**PCORI Stakeholder Advisory Council
Minutes
Tuesday April 27, 2021**

Attendance: Carole White, Sara Masoud, Ashlie Glassner, Kiki Foster, Mike Foster, Neela Patel, James Butler, Mayra Mendoza, Ginny Funk, Debbie James

1. **COVID-19 Enhancement**
	1. Update on the focus groups & surveys. Survey data collection has been completed and is undergoing analysis. The survey was completed by PLWD (N=29) and family caregivers (N=156). Preliminary findings suggest that the pandemic has increased feelings of isolation among PLWD and caregivers, worsened perceived quality of life for PLWD, and worsened perceived mental health for caregivers and PLWD. Preliminary thematic analysis of five focus groups with caregivers (N=29), two focus groups with PLWD (N=5), and three interviews with PLWD reflect challenges around isolation, relationship strain, planning for future care, communicating with PLWD, and coping strategies.

	These early analyses underscore the severity of the pandemic on experiences of social isolation, health, and quality of life of families living with dementia. Findings have the potential to be generalized beyond the current pandemic to situations where families living with dementia may face similar challenges (e.g., other natural disasters, geographically dispersed families).

1. **CER**
	1. Discuss and share ideas for future CER projects

The SAC brainstormed CER project ideas in the top priority areas for research identified over the project period: 1) Support needed at time of diagnosis; 2) Supportive care across the continuum; 3) Preparation of the healthcare team. The last section will need to be completed at the final meeting next month.

The list will be cleaned up, compiled, and uploaded to the PCORI project profile (linked in item 3 below).

Ideas for Interventions and Research Questions:

* Pamphlets that were concise and informative
* People don’t know what they don’t know
* Working with HCP around diagnosis
* How do you let people know about the available resources
* Raising awareness in the community
* Current practice – making a diagnosis – focusing on person so it is person-centered and family-centered
* Team develop list of resources around dementia
* How to give the diagnosis – is a dialogue not a one-time thing
* Focus on the person not the diagnosis
* Focus on what is most important to you and what they can do, daily routine
* How it is addressed – disease of the brain
* Accessing latest clinical research
* Peer support but how do you support the peers? Churches reaching out to their communities to find out what they need
* Comprehensive program
* Does it include just the caregiver or the PLWD too? Are they more interested in hearing from the caregiver
* Communicating with family (caregivers and PLWD together) – teaching family specific skills for talking with families and communicating
* Support needed between visits
* Journey – supporting throughout the journey
* Non-pharmacological support program for family
* Family learning process at the time of diagnosis
* Care Plan for dementia - follow the oncology model – interdisciplinary – person-focused on their quality of life
* \*\*Comprehensive care plans for every person with dementia
* Someone to prepare meals in their homes – caregivers need this extra support
* Smart houses – cameras through-out the house so you can see what someone is doing – but PLWD is awake and alone
* Someone to assist with IADLs – taking them out, etc.
* May need support with ADLs – supervision with personal care
* Room and board for caregiver who lives with them and to provide care
* Person-centered approach in home settings
* Also opportunities for social engagement – tailored approach so person still is involved
* Redesign of house – grab bars, flooring, lighting
* Caregivers who have difficulty reaching out for help, identifying who can help them, overwhelming in terms of how even to reach out for help – who would be able to support with ADLs and IADLs
* Reliable transportation
* May not always be realistic – knowing when is the right time to move – engaging PLWD in change - familiarity
1. **Moving forward**
	1. When the project is completed, all materials will be accessible on the PCORI website under our project profile: <https://www.pcori.org/research-results/2018/stakeholder-alliance-better-palliative-care-people-dementia-and-their>

Some members of the SAC shared their interest in moving forward with quarterly meetings to work on a CER project. We will finalize a plan for staying in touch at the final meeting on May 25th.

1. **Next meeting**: May 25th , 2020, 12-1pm