PCORI Stakeholder Advisory Council

# Meeting Minutes

# November 6, 2018

## Opening

The regular meeting of the PCORI Stakeholder Advisory Council was called to order at 12:00pm on November 6, 2018 in ALT-C 203, UT Health San Antonio by Carole White.

## Present (14)

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

## Agenda and meeting notes

1. Introductions
2. Ground rules: discussed confidentiality, refer to each other in first names, respecting and being mindful of each other (Carole, all)
3. Overview of the PCORI award and timeline – also reviewed PROs (Carole)
4. Capacity building, goals of Council – everyone listed their personal goals (Sara, all)
   1. Better listening skills
   2. Building awareness in community
   3. Learning to share with family/get help
   4. Improve quality of life for people living with dementia
      1. Will share more at every meeting
5. Palliative care introduction (Debbie, Neela) – symptom management, not just hospice
6. Housekeeping
   1. Payment for community-members on Council – send Carole and Sara your information for processing
   2. Bring own lunches/beverages to meetings
   3. Future meetings - will meet monthly on Tuesdays in 2018 and Wednesdays in 2019

## Thoughts and comments

* Stigmatization of the condition is the biggest problem (Bill).
* Building awareness and normalization creates a ripple effect for change (Kathy, Bill)
* Clinicians need to be trained and practice supporting their patients’ families (all)

## Tasks before next meeting

Everyone to think of goals for capacity building, skills development while on the PCOR SAC.

## Next meeting

* December 4, 2018, 12:00-13:30pm
* Webinar – choose topic(s), create agenda, pick speakers
* PROs
* Capacity building for PCOR SAC
* Web portal