## Stakeholder Advisory Council Meeting MINUTES October 8, 2019 Academic Learning and Teaching Center, room 2.206

In attendance:

Michele Porras (taking notes)

Carole White

Sara Masoud

James Butler

Kiki Foster

Mike Foster

Mayra Mendoza

Ginny Funk

Angelica Davila

Deborah James

Bill Zinsmeyer

Janet Zinsmeyer

Sheran Rivette

1. **Group updates**
   1. PCORI Conference in DC – will discuss in-depth next month

James, Sara, and Carole attended the PCORI conference in DC this year. Each will choose a presentation they attended, summarize it for the SAC, and discuss their thoughts. SAC members will be shown how to use the PCORI website to access conference recordings.

* 1. Update on the Advance Care Planning research proposal

Carole and Sara will share updates about the NIH R01 grant submission that was informed by the Stakeholder Advisory Council.

1. **Goals for care article**
   1. Carole to present overview

Carole summarized the Jennings, et al. article *Patient and caregiver goals for dementia care*.

* 1. Group discussion

The group walked through the results of the articles and shared their insight about the article. The goals highlighted in the article resonated with SAC, particularly the family caregivers. There was a lot of discussion about how caregivers have to communicate not just their personal goals but those of their loved ones living with dementia and the goals of their other family members.

They talked about how lucky they feel to have providers who listen to their personal goals but that not many people can say the same about their experiences.

Kiki and Mike – our families might not always have the same goals or priorities as us but we are the ones in charge and we are going to stick to that with the help of our doctors.

1. **Topic for webinars**
   1. Stephani Shivers, MEd, OTR/L, CDP  
      Chief Operating Officer - Community Services  
      *LiveWell* Resource Center  
        
      Stephani leads LiveWell’s operations and development and is the state lead of the *Dementia Friendly America* network and *Dementia Friends Connecticut*. Stephani currently serves as the Project Lead on an Alzheimer’s Disease Program Initiative through the Administration on Community Living, and Project Co-Lead on a PCORI Engagement Award. Her forte lies in promoting agency, autonomy and independence by maximizing people’s preserved abilities and coaching ways to promote wellbeing. Stephani is co-founder of the Dementia Peer Coalition ([www.dpc-ct.org](http://www.dpc-ct.org))

The group agrees that Stephani Shivers will be a great speaker for the webinar. She will speak about a training she has given with people living with dementia for engagement in research. The webinar will take place in May 2020 so we will need to plan an earlier webinar.

The SAC suggests a webinar on the basics of dementia or focus on young onset dementia. It should also be streamed at several locations to include people who are not easily able to commute across town for meetings.

1. **Online Community:** [**utcaregivers.org**](file:///\\cfs\links\SON\NursingDean\Caring%20for%20the%20Caregiver\Grants\PCORI\Stakeholder%20Advisory%20Council\Meetings\utcaregivers.org) 
   1. Pass out flyers to get others to join
   2. Councilmembers should post in discussion

Everyone was asked to log into the portal and begin commenting on the discussion boards. The alert system has been modified so that people should receive notifications in their emails prompting them to respond to comment threads.

1. **Next meeting November 12th, 2019 – ALT-C 2.206**