**Stakeholder Advisory Council   
Minutes  
August 25th, 2020**

**Link to August’s recorded meeting:** [**https://youtu.be/yu1AlHvYf\_8**](https://youtu.be/yu1AlHvYf_8)

***Attendance***

*Carole White*

*Sara Masoud*

*Ashlie Glassner*

*Michael Foster*

*Kiki Foster*

*James Butler*

*Byron Cordes*

*Neela Patel*

*Ginny Funk*

*Mayra Mendoza*

*Sheran Rivette*

1. **Updates on the surveys**
   1. Update on the survey responses online so far
   2. Updates from SAC on the interviews with People living with Dementia

As of August 25th, 58 people have completed the online survey (28 are caregivers, the rest are health professionals or students). There is evidence of diversity in responses and a lot of additional comments were added.

The SAC updated each other about their scheduled sessions with people living with dementia (and some caregivers) to complete the survey via Zoom or telephone.

Kiki has several lined up (and has completed 8 so far). Byron will be referring someone to Carole and Sara to schedule a survey session. Ginny and Ashlie are recruiting survey participants from the Alzheimer’s Association support group (Ashlie has 6 scheduled so far). James is networking with his community and has some sessions arranged for the next two weeks.

Mayra translated the survey and has administered it for her mother. She will be working with her brother (who is a professional translator) to further adapt the survey to capture the essence of each topic.

Neela recommended that we reach out to a contact to have the survey translated and use both Mayra’s and the other document to develop one final translated survey that captures the nuances correctly. Carole has connected with the contact and has arranged the translation.

1. **Symposium: September 22nd**
   1. Agenda (Sara share screen) – The agenda was reviewed and discussed by the SAC. A copy will be emailed along with minutes and a recording from today’s meeting.
   2. Asking the SAC to suggest questions for the speakers – The SAC should register for the symposium via Eventbrite and submit questions for speakers in their registration process.
   3. Share the flyer with people – Sara shared the flyer with everyone and will provide both pdf and image versions for email and social media sharing.
   4. SAC should register
   5. SAC Panel – the SAC reviewed the panel discussion topics. Ginny, James, Angelica, Mike & Kiki will be presenting on the panel.
2. **Interviews with some SAC members**
   1. Ashlie and Ari have interviewed some SAC members – As of August 26th, Ari and Ashlie have completed all interviews.
   2. Working on a paper with Sara and will share progress when the first draft is ready – Sara and Ashlie will provide a full draft of the manuscript to the council for their review and feedback (they will also present the paper in a more accessible format at a future meeting)
3. **COVID-19 Enhancement**
   1. Surveys to assess COVID-19 related dementia care needs / research topics – The council reviewed the draft of the questionnaire and agreed to add validated measures. Sara will send the draft for additional comments and feedback from the SAC.
4. **PCORI Annual Summit (September 16-17)**
   1. Register [here](https://www.pcorievents.org/event/51ce5d4e-230e-45a3-b2be-41eb5a3a4857/summary?utm_source=invitation080320&utm_medium=email&utm_campaign=registration-opens) today
   2. Carole and Sheran present: **Sept 16th (2:30-3:30pm CT)**
5. **Other announcements** 
   1. James’ book: *Why is Everyone Whispering Around Me?* James wrote a book! He will share about why and how he compiled this book at the next meeting. You can buy a copy here: <https://www.westbowpress.com/en/bookstore/bookdetails/797657-why-is-everyone-whispering-around-me>
   2. Next meeting? We are meeting a week after the Symposium. Next meeting will be September 29th at 12-1pm.
   3. Happy news / life updates from the group

The Alzheimer’s Association hosted their national conference online. Visit the link below to see the 5 key takeaways from the conference.   
  
<https://www.alz.org/blog/alz/july-2020/5-takeaways-from-the-2020-alzheimer-s-association>