Measuring Disease Impact on People Living with Dementia: PCORI Pre-Summit Summary

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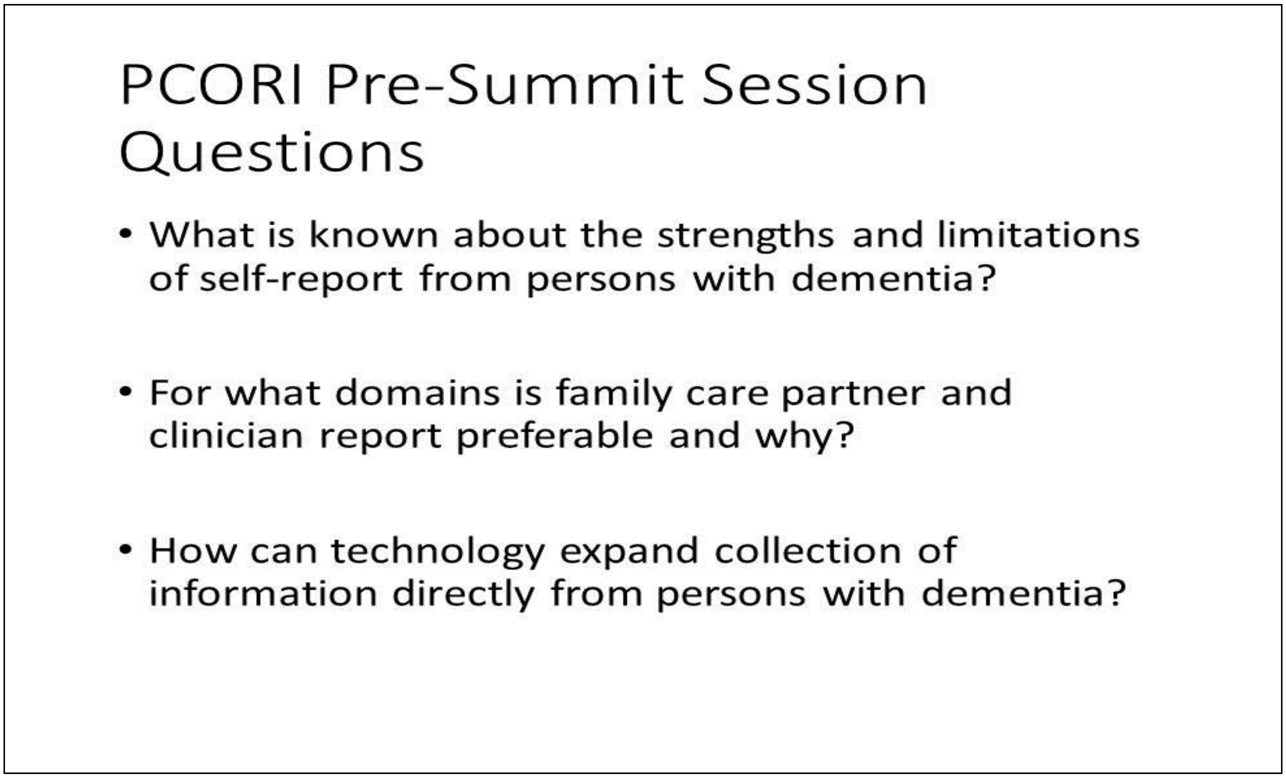
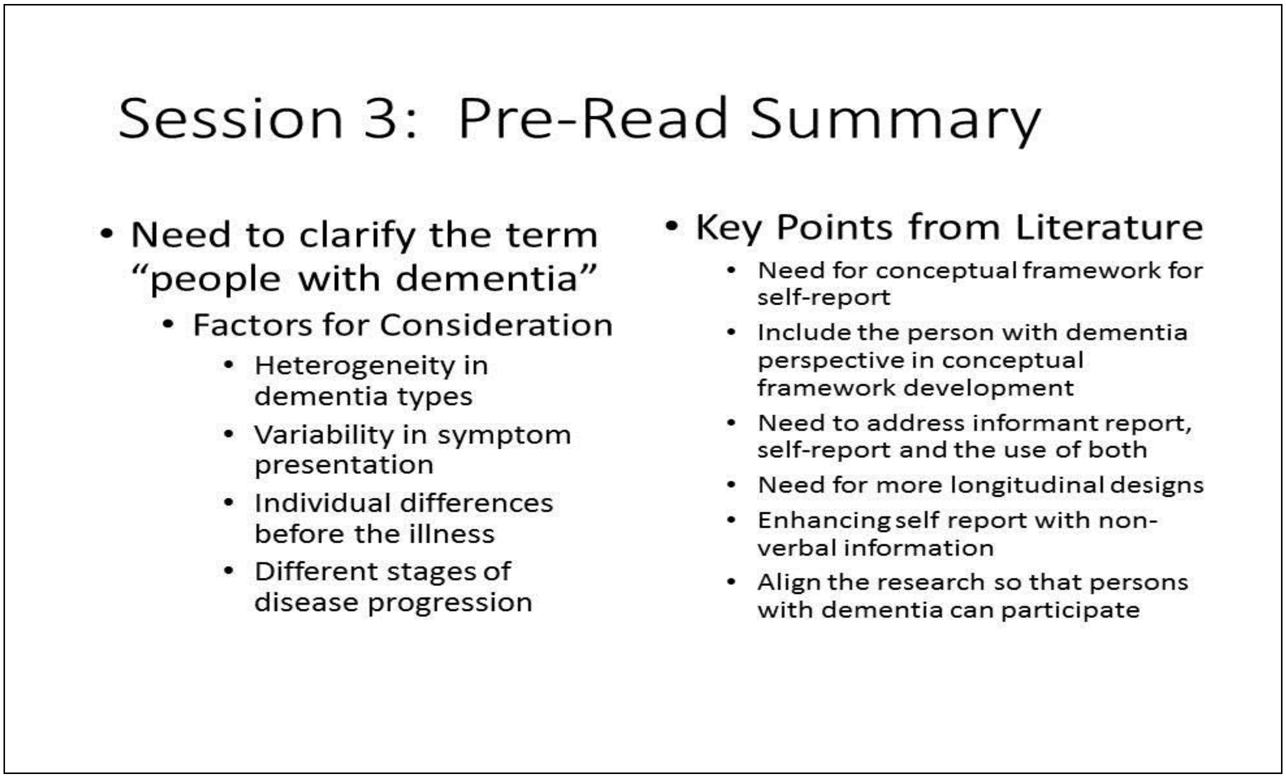
RESEARCH SUMMIT ON
DEMENTIA CARE
Building Evidence for Services and Supports

