

Memorandum of Agreement (MOA)

Date (02/18/2016)

Abbreviations:

- **CAB:** Community Advisory Board
- **CER:** Comparative Effectiveness Research
- **MOA:** Memorandum of Agreement
- **PCOR:** Patient-Centered Outcomes Research
- **PCORI:** Patient-Centered Outcomes Research Institute
- **PI:** Principal Investigator

PURPOSE & SCOPE

The following is an agreement between Research Team and Community Advisory Board members regarding the EAIN-2419 Engagement project funded by PCORI. This project will be from 10/1/2015 to 9/30/2016.

PROJECT SUMMARY

The purpose of this project is to develop a partnership with a wide range of people (stakeholders) to build a roadmap (infrastructure) to engage them in research, dissemination, and evaluation of the concept of using genetic information in PCOR and CER.

PROJECT OBJECTIVE

The objective of this project is to establish an infrastructure that includes a CAB. The project will assess and collect the CAB's opinions, suggestions and input about how genetic information may be used to improve PCOR studies.

PROJECT GOVERNANCE STRUCTURE

- PI: oversees all activities covered by the Scope of Work
- Participants: Research Team and CAB members

All participants agree upon the following:

1. Study participants will all be equal partners in this project, regardless of their roles.
2. The biggest advantage of this project is the wide diversity of personal/professional backgrounds and life experiences of participants. Opinions, suggestions, and comments of each participant are to be respected and taken into consideration equally.
3. Decisions are to be made by a consensus (agreement) of the majority of participants.
4. All participants will be given an equal time to respond to the project surveys or provide feedback. Late responses will be accepted if an extension was communicated with the PI in advance. Responses may not be considered if received after the final deadline, to comply with the overall project timeline and respect other members' time.
5. Project updates will be shared with all participants by the same means (e.g., email and project website).
6. Documents related to project activities (such as meetings' agenda, presentation slides) will be finalized by the same review process:
 - I. The PI will send a draft of meeting agenda to Research Team for their review/input. The revised document will be then shared with the CAB members for their review. The final meeting agenda will be posted on the project website.

- II. The presenters for each meeting will be determined by the PI after consulting with the participants.
 - III. The PI will inform each presenter how to prepare their personal presentations.
 - IV. Presenters will send their presentations to the PI to be reviewed with respect to length, content, and relevance to the project.
 - V. The PI will send the presentations to other participants with the relevant background for review. Then Ms. Knackstedt, our Health Literacy consultant, will review to make sure the language is easy to understand for our non-scientific members.
 - VI. If changes or edits needed, they will be communicated with the presenter. The final version of the presentations will be sent out to all participants by email and posted on the project website.
7. We will try to have live discussions of the topics covered in PowerPoint presentations. However, due to our members' locations and different time zones, we may not be able to find a day/time for a call conference that works for all participants. We will use a combination of personal meetings with local members, call conferences, and email communications to make sure we reached out to all participants.
 8. All participants are entitled to authorship if publications (manuscripts or posters) are written from this project. Authorship will be established according to the relative contribution of the PI and other participants.
 9. All participants consent to comply with rules of confidentiality. All participants will respect the privacy of fellow members. They should not share what is said in the project discussions with others. They will report only aggregate group data in posters and future manuscripts.

Amendment: This MOA may be modified or amended by the written agreement of Research Team and CAB members, if needed, during the course of the study.

Final version of the MOA will be submitted to PCORI at the end of the project.

STATEMENT OF AGREEMENT

It is mutually agreed upon and understood by and among the participants that:

This MOA confirms an entirely voluntary commitment among the project participants. It confirms that participants will cooperate and work together to achieve the project's objective described above. It also ensures open, honest and transparent communication among participants and with the PI.

Participants

NAMES