**PCORI Stakeholder Advisory Council   
Minutes  
Tuesday March 23rd, 2021**

**Link to recording will be uploaded here:** <https://www.youtube.com/channel/UCpu48_7aPREc9Tcyk_X3HCw>

**Attendance:**

*Carole White*

*Sara Masoud*

*Ashlie Glassner*

*Bill Zinsmeyer*

*Janet Zinsmeyer*

*Debbie James*

*Cesar Alvarado*

*Mayra Mendoza*

*Ginny Funk*

*Byron Cordes*

1. **COVID-19 Enhancement** 
   1. Update on the focus groups & surveysData is currently being analyzed and an update will be shared at the next meeting. All focus groups are completed (9 total) and around 220 surveys collected.

1. **Debrief: Annual Symposium**
   1. Share attendee feedback We reviewed the evaluation feedback at the meeting. The comments will be emailed to the SAC.   
        
      Feedback was overwhelmingly positive. The personal testimonies to accompany research findings and statistics was important to attendees.   
        
      All the speakers were praised highly and the format was well received. Some comments about the length of the program but otherwise the format was good.   
        
      Other comments about the language used by Councilman and Senator and need for more sensitivity to using certain language (person first, avoid ‘suffering from dementia’, etc.).
   2. YouTube Playlist of the symposium: <https://www.youtube.com/playlist?list=PLkphnZxAorfIgT9A4bD4xJE3cbvOc2RgL>
2. **Manuscripts**
   1. Priorities paper: Resubmitted March 22 to *The Journal of Patient Reported Outcomes*
   2. SAC Engagement: Under review in *Research Involvement and Engagement*
3. **Moving forward**
   1. When the project is completed, all materials will be accessible on the PCORI website under our project profile: <https://www.pcori.org/research-results/2018/stakeholder-alliance-better-palliative-care-people-dementia-and-their>
   2. What are your interests moving forward?
   3. Quarterly meetings?

The SAC was encouraged to start thinking about their interests moving forward. Would they like to continue meeting quarterly to work on projects and potentially applying for funding? Quarterly meetings might be better or some members may want to join other committees like Dementia Friendly San Antonio, the Caregiver Advisory Council, or partner for another project.

We will continue to discuss this at our meetings for the remainder of the project period (May 2021).

1. **Group updates**

The group shared updates including an event hosting by the Alzheimer’s Association on March 30th (link below) and the new Facts and Figures Report.

**Research Update Alz Association Austin Chapter:** <https://action.alz.org/PersonifyEbusiness/Default.aspx?TabID=1356&productId=73247516&fbclid=IwAR1PJVD6uyJcwflA8v8lwtj-QeNYtYplemAxKsrPnplf77f8vgZbgzTxKsM>

Ashlie Glassner had an article published “Fighting Stigma by Engaging Persons Living with Dementia in Research” that has been shared with the group. <https://www.tandfonline.com/doi/full/10.1080/01612840.2020.1825572?journalCode=imhn20>

1. **Next meeting**: April 27th , 2020, 12-1pm