to ensure consideration of local infrastructure capabilities, the competitive service offerings of stakeholders/others, and technology trends. Understanding how existing regional infrastructure may be leveraged can guard against the buildup of redundant functional capacity that can ultimately create inadvertent competition, degrade the HIE system value proposition, and introduce technical integration challenges. Further, consideration of the currency of the chosen technology and the pace of deployment should be taken into account and an appropriate technology evolution path should be included in a supportable strategic IT plan and budget.
- Any government role in infrastructure development and deployment must be carefully examined to take advantage of known strengths while avoiding predictable barriers in procurement, contract negotiations, availability of dedicated technical resources, etc. State purchasing cycles can be very long since government requirements for limitations of liability and indemnification cannot easily be waived. The ability of State government to attract strong technical staff with state-of-the-art knowledge can be limited due to pay scales and competition for strong candidates by the private sector. Additionally, the ability to include community input for a project that will revert to being managed by the community is critical and requires that State government embrace new approaches to collaboration.
- Disaster recovery and business continuity (DR/BC) should be priority planning activities. Hardware redundancy, failover operations and software backup and restore solutions should be tested and periodically exercised in both development and production environments. Sufficient leadership support and budget allocations for DR/BC should be assured.
- Policy development should drive technology yet be considered in conjunction with technical, operational and sustainability considerations. Given constraints or limitations in these areas, it is important for the HIO to appreciate the community threshold for adopting any given technology solution or changes in policy. Maintaining the policy-technology balance is a painstaking process that requires ongoing attention; failures in either aspect increase the risk of failure overall.
- HIOs must have a clear understanding of the level of support and participation that must be demonstrated and sustained by key stakeholders to foster success of a given HIE effort. Collaborative development models have the potential to enhance buy-in and produce well-informed technical solutions, however, heavy handed partners and opinion leader bias can thwart years of productive work and progress. Appropriate governance, management and performance measurement processes must be in place to drive sound decisions and ensure progress over time.

## Conclusions

The Rhode Island HIE system infrastructure experience included many opportunities for learning in spite of a series of delays in HIE system deployment. Intense effort was made to maintain balance between a comprehensive policy and legal framework and the complex, rapidly aging HIE technical solution required to comply with it. RIQI responded by seeking opportunities to leverage the current *care* infrastructure through interoperability with emerging technology models, namely Direct. This was an essential tactic that may help preserve the technical viability of the statewide model in Rhode Island amidst a Federal HIE culture where creating an “exchange”, the noun, is no longer the dominant thinking.

The lack of a long-term funding model will continue to be the greatest challenge to the continuation of Rhode Island’s HIE experience. Expanding and communicating the current *care* value proposition, ensuring technical alignment with local and regional stakeholders and garnering much needed political support will be important focal points for future growth.

## Business and Technical Operations

### Developing Partnerships and Programmatic Linkages

As described above, the Rhode Island Health IT Project was primarily conducted as a public-private partnership. The post-project effort continues to build on roles and relationships established during the project period. Further, as the key government stakeholder and collaborator, HEALTH actively pursued programmatic linkages with the Rhode Island Office of Health and Human Services which administers the State Medicaid program. HIE system development has been viewed as an opportunity to have a positive impact on Medicaid beneficiaries in the State. From September 2007 through the present time, funding has been provided through a multi-year Medicaid Transformation Grant to pursue linkages between the RI SRD Project and Medicaid. Following are notable results:

Quality Partners of Rhode Island (QPRI, the State Quality Improvement Organization) performed technical assessments for 12 long-term care (LTC) facilities to determine eligibility for computers or computer hardware/software upgrades. All computer purchases and installations were completed by March 31, 2011. Additionally, in January 2011, QPRI began a communications and marketing strategy within the LTC community to advance the goal of having 100 percent of eligible nursing homes recruited as current *care* enrollment partners. As of March 31, 2011, the number of enrollment partners increased from 20 to 52 nursing homes. This reflects a shift from 23 percent of the eligible facilities to 65 percent participating as enrollment partners. QPRI is continuing its promotion of enrollment in the LTC community (for the remaining 35 percent) in the next phase of funding under the Beacon Communities grant.

In addition to recruiting 30 new LTC facilities as potential current *care* user sites, RIQI piloted an Assistant Outreach Specialist program at the Comprehensive Community Action Program’s sites (Coventry, Cranston), and the Thundermist Community Health Center’s West Warwick site. While these practices initially signed up over 1,000 new patients, the overall strategy did not seem to be an effective one. The concept of having enrollment outreach staff sitting in health center waiting rooms approaching individuals to enroll in current *care* was not well received. Those health centers that were able to include enrollment as part of the health center intake and encounter workflow were much more successful in enrolling their patients. In the upcoming year, RIQI will continue to explore the opportunity of expanding the program into

more health care settings and provider offices where there is a trusted relationship between the patient and the provider.

The pace and direction of HIE movement has allowed for consideration of new opportunities to achieve the needed points of information access to support improved resource utilization across the State's Medicaid system. An effort is underway to develop functional requirements to connect the Medicaid Management Information System (MMIS) to *currentcare* via a "Medicaid Hub" which, if implemented, would make it more practical and secure for the State to contribute new types of data to support HIE. Thus the concept has emerged of a single point of entry for Medicaid providers to an MMIS-to-*currentcare* hub to allow flexibility in information access and related services that can be facilitated as *currentcare* evolves.

Outreach, education and enrollment of Medicaid beneficiaries in *currentcare* is a key focal point of consumer engagement. All RI Beacon Community partners have signed Letters of Agreement for *currentcare* and over 90 percent have begun enrolling their patients into *currentcare*. (Designated Beacon partners are comprised of 20 practices across 39 practice sites including single physician practices, private group practices, Health Centers, and hospital-based clinics.) Women & Infants Hospital has expanded the *currentcare* sign up program in the Pediatric Department clinics including the Brown Center for the Study of Children, Audiology and Follow Up (Follow up to Neonatal Intensive Care).

## **Role of Stakeholder Preferences / Opinions on Business and Technical Operations**

Stakeholder preferences and opinions served as the basis for nearly all the State's business and technical decisions during the development phase of *currentcare*. As a public-private collaboration, the project's committee structure was designed to provide community-informed decision making by consumers, providers, legal/policy advisors, technical experts and business leaders. In addition, the lack of dedicated technical resources at the State and RIQI reinforced the need for and dependence on stakeholder guidance for technical development. The Steering Committee or HEALTH's AHRQ contract to RIQI for governance did not require specific business action by RIQI, such as deployment of staffing and operations models, until after RIQI became the State-designated RHIO. Once the designation was made, the project structure changed given HEALTH's foresight to begin the process of incrementally shifting resources and responsibilities to RIQI over a 2 year period to allow a phased approach for capacity building. A first step included the transfer of consumer engagement and enrollment responsibilities from HEALTH's vendor, Clarendon, to RIQI. This was followed by shifting provider engagement activities from the State's initial contractor (Quality Partners of Rhode Island, the State Quality Improvement Organization) to RIQI. The last and final component to be transferred was the technical management and oversight for developing and deploying *currentcare* which occurred during the summer of 2010.

In its role as the State-designated RHIO, RIQI assumed full governance and management responsibility for *currentcare* business and technical operations. Further, RIQI was contractually compelled by the State to incrementally produce specific business, operating and technical deliverables to complete the AHRQ-funded work to deploy *currentcare*. Today, RIQI continues to maintain community dialogue on technical and business decisions through its working groups and sub-committee structure as depicted in [Figure 4](#).

