

Consumer Advisory Group Meeting

March 13, 2014 12:00 P.M – 1:30 P.M.

Name	Organization
In Person	
Alec Ziss	CapeCare
Amy Caron	EOHHS
Darrel Harmer	EOHHS
Kathleen Donaher	Regis College
Phone	
Lucilia Prates	Medicare Senior Patrol
Winnie Tobin	MITSS Communications Director
Lisa Fenichel	eHealth Consumer Advocate
Eileen Elias*	Director Disability Services Center
Support Staff	Massachusetts eHealth Collaborative
Micky Tripathi	Massachusetts eHealth Collaborative
Mark Belanger	Massachusetts eHealth Collaborative
Jennifer Monahan	Massachusetts eHealth Collaborative

* Provided feedback on materials but was unable to attend the meeting.

Review of Materials and Discussion:

Discussion: Phase 2 Consent Patient Education Materials

This material is hot off the press. This group reviewed the first draft of materials in February. Those edits and recommendations were provided back to The Executive Office of Health and Human Services (EOHHS) and last week the materials were reviewed by a plain language specialist. The purpose of today's meeting is to take a closer look at things like tone, message, how it reads, is there a risk versus benefit balance and is there anything missing that you feel is critical for patients to know. The materials will also be reviewed by the Provider Advisory Group and the Consent Sub-Group next week.

- Question: What level of reading is this at now?
 - Answer: The language specialist does not like the idea of assigning grade levels. She looks at things like how many multi-symbolic words are in the document.
- Question: I missed the call last month- where do we see this content ending up? Will it be a pamphlet, one-pager or poster?
 - Answer: There is a policy wrap-up around this that says what participants must do- they must inform patients about the Phase 2 services. They can take the template and use it "off the shelf" or they can use it as a suggestion. Some organizations may need to combine HIway educational materials with existing materials for different reasons.
- Question: Can providers pick and choose?

- Answer: Yes, they have flexibility on what they want to use or not use. The reality is that we will not really know if providers are doing this- but it is a contractual requirement to describe the Relationship Listing Service (RLS) to patients.
- Question: Will there be any testing of materials along the way?
 - Answer: We are not anticipating doing any testing as of yet. At the last Health Information Technology Council (HITC) meeting there was a lot of feedback on the role EOHHS wants to play. Right now there is a lot of complexity- for example Tufts Medical Center has their own private Health Information Exchange (HIE), the New England Quality Care Alliance (NEQCA) HIE and are using the vendor specific (eClinicalWorks) HIE.
- Comment: As a process, consent needs to be revisited every time there is an interaction. There has to be some commonality that is linked to informed consent.
 - Response: That would be difficult to operationalize. The amount of time we are already asking providers to spend on this issue will take away from patient care.
 - Response: This needs to be a bigger part of patient care. To require a snapshot one time is not meaningful.
 - Response: There is an explanation in the materials that says you can change your consent preference when you want to.
- Comment: I think measuring quality indicators around consent would make all of this more viable.
- Question: As things change with the HIE, or a provider closes a practice, will they be grandfathered in?
 - Answer: Right now the policy says that you must get a new consent for any changes in HIE functionality. A lot of this is not so much another group superseding another group- it is really a 360 degree process.
- Comment: Again, this information needs to be quantified- we need to get data from places where this is already happening throughout the country. Get information on what is the process.
- Comment: Overall I think the materials are very good.
- Comment: My hope would be that this is just a top layer- people can dive down if they want to with more information. It is simple which is good, but I think there might be people that need more information in addition.
- Comment: As part of the literacy process we need to do testing. We are so used to the jargon and the context. We have no clear feedback from someone who has never seen this.
 - Response: We will take that back to EOHHS and look to talk offline about testing the materials.
- Comment: As I was reading this I felt like it did not tell me enough- for some people this might be insulting.
- Comment: In the first part of the document, “hacking” needs more explanation. It seems to be saying there is not much of a risk.
 - Response: I think that may be more of an information ordering issue.

Questions posed to the group:

What do you fear will be exposed?

- Comment: A lot of information- birthday, address, and then someone could use the MRN to locate my record.
 - Response: It would be close to impossible to unencrypt a message, and it would take a great deal of work to locate a specific MRN. Right now the only thing being exposed is the basic demographic information needed to accurately match patients.
- Comment: We are not naming the RLS- it seems to describe it, not actually name it. We could also call out what the RLS does not contain.
- Question: How are providers going to be able to explain the RLS in more detail to patients?
 - Answer: EOHHS is working on staff training materials- this is the patient facing document. Providers and front office staff will be given information on how to explain this stuff. It will include FAQ's which were created with the help of this group, explanation of key terms, and provide contact information for the patient to get more information- on the EOHHS website for example.
 - Response: The providers should get some information on how this will change their workflow, especially for small provider offices.

After reading the first three paragraphs, do you know what the HIway is?

- Comment: No, it creates too much anxiety.
- Comment: The concept of "network" needs to be explained further.
- Question: I thought we spoke about using a glossary?
 - Answer: The language specialist said that was another "no, no" for this kind of material- if it needs to be explained it shouldn't be in the document.
- Comment: We still need to think about other cultures and languages- there are a number of communities who will need education tailored to their patients.
 - Response: It is going to be hard to get this into other language- I do not think this can be translated into Portuguese. "Opt-in" would be an example.
 - Response: It may be best to have EOHHS maintain control over translation rather than relying on participants.
 - Response: Participants will also be able to use parts of this educational information- tailor it to their patient population.

When you read this did you have a good sense of who could use the HIway?

- Comment: It is not clear that not all providers are on the HIway.
- Comment: Need to explain "sharing"- should move away from that word.

Did you get the sense that this was voluntary?

- Comment: No, if it is given with things like the Notice of Privacy Practices (NPP) it looks mandatory for treatment.
- Comment: Permission, consent and authorization sound too legal. I think of consent as more as a procedure.

Is it clear to you that this is not exposing or storing medical information?

- Comment: We should explain how this works in comparison to faxing.
- Comment: The materials do not portray confidence in the system- we should highlight powerful use cases like the ED- providers usually fly blind
- Comment: One of the most common issues we see is safety- reconciling patient medications.

Is it clear that you will give consent at each organization?

- Comment: I do not think people will understand what “organization” means- every single provider at the organization, or just some?
- Question: What if an organization is bought up by another?
 - Answer: That would be the responsibility of the organization that is acquiring them, which is the way this is done today.

Is it clear that you can revoke your opt-in?’

- Comment: No, it is not clear.
- Comment: I have concern that there is no information on the duration of the consent.
- Comment: Consider adding that eventually consumers will have access to the HIway.

Is it clear what information the state has?

- Comment: No, the only place I see this in the box saying this is managed by the state and funded by the US Government. It makes me think the information is also being accessed there.

Please send any additional feedback to Mark Belanger and Amy Caron.

Next steps

- Key points and recommendations synthesized and provided back to Advisory Group for final comments
- Presentation materials and notes to be posted to Executive Office of Health and Human Services HIway website
- Next Advisory Group Meeting – TBD
- HIT Council – April 7, 2014, 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>