Legal & Policy Advisory Group Meeting
March 18, 2014 2:30-4p

Name	Organization
Kathleen Snyder	EOHHS Legal
Sarah Moore	Tufts Medical Center
David Szabo	Edwards Wildman Palmer LLP
Darrel Harmer	EOHHS
Sean Kennedy	MeHI
Adam Tapply	Center for Health Information and Analysis
Support Staff	Massachusetts eHealth Collaborative
Micky Tripathi	Massachusetts eHealth Collaborative
Mark Belanger	Massachusetts eHealth Collaborative
Jennifer Monahan	Massachusetts eHealth Collaborative

Review of Materials and Discussion

Project Updates

- HIway Operations Update (as of February 2014) (Slide 2)
    - This was a slide from the last Health Information Technology Council (HITC) meeting. It gives a 13 month view of transaction volumes.
    - Four new Participation Agreements (PA's) were competed in February- the Carson Center for Human Services, Fairlawn Rehabilitation Hospital, Mount Auburn Hospital and Dr. John D. Murdock. We can get the full customer lists out more regularly if people are interested.
    - There are now 132 HIway participants, 104 participants are live and 5 participants went live. Total transactions in February- 109,021, putting totally transactions above two million- 2,096,557. Those transactions are mainly around quality reporting and Public Health reporting- starting to see more provider to provider transactions rise as more trading partners come online.
- Mass HIway Release Schedule (Slide 3)
    - This is a slightly different list than you are used to seeing on the update, this is a more detailed plan of the development timeline - a 6 month horizon on the programs they are planning to release. In the near term registries will be going live, there is a plan for the provider directory upgrade and a webmail upgrade in April. The webmail is a very light weight viewer which will allow places like long term care facilities to use the HIway. External Data Representation (XDR) will be out in April. The Executive Office of Health and Human Services (EOHHS) continues to make good progress with Health Information Service Provider (HISP) to HISP connectivity. Right now there are 6 different HISP's at different levels of testing.

- Question: Any information on what the HISP to HISP connection will look like when they go live?
    - Answer: A lot of work is being done right now to assure they are encrypting and decrypting properly. There are variances in the way vendors interpreted the Direct standards - this might be a messy iterative process for a few more months. There are some HISP's that are newer to the game and will likely take longer to implement.

- Last Mile Program Wrapped Up on February 7th (Slide 4)
    - The Last Mile Program concluded with the end of the Statewide HIE Cooperative Agreement with ONC. The Massachusetts eHealth Institute (MeHI) Grantees will now receive assistance from EOHHS. The HIway will look to MeHI to assist with the education, outreach and overall communication.
    - Comment: MeHI, in addition to the learning efforts, will be focusing on use case development. The hope is to take a deeper dive into the use cases and start to build a use case library. Future participants can use the library to think through their potential use cases and collaborate with others.

Discussion: Phase 2 Consent Policy and Documents

- Mass HIway Phase 2 Document Architecture (Slide 6)
    - The team at EOHHS has been working on several documents. There is an arrow going through this slide because consent changes flow through all of the documents. Because of the Chapter 224 language around consent and the fact that data will be stored by the Commonwealth for the RLS, there is a need to look at a few different documents and update them. First is the Phase 2 services addendum – for participants going from Phase 1 to Phase 2. There is a set of policies and procedures, a consent template and consumer education materials. The educational materials will not be required, but encouraged. Participant training guides will be used to educate new participants and the website resources will be available for download as well.
- Consent Policy - Scope of Consent (Slide 7)
    - There is not a whole lot new here. As has been the case, participants are responsible for getting patient permission- permission pertains just to the HIway. Participants still need to get any additional consent for things like sensitive conditions.
- Consent Policy – Levels of Consent (Slide 8)
    - There are two levels of consent that are mapped to the Phases – Push/Direct Messaging and query and retrieve. The stance on the consent for Phase 1 is the same- participants need patient permission and the consent form must name the HIway. For query and retrieve they must also get permission to publish demographic information to the RLS.
- Consent Policy – Forms and Language (Slide 9)

    - The policies on how Phase 2 consent will work came out pretty flexible- there are no prescribed forms or language. The idea is that the HIway will produce some template language- hopefully people will find that useful. Participants do have the flexibility on whether or not to use the HIway materials. The hope is that this will be more market driven, rather than HIway produced. A number of workgroups are digging into this now. The end product will be something that the community has developed together.
- Consent Policy – Duration of Consent (Slide 10)
    - Consent is not time limited and does not expire. There are a few things that trigger a need to gather new consent- if a Participant is moving up to the Phase 2 services there is a big step up in functionality - if a Participant is brand new and wants to do Phase 1 and Phase 2 the recommendation is to use the Phase 2 consent form. The other trigger is when a minor turns 18. Participants should follow the law and their own internal policies for dealing with minors.
    - Question: Does that mean it is up to the organization to send that ADT, or will that be something the HIway will do to block the minors?
        - Answer: We should know fairly quickly if we can do an automatic shut off. We will keep you posted on where that lands.
    - Question: When would you do the auto change?
        - Answer: If a patient turns 18, assuming they had guardians consent before, you now need the patients consent. There is a technical backstop that could be created to shut off the minor on his or her birthday.

Does the group feel the HIway should do an automatic flip, or would you prefer that the participant is responsible for monitoring age?