Relative to the full scope of its business, RIQI generally operated with a significant amount of latitude as it engaged numerous technical partners in HIE initiatives and grew the organization

by nearly 40 staff to create in-house capacity and service capabilities. Most notable among these services are those necessary to address the stakeholder and legal requirements for *currentcare*'s two-part consent model. RIQI operations include provider relations and consumer enrollment functions performed by outreach specialists and data entry technicians whose jobs are centered on engaging provider organizations and supporting the registration of consumers in *currentcare*.

In addition to informing the consent model for *currentcare*, provider and technical stakeholders formulated requirements for a delegated user administration model. In this model, the *currentcare* system includes the capability to enable participating provider organizations (groups) to create, update and delete users associated with their group, assign roles (permissions) in the system and associate/disassociate licensed providers with the group. This distributed model allows provider organizations to define the scope of "authorization to view" for their practices and addresses the practical issues of ensuring appropriate user authentication and accurate, timely management of user access controls over time. Prior to the next phase of "user go live", RIQI will train user organizations and, specifically, persons from these organizations that will serve in the delegated user administration role. Further, RIQI will have the capability to monitor user activity and produce reports at the group level to help user administrators maintain the currency of active/inactive user accounts. Mutual expectations for RIQI and participating provider organizations are detailed in a *currentcare* User Agreement to be executed prior to the respective group's go live.

Technical stakeholders have had tremendous influence over the design and operation of the connectivity and technical infrastructure that supports the transmission of health information from the data submitting partner to *currentcare*. Among the guiding principles for the DSP infrastructure is the requirement that *currentcare* not impact DSP production systems, and that all data transmission adhere to applicable privacy and confidentiality laws and be subject to stringent security protections. The technical solution for *currentcare* consent infrastructure, a.k.a., the Participation Service, includes a "black box" participation gateway server physically positioned behind the DSP firewall. The participation gateway receives a real time copy of health information as it comes off the DSP production system; the demographic information is parsed and sent to the *currentcare* "hub" to test for a match among consented patients. An affirmative match triggers the participation gateway to send the full health data transaction to that DSP's edge gateway in *currentcare*. Given the reality that some health data is not released, with the passage of strict breach notification law under HITECH, the DSPs added a requirement for a transaction audit log. All of these requirements and the mutual responsibilities of both RIQI and the DSPs are enumerated in *currentcare* Data Sharing Agreements signed by each party prior to the respective DSP go live.

## **Identifying Data Elements for Sharing**

Proposed core data element categories were among the earliest project deliverables submitted in December 2004. Rhode Island noted three basic considerations that should drive decisions on which data should be pursued first. These include the following:

- Technical feasibility
- Value to stakeholders
- Potential for improving care outcomes

While the list of potential data categories was quite extensive, project stakeholders quickly narrowed the field. As described and illustrated in [Appendix A-2](#), in June 2005, a formal data prioritization plan was developed and approved which focused initial efforts on the exchange of laboratory and medication history data.

In current operations, RIQI is receiving laboratory information from several sources and ADT feeds from at least one hospital source (more to go live soon). In an effort to increase the value provided by *currentcare*, RIQI will also begin to support automated provider notification of patient events, such as hospital and emergency room admissions and discharges, via Direct messaging to providers based on the ADT messages sent to *currentcare*. Additionally, *currentcare* is now receiving clinical care summary documents from at least one provider practice's EHR using Direct messaging. This capability will be expanded. RIQI continues to engage current and prospective DSPs in strategic, tactical and technical planning to ensure goal alignment for data exchange through *currentcare*. Today, there is a demand to participate in *currentcare* and RIQI maintains a schedule of DSPs slated to go live with data exchange. At the time of this report, the *currentcare* "DSP go live" schedule includes the following data submitting partners:

- Care New England (Integrated Delivery Network)-already live with some data types
- Lifespan (Integrated Delivery Network)
- Quest Diagnostics
- South County Hospital
- Blackstone Valley Community Health Care
- Surescripts
- Memorial Hospital of Rhode Island
- Several provider offices

## **Implementing Data Sharing**

Lab results data was the first health information to flow into *currentcare* and has been accumulating since April 5, 2011. This data is from East Side Clinical Laboratory, a large regional lab transmitting approximately 115,000 transactions per month to the *currentcare* participation gateway with about 15 percent of these results being accepted into the associated edge cache repository after successfully matching to consented patients. The capability to exchange medication history information has been difficult to accomplish. At the time of this report, the implementation schedule for the exchange of medication history is 4<sup>th</sup> Quarter 2011.

The timeline set forth in the section, Formation of the Project: Rhode Island Health IT Project Chronicle of Events (September 2004 – June 2011), Background describes the events leading up to the first HIE through *currentcare*. In Rhode Island, implementation of data sharing took 6.5 years in a "pre-HIE" environment where there were two large dominant health systems with the technology to connect a majority of providers, heavy emphasis on collaboration and a 501(c)3 to lead it, heavy reliance on stakeholder technical expertise, strong consumer and policy drivers, and State government as the prime contractor. Natural disaster notwithstanding, these factors have created a dynamic that has forced examination of project decisions at every turn, led to the passage of law and promulgated regulations specific to the HIE system, and otherwise heavily influenced the project implementation schedule.

## **Maintenance of Technical Infrastructure**

RIQI maintains all technical infrastructure for *currentcare* in a secure offsite data center. Prior to DSP go live, full network and application level security and penetration testing was performed to ensure compliance with applicable laws and RIQI privacy and security policies. To support technical operations, over the past 2 years RIQI has added a full staff of information technology and data management professionals to monitor the system, assist in deploying *currentcare* at DSP sites and effectively address any technical issues that arise.

## **Impact on Sustainability Plan**

RIQI has been able to obtain approximately \$27 million in Federal grant funds for the State HIE, Beacon Communities and Regional Extension Center programs through 2014. These funds are program specific to support near-term operations and the grant program requirements go well beyond the expansion of *currentcare* including supporting EHR adoption and other practice redesign efforts intended to improve a set of health care metrics. A final long-term funding model has not yet been defined. Based on the outcomes of several proposed long-term funding initiatives, it appears that there may be some relationship between the lack of a proven value proposition and the lack of broad support required to secure long-term funding.

Delays in *currentcare* implementation have directly impacted RIQI's ability to demonstrate value from this specific HIE component, however, RIQI has made a committed effort to perform methodologically sound financial, business and value analyses and used these results to communicate to both the public and private sector stakeholders the details of a proposed "commercial claims assessment" for the State HIE infrastructure overall. Nonetheless, support has been mixed and there have been a few unexpected opponents that generally have business interests to protect. RIQI continues its efforts to demonstrate value across a range of HIE initiatives and is determined to construct the right "Plan B" proposal that will lead to a critical mass of community support and, ultimately, long-term sustainability of State HIE infrastructure.

## **Lessons Learned About Business and Technical Operations**

Rhode Island has experienced many of the same lessons as other large scale HIE initiatives; however, the implementation of *currentcare* has produced the following lessons that have had a greater impact on the course of the Project:

The right balance between stakeholder dependence, organizational self-reliance and government intervention must be established early on. In Rhode Island, the benefits of stakeholder engagement and collaboration have been apparent, however, delays in building RIQI's own internal organizational capacity, once designated as the RHIO, impacted its ability to take decisive action on issues that would ultimately impact business and technical operations. This dynamic was especially true in the presence of dominant stakeholder organizations and in cases where competitive priorities were at play. There is a benefit to the HIO being at par with its stakeholders in terms of in-house knowledge, skills and strategic insights. While RIQI served as the governing entity from the inception of this project, it was not until RIQI was designated as the HIO that its Board of Directors began to understand the commitment, scope and magnitude of the work ahead. The RHIO designation served as an awakening to the Board and at that point they realized their responsibility, became more engaged and began to operate as if accountable for the Project overall. In Rhode Island, creating early self-reliance for the HIO would mean identifying a State-designated entity at a much earlier stage of the project to enable a more aggressive transition of the technical and business operations from the State to RIQI. A change

in the timing of the transition may have allowed the project to proceed on a more accelerated development and implementation schedule and achieve earlier value creation.

