## Stakeholder Advisory Council Meeting Meeting Minutes July 9, 2019

Opening

The regular meeting of the PCORI Stakeholder Advisory Council was called to order at 12:00pm on July 9, 2019 in ALT-C 2.206, UT Health San Antonio by Carole White.

Present

Carole White, Sara Masoud, Debbie James, Sheran Rivette, Kiki Foster, Mike Foster, Yolanda Forney, Byron Cordes, Janet Zinsmeyer, Bill Zinsmeyer, Neela Patel, Dianne Teran (Alzheimer’s Association), Angelica Davila

1. **Symposium debrief**
   1. Breakout sessions/findings: Key lessons learned

All facilitators of breakout sessions turned in their notes. Thoughts and recommendations from the SAC are listed below.

* The event was an overall success and people seemed to enjoy the presentations and the information provided to them.
* Some of the speakers were too long and technical – they should focus more on designing the presentations for families and people living with dementia
* Suggest limited content to 30 minutes per topic with plenty of time for discussion
* Try having more speakers be clinicians rather than researchers
* Think of who is in our audience and what is most important to them
* All the presentations had value but could be adapted to deliver information more effectively to the audience. Don’t eliminate content, just adjust delivery.
* Consider offering different tracks for varied audience
* Provide a pamphlet or conference book with the presentation slides and space for notes
* The setting was comfortable and accessible for the diverse audience. Families and professionals were side by side learning together
* Should include identifiers on the nametags (credentials, role) to help people connect with each other more
* Offer a safe space for people to go decompress – there is a lot of onsite processing of information that might be difficult for some people to hear
* People need to share their experiences first before getting into answering research questions
* The conference really emphasized the need for a dementia friendly city
* Information is needed that is sensitive to gender dynamics
* “Seldom heard” communities need to be met where they are

1. **SAC: Moving forward**
   1. Governance/sub-committees: How do we make decisions together?
      1. Co-chair to plan agendas
   2. Suggestions for other people living with dementia and family caregivers to join our board
      1. Core principles of involving people with dementia in research

Mike has volunteered to serve as co-chair for the Council. He will meet with Carole and Sara a week before each monthly meeting to debrief from the previous meeting and plan the upcoming agenda.

Subcommittees can be formed based on upcoming action items.

The group will review the Alzheimer’s Disease International meeting abstract submission and send feedback to the group before August 23rd.

The SAC briefly reviewed the Core Principles of Involving People Living with Dementia in Research and will plan to discuss in more detail at the next meeting after taking home to review.

1. **Grant updates**
   1. Moving into Year 2
   2. Sign invoices for prior approvals
   3. Annual meeting – James was awarded a scholarship!

The SAC briefly discussed Year 2 deliverables and will revisit this at the next meeting.

James, Carole, Sara, and Neela will be attending the PCORI conference in September 2019.