PCORI Stakeholder Advisory Council

# Meeting Minutes

# December 4, 2018

## Opening

The regular meeting of the PCORI Stakeholder Advisory Council was called to order at 12:00pm on December 4, 2018 in ALT-C 206, UT Health San Antonio by Carole White.

## Present

Carole White, Sara Masoud, Debbie James, Sheran Rivette, Bill Zinsmeyer, Janet Zinsmeyer, Mayra Mendoza, Alicia Parker, Kathy Beer, Tommy Beer, Angelica Davila, Kiki Foster, Mike Foster, Neela Patel, James Butler, Yoli Forney, Ginny Funk

## Agenda and meeting notes

1. Webinar is on January 29, 2019 @ 12:00-1:00pm
   1. Agenda: focus on PCOR, with brief overview of dementia basics
   2. Speakers: Yasmeen Long (PCORI), Ginny Funk (AA), Neela Patel (UT Health)
      1. Neela: Dementia overview
      2. Yasmeen: What is PCOR
      3. Ginny: How can PCOR help support people living with dementia and family caregivers (examples from past)
   3. Promotion: everyone on SAC to reach out to their networks
      1. Virtual and printed flyers will be ready by the end of the week
      2. Every SAC member to bring 5 people in-person or at least over the phone

## Thoughts and comments

* Where does PCOR happen? Who funds it? Where does it take place? These are things we would like to learn from the webinar (Bill)
* The group would like to see more than just Yasmeen speak (agreed on 3 speakers to give a robust explanation of what Alzheimer’s/dementia is and how PCOR is conducted and can help)
  + Other forms of dementia are often overshadowed by information about Alzheimer’s disease
* (James) We need to see the value of the identity of people living with dementia restored
  + “We all have a heart” – detaching stigma and seeing people living with dementia as human beings who also have feelings and identities separate from their conditions
* People who are living with dementia and don’t know about it need to be reached by the SAC (Kathy)
  + These are the people who need our support the most but they are also the most difficult to reach
* We can’t lose site of the caregivers (Kathy, Sheran)
* What else can be done to get people to understand exactly what it means to live with dementia? (Kathy)
  + Caregivers live with it too (Sheran)
* Family should be the #1 resource for people living with dementia and their family caregivers, but this isn’t always the case (Bill, Mike)
* People tend to “whisper what the fear” (James)
  + We need to see where people are coming from when they avoid talking about dementia/engaging with people who are living with it/family caregivers
* We should consider creating a short video on these important topics (Debbie)
  + Toolbox?

## Tasks before next meeting

Everyone needs to push the webinar and reach out to their networks

## Next meeting

* January 9, 2018, 12:00-13:30pm
* Webinar – finalized agenda, promote the event
* Discuss palliative care
* Capacity building for PCOR SAC
* Symposium – briefly discuss