Prior to full adoption, key policy decisions should be deeply tested for feasibility relative to their impact on business and operations. RIQI has made major investments in staffing and the effort needed to establish sound procedures to enable compliance with all policy and technical requirements such as enrollment and delegated user administration.

Develop a medium-term IT strategy that includes a technology and infrastructure model flexible enough to allow adaptation to shifting Federal guidance, market dynamics and technology evolution. The current *care* infrastructure was augmented by RIQI to address new needs and opportunities and, due to sound decisions made early in the Project, the technical model was flexible enough to accommodate the evolution. It is also important to recognize that technology solutions are always evolving and new products are constantly being produced. It is critical to be prudent in any consideration of the promise of new solutions or the influence of stakeholders who, for their own business reasons, want their technology solution to be the solution of choice. An HIO has to balance “staying the course” with the need to remain flexible long enough to allow for progress to be made. Mid-course corrections must be informed by a high degree of confidence and broad support for change in the given solution / development path.

## **Conclusions**

Substantial planning and effort is required to stand up an effective Health Information Organization. It is imperative to achieve a clear understanding the full impact of the functional HIE system on business and technical operations, including all implications for policy compliance. Such insight is critical to establish operational feasibility, plan staff models and develop organizational procedures. The HIO must be positioned to take an early leadership role in strategic and operational decisions about HIE system deployment while at the same time engaging stakeholders, being responsive to their requirements and effectively managing stakeholder relationships.

## **Legal/Policy**

### **Policy Development and Implementation**

Table 1 below lists 19 policies and 2 contractual agreements developed using a highly collaborative process throughout the RI SRD Project. Also included in the table is the development and refinement “path” through the various stakeholder committees that was used to move the policy to final approval by the Steering Committee and/or RIQI Board of Directors.

Policy implementation has been addressed by both HEALTH and RIQI through a process which includes: 1) identifying/defining/deploying functional requirements for the HIE system to support proposed policy; 2) establishing the operational support for the policy including development of detailed procedures and/or supporting documentation and training; and 3) understanding and preparing for regulatory compliance as applicable.

### **Role of Legal Counsel**

Legal counsel was instrumental in providing sound guidance and support for policy and contract development. RIQI counsel co-chaired the RIQI Policy and Legal Committee that directed much of the effort. Counsel drafted a number of policies and all contractual agreements

and worked with committees and staff to refine them for approval. State legal counsel was consulted in matters where there was a State interest, most notably matters related to legal liability, ownership of assets, contract performance, etc.

### **Specific Legal/Policy Discussions (including role of stakeholder preferences / opinions)**

An in depth account of the Rhode Island Health IT Project policy development process and outcomes is discussed in the [Evaluation Results](#) section of this report.

**Table 1. Currentcare—RI Health Information Exchange: Description of policies and procedures**

\***LEGEND:** CAC=Consumer Advisory Grp | PAP=Professional Advisory Panel | PLC=Policy & Legal Cmte | TSG=Technical Solutions Grp | SC=RI Steering Cmte | ILR=Internal Legal

Ref	Policy Name	Path thru Committees	Policy Description	Target Approval Date	SC/Board Approval
1	Role-Based Permissions	PAP, TSG, ILR, SC	The purpose of this policy is to establish permission/ authorization to users for accessing functions and information within the HIE.	3/27/08	-SC-3/27/08
2	Consumer Enrollment / Patient Authorization	Enrollmt Wrk Grp, CAC, TSG, ILR, SC	This policy describes the consumer's choice to enroll or terminate participation in the HIE, and the procedure by which the consumer can express that choice.	4/24/2008	-SC-4/24/08
3	Complaints	CAC, PAP, ILR, SC	This policy describes the process in which complaints on a range of issues are handled and processed by an HIE user organization, the RHIO, or the Department of Health.	5/22/2008	-SC-5/22/08
4	Temporary Authorization	PAP, TSG, CAC, PLC, ILR,SC	The purpose of this policy is to set the rules and responsibilities for any authenticated individual HIE user to gain temporary authorization to access patient information through the HIE for a limited time in unanticipated or unscheduled situations.	5/22/2008	-SC-5/22/08
5	Provider Enrollment	TSG, PAP, ILR, SC	The purpose of this policy is to establish the process and requirements to register provider organizations and affiliated personnel as users of the HIE.	1/22/09	-SC-1/22/09
6	Provider Authentication	TSG, PAP, ILR, SC	The purpose of this policy is to establish the standards by which providers' identity and credentials will be verified for the purposes of enabling and monitoring access to the HIE.	1/22/09	-SC-1/22/09
7	Uniform Patient Authorization Form**	PLC, CAC, PAP, TSG, SC, ILR, Board	The purpose of this document is to implement a standard form (with consistent language explaining the HIE) that patients will use to enroll in the HIE.	6/24/2008	-SC-6/26/08

**Table 1. Currentcare—RI Health Information Exchange: Description of policies and procedures (continued)**

\*LEGEND: CAC=Consumer Advisory Grp | PAP=Professional Advisory Panel | PLC=Policy & Legal Cmte | TSG=Technical Solutions Grp | SC=RI Steering Cmte | ILR=Internal Legal

8	Response to Breach of RI HIE	PLC, PAP, CAC, ILR, SC	The purpose of this policy is to establish a process used by the RHIO to respond to any breach of security and/or confidentiality of protected health information in the HIE. Was updated to reflect new provisions in HITECH.	7/24/2008	-SC-7/24/08
9	Notification of Breach of RI HIE	PLC, ILR, SC	This policy establishes the process by which the RHIO will determine the appropriate level of notification to consumers and users if a security breach of the HIE occurs. Was updated to reflect new provisions in HITECH.	7/24/2008	-SC-7/24/08
10	Provider Search/NPI Matching	TSG, PAP, ILR, SC	This policy will define the basis for establishing and maintaining unique provider identifiers in the HIE for purposes of creating a master provider directory. TSG RECOMMENDS DELETION.	N/A--DELETED	SC approved deletion - 1/22/09
11	Termination of Participation (Detailed Policy/Procedure)	TSG, PAP, CAC, ILR, SC	This procedure describes the consumer's choice to terminate participation in the HIE.	Aug-08	-SC-10/24/08
12	Revocation of Authorization to View (Detailed Policy/Procedure)	TSG, PAP, CAC, ILR, SC	This procedure describes the consumer's choice to revoke authorization for specific facilities to view their information in the HIE.	Oct-08	-SC-10/24/08
13	Monitoring Information Access**	PLC, TSG, ILR, Board	The purpose of this policy is to establish the RHIO's process for auditing HIE users' use of the HIE and the mandatory elements of the audit record.	Apr-09	-SC-4/23/09
14	Enrollee Request for Disclosure Report	TSG, PAP, CAC, ILR, SC	This policy establishes the conditions and process by which the RHIO will make available to patients an account of disclosures of their protected health information through the HIE.	Apr-09	-SC-4/23/09
15	Enrollee Request to Amend Health Record	TSG, PAP, CAC, ILR, SC	The purpose of this policy is to explain how the RHIO will advise patients who request to make amendments and/or notations to their health record.	Apr-09	-SC-4/23/09

**Table 1. Currentcare—RI Health Information Exchange: Description of policies and procedures (continued)**

\***LEGEND:** CAC=Consumer Advisory Grp | PAP=Professional Advisory Panel | PLC=Policy & Legal Cmte | TSG=Technical Solutions Grp | SC=RI Steering Cmte | ILR=Internal Legal

