

EAIN 2419–In-Person Group Discussion (PPT#1)

Agenda

1. Project's Website

- Future plans
 - Archive of communications/minutes/surveys/meeting presentation
 - Calendar
 - Date: Task1
 - Date: Task2
 - Date: Task3
 - Feedback box
 - Log-in option

Q: any comments/suggestions?

2. PCORI Visit-3/24/2016 (Washington DC)

- Share update on EAIN-2419
- Collect feedback/suggestion from PCORI
- Discuss invoice/budget issues

Q: any comments/suggestions?

3. Meeting#1 Presentation

- Comments received (minor editing: color & text amount/slide)
- Additional suggestions?

- Meetings#2-6 preparation
 - Finalize agenda (what topics to be covered in each meeting?)
 - Post the finalized agendas on the project's website
 - Contact members to get input on meetings' slides

- Meeting#2:
 - Genetics
 - Precision medicine initiative
 - Patient stories
 1. Our members (PPT presentation)
 2. Publicly/online available-patient presentations (URL links)

Q: any comments/suggestions?

4. Schedule for Meetings#2-6

- Last week of March through July
- Work with members to prepare their slides

Q: any comments/suggestions?

5. Future in-Person Meetings (Group Discussions)

- We would like to have a similar short in-person meeting after each Meeting (#2-6).
- Is it OK to contact/invite you to future in-person meetings?

EAIN 2419-In-Person Group Discussion (PPT#1)

Minutes

Date: 03/03/2016

Place: CMH, 4th floor conference room

Time: 12:00-12:30pm (Lunch Meeting)

Attendees (N=11):

Andrea Bradley-Ewing
Sheryl Chadwick
Broderick Crawford
Emily Farrow, PhD
Mary Kinart
Angie Knackstedt
Matthew McLaughlin, MD
DeeJo Miller
Ayten Shah
Zohreh Talebizadeh, PhD
Darcy Weidemann, MD



DISCUSSION POINTS:

- Welcome message from Zohreh (ZT)
- Overview of the project's website
 - Future website features
 - Calendar - archive of events/activities for the project
 - Feedback box
 - Log-in option
- ZT will have a PCORI visit in Washington, DC on 3/24/16 to inform them about the progress made with EAIN 2419.
 - Brief overview of the visit schedule
 - Budget/invoices issues to discuss with PCORI staff
- Meeting#1 structure was approved by all of the present members. It was agreed that we will maintain the same structure for the following five meetings.
 - Darcy: I'd like to emphasize that there was just right amount of information on the Meeting#1 presentation: not too long, not too short.
 - DeeJo: I got confused, when I received an invitation for the survey, did not realize the meeting was in form of a presentation. But now I understand. It was a nice format.
 - Sheryl: I appreciate reminders, they are helpful.
 - ZT: We made a lot of changes for the Meeting#1 agenda and its format in order to come up with the right/convenient method of communication for our members.
 - Darcy: It would be nice to make all comments/feedback available to all members, so we are aware of what was suggested.

- ZT: we plan to send out another update email to share this Meeting's minutes and list of all comments we received through the survey with all participants. Also, the Feedback box will be built soon on the website.
 - Reminder: remember to "refresh browser" for every page of the website to see the most updated version. We are working on fixing this technical issue.
 - Some comments in the survey were related to formatting and the amount of information on slides. We incorporated the suggested changes.
- As a next step, we will finalize agenda for the next meeting and post it on the website. ZT will contact contributors to the Meeting#2. Specific topics will include: overview of genetics, Precision Medicine Initiative, as well as patients' presentations (both our members and available online presentations).
 - Tentatively, we target to have Meetings# 2-6 on the last weeks of March through July, so we have some time in case schedule changes are necessary.
 - All present members agreed to be contacted for future to in-person group discussions.
 - Andrea: how about using Webex, so more members may attend the meetings?
 - ZT: we were considering Zoom tool, but our concern was about potential technical issues that people may face, to avoid wasting valuable time of our members on fixing those unexpected technical issues.
 - Personal introductions made by all present members.
 - Brief overview of recent RareKC conference held in Kansas City organized by our CAB member, Kelly Ranallo, and other parents.
 - A group picture was taken. It will be posted on the project's website.