EAIN 2419–Meeting #2 in-Person Group Discussion

Agenda

1. **PCORI Visit-3/24/2016 (Washington DC)**
   - Shared update on EAIN-2419
   - Thanks to Kelly Ranallo

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. **Project Website**
   - **Updates**
     - Archive of communications/minutes/surveys/PPT presentation (*to be updated periodically*)
     - Calendar (*to be updated periodically*)
     - Patient Stories (*to be updated periodically*)
   - **Future plans**
     - Feedback box
     - Log-in option

Q: any comments/suggestions?

4. **PPT#2 Presentation**
   - Comments received
     - Genetics Part
     - Patient Stories

Q: additional comments/suggestions?

5. **PPT#3 Presentation**
   - Examples of published epidemiological/patient outcomes studies done by including genetic information
   - Examples of genetic research done by our CAB members (Scientists) in relation to patient outcomes
   - Additional Patient Stories

Q: any comments/suggestions?

EAIN 2419–Meeting#2 in-Person Group Discussion

Minutes

Date: 4/19/2016
Place: CMH, 2nd floor Anesthesia conference room
Time: 12:30-1:00pm (Lunch Meeting)

Attendees (N=14):

Jeff Blackwood
Andrea Bradley-Ewing
Mark Bryant
Sheryl Chadwick
Emily Farrow, PhD
Mark Hoffman, PhD
Mary Kinart
Angie Knackstedt
Matthew McLaughlin, MD
DeeJo Miller
Angie Myers, MD
Kelly Ranallo
Ayten Shah
Zohreh Talebizadeh, PhD

PPT#2
group discussion
Sorry!
We forgot to take a picture

DISCUSSION POINTS:

- ZT and Kelly Ranallo had a PCORI visit in Washington, DC on 3/24/16 to inform them about the progress made with EAIN 2419. Thank you Kelly for your input for this meeting.
  - Brief overview of the visit. PCORI staff was pleased with the progress made with EAIN 2419, especially the project website.
  - Our meetings structure (PPT, survey, in-person group discussion) was approved by PCORI staff
  - Any comments?
- Project website updates:
  - Archive of our communications, discussion minutes
  - Survey results
  - PPT presentations
  - Calendar of events
  - Patient stories
  - Future plans: login option with a tracking feature, and a feedback/comment box.
  - Any comments?
  - Mark: I can help you with the tracking feature
- ZT had a monthly report with the PCORI program officer today. The officer was very pleased with the progress we made with EAIN 2419. Thank you all for your input for this project.
- We received comments for the PPT#2 thru our surveys, five more are still pending. As soon as we have all of them, the results will be posted on the website. In general, two topics were raised:

- Genetics part could have been expanded more. Our justification for keeping it short was not to make the PPT#2 too long, and we decided to include a NIH booklet describing the topics of genetics in an easy to understand language.
- Patient stories were highly scored by our participants. We wanted to really highlight patients' part in the PPT#2. We will include a few more patient stories in the PPT#3. Please, if you have a patient story to share with our participants, let ZT know, we will consider it for our next presentation.

- ZT plans to work with scientific members of the CAB to give us a few examples of genetic research project that are related to outcomes research, even indirectly, that also included genetic risk factors to improve patient health care. Please if you are aware of any published work, or studies done by you or your colleagues that may be informative for our participants, let us know.

- **Comments:**
  - Kelly: I think the videos imbedded into the PPT#2 were a great informational resource. It is very important that we learned about what really disclosing genetic data means to patients and families, how it is being managed, and we also heard providers' perspective.
  - It was also very interesting to hear Francis Collins' talk about what patients struggle with and them going to 23andMe. How do we train an entire generation of health care providers to understand genetic information and communicate the results back to patients? If I bring my genetic results to a physician, he would not know what they mean and how to apply the results.
  - ZT: Seth's family story made me appreciate more the fact that there are genetic issues running in some families, and it would be necessary to consider the whole family as a case, not just an individual. That is why we tried to include different stories in the PPT#2 to make you aware of the range of complexity.
  - Jeff, since you asked how you could contribute more to this project with respect to your background, I 'd like you to share with our team what kind of work your company does, what is the best way to archive patients' data, because eventually it will benefit the research part.
  - Mark, it would be great to hear about challenges and progress made with respect to connecting electronic medical records with genetic data. It is a long process, but it would be informative for our team to learn in future presentations about technical aspects.
  - Another question is how much providers want to know about incorporating genetic data in health care. They may not have skills or tools to make decisions.
  - And for patients too: how many patients actually want that information, how to address stigma, and health literacy.
  - Cost issue: whether or not a family has an insurance, there will be out-of-pocket cost. Could people afford it?
  - Number of genetic counselors: 1 for every 85,000 people in some places. How long would people have to wait for a session?
  - We cannot expect genetic counseling to be done by basic physicians, they are not geneticists.
- Great discussion! This is the kind of points that we hope to summarize at the end of this Engagement project: we would like to identify and document a list of limitations/ requirements that will be then shared with PCORI.