16	Data Corrections/ Amendments and Provider Notification	TSG, PAP, PLC, ILR, SC	This policy describes the process by which Data Submitting Partners will notify the HIE system of any corrections or amendments to patients' health information that had been previously submitted to the HIE by the DSP and the extent of the RHIO's responsibilities pertaining to provider notification.	Apr-09	-SC- 4/23/09
17	Data Sharing Agreement** (contract)	TSG, PLC, ILR, SC	This agreement describes the mutual rights and responsibilities of the RHIO and the Data Submitting Partners pertaining to the management and maintenance of all mechanisms by which health information about enrollees in the HIE will be submitted to the HIE.	May-09	-RIQI- 2/11
18	HIE End User Agreement (contract)	PLC, PAP, ILR, SC	This agreement describes the rights and responsibilities of provider organizations who will be accessing the HIE and managing individual users of the HIE. Was initially used for RIQI's Limited EHR Aggregation Project.	May-09	-RIQI- 6/10
19	Enrollee Request to Access Health Record	TSG, PAP, CAC, ILR, SC	This policy describes the steps by which an enrollee can access the enrollee's record held by current <i>care</i> pursuant to the law as provided for in HIPAA and HITECH.	Oct-09	-SC- 10/22/09
20	Recourse for Data Sharing and User Agreement Violations**	PLC, PAP, CAC, ILR, Board	The purpose of this policy is to establish the consequences for data submitting partners and HIE users who violate the terms of their agreements with the RHIO.	Jun-09	-SC- 1/28/10
21	Policy Review and Management Policy	PLC, SC, Board	The purpose of this policy is to establish the basis for the review and management of current <i>care</i> policies by the State designated RHIO in compliance with regulatory requirements.	Sep-10	-SC- 9/23/10

## **Lessons Learned About Legal/Policy Development**

One of this project's achievements is the development of a set of policies that support the RI HIE Act of 2008 which stipulates privacy and confidentiality protections for current *care* that are more strict than some State and Federal health information privacy laws. Among the key lessons learned: 1) the Rhode Island community places a high value on the collaborative policy development process; 2) HEALTH was perceived as the appropriate agency to lead the HIE effort initially; 3) policy and technology solution development are integral activities that must be deliberately reconciled during design, development, testing and deployment cycles; and 4) prior to final approval, HIOs and stakeholder organizations should evaluate the feasibility of policy implementation especially from operational and sustainability perspectives.

## **Conclusions**

The collaborative policy development process was highly valued by stakeholders. However, it is as yet undetermined whether the foundational Rhode Island HIE consent policy is sustainable as implemented. The Evaluation section below addresses conclusions pertaining to policy development in detail.

## **Evaluation<sup>2</sup>**

This section borrows heavily from the RI SRD Project Final Evaluation Report prepared by a team from Brown University under contract to the State.

### **Developing the Evaluation Plan**

The initial project evaluation proposal was to employ a standard health services approach to evaluation based on Donabedian's structure-process-outcome model. For structure, the evaluation team would assess the HIE model that would be built (computer systems in place, quality of data, etc.). For process, the team would examine the extent to which the HIE was used. For outcomes, the team developed a number of indicators to assess the impact the HIE would have on the quality of medical care in the State as well as potential cost savings.

The initial evaluation plan was based on the belief that the HIE would be developed and implemented statewide early enough in the AHRQ funding period so that evaluators would be able to broadly measure its structure, process and outcomes at a statewide level. The evaluation team continued to refine the specifics, updating the plan based on input from AHRQ and its designees. The evaluation team also continued to review the literature and follow the progress of the HIE development which allowed for adjustments to the plan to reflect the realities of the implementation.

### **Case Studies Approach**

It eventually became clear that given the pace of development of the Rhode Island HIE, the system would not be in place statewide in all care settings early enough in the AHRQ funding period to make feasible the broad based evaluation plan that was initially envisioned. Therefore, adjustments were made to the evaluation approach to focus on multiple case studies of specific

---

<sup>2</sup> Vivier, P. M. et al. (Final Evaluation Report, Sept 2010) State and Regional Demonstration in Health Information Technology: Evaluation of the Rhode Island Experience. Brown University.

care settings. Evaluators still hoped to do some broad based measures of structure and process similar to what was initially proposed. However, the main focus, particularly the evaluation of the impact of the HIE, would be on four specific care settings:

- Nursing Homes
- Newborns (hepatitis B and Group B strep)
- Pediatric Emergency Department
- Adult Emergency Department Chest Pain Unit

These four settings were identified as having the best potential for demonstrating an impact of the HIE system. Baseline studies were undertaken to determine if it was feasible to eventually perform impact studies and to assess if it was realistic to expect an impact from the HIE. This work was based on input locally, nationally and reviews of the literature. By having four case studies in different care settings, evaluators had the ability to refine the focus of the final evaluation based on the findings from the preliminary studies. The evaluation team would also be able to make adjustments based on the timing of the implementation of the HIE in different care settings.

While work on the preliminary assessments for each of the case studies was underway, it eventually became clear that the Rhode Island HIE would not be implemented sufficiently in any care setting to allow an evaluation as designed in the case studies approach as planned. The case studies were halted and the evaluation plan shifted to a policy analysis approach as described below. However, one of the case studies, nursing homes, became a special focus in the policy analysis. While the other three topics did not become integral parts of the final evaluation report, project stakeholders did learn from the experience.

### **Policy Analysis**

As it became clear that the timetable for data sharing using the RI HIE system made it impossible to carry out the case studies approach, it also became increasingly clear that a number of key issues had a dramatic impact on Rhode Island's HIE initiative during the AHRQ funding period and would continue to have important implications for HIE development in Rhode Island well past the AHRQ funding period. It was therefore critical to closely examine these issues as the major focus of the evaluation. These issues have shaped Rhode Island's experience. It is expected that they will have important implications for Rhode Island in the future and offer lessons applicable to other States. Ultimately, the evaluation team identified three key aspects of the Rhode Island experience that would be the main focus of the final project evaluation:

- Government (Department of Health) as Initial Lead Agency
- Community Decisionmaking
- Opt-In Enrollment Strategy

Focus groups (with up to 10 participants in each) were undertaken to examine each of the three issues. Two additional focus groups were undertaken as part of the evaluation. One was with representatives of the Rhode Island Quality Institute to evaluate their experience with the HIE project. The other was with the Rhode Island Department of Health to examine their experience with the HIE development process.

Given the central importance of the affirmative (opt-in) consent model and the resulting enrollment efforts, additional work was done on this topic beyond the focus groups. Since one of

the many needs the HIE system is intended to address is to provide timely and complete information during transitions of care and given the unique characteristics of the nursing home environment (resident population, significant number of patients with authorized representatives, etc.) a decision was made to target some of the first HIE enrollment efforts in long-term care settings. The final evaluation plan included specific evaluation of enrollment practices and results in the long-term care environment at eight Rhode Island nursing homes.

The ability to evaluate the success of other enrollment strategies such as the Medicaid mail campaign, provider office enrollment, targeted media campaign and employer open enrollment, proved to be less feasible due to the inability to collect the necessary data and the overlap of simultaneous strategies. However, a detailed descriptive analysis of the factors and events leading to the development of the RI HIE authorization (a.k.a., consent) policy and the emergence of multi-pronged strategies for consumer enrollment were included as a supplement to the core evaluation components.

## **Implementing the Evaluation Plan**

The project evaluation plan evolved from a structure-process -outcome approach to an approach that analyzed the policy decisions made with regard to governance, community involvement and privacy protections. Two separate reports were produced that described the core elements of evaluation: 1) An analysis of key policy questions derived from focus groups of engaged stakeholders; and 2) an analysis of consumer enrollment processes and outcomes in long-term care facilities. Lastly, the evaluation report included a summary of the preliminary work performed to target high impact clinical settings for the HIE system and a supporting document that provides a comprehensive description of the structure and process used to develop and implement the policy and technology framework for current *care*.