- Response: I would prefer the HIway shut it off, and send an auto notice- something like "In 30 days this patients consent will expire."
- Response: From a policy perspective, there is a benefit to leaving them in the RLS- that age group is not seeing a primary care provider regularly, but are often in car accidents.
- Response: There is enough potential for conflict here if we say we will honor the consent until it is cancelled. There should be a way to ping the organization to say that the patient is turning 18- there is the potential for a lot of issues if the individual diverges from what their parents preferred.
- Response: At Tufts it comes down to what the right thing to do is- an adolescent may have an accident where the information is useful, but at the same time the

parent gave permission when they were a minor. It is easier for us to query and change consent.

- Response: For small doctors they would need to run a report every day. In an adolescent practice that could be a larger burden.
- Response: I have discomfort with having a policy to keep it [consent] switched on.
- Response: Other organizations have indicated that when a parent gives consent for their child, at age 12 they need a new consent form, then again at 18.
- Response: At the risk of overcomplicating things, if we are talking about a system that is tied to a patient portal there are serious legal obligations around access to the portal.
- Response: Until you have a "quilted" consent model it just becomes unmanageable.

- Consent Policy – Changes in Consent, Audit Logs (Slide 11)
    - Patients can change their consent preference as many times as they want and participants must be able to process those changes- including notifying the HIway.
    - Question: Do we need to track the changes in consent?
        - Answer: The HIway will never see a patient who did not give consent- Orion is dumping any ADT that has a "no" flag. The HIway only knows if someone changed from a yes to a no- that would be in an audit log. If the patient goes from a no to a yes the HIway would just see that the latest consent is a yes.
    - Question: Do you expect anyone to ask for that? Saying you got my consent wrong. I would think participants would want to keep a log.
        - Response: eClinicalWorks only keeps the date of the last consent change.
        - Answer: For audit logs we are asking the point of contact to always remain with the participant. If a participant asks you for disclosure of information that pertains to the HIway, it would be up to you to contact the HIway Operations Team. They can see and track when the patient has a published event on the RLS, that someone viewed the RLS for that patient and when someone has queried for that information. They cannot see a response to the query. Limitations are by design.

For Discussion: Document Review

A lot of work went into determining what patients really should know about the HIway. When all was said and done the educational materials were close to 8 pages – we received feedback that said we need to shorten the document so patients can understand it better. A plain language specialist took a first whack at the materials- she cut a lot and we ended up with the document here. We have been vetting this with the Provider, Consumer and Consent Advisory Groups. The main goal is striking a balance- short but gets across the key points. Today we would like to get your initial reactions to the materials, feel free to send any further feedback to Mark in an email.

This is a document given to patients either at an intake area of a hospital or front desk at a provider office- it could also be sent via portal or mail ahead of time. The content is the main thing we are worried about at this stage. It explains what the HIway is, who can use it, lets the patient know this is not mandatory and there is no storing of medical data- this is about transport and location not actually holding health information like an EHR. A group is working on an illustration to add to this.

There is a list of benefits based on a lot of other literature and the Platinum Spike event- the goal being to highlight the safety, quality and convenience benefits. On the second page it drills into more detail- it tries to lay out the risks of having information sent over the HIway and what it means when you say "yes."

Recognizing that this content is completely rough, do you have some initial thoughts? Hopefully we can put some information in boxes and include a graphic to help with length.

- Question: Is it worth mentioning insurance companies- and when an insurer will have access to data on the HIway?
    - Answer: We had a discussion with this group, we had decided initially that maybe they should not be included, but then thought through the benefits. There are a lot of issues around payers that still need to be worked out. We are still anticipating that there will be some role for payers but we need to define what that role is before we mention them. I think two of the hot button issues are the insurance industry and then the role of the government. We might want to say not now, but in the future.
- Comment: It is hard because we cannot show an example now because we do not have any. We want people to understand what they are consenting to, not give misinformation. They need to know that certain demographic elements will be sent to the RLS and who would have access to them.
- Comment: We should add something positive about insurers, care management for example. Also, what more can we say about the limitation of how the government can access this information?
- Comment: We could have something that says, "Access is limited to x." Maybe say "only authorized individuals involved in monitoring the system."
- Comment: I think as patients we are concerned about what the payers see and what they can do with it. This needs to negate the idea that they can go in and get more than what they could have.
- Comment: This is where the balance is really difficult especially when you take into account some of the language barriers and varying literacy levels. We do not want participants to take too much information out of the educational materials and mislead patients.
- Comment: If we are going to say insurers above I think we need to hit it with an example. If we do not include it now then we would need to re-consent patients when insurers do join. It needs a solid example, something like a big inconvenience (prior authorization etc).

- Comment: It is hard because this is graduate school content, needed at something like a 7th grade reading level.
- Question: Who pays for the education materials?
    - Answer: The participant would be expected to pay. It would be something like a pdf they can download from the HIway website and take it as is, or just use it for guidance.
    - Response: I see this as a potential barrier if it is going to cost them.
    - Response: For the small guys they are not paying a lot for use. It would be the cost of printing copies on their printers.
- Question: How many languages will this be provided in?
    - Answer: Right now we are leaving it up to the practice.
- Question: The material is about query and retrieve, what about consent for just the Direct services?
    - Answer: This is intended for the participants who have signed up for the Phase 2 services.

Next steps

- Key points and recommendations synthesized and provided back to Advisory Group for final comments
- Presentation materials and notes to be posted to EOHHS website
- Next Advisory Group Meeting – Not yet scheduled - TBD
- HIT Council- April 7, 3:30-5:00 One Ashburton Place, 21st floor.

HIT Council meeting schedule, presentations, and minutes may be found at http://www.mass.gov/eohhs/gov/commissions-and-initiatives/masshiway/hit-council-meetings.html