

## Agenda

### 1. Welcome note & Group picture!

**Q: any questions?**

### 2. Overall Structure (distribution of materials and feedback collections)

- a. PPT presentation-Email
- b. Survey-Email
- c. In-Person Group Discussion-Lunch Meeting
- d. Feedback collected/shared with all participants-*Website*

**Q: any questions?**

### 3. PCORI call (5/20/2016)

- a. Feedback/comments
- b. Interim progress report
- c. New LOI submission-June 1<sup>st</sup> deadline

**Q: any questions?**

### 4. Project Website

- **Updates (to be updated periodically)**
  - a. Archive of communications/minutes/surveys/PPT presentation
  - b. Calendar
  - c. Patient Stories

**Q: any comments/suggestions?**

### 5. PPT#3 Presentation

- a. Comments received
  - Examples of genetic research done by our CAB members/literatures

**Q: additional comments/suggestions?**

### 6. PPT#4 Presentation

- a. Existing resources that include patient genetic data and clinical information
  - PCORI & non-PCORI resources
- b. Examples of technologies facilitating research
  - ABPathfinder, LLC & Prometheus, LLC
- c. Overview of Electronic Medical Record (EMR) systems
  - Objectives & Challenges

**Q: any comments/suggestions?**

## EAIN 2419-Meeting#3 in-Person Group Discussion

### Minutes

**Date:** 5/26/2016

**Place:** CMH, 4<sup>th</sup> floor conference room

**Time:** 12:30-1:00pm (Lunch Meeting)

#### Attendees (N=7):

Andrea Bradley-Ewing  
Sheryl Chadwick  
Broderick Crawford  
Angie Knackstedt  
Kelly Ranallo  
Ayten Shah  
Zohreh Talebizadeh, PhD



#### DISCUSSION POINTS:

ZT: Thank you everybody for joining our In-Person Group Discussion. Just a quick overview of our communication structure. As you know by now, we have a PPT presentation emailed to all participants, followed by a survey to give us your feedback about the content of the PPT. Then we have an In-Person Group Discussion. Any questions?

Last week I had a phone call communication with an EAIN program officer, who reviewed materials from our previous meeting (comments, feedback, survey results). She was pleased with our progress and thought we had collected very useful comments, exactly what was needed for this type of engagement project. I want to remind you to share your opinion on all aspects of the project, both positive and negative. At the end of our last In-Person Group Discussion we had a nice exchange of opinions on bioethics and other topics, which was very informative.

Another reminder to check updates on the project website. At the end of this Engagement activity we hope to collect a long list of needs, requirements, questions, as well as areas for improvement.

We are halfway through with this project, so I am working on the Interim report for PCORI.

I am planning to submit a new LOI in June. With the experience and infrastructure that we developed in EAIN 2419, I want to submit a new application that will be more disease specific, most likely, autism, or neurodevelopment conditions. This new project may have more implementation aspect to it. I would be happy to extend our relationship with EAIN participants to working on the new project. If you are interested to continue working with us, please let me know.

Broderick: Can you share a reason or benefits of going with something like autism versus other conditions?

ZT: There is no benefit. I feel more comfortable to work on autism, because it is my area of expertise, I know how to reach out to autism community. It is my personal strength. Also, if we could focus on one disease and develop something tangible, especially with adding an

implementation aspect to it, then later our model could be applied to other diseases. I thought I would better stay within my area of expertise to develop a model, hopefully, others, who are experts in other diseases, may follow our model. Also, a number of our CAB members are parents or experts in autism.

Broderick: Thanks, it makes sense!

Website updates: Patient stories, Calendar and all communications, as well as all the materials for Meetings 1 and 2 (PPTs# 1 and 2, surveys, minutes), and PPT#3 have been posted on the project website. Any additional comments for the PPT#3 are welcome. I noticed 2 sets of comments from our members related to genetic work done by our scientific CAB members. Some people were excited to learn about findings of those studies, others could not fully understand scientific language. We envisioned this, and even included a disclosure in our PPT#3. The purpose of this project is to share some examples, but because we have technical and non-technical people on board, it would be impossible to clarify all terminology considering time and effort we have for this Engagement project. It would require significant amount of time and expertise to convert all the scientific terminology into lay language. This is not a methodology work. We are not called to take any action, we are just trying to familiarize our participants on different topics, and develop materials to think about how to move forward.

Angie: In relation to those comments, it would be relevant if you do go to some kind of intervention project, where it would be very important to have lay language for whoever you would be working with, and use those as lessons learned to take forward.

Andrea: A glossary would be nice to have, or connect to other sources that may have already been developed.

Angie: They are beginning to look into that, I know there was an IOM roundtable session on Precision Medicine in genetics related to health literacy. I think we go along with this process.

ZT: it would be great to take advantage of those sources moving forward. We will not ignore this kind of developments. It is beyond our current efforts, but it definitely needs to be done. Our current Engagement project is not a disease specific, but it is another reason I want to develop a project around one particular disease, so we can provide a detailed background information, recruit members familiar with the topic from both clinical, scientific areas, and patient representatives.

Kelly: From PCORI standpoint, this is the biggest challenge. You lose the majority of patient members because they can't understand terminology, investigators do not have time to make a conversion of terminology to bring us along with them. And then interpretation of the results on the back end. It will remain a big obstacle until they come up with some systematic approach.

Visual representation is often helpful in explaining complex context. Otherwise, poor level of understanding may be intimidating for lay people.

ZT: I've learned so far, some researchers may not be interested or see any value, that this kind of research exists. How can we identify researchers or physicians who might be interested in working with PCOR culture?

For the PPT#4 we will cover 3 topics

- Existing resources that include patient genetic data and clinical information. We are aiming to select at least 2-3 major networks. One of them, PCORnet, is funded by PCORI. And outside PCORI, eMERGE, funded by NIH. Those resources may be useful for future genetic work. We would like to inform our participants about those existing resources to make them think about developing future research projects.
- Examples of existing technology that may facilitate research: Pathfinder and Prometheus. We have CAB members from these companies. We will describe their work and how those technologies have been used to improve research in general.
- Overview of EMR. We keep hearing about those, but do not really know much. The medical field is moving toward implementing those systems. It would be great to provide at least a general idea. We will get input from two CAB members, Mark Hoffman and Laura Fitzmaurice, on this.
- Since everybody liked videos, we will include video clips describing those topics.

Kelly: it would be nice to have an overview of REDCap, and integration of EMR with REDCap. I believe it is standard across hospital organizations that is being accepted as the platform for research based data collection, and systematically it would be great if EMR could be integrated directly into REDCap versus having separate data entries. There are challenges, like data being collected based on different platform that makes integration difficult. It brings along additional expenses for hospitals to be able to share patients' data between health care providers.

Broderick: It is interesting to learn, as researchers do their work, how is that information being put in a system that they can use to query data collection source, on nationwide scale.

ZT: It is a very good point. We can give an overview of 2-3 different platforms, like REDCap, and highlight the lack of compatibility between different platforms. We will try to avoid too technical terms, and provide a broader understanding.

Andrea: It would also be great to talk about fear that people have about having EMR, the same as about genetic testing, regarding who exactly will be able to see the data. How it may influence their ability to get a job, insurance, or not to be discriminated. How much protection the patients have, considering sometimes tricky language in consent forms. There is often lack of communication and explanations between medical field and patients, which produces misinterpretations and lack of trust.

ZT: Absolutely. It is essential to communicate right information and educate all stakeholders. I am glad you brought up the topic of bioethics, and in PPT#5 we are going to cover that part.