To assess the implementation process of current *care* in Rhode Island, five 2-hour focus groups were conducted with a sample of individuals who had participated in the HIE working group committees. Each focus group had one primary topic, and all focus groups also discussed all issues:

- 1) The community decisionmaking process;
- 2) The public private partnership;
- 3) The opt-in enrollment decision;
- 4) Department of Health (HEALTH) perspectives; and
- 5) Rhode Island Quality Institute (RIQI) perspectives.

Focus groups were audio taped, professionally transcribed, coded, and rigorously analyzed for themes on the subjects of interest and the related areas that emerged.

Implementing the plan for evaluation of enrollment practices and outcomes generated direct questions about the implications of the RI HIE consent management model through an analysis of consumer enrollment processes and outcomes in nursing homes. The overall goals of the evaluation were to understand: 1) what nursing home characteristics and/or processes appear to be associated with higher versus lower enrollment; and 2) what recommendations nursing home administrators and HIE champions have for improving enrollment efforts.

Evaluators collected both quantitative and qualitative (i.e., interview) data to understand the factors associated with higher versus lower resident enrollment in the HIE system. The study's outcome was the proportion of a nursing home's residents who had signed HIE consent forms.

This outcome was based on residents present in the facility at 6 months after the enrollment effort began, and because of this it reflects both a facility's initial enrollment efforts as well as its efforts to enroll newly admitted residents.

## **Results**

### **Policy Analysis: Focus Groups**

The outcome of focus group evaluation of policy-making processes and decisions confirmed an overall broad-based sense of community pride in the work carried out to date to build a statewide HIE system. The focus group evaluation also reflected stakeholders' general agreement with the community collaboration approach and the consent policy direction that was undertaken. Further, the focus groups highlight and clearly articulate the inherent challenges and tradeoffs that have occurred, and continue to occur, with the current implementation.

Key findings from the focus group participants include:

#### **These community decisionmaking process**

- Trust in the process was perceived as strong.
- Transparency of meetings and the decisionmaking process was maintained.
- Patience and consensus-building contributed to most decisions.
- Praise was expressed for strong leadership and staff support.
- Community involvement was considered imperative in key policy decisions.

#### **Leadership and the public private partnership**

- The value of the public private partnership was asserted.
- HEALTH was perceived as the appropriate agency to lead the HIE initially.
- HEALTH has valuable experience, but has additional priorities and moves slowly.
- RIQI was perceived as able to maintain key players in the HIE process.
- RIQI was praised for attracting large grants to continue implementation.
- There was concern about RIQI board members' competing private interests.
- Guarded optimism was expressed about the HIE's long-term viability.

#### **The opt-in enrollment decision**

- Community consensus process leading to the opt-in decision was praised.
- The opt-in decision was described as a national model of privacy rights.
- The HIE Act of 2008 was seen as a triumph.
- The opt-in model was seen as causing higher costs and slower enrollment.
- Technological challenges from opt-in enrollment were perceived as complex.

The focus groups as a whole displayed remarkable unanimity of pride about the community decisionmaking process and the major decisions undertaken. While acknowledging frustration at times about delays and increased costs, participants also asserted that the decisions were sound. Participants claimed that RI is a national model in HIE implementation.

### **Enrollment Analysis: Long-term Care Facilities**

For nursing homes, the value of and need for the HIE system is perceived to be high, however, the nursing home environment has both significant advantages and challenges for enrolling residents. The nursing home study describes how efforts to enroll nursing home residents in current *care* met with varying success. After 6 months of effort at eight Rhode Island nursing homes, the proportion of residents with signed consents ranged between 10 percent and

100 percent and, in five of the eight nursing homes, less than 50 percent of the residents enrolled. Nursing homes with higher enrollment rates, compared to those with lower rates, had lower proportions of short-stay residents, greater success in other enrollment efforts (i.e., obtaining advance directives), and devoted more (initial) time to the enrollment effort. Interviews among staff in facilities with higher enrollments described active staff engagement with residents and families.

Also, these high enrollment facilities had enrollment processes reflecting more active (e.g., picked up phone, other) rather than passive (e.g., mail, other) processes. The more successful processes were described as active engagement with residents and families by staff members familiar with residents and families (or surrogate decisionmakers).

Acknowledging the key role staff play in the HIE enrollment process, administrators and HIE champions recommended social service and nursing staff as the most appropriate to serve as champions of the enrollment process. Some (particularly those at large facilities) suggested utilizing staff from both areas. Recommendations by administrators and champions are below.

**Enrollment Recommendations by Administrators and HIE Champions**

- Have an ongoing communication process with families.
- Use primary nurses who have relationships with residents.
- Use social services staff.
- Delegate responsibility to more than one staff person.

Residents and nursing home staff believed the HIE system was less relevant for rehabilitation and/or short-stay residents. In fact, this thinking probably contributed in part to the lower rates of enrollment observed in facilities with higher proportions of therapy residents. Since therapy and/or short-stay residents are the very persons who are likely to have multiple transitions, nursing home staff needs to be educated about the importance of these enrollments. Additionally, the creation and use of scripts applicable to therapy and/or short-stay residents may help sensitize rehabilitation and/or short-stay residents to the importance of HIE enrollment. Also, while nursing homes have less opportunity to develop relationships with short-stay residents, efforts leading to more sustained resident/family-staff relationships for both short and longer-stay residents (such as consistent staff assignment) will also be likely to lead to more successful engagement of residents/families in activities that necessitate trusting relationships (such as completion of HIE enrollment consents or advance directives. A summary of recommendations follows.

### **Recommendations to Improve HIE Enrollment Rates**

- Educate nursing home staff on the importance of enrolling short-stay residents.
- Share successful enrollment processes (and scripts) and integrate these processes into sample enrollment procedures.
- Develop scripts relevant to short-stay residents to sensitize these residents to the importance of HIE enrollment .
- Ensure written materials on the HIE system (brochures, other) include concrete examples on how information access afforded by the system can improve emergency care and physician communications.
- Educate nursing home administrators on how trusting resident/family-staff relationships appear to contribute to successful enrollment efforts.
- Encourage nursing home administrators to select staff most familiar with residents and families (or surrogate decisionmakers) to participate in their HIE enrollment efforts.

In conclusion, leaders for the Rhode Island project made the decision to not merely engage the broader community to provide input on the HIE system planning and implementation process, but rather to use a community decisionmaking process where committees with broad membership were given decision making capacity. Over the course of the project, there were delays in system development related to administrative, technical and policy complexities and the challenges of consensus building. Fundamental methodological challenges for the evaluation resulted from the absence of a production-level HIE system prior to the end of the project period necessitating major changes in the evaluation plan. As such, through the various components, the project evaluation examines the rationale for Rhode Island's chosen approach, the resulting policy decisions, how policies were implemented and the implications for the process and results. It is hoped that the project's contribution to the HIE body of knowledge can be used to emphasize the need to understand and actively manage the complex relationship between the propensity for change in social and health systems and the conditions required for acceptance of technology as a tool for progress in a given community.

