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Health Information Exchange (HIE) Advisory Commission
August 6, 2015
Meeting Minutes (DRAFT)

Attendance:

Commission Members: David Gorelick, MD (Chair); Nicole Lagace; Lisa Shea, MD; Ted Almon
State Staff: Melissa Lauer (RIDOH); Amy Zimmerman (EOHHS); Nicole Alexander-Scott, MD, MPH (Director of Health)

Guests: Amy Nunn, ScD (Rhode Island Public Health Institute), Laura Adams (Rhode Island Quality Institute), Elaine Fontaine (Rhode Island Quality Institute), Mike Dwyer (Rhode Island Quality Institute), Alok Gupta (Rhode Island Quality Institute), Darlene Morris (Rhode Island Quality Institute), Lauren Morton (Blue Cross Blue Shield of Rhode Island)

1) Meeting Called to Order: at 3:34PM by Chair, Dr. David Gorelick.

- a) Introductions
- b) A motion was made by Mr. Almon to approve the minutes and seconded by Ms. Lagace. The minutes (May 28, 2015) were approved unanimously.

2) Public Comment:

- a) Ms. Adams gave an overview of RIQI and its various functions.
- b) The placement of the public comment session at the beginning of the agenda was questioned by Mr. Almon and discussion ensued. No specific recommendation was made.

3) HIE Data Release for Public Health Functions

- Director Alexander-Scott has requested the Commission's input on HIE data release for Public Health Functions. Ms. Lauer presented a few example data uses within the Department of Health (DOH) and also with DOH research partners for context.
 - RIQI has received a handful of requests from the DOH to date, including CurrentCare Viewer access for the State Medical Examiner and for the State Epidemiologist.
 - Mr. Almon asked how the All Payer Claims Database (APCD) could be used to fulfill those data needs of DOH. Mrs. Zimmerman answered that the APCD is fully de-identified and under the APCD law there is a Data Release Review Board which reviews data requests to be approved by the Director of Health. The APCD is claims data only, while the HIE contains clinical data such as test results.
 - Dr. Shea emphasized the difference between a Medical Examiner request for a specific individual and data file releases for a researcher, since there are study participant requirements for research.
- a) Review of HIE legislation and regulations regarding data release**
- i) Excerpts from the Health Information Exchange Act of 2008 and the Rules and Regulations Pertaining to the Health Information Exchange were reviewed (see Appendix 1). Mrs. Zimmerman summarized that within the context of the law,

- there are three types of disclosure – 1. Treating provider, 2. Operations and maintenance (RIQI), 3. To a public health authority for its functions.
- b) Review of Public Health Functions
- i) A list of chapters of the Rhode Island General Laws which pertain to the Rhode Island DOH and its functions was distributed (Attachment 2). Additionally, Commission members and guests received a DOH organizational chart dated July 17, 2015 (Attachment 3). Ms. Lauer described the functions of the six divisions of the DOH.
- c) Potential data release model and criteria
- i) A draft data release model was distributed (Attachment 4). Ms. Lauer presented the flow of data request to data release as illustrated by the chart.
- ii) The data release chart illustrates that all requests will be compared against a criteria by the assigned DOH staff. These criteria will be recommended to the Director of Health by the HIE Advisory Commission. In scenarios where the staff is unable to make a clear determination against the criteria, the request will be presented to the HIE Advisory Commission for comment and recommendation.
- d) Discussion regarding data release recommendations
- i) Ms. Lauer asked Commission members for their input on:
- (1) The data release model
- (2) Potential criteria for state staff to use in order to determine whether a data request meets the requirements of the law for data release.
- ii) Mrs. Zimmerman emphasized that it may take several meetings to fully develop criteria.
- iii) Commission members commented the following:
- Dr. Shea observed that if the volume of requests is huge, there may need to be a sub group of the HIE Advisory Commission to review data requests regularly.
 - Dr. Gorelick suggests that before requests get to the Commission, the proposals be prepared by state staff to reduce the burden of reviewing multiple requests.
 - **There was consensus that the data release flow chart was acceptable as presented**, but Dr. Shea recommended that receivers should have to report back to the Commission on the outcome of the research and/or data use. Mrs. Zimmerman suggests this could be worked into the MOU. Dr. Gorelick agrees that there should be a feedback loop so at a specific time there must be a report back to the timeframe. Ms. Nunn mentions that an Institutional Review Board (IRB) requires feedback annually.
 - Ms. Nunn provided input on how the IRB process works: A researcher must report back to the IRB and must meet Helsinki Medical Research Guidelines. Mr. Gupta adds that in a study the IRB will required to have informed consent for all study participants. Ms. Nunn notes that a waiver can be applied for in very large studies, but usually is only granted if the records are de-identified. Ms. Fontaine states that under current law, even with IRB approval and informed consent of study participants, RIQI is not allowed to release records.
 - Mrs. Zimmerman mentioned that the Department of Health (DOH) has an IRB, and that there is often a question of how to differentiate between evaluation

and research, and when something has to go to the IRB. There will need to be some coordination and work with the DOH IRB.

- Ms. Lagace asks if the current enrollment authorization form mentions the potential for public health authorities to have access to identifiable information. She is asking how well someone who opts in understands that their identifiable records could be shared for this purpose. **It is requested that the current enrollment authorization form be shared at the next meeting.** Ms. Lagace also mentions that she opted in years ago and had to check with her physician to learn that she was enrolled. She notes concern that participants in the HIE might not understand during consent the far-reaching opportunities for access. Ms. Lagace questions whether there should be some more communication on enrollment.
- Dr. Shea asks what happens if the medical board wants to review data on doctors, with or without an investigation? Ms. Lauer answers that that could be a potential use of HIE data as a public health function, but it would have to stand up against the criteria.
- Dr. Gorelick asks Ms. Adams if RIQI has had any requests yet.
 - Ms. Adams answers that there have been three requests, but they all occurred this year and it is possible that the frequency of requests could pick up. The Dean of Medicine and Biological Sciences at Brown University is now on the RIQI board, and she expects it to increase awareness in the research community. All three requests had already received patient consent.
 - Ms. Adams adds that these studies are on hold because even with patient consent, the HIE cannot release data.
- **Dr. Gorelick asks that IRB criteria or a summary of the IRB process be provided at the next meeting.**
- Dr. Shea also mentions that for potential data requests, the Commission will review both processes that do go through an IRB and also processes that do not go through the IRB.
- Dr. Shea recommends that the first criteria be: Does the data need to be identifiable?
- The Commission members agree that due to the work needed to create criteria and put a process in place, an additional September meeting should be convened.

4) Schedule and Topics for Future Meetings

- A new meeting has been scheduled for September 9, 2015 from 3:30PM to 5:00PM. The topic of this meeting will be establishing criteria for public health data releases.
- The October 1 meeting date is being rescheduled for October 22, 2015 from 3:30PM to 5:00PM.

5) Meeting Adjourned at 5:00 PM