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 (6/21/2016)**
   a. Feedback/comments (interested on CAB opinion on the information shared in PPT4)
   b. Interim progress report-Approved (**Thanks** to ALL of you for your contributions!)
   c. New LOI submitted-June 1st (Pending)
   Q: any questions?

4. **Project Website**
   a. Updates (to be updated periodically)
   Q: any comments/suggestions?

5. **PPT#4 Presentation**
   a. Existing resources (PCORnet, eMERGE)
   b. Examples-Technologies (Pathfinder, Prometheus)
   c. Electronic Medical Record (EMR) systems
   Q: additional comments/suggestions?

6. **PPT#5 Presentation**
   - Overview of the ethical issues and genetic testing
   - Overview of the ACMG guidelines and genetic testing
   - Questions that patients wish would be addressed by genetic research
     o Feedback collected from our study participants
     o Comments gathered from reports/publications
   - Barriers that patients, physicians, scientists, and outcomes researchers may face in using genetic information in health care decision making
     o Feedback collected from our study participants
     o Comments gathered from reports/publications
   - A potential road map: HOW experiences learned from this engagement project may be used to promote incorporating genetic information in patient outcomes studies:
     o Potential steps for engaging stakeholders
     o Potential technical needs
     o Potential key stakeholders and community-level individuals (both scientific and non-scientific) for the implementation of the identified steps

   Q: any comments/suggestions?

Minutes

Date: 6/21/2016
Place: CMH, 4th floor conference room
Time: 12:00-12:30pm (Lunch Meeting)

Attendees (N=8):

Andrea Bradley-Ewing
Sheryl Chadwick
Emily Farrow, PhD
Angie Knackstedt
DeeJo Miller
Ayten Shah
Zohreh Talebizadeh, PhD
Darcy Weidemann, MD

DISCUSSION POINTS:

ZT gave an overview/reminder on the structure of the project meetings.

Today I had a monthly phone call with the PCORI program officer. She was very interested to see our members' feedback/opinion on topics covered in the PPT#4. As I shared with you on our last in-person group discussion, I submitted an interim progress report to PCORI, which was received with appreciation to our work. Thank you to all of you for being a part of this effort.

I also submitted a LOI for another Engagement project, which is focused on autism. If we are invited to submit a full proposal, we would be happy if you choose to continue working with us on this new project. Project website is being updated periodically, feel free to email me with any comments related to the website.

In our PPT#3 we covered topics like existing resources: PCORI funded (PCORnet) and NIH funded (eMERGE). We try to include You Tube videos related to the topic because many members gave positive feedback about videos included in the PPTs. Our CAB member, Olivia Veatch, an investigator from Vanderbilt involved with eMERGE, sent me additional information/update on eMERGE about a couple of new websites or tools they've developed. Olivia thought it might be informative for our CAB members to learn about those activities. This additional information will be provided for your review through the project website.

While preparing our slides about EMR, we noticed it would be very challenging to provide this technical information in a lay language. So far, I've learned that it would be impossible to convert all details of the technical information provided in this project, word by word, into a lay language. However, we may provide a lay abstract for complicated topics, and then the rest would be in technical terms, like with any scientific publication or application.

Angie: Yes, plain language summaries are provided in many fields and seem to be helpful.

Andrea: Or provide a glossary of acronyms.
ZT: That would be easy to address. Should we have it posted on the project website?

Andrea: It may be a PDF attached to a PPT, so the members can view them at a time of reviewing the PPT.

ZT: Sure, we may even have it provided both ways: posted on the website and attached to PPTs.

DeeJo: I would appreciate a summary in an easy to understand language. I usually ask health care providers to give me such a summary when I discuss health related issues to make sure I fully understand and to be able to share this information with the members of my family.

ZT: In relation to our last PPT#4, considering that it included technical terms, do you think we were able to provide information clearly?
All present members agreed.

Sheryl: definitions were very helpful, like what is PCORnet.

ZT: Were you aware of this kind of resources before?
All present members said NO.

ZT: It is good to hear that you found this presentation informative, and we would like to assess the educational impact of these materials from members' perspective, in the upcoming Project Evaluation Survey #2.

In the next PPT#5 we would like to cover ethical issues in relation to genetic testing, maybe review guidelines of the American College of Medical Genetics. Some of our members may not be aware of the existence of these guidelines. We already started gathering information on this topic; please send us any relevant information you may have. Also, we will be talking about identified barriers. Do not forget to provide your comments in the survey.

Sheryl: I am interested to know providers', scientists', researchers' opinion on direct-to-consumers genetic testing companies, like 23andME.

ZT: Actually, I've received an email from them recently, informing me about their newly established pipeline for research and inviting to send samples for research purpose. And in our PPT#2 we shared experiences of our CAB member, Seth Bittker, about genetic testing done through 23andMe.

Andrea: I have a question about the PCORI funded Greater Plains Collaborative project. There are many different hospitals engaged in that network. Do they include any genetic data?

ZT: I do not know exactly, possibly for Phase II they may want to expand and include genetic part. For now, in Phase I, they just aim to establish an infrastructure.

Andrea: For future, when they have the infrastructure established, it would make sense if they added a genetic component.

ZT: I am sure eventually it will be done. This brings us back to the purpose of our engagement project. If we want to incorporate genetic information and follow PCORI standards by including patient-centeredness into developing hypotheses, as well as identify the most important questions for patients, then it requires a different approach. I am hoping with our project to start drafting a pipeline/roadmap that would provide some guidelines on how genetic information may be incorporated in PCOR studies.