## Recommendations for Future Research

AHRQ is to be commended for the forethought and insight that led to the decision to allow a 5-year development, deployment, and evaluation timeframe for the SRD projects. So much was learned, especially as the political, economic, and industry landscape shifted over the course of the contract period. Future research is important to generate answers to essential strategic questions pertaining to the value proposition for electronic HIE. These questions could include the following:

- Research question 1. How might an HIO achieve long-term financial sustainability under an opt-in authorization model which requires affirmative consent prior to patient data flow to the HIE and additional authorization to permit disclosure to participating, authorized users?
- Research question 2. What is the financial impact and level of customer satisfaction among various opt-in authorization models that have been fully implemented?
- Research question 3. What is the range of variability in the legal definition of “disclosure” of health information in an electronic HIE system?
- Research question 4. What is the optimal role of the State in regional / statewide health information initiatives? How does this impact health information infrastructure maintenance and operations? Strategic IT planning? Regulatory oversight? New program development?
- Research question 5. What opportunities exist to leverage regional / statewide health information infrastructure to support Medicaid administration and care coordination?
- Research question 6. What is the ideal technical infrastructure to support broad HIE goals in environments where dominant stakeholders have deployed mature HIE technology solutions?
- Research question 7. What entities does the public trust the most to maintain and operate a HIE network; community based organizations and/or other private or quasi-public entities versus government? Who and how are HIOs held accountable; what is the role of State government in the accountability of HIOs and HIE systems?

## Appendix A: Select Project Artifacts

- A-1: RI SRD Project Steering Committee Decisionmaking Guidelines (approved June 23, 2005)
- A-2: Data Prioritization Plan (approved June 23, 2005)
- A-3: Rhode Island Information Technology Principles (approved August 25, 2005)
- A-4: Rhode Island's Shared Vision for Health Information Exchange (approved November 30, 2005)
- A-5: RI AHRQ Health IT Project: Prioritization of Initial Data Uses (approved September 28, 2006)
- A-6: RI HIE Patient Authorization Policy Statement (approved September 27, 2007)
- A-7: RIQI Committee Membership Policy (enacted 2008 by RIQI Board)
- A-8: Special Communication to RI SRD Project Steering Committee—Final Meeting (September 21, 2010)

**RI AHRQ Health IT Project Steering Committee**  
**GUIDELINES FOR STEERING COMMITTEE DECISION-MAKING**  
**June 23, 2005**



**DECISION-MAKING OBJECTIVES**

- To adopt guidelines that support achievement of consensus on all decisions put forth for a vote by the RI AHRQ HIT Steering Committee where consensus is defined as *no single voting member present or by proxy being in opposition of a group decision.*
- To implement a decisionmaking process that accommodates and considers differences in Steering Committee member positions.

**DECISION-MAKING GUIDELINES**

1. The Steering Committee will be provided well-formulated issues and supporting materials for consideration prior to a vote.
2. The Steering Committee will be given an appropriate interval of time to review materials, identify, discuss and resolve issues.
3. No decision will be voted prematurely, that is, the Steering Committee will revisit and adjudicate decisions in productive discussions until such time as they can be reasonably expected to be approved.
4. At the discretion of the Steering Committee, agreed upon criteria and decisionmaking methods will be applied to support achieving a consensus vote.
5. A voting quorum of 50 percent Steering Committee member attendance is required to conduct a vote. The Steering Committee reserves the right to postpone a critical vote if the group agrees that participation is too low.
6. Votes will be conducted by voice vote of Steering Committee members in attendance.
7. In the event that a Steering Committee member is unable to be present for an anticipated vote, proxy voting will be permitted if the member's vote on a specific decision is submitted in writing prior to the vote.
8. The Steering Committee will not knowingly make decisions imposing actions that stakeholders cannot perform due to constraints known at the time of the vote.
9. The Steering Committee may require budget analyses to determine the potential impact of decisions on project subcontracts and/or other financial considerations. In such cases, a budget impact analysis must be provided to inform decision making.



## DATA PRIORITIZATION PLAN

Approved June 23, 2005

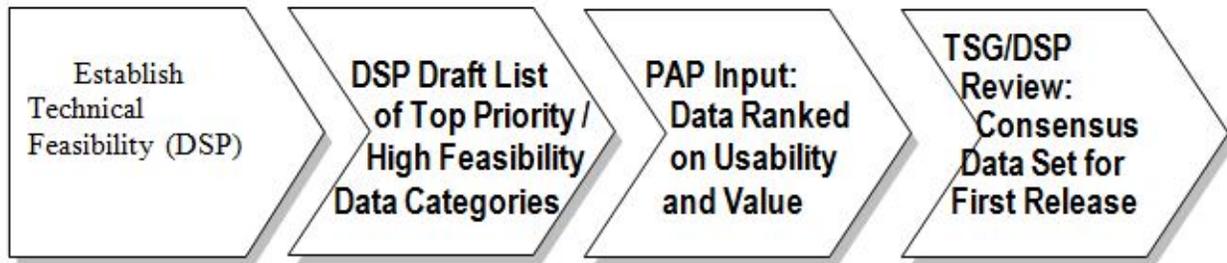
**Submitted to the RI/AHRQ Health IT Project Steering Committee by:**

- Data Sharing Partners (DSP) Group
- Professional Advisory Panel (PAP)
- Technical Solutions Group (TSG)

### PURPOSE

To identify a priority data set, based on “feasibility and desirability of use”, to be exchanged in the statewide Health IT System proof of concept, prototyping and initial deployment in the Rhode Island healthcare community. Specific objectives of this data prioritization plan include: 1) supporting achievement of AHRQ contractual requirements for clinical data exchange and 2) promoting broad adoption and use of the Health IT System.

### PROCESS



**Baseline Demographic Data Set**  
(Supports patient identity management and information linkages.)

### APPROVED RECOMMENDATION

- The RI/AHRQ Health IT Project will evaluate and implement a top clinical priority data set (which includes laboratory information) and pursue feasibility of the administrative track with Rhode Island Quality Institute Board-level action.

#### TWO-TRACK DATA PRIORITIZATION PLAN

PRIORITY	ADMINISTRATIVE TRACK	CLINICAL TRACK
1	Insurance Eligibility Information	Lab Information
2		Medication Information
3		Reports
4		Phone numbers/contact info.



## Information Technology Principles

Approved August 25, 2005

- **BACKGROUND**

This set of IT Principles were developed based on the input from Rhode Island stakeholders through a formal needs identification process intended to identify important considerations for a proposed statewide health data exchange system. These principles represent Rhode Island stakeholder values related to information technology and, specifically, the goals of the Rhode Island AHRQ Health IT Project (the project).

### DATA MANAGEMENT PRINCIPLES

1. **Common base of data:** A common base of data must be created to facilitate sharing and minimize redundancy. This data may be physically *or* logically consolidated (there may or may not be a central database).
2. **Comprehensiveness:** The goal of the system is to create as comprehensive a patient record as possible, and to consider the complete patient record.
3. **Accuracy:** Data must be accurate and complete (there is often a tradeoff between these two).
4. **Timeliness:** Data must be available in as near real-time as possible from the point of creation.
5. **Security and confidentiality:** Data must be safe from harm and accessible only to those with a "need to know." More specific rules should delineate the boundaries around data access from all perspectives (patient, provider, payer, others).
6. **Ease of access:** Data must be easy to access for all groups of authorized users regardless of their level of technical expertise. Ease of use comes first and foremost for healthcare providers who access systems.
7. **Multiple uses:** The primary uses for Protected Health Information are clinical support and public health surveillance. The project will plan for additional uses of de-identified data, including research, planning, evaluation, and quality improvement.
8. **Purposeful collection:** Data must be collected only once, as close to the source where it originated.
9. **Documentation:** Detailed information about data must be created, maintained, and made available to assist in data quality assurance.
10. **Population-based:** The system should populate records prospectively, starting with birth record information, and retrospectively using historical information, to construct as complete a health record as possible. Accurate patient matching is crucial to this capability. Accommodation needs to be made for patients who are born outside of the State to ensure that their records are included.

## SYSTEM APPLICATION PRINCIPLES

11. **Ease of use:** Applications must be easy to use for both novice and expert users, and should pose minimal adverse impact on existing business and clinical processes and activities.
12. **Consistency:** Interfaces should be similar enough to present a consistent look and feel, though different interfaces might be necessary for different types of users.
13. **Adaptability:** Applications must be easily adaptable to changing functional and technical requirements.
14. **Ensuring data quality:** Applications must help ensure valid, consistent, and secure data while presenting minimal obstacles to smooth and efficient user.
15. **Visible benefit:** Applications must present visible, tangible benefits to end users.

