

EAIN 2419-Meeting#2 PPT Presentation Evaluation-Survey Results

32/33 members responded =97%

For the following statements, please indicate to what extent you disagree or agree with “0” indicating “strongly disagree” and “10” indicating “strongly agree”. There are no right or wrong answers, it is important that the responses reflect your individual experience and opinions.

1. "The information in the PPT#2 presentation was provided in an easy to understand manner"	Rating Average	Response Count
	9.03	32
	<i>answered question</i>	
		32
2. "The overview of the concept of genetics was provided in an easy to understand manner"	Rating Average	Response Count
	8.75	32
	<i>answered question</i>	
		32
3. "The information about Precision Medicine Initiative was provided in an easy to understand manner "	Rating Average	Response Count
	9.16	32
	<i>answered question</i>	
		32
4. "Patient personal stories were informative and provided in an easy to understand manner"	Rating Average	Response Count
	9.41	32
	<i>answered question</i>	
		32
5. Would you like to schedule a personal meeting and/or call with the PI for further clarification of materials discussed in the PPT #2 presentation?	Response %	Response Count
Yes, I would like to schedule a meeting	6.3%	2
No, not at this point	93.8%	30
	<i>answered question</i>	
		32

Additional Comments

Meeting#2 presentation (PPT#2)

- 1) I thought it was good, the slides were well-laid out and easy to follow and very comprehensive!
- 2) I think an earnest effort was made to impart the information in a manner that was easy to understand. Unfortunately, for those of us who lack a scientific background, understanding genes and genetic structure was a daunting task. I think my difficulty had more to do with the subject matter than the presentation.
- 3) Needs a bit of framing to understand the context and perspective of this information

PPT#2-Information about the concept of genetics

- 1) The genetics was wonderfully presented and could be easily understood by a patient with no background in genetics.
- 2) Same comment as above.
- 3) Not really the focus of this and several stories were not clearly attributable to genetics - which is ok
- 4) All info is in secondary resources.

PPT#2-Information about the Precision Medicine Initiative (PMI)

- 1) It was easy for me but not sure about the general population without scientific and medical knowledge
- 2) I felt like my understanding of Precision Medicine Initiative was better than my understanding of genetics.
- 3) Not the focus of these anecdotes, i don't think.
- 4) I would not assume that everyone knows what the Precision Medicine Initiative is.

PPT#2-Patient personal stories

- 1) It looks great! I am also interested in the stories of the other patients. I also wanted to say that I very much appreciate what you are doing to try to help all these people like me and my family. Thank you again
- 2) Very moving stories
- 3) I think the patient personal stories were helpful.
- 4) They are very impactful stories, just not sure what the 'message' was.
- 5) I liked the patient stories.
- 6) Very compelling
- 7) Great stories! Love the 23andme one, very interesting

PPT#2-Project website

- 1) Project website is very well designed and presents the information in a straightforward helpful way.
- 2) This study is well organized. The subject matter is difficult for this respondent but presented in a manner that was easier to understand.
- 3) The personal stories were incredibly touching and serve as a great reminder of why this work is so important for current and future generations.
- 4) I think having as many videos with transcripts of what the person said (in case a video dose not work) allows makes for a more interactive website. "Teasers" such as 'Why my child's cancer treatment didn't work' might be better than 'Click this video'.
- 5) The patient stories were excellent and illustrated in a concrete way exactly what people hope to get - and often don't get - from genetic testing and precision medicine today.

PPT#2-Overall suggestions/comments

- 1) Is there a schedule that breaks down what each of the study presentations will cover? I just see the number, but not the subject/goals of the presentations on the calendar.
- 2) Happy to see increasing engagement and interest in this topic.
- 3) The information presented, particularly about the output of 23andMe was very helpful. It's also good to know about other people's experiences in dealing with complex disorders.
- 4) Nice selection of information (videos, reading material, websites, etc) and patient stories to provide a nice learning experience.
- 5) Thanks for the explanations and links, very helpful in understanding the 'big picture' of what this project is trying to do.
- 6) I enjoyed learning about this slide series.