

Meeting of the RI AHRQ Health IT Project Steering Committee
April 27, 2006 ♦ 7:00am – 9:00am

Robinson C. Trowbridge Center at Kent Hospital ♦ 10 Health Lane ♦ Warwick, RI

MEETING MINUTES

MEETING ATTENDEES (*indicates participation by teleconference)

Steering Committee

- Ted Almon**, Consumer
- Fadya Al Rayess, MD**, Chad Brown Health
- Bryan Barrette**, RI Department of Health
- Kerrie Jones Clark**, RI Health Center Assoc.
- Carol Cotter**, Lifespan, Co-Chair
- Gary Croteau**, South County Hospital
- Lisa Dolan-Branton**, AHRQ
- Yul Ejnes, MD**, RI Medical Society
- Jim Feeney**, East Side Clinical Laboratory
- Steve Foley**, Prov. Community Health Ctrs
- Heather Larch**, Pharmacist
- Kathleen Mahan**, SureScripts
- Maria Montanaro**, Thundermist Health Ctr
- Steven Mueller**, United Health Networks
- Pat Moran**, Hospital Association of RI
- Ray Ortelt**, Pawtucket Memorial Hospital
- Cedric Priebe, MD**, Care NE, Co-Chair
- Ray Sessler**, Neighborhood Health Plan of RI

- Tracy Williams**, RI Dept. of Administration
- John Young**, RI Department of Human Svcs

Management Committee

- Laura Adams**, RIQI
- Deidre Gifford, MD**, Quality Partners of RI
- Jeremy Giller***, Clarendon Group
- Leonard Green**, RI Department of Health
- Laura Ripp**, Consultant, Project Staff
- Melinda Thomas**, Department of Human Svcs
- Patrick Vivier, MD, Ph.D.**, Brown University
- Judy Wright**, RIQI
- Amy Zimmerman**, RI Department of Health

Other Attendees

- Mary Ellen Casey**, Quality Partners of RI
- Reid Coleman, MD**, Lifespan
- David Gifford, MD**, RI Department of Health
- Jeff Newell**, Quality Partners of RI

MEETING PURPOSE

To discuss project status; review and discuss implications of data stewardship, the Governor's health IT funding initiative and other emerging aspects of the Health Information Exchange project.

AGENDA

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| 7:00 – 7:05 | 1. Call to Order, Welcome and Introductions
<i>Carole Cotter, Lifespan, Steering Committee Co-Chair</i> |
| 7:05 – 7:10 | 2. Consideration for Approval: 3/23 Meeting Minutes
<i>Carole Cotter, Lifespan, Steering Committee Co-Chair</i> |
| 7:10 – 7:45 | 3. Project Update
<i>Carole Cotter, Lifespan, Steering Committee Co-Chair</i>
<i>Amy Zimmerman, Rhode Island Department of Health</i> |
| 7:45 – 8:00 | 4. Status of the Governor's Bond Issue
<i>Cedric Priebe, MD, Care New England, Steering Committee Co-Chair</i>
<i>Tracy Williams, RI Department of Administration, Division of Information Technology</i> |
| 8:00 – 8:20 | 5. Naming the RI Health Information Exchange: Narrowing it Down
<i>Carole Cotter, Lifespan, Steering Committee Co-Chair</i>
<i>Jeremy Giller, Clarendon Group (feedback from Consumer focus groups)</i> |
| 8:20 – 8:45 | 6. Data Stewardship Issues and Process: Continued Discussion
<i>Cedric Priebe, MD, Care New England, Steering Committee Co-Chair</i> |
| 8:45 – 9:00 | 7. New Business: Memo from Ted Almon—What approaches will foster cooperation among competing health entities to promote success of the health information exchange in RI?
<i>Cedric Priebe, MD, Care New England, Steering Committee Co-Chair</i>
<i>Ted Almon, Consumer member</i> |
| 9:00 | 8. Recap Next Steps and Adjourn
<i>Cedric Priebe, MD, Care New England, Steering Committee Co-Chair</i> |

MEETING SUMMARY

1. Call to Order, Welcome and Introductions

Carole Cotter, Co-Chair, opened the meeting at 7:02am and welcomed the group. Tracy Williams, RI CIO, requested that the item titled, "Status of the Governor's Bond Issue" be moved forward in the agenda so she could provide a report to the Committee immediately after the Project Update. The agenda was resequenced as requested.