## INFORMATION INFRASTRUCTURE PRINCIPLES

16. **Platform neutrality:** Various platform architectures might satisfy the needs of the project.
17. **Reliability:** The system must operate reliably and be resilient to natural or technical disasters.
18. **Leverage networks:** Wherever possible, existing networks should be leveraged to minimize cost and complexity.
19. **Use of the Internet:** Secure use of the Internet should be encouraged as appropriate.
20. **Standards:** Where relevant, national standards for healthcare information technology should guide technical decisions.

## ORGANIZATIONAL PRINCIPLES

21. **Support of mission:** Information technology initiatives must support the specific mission and goals of the project.
22. **Cost effectiveness:** Information technology must contribute to the cost effectiveness of the processes it supports, and needs to be cost effective for each partner to participate.
23. **Data stewardship:** Data stewards serve as custodians for data in their care, and are responsible (along with all providers and users of data) for ensuring the proper documentation, collection, storage, accuracy and use of data within their purview.
24. **Governance:** The project should have clear and strong processes for governance, consistent with the project proposal and the highest standards of the participants.
25. **Scope management:** The project recognizes the need for clear identification and careful management of its scope and activities.



APPROVED NOVEMBER 30, 2005

RHODE ISLAND'S SHARED VISION FOR HEALTH INFORMATION EXCHANGE

Rhode Island will promote the use of information technology and confidentiality protections to support the authorized exchange of electronic health information to improve the quality, safety, and value of health care provided in the state. To that end, Rhode Island will create and sustain a statewide secure health information system that will:

- 1) Allow individuals seeking care in Rhode Island to authorize their health services providers, and others whom they designate, to have access to their health information, solely for approved purposes, when and where it is needed;
- 2) Adhere to sound policies, design principles and interoperability\* requirements to support the exchange of information in a meaningful, lawful, and efficient manner; and
- 3) Maximize the effective use of technology by patients, providers, policymakers and researchers to realize significant and continuous improvements in the quality and outcomes of health care delivery in the state.

RHODE ISLAND / AHRQ HEALTH IT PROJECT GOALS STATEMENT

From September 2004 through September 2009, the Rhode Island/AHRQ Health IT Project will design, implement and evaluate the foundation for statewide comprehensive electronic health information exchange, using affordable technologies and leveraging technologies already in place. Specifically, the Rhode Island Department of Health (HEALTH) and its partners (including consumers, healthcare practitioners, stewards of health data, and industry stakeholders) will develop the capacity:

- To connect a core set of personal health data from various health care providers, and
- With an individual's consent, make the information easily available and accessible to providers for use in that individual's care.

\*Interoperability: The capability of two or more hardware devices or two or more software routines to work harmoniously together.

## RI AHRQ Health IT Project: Prioritization of Initial Data Uses

APPROVED by RI AHRQ HIT Project Steering Committee

September 28, 2006



- **Intent:**
1. Define the use of health data from a point of prioritization rather than limitation until the spectrum of possible data uses is defined.
  2. HEALTH is a data sharing partner with somewhat different needs than other DSPs that may be more clinically focused. Specifically, HEALTH has a need to understand the policy, technical and infrastructure requirements for its authorized public health activities that may be related to the HIE. Recognizing that these needs are somewhat further down the list of data use priorities in the initial HIE build, they remain important for HEALTH to define, without undue restrictions, in its role as a DSP.
  3. The scope of the RI HIT/HIE Project is becoming increasingly blended with other initiatives (and funding streams); therefore, undue restrictions on the Project may inadvertently impose restrictions on other activities.

---

Within the larger context and long-term objective related to the creation of a health information exchange for the State of Rhode Island, the AHRQ State and Regional Demonstration contract helps to meet short- and intermediate-term goals that must be achieved related to proof-of-concept and viability. Included in these goals is the successful implementation of the Master Person Index (MPI) as a core element of RI's health information exchange capability to be developed under the AHRQ contract. To help assure our collective success in the RI AHRQ Health IT Project, we, the Project Steering Committee, recommends prioritizing the initial uses of protected health information (PHI) submitted by the Data Sharing Partners (DSPs) under the scope of this Project as follows:

1. It is understood that designated HIE System developers and technical managers authorized by and/or under contract to HEALTH will be able to access data, including PHI, in the initial HIE for a legitimate and allowable range of system development, testing, and data management purposes as explicitly provided for in business associate agreements and as allowed by HIPAA and Rhode Island state law. It is understood that project evaluation activities, where access to identified data from the system is needed, will be permitted within agreed upon IRB boundaries and conditions during the project period.
2. Other than as stated in #1 above, PHI with the identity of the individual will only be used for clinical care and other such purposes as allowed by HIPAA and Rhode Island state law. "Clinical care" is defined as direct patient care and the coordination of that care by the physicians and affiliated practitioners with an active care relationship with the patient.

**Recommended  
For Approval**

**9/27/07**

## **RI HIE Patient Authorization Policy Statement**

The Rhode Island Health Information Exchange (RI HIE) will serve as a point of access and/or storage for protected health information (PHI). PHI with the identity of the individual will be released only for purposes of direct patient care and the coordination of that care by the physicians and affiliated practitioners having an active care relationship with the patient; and for system development, testing, data management and project evaluation. In support of such uses, the HIE must obtain explicit authorization from patients before participating sources of health information can transfer the patient's health information to the HIE. Healthcare providers must be authorized by the patient and authenticated by the HIE prior to viewing the patient's health information through the HIE. No other legal uses of PHI that may be proposed in the future will be implemented unless approved by a designated authority according to an accepted process and with public notification. Participation in the HIE is voluntary and patients may terminate their participation at any time.

*Recommended for Approval by the RI HIT Project Steering Committee,  
September 27, 2007*

# Rhode Island Quality Institute

## COMMITTEE MEMBERSHIP POLICY RIQI 2008

### **Purpose \***

The Rhode Island Quality Institute acknowledges the importance of individual participation on committees in achieving statewide improvement in health care quality, safety and value in RI. As committee members are volunteers, there is a need for *flexible* attendance policies, however, it is important to have consistency of participation to:

- 1) ensure a broad range of perspectives
- 2) move forward expeditiously, while gaining consensus
- 3) acknowledge the individuals that have contributed to the development and policies of the HIE

Please note that while committee membership does not imply endorsement by every committee member, it does indicate that each member contributed by sharing their perspectives. Therefore, attendance at committee meetings is critical not only to the representation of all viewpoints, but the promotion and protection of the individual committee members.

The following policies are designed to help everyone understand the responsibilities and expectations of committee work. The intent is to ensure a more positive and productive committee experience for all involved.

### **General Tenets**

1. Committee members are appointed by the RIQI staff and Chair or Co-Chairs of each committee. While many committees are populated with volunteers (non RIQI-staff), this is a distinctly different concept from an individual volunteering to be a committee member. Volunteers are welcomed, but may not be appointed for a variety of reasons (constituency represented, committee at maximum size, etc.).
2. Committees serve many purposes (pooling of skills and resources, distribution of efforts, sharing of information and ideas).
3. Committee members are appointed based on expertise and/or position and on the contributions they can make to the work of a particular committee.
4. In keeping with the transparency principle of the RIQI, the membership of committees is public information. Committee appointees are made aware of this upon appointment .
5. A review of the list of active members of each committee is conducted annually at the time of the RIQI Annual Meeting of the Board. At this time, membership is evaluated in terms of such characteristics as appropriateness, degree of expertise and diversity of perspective. Changes to the membership may occur at this time in order to strengthen the effectiveness of committees.

