## Stakeholder Advisory Council Meeting MINUTES January 27, 2019

## Alzheimer’s Association 10223 McAllister Fwy

1. **Symposium** – preferred theme, dates, times, speakers.
   1. Prioritizing research questions at the symposium (modified Delphi method)

Everyone agreed that one weekday and one Saturday event would be ideal. In two different months not necessarily with the same attendees but some overlap is good.

An over-arching theme should be about involving the voices of families living with dementia in research about their care. How do we support families living with dementia in dementia care research?

Speakers like Jan Dougherty, Lee Jennings, and Cynthia Huling-Hummel are appealing to everyone in the group. We will confirm speakers at the next Stakeholder Advisory Council meeting.

We should keep speakers to 20-30 minute segments broken up with breaks.

Part of the symposiums will be to break into groups to do a modified delphi method (Morbey, et al.) to prioritize the long list of research questions we have generated over the last year or so.

Mike recommends that we cover what types of dementias there are and start each symposium with a brief review of what is dementia to make sure everyone feels informed and on the same level.

1. **Webinars**
   1. **Webinar # 1**: May 2020 – Stephani Shivers & Bob Savage – Discuss the creation of a training program for people living with dementia, caregivers, and researchers to work together
   2. **Webinar #2**: What is your preferred topic/focus for this webinar?

The SAC suggests that one of the webinars or a speaker at the symposium (or both?) should cover early onset dementia since that is a topic that is often overlooked because it is considered rare and is so unique from other dementias in many ways.

We will confirm what speakers have agreed to the webinar. As of now, Stephani Shivers or LiveWell (also a PCORI Engagement Award recipient) will be presenting a webinar in May on their trainings with people living with dementia.

1. **PCORI Project for Scale Development: Survey Opportunity –** Share information about the survey and what it is for

The SAC has agreed to allow Carole to send on their names to the other PCORI group conducting a survey for scale development.

1. **Research Summit on Dementia Care Article –** introduce the article and encourage them to read through at home.

The SAC has been emailed a copy of this article and it was printed out for people who do not have access to a printer at home.

Carole will break down this article and present on it to the group next month.

1. **SAC Research questions** – review three of the questions identified by the Stakeholder Advisory Council (space for notes on back)  
   1. What are the supports that people need following a diagnosis of dementia?

Should caregivers be referred to support groups right at diagnosis? What about people living with dementia?

How should people be given the diagnosis?

How can people in rural communities be connected to resources they need?

How early should caregivers be trained in caring for a person living with dementia?

* 1. What are caregivers needs in managing care for a person living with dementia in the home?

What is a care team?

What are the impacts of having a care team on a caregiver’s quality of care and mental health?

Teams have different goals – can you set up a criteria for building a care team? What would that criteria look like?

What kind of support do caregivers need in the home that help them provide better care?

When do you decide to move your loved one living with dementia into a care facility?

Core teams in groups - how can caregivers invite people to be part of their support network/care teams?

Does having good support in providing care at home help people living with dementia and/or caregivers stay in the homes longer?

* 1. Are outcomes better for families living with dementia who attend a support group?

What is best practice for ensuring people learn about support groups?

How can we educate about the importance of resources?

What is the importance of the frequency of support groups?

What are the outcomes that result from support groups?

Improved knowledge about resources

Emotional health and the diagnosis

Social support

1. **Next meeting February 24th 2020 at the Alzheimer’s Association 10223 McAllister Fwy**