**Stakeholder Advisory Council   
Minutes  
July 28th, 2020**

**Link to recorded meeting:** [**https://youtu.be/XHZoM2WgZKs**](https://youtu.be/XHZoM2WgZKs)

*Attendance:*

Carole White

Sara Masoud

Debbie James

Ashlie Glassner

Patricia Prado

Michael Foster

Kiki Foster

James Butler

Byron Cordes

Ginny Funk

1. **Update on the surveys – share the process with everyone**
   1. The purpose and process of the surveys.
   2. Feedback on how best to uplift the voices of persons living with dementia in their responses.
   3. Ethics and research – covering confidentiality and respect

The SAC discussed progress on the surveys and administration procedures for the prioritized list of research topics.

An outline of the process was developed in a subgroup of the SAC at a training in the previous week. During this training volunteers from the SAC described the process of administering the surveys for persons living with dementia and care partners. An step-by-step guide and templates were created to help the SAC invite stakeholders to complete the survey.

This outlined procedure was walked through in the meeting. The SAC provided feedback and asked questions for each step. Some minor languaging in the procedures were modified but otherwise there was consensus on the process.

Ginny and Neela (Neela shared in a PCORI check in call this morning) shared that they have had great experiences since COVID-19 connecting directly to persons living with dementia. Prior to COVID-19, their interactions typically involved the care partners and now they are able to communicate more directly.

This is beneficial insight for the study which hopes to administer the surveys to persons living with dementia without their care partners present (when possible) so their voices can be unbiased by their loved ones’ presence.

James shared that he is grateful for the flexibility to reach out to his community with the support of the rest of the team.

SAC members will receive a final draft of the survey (with their feedback integrated) by Monday next week.

1. **Symposium: September 22nd –** *(Sara will send an invite to save the date)*
   1. Rev Dr. Cynthia Huling Hummel, PCORI (Rachel), Panel from SAC, Jan Dougherty
   2. Doubling as webinars
   3. Other symposium will be in October

A save the date was sent to the SAC. They will be provided a flyer and email template to help spread the word about the symposium.

The symposiums will double as webinars (confirmed with program officer earlier today).

1. **Interviews with some SAC members**
   1. evaluate our work using Scottish Guidelines

Ashlie Glassner and Arielle Chinea have been interviewing SAC members to better understand their experience on this project. The interviews are built around the Scottish Principles for Engaging People Living with Dementia in research. They will give insight on how effective the project team has been to meet these principles.

1. **COVID-19 Enhancement – begins August 1st**

Given the amount of PCORI activity that has been happening this month, there was not much discussion around COVID-19 enhancement, just a reminder that the questionnaire will need to be developed with the SAC to assess dementia care needs during times of COVID.

The group will connect about this after the official start date for the enhancement on August 1st (next week).

1. **PCORI Proposal: *Hearing the Unheard* – submitting this week**
   1. Latinx-focused project to raise awareness and education
   2. Community Health Workers (CHWs)
   3. South Texas
   4. Need LOS from Alzheimer’s Association

The proposal was discussed in the last meeting, so an update was shared today. The full proposal will be submitted this week. The group discussed the importance of this project and excitement for it potentially being funded.

1. **Meeting next month: August 25th at noon via Zoom**

An invite will be emailed later today.