2. Consideration for Approval

■ 3/23 Meeting Minutes

Ms. Cotter directed the group to the last meeting minutes and asked for comments and corrections. A motion was made and seconded to approve the March 23, 2006 as written. All Steering Committee members present voted in favor of approval.

Action Items:

March 23, 2006 meeting minutes are accepted as written.

3. Project Update

Amy Zimmerman referred the group to the Project Update handout summarizing project activities completed during March and those planned for April. Key points of the update included:

■ RI Health Information Exchange (HIE) Request for Proposals (RFP)

Responses to the HIE RFP are currently under evaluation by the official State Review Committee. Reviewers are seeking a balance between concepts advanced by the Technical Solutions Group and Data Sharing Partners and what is technically desirable and feasible. The Review Committee expects to be able to achieve this balance. Community (unofficial) reviewers that have signed non-disclosure agreements and completed a conflict of interest addendum will be engaged in the review process to provide perspective and feedback to the Review Committee.

Action Items:

Continued updates will be provided on the status of proposal review and evaluation process.

■ Subcontract Status

The contract with Brown University for project evaluation has been fully executed, a purchase order has been issued and a kick-off meeting is pending to begin planning the draft evaluation plan deliverable due in September 2006.

Expecting notice by May 5, 2006 from RTI International as to RI's status in the award of contracts for the Health Information Security and Privacy Collaboration (HISPC) initiative. HEALTH is seeking permission from the RI Division of Purchases to contract with the Rhode Island Quality Institute to help support this broadly collaborative, statewide effort.

Action Items:

Contracting activities are ongoing. Continued updates will be provided.

■ **Consumer Advisory Committee (RIQI)**

Jeremy Giller, Clarendon Group, provided an update on the Consumer Advisory Committee (CAC), co-chaired by Marti Rosenberg (Ocean State Action) and Mary Jones (consumer). Membership of this committee is still evolving. Clarendon has been conducting consumer focus groups and have completed three sessions of four (Spanish-speaking group to be convened). The groups spanned a range of demographic, academic and economic characteristics. In general, emerging themes from the focus groups include: (1) A desire for comprehensive capability for information sharing in support of their health care. Consumers felt the idea of providers across disciplines being able to communicate about their care was a strong and important attribute of the health information exchange concept; (2) An emphasis on security of health data as the number one concern followed by how much control consumers have over who has access to their information. Controlling access to electronic health information was important but consumers also wanted such a system to have the capability to produce an audit log. Further, consumers preferred to be notified when access occurred.

Amy Zimmerman noted that Clarendon has produced a literature review reflecting current knowledge of consumer attitudes on health care information exchange. Tracy Williams noted that there is a identity theft bill under consideration which will have some notification provisions, especially as it relates to consumer access to information requests. As an example of how consumer considerations may impact the HIE, Lenny Green noted that in the State's Vital Records, birth records are managed and provided in English, however, instructions and information about them is provided in many different languages. Instructive information on the HIE will likely need to be offered in several languages to support consumer understanding.

Action Items:

Clarendon will provide a final report on focus group outcomes that will be used in the CAC to inform discussion and decisions. Amy Zimmerman will forward the Clarendon consumer literature review to the Steering Committee.

■ **Administrative Data Exchange (RIQI)**

John Young provided an update on Administrative Data Exchange. He noted that at this time, meetings have been conducted with all payers and there seems to be a common interest in pursuing the issue of data sharing. A formal work group will be organized. Carole Cotter noted that this work should provide an opportunity for participation by all payers and noted that there are some ongoing initiatives that should be included within the scope of considerations by an Administrative Data Exchange committee.

Action Items:

Carole Cotter will provide a list of people participating in current administrative data initiatives to the Administrative Data Exchange group. Continued updates on progress and constitution of a working group will be provided.

