

EAIN 2419-Meeting#1 PPT Presentation Evaluation-Survey Results

All members responded (N=33)

For the following two statements, please indicate to what extent you disagree or agree with "0" indicating "Strongly disagree" and "10" indicating "Strongly agree".	Rating Average	Response Count
1) The information in the Meeting#1 presentation was provided in an easy to understand	8.82	33
2) The information in the Project's website was provided in an easy to understand manner.	8.79	33
<i>answered question</i>	33	33
<i>skipped question</i>	0	0

2. I agree with the information described in the project's Memorandum of Agreement (MOA).

Answer Options	Response %	Response Count
Yes, I agree	100.0%	33
No, I do not agree	0.0%	0
<i>answered question</i>		33
<i>skipped question</i>		0

3. I agree with the suggested structure for the meetings.

Answer Options	Response %	Response Count
Yes, I agree	100.0%	33
No, I do not agree	0.0%	0
<i>answered question</i>		33
<i>skipped question</i>		0

4. I agree with the selection of topics to be covered during the course of this project.

Answer Options	Response %	Response Count
Yes, I agree	100.0%	33
No, I do not agree	0.0%	0
<i>answered question</i>		33
<i>skipped question</i>		0

5. I would like to have a personal meeting and/or call with the PI for further clarification of materials discussed in the Meeting#1 presentation?

Answer Options	Response %	Response Count
Yes, I would like to have a meeting/call for further clarification	6.1%	2
Not at this point	93.9%	31
<i>answered question</i>		33
<i>skipped question</i>		0

Additional comments/suggestions about the Meeting#1 presentation (optional)	N=2
<p>1) <i>The website looks great and the project is structured to bring focus to some very important issues! Thank you for your work and for including me in this effort.</i></p> <p>2) <i>The background information that was provided on the website was extremely helpful to clarify the goal of this study</i></p>	

Additional comments/suggestions about the Project's website (optional)	N=4
<p>1) <i>I think that your Powerpoint presentation/introduction to the project is very comprehensive and understandable. I'm happy to be part of your CAB for this project.</i></p> <p>2) <i>The PowerPoint presentation was well written. I think there is some additional benefit to be gained by interaction between the presenter and audience.</i></p> <p>3) <i>There was a lot of information to digest. Would be good to send members a reminder as to where they can find the information on the website and maybe have a condensed version/summary available for them to go back to.</i></p> <p>4) <i>I think sharing the study goals at a higher granularity by Dr. Talebizadeh with collaborators would be helpful initiating discussion for future sessions.</i></p>	

Additional comments/suggestions about the MOA (optional)	N=1
<p>1) <i>I viewed the MOA online. I should have printed a copy. My recollection is the MOA did not require my signature.</i></p>	

Additional comments/suggestions about the suggested structure for the meetings (optional)	N=2
<p>1) <i>My only concern is that I don't understand how I will provide better input back to the team. Will there be an opportunity for a discussion of the topics? A conference call or GoToMeeting?</i></p> <p>2) <i>Regards to having collaborators on this sturdy from different time zones and schedules, I think PowerPoint presentations are very useful and convenient.</i></p>	

Additional comments/suggestions about the selection of topics to be covered during the course of this project (optional)	N=3
<p>1) <i>I think less reliance on electronic mail and PowerPoint presentation and more personal interaction would be helpful.</i></p> <p>2) <i>Could also consider adding a topic of barriers to obtaining genetic information (ie. in clinical practice I frequently have parents who want to do genetic testing but have trouble obtaining prior authorization from insurance companies to cover testing which is often quite expensive). Additionally, physicians have little if any training on how to identify appropriate testing and how to identify resources to facilitate ordering genetic testing</i></p> <p>3) <i>I agree, but I think this agenda should not be fixed yet and it is key that we obtain buy-in and additional input from CAB members and prioritize the topics to be covered.</i></p>	

Additional overall comments/suggestions (optional)	N=10
<p>1) <i>I look forward to this.</i></p> <p>2) <i>I think that this PCORI initiative has been well-thought out and has a high probability of producing valuable information regarding patient input into the availability/use of genetic data.</i></p> <p>3) <i>The project appears clear. I think you have a good number of stakeholders.</i></p> <p>4) <i>What a blessing it is that our paths have crossed. I have a TREMENDOUS interest in this area and I couldn't agree more with your proposed study. I am sincerely looking forward to working with you and the team on this project.</i></p> <p>5) <i>The materials are very well thought and nicely written with appropriate contents.</i></p> <p>6) <i>This is great, I am sorry I was slow!</i></p> <p>7) <i>Really fabulous materials!! You are doing a great job!</i></p> <p>8) <i>Thank you for making it easy to contribute to this amazing effort!</i></p> <p>9) <i>I would consider providing patients/families with the resources that they can learn about the disease condition and related risk factors or in general raising awareness related to genetic diseases and risk factors is as a prerequisite. Patients and families can help this study by sharing a list of questions they have about the condition, their concerns and worries, related to possible prevention or treatment protocols and so on. Thank you!</i></p> <p>10) <i>Thanks for including me.</i></p>	