## Stakeholder Advisory Council Meeting Minutes June 23, 2020

*In attendance:*

Carole White

James Butler

Sara Masoud

Kylie Meyer

Debbie James

Kiki Foster

Mike Foster

Yolanda Forney

Byron Cordes

Ginny Funk

Ashlie Glassner

Mayra Mendoza

Angelica Davila

Sheran Rivette

Patricia Prado

1. **Good news?** Take a moment to share good news from the past week

Council members shared good news and updates from the last few weeks. Lots of happy Father’s Day updates.

Many of the members are reading the same book right now *An Alzheimer's Journey* recommended by Kiki Foster and purchased for the group by Byron Cordes.

This meeting was recorded.

1. **Modified Delphi survey** – review two formats and provide feedback
   1. Focus on structure, fonts, colors, design, and organization

Sara, Carole, Debbie, Angelica, Sheran, and Neela met several times to refine the long list of questions.

Members of the SAC advised to revise the instructions and adjust the demographic form. Also suggested to change the questions into statements/topic areas since members said they have the desire to try to answer the actual questions instead of rating them.

1. **Survey outreach**
   1. Everyone will disseminate at least 10 surveys to other stakeholders in dementia care (your contacts)
   2. Families living with dementia will complete the survey one-on-one, others will complete them on their own
      1. Volunteers from the SAC to administer the one-on-one surveys with families living with dementia

Carole walked the SAC through our anticipated process for survey distribution and our rationale for one-to-one surveys with families living with dementia.

From discussion: People that are family caregivers or people living with dementia might respond better to other caregivers or people living with dementia. This is why meeting in smaller groups over zoom might be more beneficial for families living with dementia.

Ginny – we can contact people from the support groups including those who used to attend the meetings with us. Yoli will reach out to her support group and families who would do these surveys. James has a group of people he knows will be interested in doing the surveys in-person.

In two weeks, Sara and Carole will set up a training meeting with the people from the SAC that are interested in helping us do these surveys.

We have a little extra money in the budget to compensate the people from the SAC who will be spending additional time to do these surveys.

Carole re-stated again that it is critical that we set research priorities that are relevant and important to families living with dementia.

**Next steps**

1. Revise the list with feedback from today and put in survey format
2. **By Monday June 29th**: Send to the group for comments and feedback on design and questions
3. Council member feedback by **Monday July 13th**. Can e-mail notes, edit the document, print and mark by hand, and/or set up a call with Sara and Carole to share feedback
4. **Before July 21st**: pick date for symposiums and reach out to speakers
5. **Before July 21st:** We will make final changes to the survey with SAC feedback and will provide an e-mail template along with the final surveys to the SAC
6. SAC will send it out to at least 10 people in their networks via e-mail with the script
   1. Can also be printed and mailed with a return envelope
7. **Week of July 21st:** SAC member volunteers will meet to discuss how the surveys will be given in-person to people living with dementia and family caregivers
8. **Before August 18th**: SAC collected their responses and given to Carole and Sara
9. Based on responses in the first round, 80% threshold, we will decrease the items on the list (hopefully 20-25 items)
   1. Send out again to more people including the first people to respond
10. **By September 4th**: Collect second round of responses and prepare for discussion at the symposium
    1. **3rd week of September**: Panel of SAC members to discuss results and process
11. Send PCORI the final prioritized list
12. **Project updates**
    1. Current project extended through March 2021
    2. Symposium & webinars

Still planning for a virtual symposium in the fall with the same speakers who would have come in-person, 1.5-2 hours max. In the first symposium, focus on the questions and see if there is any more discussion from the audience to finalize them in early September

The second symposium will focus on COVID-19 and our enhancement project.

**Symposiums**

* 1. First one will be virtual in Sept 2020 (probably Sept 15 or 22)
  2. Second one will be in October 2020 – results of covid-19 survey effects on dementia care

1. **Other Updates** 
   1. Enhancement award – we got it!
   2. PCORI LOI for Latinx engagement – invited for full proposal

The enhancement award will extend this project through March 2021. What we will do is develop a list of questions related to COVID-19 that will help us understand the many perspectives of what the virus has meant for dementia care, for families living with dementia, people in long term care, care management, pastoral services, clinicians, etc.

We will develop questions and will ask them of a group of people and ask them a few months later to capture changes in their responses over time. This will give a broader perspective of what covid-19 has meant for dementia care.

PCORI application – we were invited to submit a full proposal for a project to do outreach and engagement with Latinx families in south Texas (San Antonio and Rio Grande valley). How can we raise awareness with Latinx families and Black community members about their involvement in research as collaborators not just as participants. Due by end of July 2020.

Group updates – Ginny will share the Alz Assoc July calendar and updates about their online events. Summit will be online, short Zoom seminar on August 8th.

Alzheimer’s Association international conference is for free online this July – great opportunity to attend an international conference for free. Sara will send the link out