■ **Policy and Legal Committee (RIQI)**

Amy Zimmerman provided an update on the Policy and Legal Committee (PLC) and its committees. Of special note, the group has been focused on consent and uses of data. A subset of PLC participants met with the Professional Advisory Panel (PAP) at its April 26th meeting to gain additional insights into provider perspectives on specific issues

around patient consent and provider authorization matters. The synthesis of these issues will be addressed in the larger PLC group. As a complement to this work, the PLC will have a key role in helping RI address a specific range of policy and legal issues for health information exchange as part of the RTI/NGA HISPC initiative, should RI receive an award.

Action Items:

Continued updates on PLC activities will be provided.

■ **Professional Advisory Panel (PAP—QPRI)**

Dr. Deidre Gifford, Quality Partners of RI (QPRI), provided an update on the recent PAP meeting conducted April 26, 2006. PAP members in attendance were joined by PLC members Joan Flynn, Maureen Glen, and Linn Freedman, attorneys; and Dr. David Gifford, PLC Chair.

The purpose of the meeting was to engage PLC and PAP members in a dialogue to gain clarity on several issues that PAP members felt were critical to understand from a legal and policy perspective. Three issues were discussed during the PAP meeting. Two of these issues had been advanced to the PLC for consideration through a formal Request for Action; an additional issue was added.

In summary, on the issue regarding patient choice to “opt-out”, i.e., formally decline participation in the planned RI health information exchange (HIE), the PAP opinion is that patient participation in the HIE should be “all or nothing”. That is, for patients who accept the use of the HIE to access their protected health information (PHI), all available PHI should be made available to authorized providers in support of clinical care. Some PLC members advanced an option for patients to have a choice to opt-out of allowing data into the HIE at individual clinical encounters.

A second issue included whether a primary physician could transfer rights of access to their consenting patient’s data in the HIE to a consulting physician (through a clinical referral). The PAP position included allowing current practice to prevail, thereby allowing a provider to share patient information with consulting physicians for purposes of clinical care without requiring patient consent for disclosure. PLC positions ranged, however there was some clarity about the realities and complexities of any other approach.

A third issue related to whether or not patients could be permitted to control access to PHI at a discrete data level. That is, for given sets of information in the HIE, should patients be permitted to block certain parts of that information from otherwise authorized users. PAP members generally believe that all information available in the HIE should be accessible by authorized providers, i.e., no blocking should be allowed, with the exception of legally protected classes of information. PLC opinions varied on this issue. The PAP stressed the need to have access to as much information as needed to make sound clinical decisions. Regarding the type of provider that may have access, there were questions in the PAP and also reflection in the consumer groups that imply the need for role-based access. That is, access to PHI should be limited to providers with a “need to know” and time restrictions on access to PHI in the HIE by certain types of providers should be considered.

Overall, the discussion was productive; PAP and PLC perspectives were shared and the legal and policy basis for these critical HIE issues was informed. As noted above, the PLC will develop a formal response to the questions discussed.

Action Items:

Continued updates on PAP activities will be provided.

■ Pharmacy Subgroup (QPRI, other)

Jeff Newell (QPRI) updated the group on current Surescripts projects focused on electronic prescribing (eRx) information with an intent to expand work on medication history.

Action Items:

Continued updates on pharmacy data exchange issues will be provided.

■ Other Updates

Ms. Zimmerman updated the group on the Connecting Communities for Better Health meeting in DC (a program of the eHealth Initiative). An InformationLinks meeting was also conducted as an additional conference activity. RI was represented at both meetings. Of special note is the growing recognition of the need to involve public health and state governments in HIE initiatives. In some ways, RI is advancing some mature thinking especially around accountability for data use at a state level. RI must answer questions regarding how the HIE is held accountable for information management. Additional considerations included how best to increase RI collaboration with or involvement in other surrounding state initiatives such as Massachusetts and how RI should pursue opportunities to leverage progress being made in Medicaid information system and technology architecture initiatives (MMIS/MITA).