### **Responsibilities of Committee Chairs:**

The Chair will **communicate** the following to all members of the committee:

- Committee charge, communication norms, and work requirements
- Approved appointment process (how individuals become members of their committee)
- Policy of duration of appointment to the committee
  - The ‘renewal option’, reviewed annually, or periodically.
- Meeting schedule, location and length of meetings
- Time estimate for work outside the committee meetings
- Event participation requirements
- Policies on minute taking and other administrative duties
- Subcommittee expectations, if applicable
- Current membership rosters, including contact information

In addition, Committee Chairs, will:

- Commit to deliver results
- Organize work for committee members

- Balance the interests of all involved
- Participate in the annual review of active committee membership

In addition, each Chair is expected to represent the work of his/her committee to the Committee of Chairs and/or the RIQI Board. Chairs also have the responsibility to seek approval if they believe it is appropriate to redirect committee members or to review, re-organize or change the scope of the committee. In the absence of directing change to scope or charter, Chairs must focus committee members in a manner that is observant of the scope and charter of the committee.

**Responsibilities of Committee Members**

- Attend meetings and actively participate in discussions
  - Regular attendance shall be defined as attending 65 percent or more of regularly scheduled meetings
  - Attendance which drops below 65 percent should be reviewed by both the committee member and committee Chair to ascertain whether or not the member desires to or otherwise should be replaced
- Assist (when appropriate) in creation of committee documents and processes
- Notify committee chairs when unable to attend a meeting and follow up with the chair or other committee member to obtain minutes, assignments and other information
- Discuss any concerns openly within the committee forum and refrain from discussing concerns outside the committee forum if they are not raised within the forum.

# Rhode Island Quality Institute

## SPECIAL COMMUNICATION TO THE RI HIT PROJECT STEERING COMMITTEE

**TO:** RI Health IT Project Steering Committee and Participating Stakeholders

**FROM:** David Gifford, MD, Director, Rhode Island Department of Health  
Amy Zimmerman, Chief, Health IT, Rhode Island Department of Health  
Laura Adams, President & CEO, Rhode Island Quality Institute



**DATE:** September 21, 2010

**RE:** RI HIT Project Closure

### RI HIT PROJECT INCEPTION (2004)

Today, Rhode Island is known for its leadership in advancing policies, principles and technologies to firmly establish secure electronic health information exchange as a fundamental tool to improve healthcare quality, patient safety and health outcomes. Progress in Rhode Island has been made possible by the vision and ongoing efforts of community and industry leaders, state government and countless organizations and individuals. An important source of momentum behind today's progress began with a decision to respond to a 2004 call for proposals from the federal Agency for Healthcare Research and Quality (AHRQ). AHRQ set out to fund a broad portfolio of projects for the purpose of planning, implementing, and evaluating the impact of various information technologies on the quality, safety, and efficiency of health care delivery. At the request of the collaborative community represented by the Rhode Island Quality Institute (RIQI), the Rhode Island Department of Health (HEALTH) responded with a proposal and was one of six states to be awarded a 5-year, \$5 million contract. Thus, the Rhode Island Health Information Technology (RI HIT) Project was launched to pursue *a phased approach to design, develop, test, deploy and evaluate an initial health information exchange (HIE) system to support the secure and reliable exchange of defined electronic health information as prioritized by the Rhode Island healthcare delivery community and governed by RIQI*. The proposal named HEALTH as the entity responsible for contractual and operational support to build the initial HIE system with the intent to transition full responsibility for long-term operations, expansion and sustainability to RIQI.

To guide the effort, the RI HIT Project Steering Committee was constituted on March 30, 2005 under the auspices of RIQI to carry out four key roles:

- Represent the interests of key Rhode Island stakeholders in establishing the policy, technical and operational mechanisms to support statewide electronic health data exchange under the AHRQ contract;
- Assist HEALTH in providing leadership for the RI HIT Project;
- Fulfill the contractual obligation to convene a Technical Advisory Panel; and
- Confer with RIQI Board of Directors on the Project's strategic direction and implications.

### RI HIT PROJECT TODAY (2010)

The Steering Committee has supported the RI HIT Project for over 5 years under the unwavering leadership of its Co-Chairs, Carole Cotter, SVP / Chief Information Officer, Lifespan and Dr. Cedric Priebe, SVP / Chief Information Officer, Care New England. The group has supported numerous accomplishments throughout the course of the Project including:

- Established a Provider Advisory Panel and Technical Solutions Group to help inform technology and user decisions;
- Facilitated the selection, design, naming and testing of the **currentcare** technology platform;
- Spearheaded the development of a comprehensive policy framework to support the vision of a statewide HIE system;
- Supported a broad, iterative policy development and review process and ultimately approved 20 **currentcare** policies; and
- Supported legislative and regulatory measures to ensure privacy safeguards for consumers' protected health information.

The September 2010 meeting will be the last meeting of the RI HIT Project Steering Committee as the Project comes to a contractual close. This coincides with the full transition of administrative, technical, operational, management and governance responsibility of the **currentcare** platform to RIQI. The RIQI Board of Directors has approved the permanent governance and advisory structure for the statewide HIE efforts and will continue operating under the collaborative principles under which the Steering Committee has so dutifully operated. The agenda for the September 23, 2010 meeting is attached.



## RI AHRQ Health IT Project Steering Committee

September 23, 2010 ♦ 7:00am – 9:00am

Robinson C. Trowbridge Center at Kent Hospital, First Floor Conference Room  
10 Health Lane ♦ Warwick, RI 02886 ♦ 401-921-1500

**Dial-In number:** (866) 228-9900 (toll-free) or (719) 359-4032 (toll) **Code:** 365814

### MEETING PURPOSE

To communicate project status, review and approve the RIQI Policy Review and Management Policy, reflect on HIT Project Evaluation findings and bring closure to the work of the Steering Committee.

### AGENDA

- 7:00 – 7:05**      **Call to Order, Welcome and Introductions**  
*Cedric Priebe, MD, Care New England, Steering Committee Co-Chair*
- 7:05 – 7:10**      **Consideration for Approval: 6/24 Meeting Minutes\***  
*Cedric Priebe, MD, Care New England, Steering Committee Co-Chair*
- 7:10 – 7:25**      **Project Status**
- currentcare Updates
    - currentcare Enrollment (G. Christensen)
    - Status of EMR Aggregation Project (LEAP) (G. Christensen)
    - Status of currentcare technology platform (G. Christensen)
  - Status of ONC Approval of HIE Strategic Plan (L. Adams)
  - Other Updates
- Cedric Priebe, MD, Care New England, Steering Committee Co-Chair*
- 7:25 – 7:40**      **Review and Discuss RIQI Policy Review and Management Policy**  
*Cedric Priebe, MD, Care New England, Steering Committee Co-Chair*  
*Gary Christensen, Rhode Island Quality Institute*
- 7:40 – 8:40**      **RI HIT Project Evaluation: Review of Findings [Brown University]**  
*Cedric Priebe, MD, Care New England, Steering Committee Co-Chair*  
*Renee Shield, PhD, Clinical Associate Professor of Community Health, Brown Univ.*
- 8:40 – 9:00**      **Reflection on RI HIT Project; Preparing for Statewide HIE Governance**  
*Carole Cotter, Lifespan, Steering Committee Co-Chair*  
*David Gifford, MD, Director, Rhode Island Department of Health*  
*Amy Zimmerman, Chief Health IT, Rhode Island Department of Health*  
*Laura Adams, President & CEO, Rhode Island Quality Institute*
- 9:00**              **Adjourn**  
*Carole Cotter, Lifespan, Steering Committee Co-Chair*  
*Cedric Priebe, MD, Care New England, Steering Committee Co-Chair*