#DementiaCareSummit



PCORI Pre-Summit Session Questions

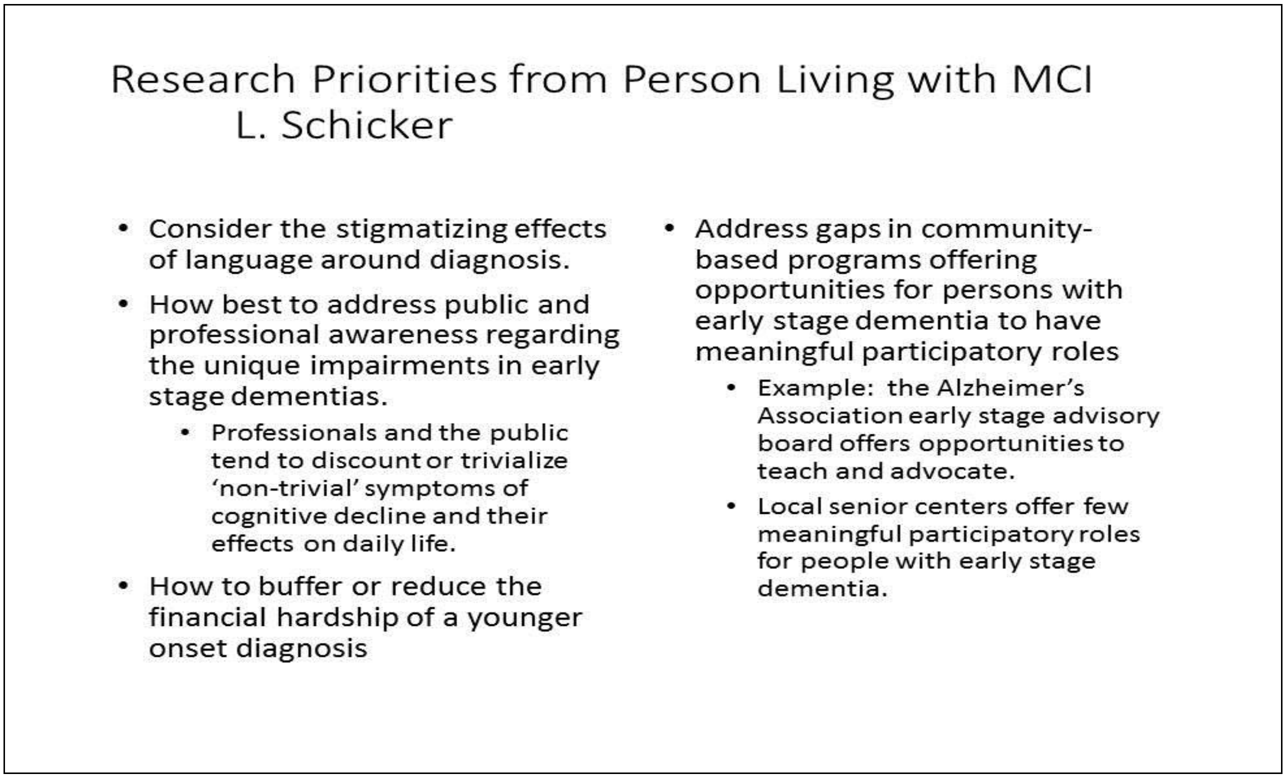
- What is known about the strengths and limitations of self-report from persons with dementia?
- For what domains is family care partner and clinician report preferable and why?
- How can technology expand collection of information directly from persons with dementia?