Laura Adams reported that AMIA has constituted a Blue Ribbon Panel to conduct a meeting to produce a consensus paper; Paul Gertman of RIQI's PLC is participating on the panel. In addition, the Office of the National Coordinator for Health Information technology (ONC) has organized a project, staffed by the American Health Information Management Association (AHIMA), to describe best practices in statewide Regional Health Information Organizations (RHIO). RI was chosen to participate. Information will be shared with AHIMA staff during a site visit in May with target publication in July 2006.

LA also noted that The Robert Wood Johnson Foundation (RWJF) is examining 14 different markets to identify opportunities for projects to move forward. A team from RWJF will be meeting with the RIQI Board to explore RI activities.

Action Items:

Staff will report on the status and evolution of these and other related issues.

4. Status of the Governor's Bond Issue**■ Discussion:**

Carole Cotter turned the floor over to Tracy Williams, RI State CIO. Ms. Williams updated the group on the outcome of the budget hearings conducted on April 12, 2006. In summary, there are nine projects requesting funding of which \$20 million is requested for HIE and \$15 million for education. These could be synergistic initiatives. The Senate Finance Committee hearing was focused on the balance of the portfolio—the letters provided by the community were very helpful in advancing the need for the HIE. In the House Finance Committee, the discussion moved to the method of financing. A revenue bond was proposed as a method for consideration. A revenue bond is

produced by a bond issuer who goes to the market to identify and engage financiers. Such a bond, and the interest to carry it, must be sustained by revenue that the HIE would produce. This approach is similar to other capital investments that the state wants to make. For example, dorms at the University of Rhode Island were financed through tuition revenue to build a building. Rationale for the proposed funding model is the need to find an equitable way to fund the infrastructure to connect both the public and private sector in the HIE. The State did not believe it should fund or risk the entire amount since private sector entities will benefit as well. Both hearings were completed and the legislative process continues. Other meetings will be conducted to move the issues forward. As for a timetable, the vote in the House and Senate will be held in June.

What happens if the bond is denied? The State will continue to pursue other options. Dr. Reid Coleman made the point that it is critical to identify who will be responsible for sustainability. Must be able to cover operating costs and pay back principle and interest on the bond. The responsible entity has not yet been identified. The role of the RIQI must be clarified. These are preliminary discussions and there are many considerations about the prospects for what kind of organization (what authority) must be positioned to take on responsibility for the bond. A more detailed sustainability plan is needed.

Action Items:

Continued updates will be provided.

5. Naming the RI Health Information Exchange: Narrowing it Down

■ **Discussion:**

Jeremy Giller introduced the topic of naming the Rhode Island HIE and informed the group that preliminary feedback on a basic subset of potential names was tested in the recent consumer focus groups. The names tested included:

- OmniCare
- UniCare
- WholeCare
- HealthIE

In summary, the word "Care" registered much better than "Health". The letters "RI" have not performed well. Consumers indicated some resistance to a reference to government in the HIE name. Names ending in -e and IE did not do well as they were felt to be "too cute". The term "information exchange" also does not register well. Themes related to care of the "whole person" performed well as did wellness themes. Acronyms were not helpful.

Action Items:

Clarendon will continue its testing in the final focus group. Staff will create another iteration of naming options again and return them to the Steering Committee for consideration.

6. Data Stewardship Issues and Process: Continued Discussion

■ Discussion:

Dr. Cedric Priebe, Co-Chair, provided a brief overview of the evolution of the discussion on the topic of data stewardship: (1) The Steering Committee highlighted the importance of addressing HIE sustainability issues → (2) Issues around uses of data in the HIE beyond clinical care were discussed → (3) A draft framework which categorized forms/levels of data exchange was reviewed → (4) a formal Request for Action (RFA) to define a process for formulating these questions was issued to the PLC → and (5) The PLC indicated that such a process must be addressed to another group, either the RIQI Committee of Chairs (not yet constituted) or the RIQI Board.

Laura Adams reported that the Committee of Chairs (a.k.a. Coordinating Committee) met on April 26, 2006. This group is primarily composed of the Chairpersons for RIQI Committees and key RI HIT Project staff/contractors. The group is charged with **Representation** of all other committees efforts, progress and intersections; **Coordination and communication** between committees or initiatives where there is overlap, intersection or a dependency; and **Prioritization** of items (structured and presented in an actionable format) that require decisions to the Board.

