Consumer Advisory Group Meeting

October 28, 2013 12:30-2:00 P.M.

Name	Organization
In Person	
Alec Ziss	CapeCare
Vanessa Pettigreu	Regis College
Kathleen Donaher	Regis College
Lisa Fenichel	eHealth Consumer Advocate
Phone	
Eileen Elias	JBS International
Amy Caron	EOHHS
Sean Kennedy	MeHI
Support Staff	Massachusetts eHealth Collaborative
Micky Tripathi	Massachusetts eHealth Collaborative
Mark Belanger	Massachusetts eHealth Collaborative
Jennifer Monahan	Massachusetts eHealth Collaborative

Date	Physical Location	Dial In
23-Oct-~~13~~ 28 10:00-11:30	In Person - MMS Middlesex Central Conference Room	Phone line open but in person attendance encouraged
18 Nov-13 12:30-2:00	In Person- Room TBD	(866) 951-1151 x. 8234356
22-Jan-14 10:00-11:30	In Person - MMS Middlesex Central Conference Room	Phone line open but in person attendance encouraged
26-Feb-14 10:00-11:30	Phone only	(866) 951-1151 x. 8234356

Review of Materials and Discussion:

The Purpose of today's meeting is to complete another review the Phase 2 policy positions before they are finalized by the EOHHS legal team. The policy positions will become part of the Mass HIway phase 2 Participation Agreement (PA) and Policies and Procedures.

EOHHS has said that they do not want to create or require a single consent form for all HIway participants, there should be flexibility with the language and format because not all practices are the same. There will be a few pieces of required information, but organizations will have the opportunity to operationalize consent gathering as they see fit. EOHHS will create/gather some consent form examples to help guide organizations.

- Question: Sounds like a lack of uniformity could create a problem?

    - Answer: This was a conscious part of the design; the forms should all be asking the same thing, but how they ask is up to the organization. There will be a user group to focus specifically on the consent requirements. The hope is that a few groups will come up with an example, and others can use theirs as guidance. EOHHS does not want to say that this is THE form you must use.
- Question: Have people been following the guidelines in the Phase 1 agreements?
    - Answer: Yes, in the Phase 1 forms you are consenting that the organization can share your information with other providers involved in your care. The Phase 2 agreement will add language around who this information is being shared with and how.
- Question: Do consumers know that the MassHIway is being used?
    - Answer: The policy position now states that the MassHIway must be named on the consent forms.
- Question: How will consumers understand what the HIway is?
    - Answer: The collateral that is developed should explain what the HIway is and how it will be used.
- Comment: Relying on a website for information is silly; many people will not access it, or cannot access it for a number of reasons. There have been materials developed already by this group.
- Comment: Education around what this all means will happen at the time of consent, in the provider office. It will be up to the provider to educate the patient.
- Comment: How is there going to be a presentation tailored to all of the consumer groups out there? Town hall meetings or presentations at specific organizations, like senior centers, will be necessary.
- Comment: The issue there is that not everyone will participate in these forums.
- Comment: At the end of the day most patients trust their providers and may not be as receptive to a presentation.
- Question: What has happened to the draft education materials this group created? It was decided that it was too high-level so someone was going to review the content? We never saw the draft again.
    - Answer: The draft was sent to EOHHS for approval and feedback; did not want to provide materials back if EOHHS was going to make changes.
- Question: Why use the Mass HIway?
    - Answer: Joining the HIway is low cost compared to other options. The information is sent more securely, care is timelier; quality of care is increased as the provider has more information on the patient at the point of care.
- Question: How will the consumer know that?

    - Answer: It should be explained to the patient; this is a way to ensure that your information is shared with your care network.
- Question: How will consent work with private HIEs like Baystate?
    - Answer: If they are going to connect they must follow the opt-in requirements of the HIway; similar to how the HISP-HISP connections will work.
- Question: Can you explain how the private companies are telling providers they cannot connect unless you pay a fee? The patient owns their information, why should they have to pay for it to be sent?
    - Answer: For connecting to a HISP, the provider organization would be required to pay a fee to the HISP. This is not a fee for the patient. There are costs the HISP must incur to make the exchange work.

Mass HIway Phase 2-Reactions to Emerging Policy Positions

Phase 2- Patient Matching and Relationship Listing Service (Setting the table for the discussion)(Slide 6)

Background: Overview of RLS and HIway Query-Retrieve (Slide 7)

A review: Patient Jen Jones, on the left, wants her PCP to share information with other providers, using the RLS and she wants Hospital A to do the same. When she sees a specialist and does not want to give consent that information will never be sent to the HIway. Looking at number two, the RLS; no medical record information is persisted; basic demographic information is the only thing sent via an Admit Discharge Transfer (ADT) message. All organizations have different ADT formats and some could put clinical information in the ADT, like reason for visit. The HIway will strip those messages, "dumping" and deleting the extra information; it is never stored. On the right side the patient has shown up at Hospital B and the provider wants to see the RLS. He or she will only be able to see patients for whom they have an established relationship; the patient must have been there before and given consent. This is for privacy, but it does create a barrier for providers seeing a patient for the first time; a referral or the Emergency Department for example. The current thinking is to have a "break the glass" function that would allow an authorized provider organization to see the listing. This would trigger the access information to be flagged or logged in some way, but those specifics are still up in the air.

