PCORI Stakeholder Advisory Council

# Meeting Minutes

# April 2nd, 2019

## Opening

The regular meeting of the PCORI Stakeholder Advisory Council was called to order at 12:100pm on April 2nd, 2019 in ALT-C 213, UT Health San Antonio by Carole White.

## Present

Carole White, Sara Masoud, Debbie James, Sheran Rivette, Mayra Mendoza, Kiki Foster, Mike Foster, James Butler, Ginny Funk, Angelica Davila, Claudia Valenzuela-Baird

## Agenda and meeting notes

1. **CITI Training Walk-Through –** Carole talked about the importance of reviewing the modules as a group in the meeting, even when some members have already taken the courses.
2. **Symposium & Toolkits June 2019**
   1. Mary Beth Gallagher will not be a speaker on the conference and Amy McLean, Nurse Practitioner at Hospice of the Valley, would replace her as speaker.
   2. *Patient involvement* is another topic is been consider for the opening on Friday, similar of the one in the Summit Alzheimer Association last March.
   3. Neela proposed a topic of “How to deal with the Diagnosis and Follow up on peoples need. Focus on Living”.
   4. The SAC will focus on “Toolkit” with purpose to get people living with dementia involved in research, so they won’t be discounted, since they can contribute greatly to the research due to their firsthand experience.
   5. Attendance is expected about 150, Carole encourage everyone to reach out to community for more exposure and more attendees.
3. **Webinar May 7th 12pm-1pm**
   1. Sara will create a flyer for the webinar and share with group
   2. SAC members proposed to have a conference room set up in The Meadows, for staff and caregivers to be able to access it.
   3. Discussion on providing more venues where people living with dementia can speak about their experiences and be listened.
   4. Neela offered to put information on the webinar in her office for more exposure.
4. **Discuss additional responses to 2 discussion questions**
   1. *From your perspective, what gaps in care do you see for people living with dementia and their families?*
   2. *What questions about dementia care would you like ti see answered by research?*
5. Kiki talked about caregivers not thinking that they do ever enough for their love ones, and Mike offered to share his point of view on this topic on a sharable format.
6. Carole recommended an article published in the International Journal of Nursing Studies written by the Caring for the Caregiver team and share a paper copy. “Transitioning into the Caregiver role following a diagnosis of Alzheimer’s disease or related dementia. A scoping review”.

## Catch up time

* 1. Mike expressed the lack of synergy when it comes to health providers on the process of diagnosis and treatment. Need to be a better way to integrate ALL provides and caregivers in the process that it’s more efficient. Kiki said “It’s a group effort, not just one person” the team should work for you and with you.

## Next meeting

* + Next meeting will be on May 14th, 2019 @ 12:00-1:30pm in ALT-C room TBA