While much of the meeting was organizational, the group did note the need for a clear definition of the RIQI role and functions as the proposed RI RHIO. The Common Framework promulgated by the Markle Foundation was noted to be a sound starting point for considering RHIO functions. A key question to be answered is, "Who is the certifying authority for data use questions?" The Committee of Chairs will proceed with addressing this, and related issues.

Amy Zimmerman noted that RI's proposal to AHRQ for the current HIT Project included some basic understanding that identified data would be used for clinical purposes and deidentified data may be used for other purposes. There is still a comfort level with this approach among participants in the Committee of Chairs. The question arose as to whether RIQI is now being assumed to be the authorized entity. It was stated that this assumption is a change from initial conceptual discussions of RIQI's role.

John Young noted that much of the required authority will lie with those who are named to support the revenue bond. As sustainability issues are considered, there may be expanded considerations for uses of data. If a different group is named as the "authorized entity", it is likely that many of the RIQI Board entities would participate. If RIBeck is the bond issuer, there are also qualifications for entities that could be accountable. A similar model is the state HIT fund for which RIQI provides oversight. The bond issues goes to who is responsible for paying the debt.

Laura Adams emphasized the importance of coming to a decision. She noted that we are at a point of transformation which requires clear articulation of responsibility and willingness on the part of the RIQI Board. If the Board agrees that it, and the supporting organizations, wish to take on this activity, then a starting point has been identified. If not, there is another process that must be pursued. In any case, the authorized entity needs to be acceptable to stakeholders.

Deidre Gifford noted that the Steering Committee has not articulated what it feels the authorized entity should include such as functions, characteristics, etc. Maria Montenegro noted that if RIQI (or whoever) assumes financial responsibility, what license/authority

will they have about uses of data? How must its governing rules change to meet stakeholder expectations and objectives, etc.? There must be a process for addressing the public's interest in this data and how it is used.

Laura Adams reviewed the timeline for a RIQI decision. The May meeting will be focused on educating the Board; a detailed process of consideration of options will continue through to the June meeting. John Young noted that the RIQI Board may not be able to thoroughly vet the issues before June, considering the depth and complexity of the considerations.

Deidre Gifford added that the Steering Committee can help articulate the expectations of this entity. Amy Zimmerman reminded the group of the scope issues relative to the initial role of the Steering Committee and some of the transitions that have taken place that illustrate the blending of issues pertaining to the HIT Project and the broader RHIO. This complexity is reflected in the governance mechanisms currently evolving. She advocates continuing to work through the process with the RIQI Board while the Steering Committee helps articulate what they feel the community requires. Dr. Coleman noted three prevailing entity models (1) government; (2) not-for-profit organization; and (3) vendor community. It was noted that a fourth model has also emerged, that of private, for-profit entities governed by stakeholder/investor organizations. No resolution was reached as to the Steering Committee role in these discussions.

Action Items:

Continued updates will be provided on the process and deliberations of the RIQI Board.

7. New Business: Memo from Ted Almon

■ **Discussion:**

Dr. Priebe directed the group to a memo in the meeting materials written by Ted Almon, Steering Committee member. He turned the floor over to Mr. Almon who presented his perspective on the HIE and how he feels the group could improve its focus on solving the most pressing problems. Mr. Almon believes we are operating in a competitive health system and these forces are contrary and in opposition to moving forward and making decisions about the HIE. He advised that the group go back to its original purpose to build a system that puts the patient in the middle but that provides enough support for consumers so they can reap the benefits of the system. Mr. Almon also believes that the HIE should be operated by the most neutral entity possible that most people would trust. He suggested that the State could fill this role. Steering Committee members were appreciative of Mr. Almon's perspective and acknowledgment of the complexity of the planning and operating environment for the envisioned HIE. Time constraints precluded further discussion.

8. Recap Next Steps

- The next Steering Committee meeting is scheduled for Thursday, May 25th at the same location.

9. Adjourn

- Dr. Priebe thanked the group and adjourned the meeting at 9:05 am.