- Question: In this scenario the specialist is not getting the information because the patient did not give consent. What if the specialist feels it is necessary to review some parts of the patient's information, medications for example?

    - Answer: The system would not be able to do that. It is not that the specialist will or will not get the information, here Jen Jones is saying she does not want the specialist to be listed on the RLS. The permissions regarding opt in and opt out are around what gets revealed; where does the patient have records and how often has the patient visited this particular location. Data segmentation with Electronic Health Records is years away right now.
- Question: What if one hospital owns your PCP and your specialist?
    - Answer: This is a challenge; physicians on the same network often have the capability to view all patients in that network.
- Comment: If we were to design this perfectly there will be a kiosk at every office; the patient can say I want this to be sent here, but not there.
- Comment: The challenge is that consent must be collected at each location; the PCP and the specialist.
- Question: Why were those pieces of the RLS chosen? Date, location and number of visits?
    - Answer: This gives the provider some sense of how recent the record is and how much information they can get. A complex patient could have 30 providers listed on the RLS, the date will allow the provider to query the location where the patient received recent care. There is high utility in knowing where the patient has records, as you can imagine right now, if the patient does not provide that information the office must call around to find records.
- Question: Who is the overseeing things like the break the glass cases? Auditing etc?
    - Answer: EOHHS
- Question: Will the state be able to see clinical information? State employees and so forth?
    - Answer: Which state agencies can see what is still being worked out. There would not be a way for someone to simply login to a system and search for a patient. The Department of Public Health (DPH) gets a number of reports right now. What they would like to be able to do is better match patient records; utilize the HIway for consistency purposes. The patient matching software, Initiate, runs probability algorithms to "de-dup" patients (Jen Jones is also Jenny Jones). DPH is already doing this matching today; they are saying they should be able to leverage the technology. Not all of the state agency issues have been resolved.
- Question: Isn't this problematic; the data is not going to be de-identified? If I were a consumer knowing this I would say no.

- Answer: This information is already being sent to DPH; syndromic surveillance for example. We can get back to the group on the thinking behind the other agencies.

Looking at number 5 in the diagram, request for the patient record, the patient record information is sent back after the data holding entity has reviewed the request. How the data holding entity wants to respond is completely up to them. When the record is sent back, it is going to the provider organization; the HIway is never holding clinical data. Eventually some organizations may automate with frequent trading partners. Part of the benefit of the HIway is that organizations will always know who is requesting the information.

Policy Position for Reaction: Consent (Slide 8)

- Question: Are we deciding if these policies are a good idea?
  - Answer: Yes, as well as feedback about how to make this more understandable and accessible; how will we communicate the consent process to both patients and providers.

Supplemental: Screen Shots of Mass HIway Provider Portal

Login Page (Slide 2): A screenshot of the login page was provided.

Landing Page (Slide 3): When you login, you are then provided with an introduction; arrows demonstrate how you can search for a patient record or you can generate a medical record request if you already know where the record sits.

Demographics (Slide 4): The fields for demographic information were shown. There will only be results shown if there is an exact match to deter any fishing.

- Question: Do you need all of it; there are 7 fields to choose from?
  - Answer: That has not been sorted out yet, current thinking is somewhere around 5 fields. If you put in three out of seven for example it will never say here are the two people it might be. Instead, it will ask you for more information.

Patient Summary (RLS) (Slide 5): On the left side you can where the patient has records, last date of visit and roughly how many visits.

Relationship Selection (Slide 6): The provider can click on Mass General; it will display the organizations basic information. The options for communication are also provided on the right side. In this case there are two options: Cross entity viewer or medical record request.

Medical Record Request (Slide 7) : A confirmation that a request has been sent is provided; you can get a request ID for audit purposes. This is where it will be recorded who logged in.

- Question: There is no identifying information of who asked?
    - Answer: Yes, in this case the persons login ID would be recorded; you could identify which user logged in.

Cross Entity Viewer (Slide 8): In this case Mass General has the capabilities to make the record available to the user in a separate browser window, independent of the HIway portal.

Next steps

- Key points and recommendations synthesized and provided back to Advisory Group for final comments
- Letter to be presented to HIT Council about issues that AG deems important.
- Presentation materials and notes to be posted to EOHHS website
- Next Advisory Group Meeting – November 18, 12:30-2 P.M.
    - **In person (Room TB** – – (866) 951-1151 x. 8234356
- HIT Council – August 7, 2013, 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