Session 3: Pre-Read Summary

- Need to clarify the term "people with dementia"
  - Factors for Consideration
    - Heterogeneity in dementia types
    - Variability in symptom presentation
    - Individual differences before the illness
    - Different stages of disease progression

- Key Points from Literature
  - Need for conceptual framework for self-report
  - Include the person with dementia perspective in conceptual framework development
  - Need to address informant report, self-report and the use of both
  - Need for more longitudinal designs
  - Enhancing self report with non-verbal information
  - Align the research so that persons with dementia can participate

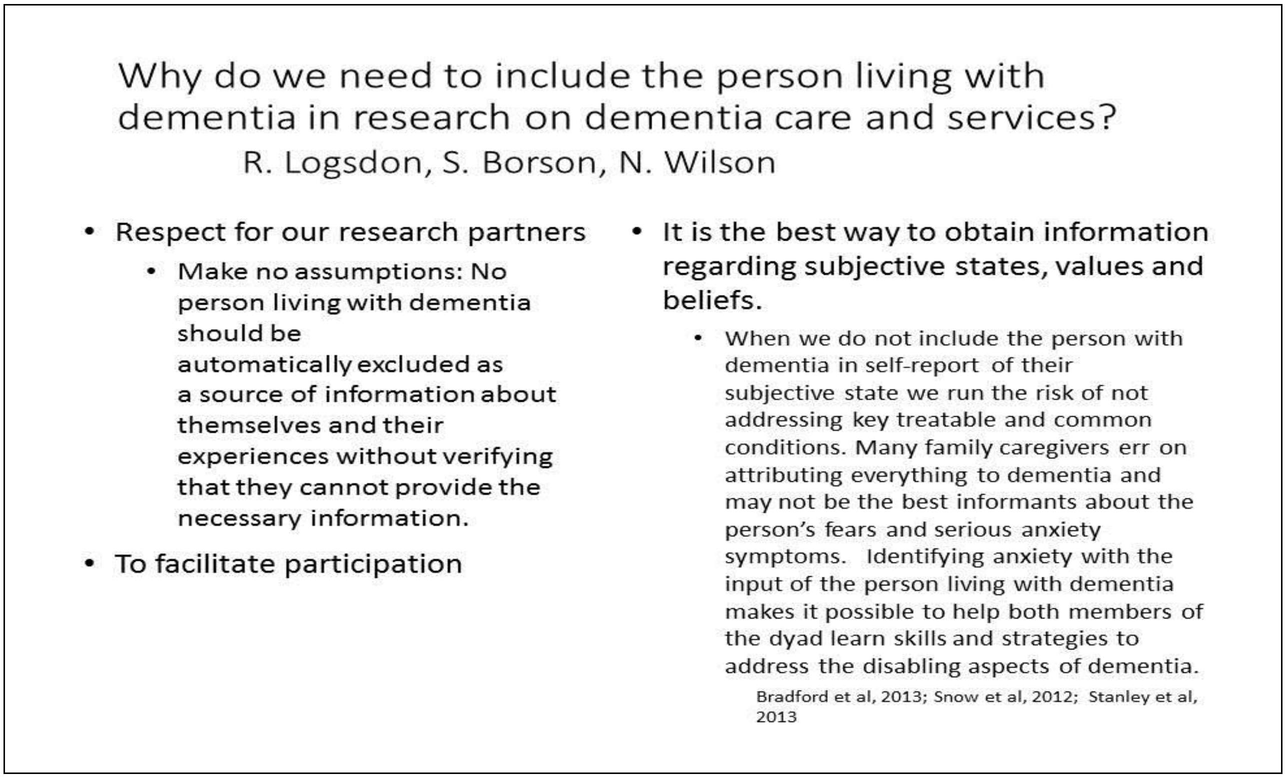


Research Priorities from Person Living with MCI

L. Schicker

- Consider the stigmatizing effects of language around diagnosis.
- How best to address public and professional awareness regarding the unique impairments in early stage dementias.
  - Professionals and the public tend to discount or trivialize 'non-trivial' symptoms of cognitive decline and their effects on daily life.
- How to buffer or reduce the financial hardship of a younger onset diagnosis

- Address gaps in community-based programs offering opportunities for persons with early stage dementia to have meaningful participatory roles
  - Example: the Alzheimer's Association early stage advisory board offers opportunities to teach and advocate.
  - Local senior centers offer few meaningful participatory roles for people with early stage dementia.

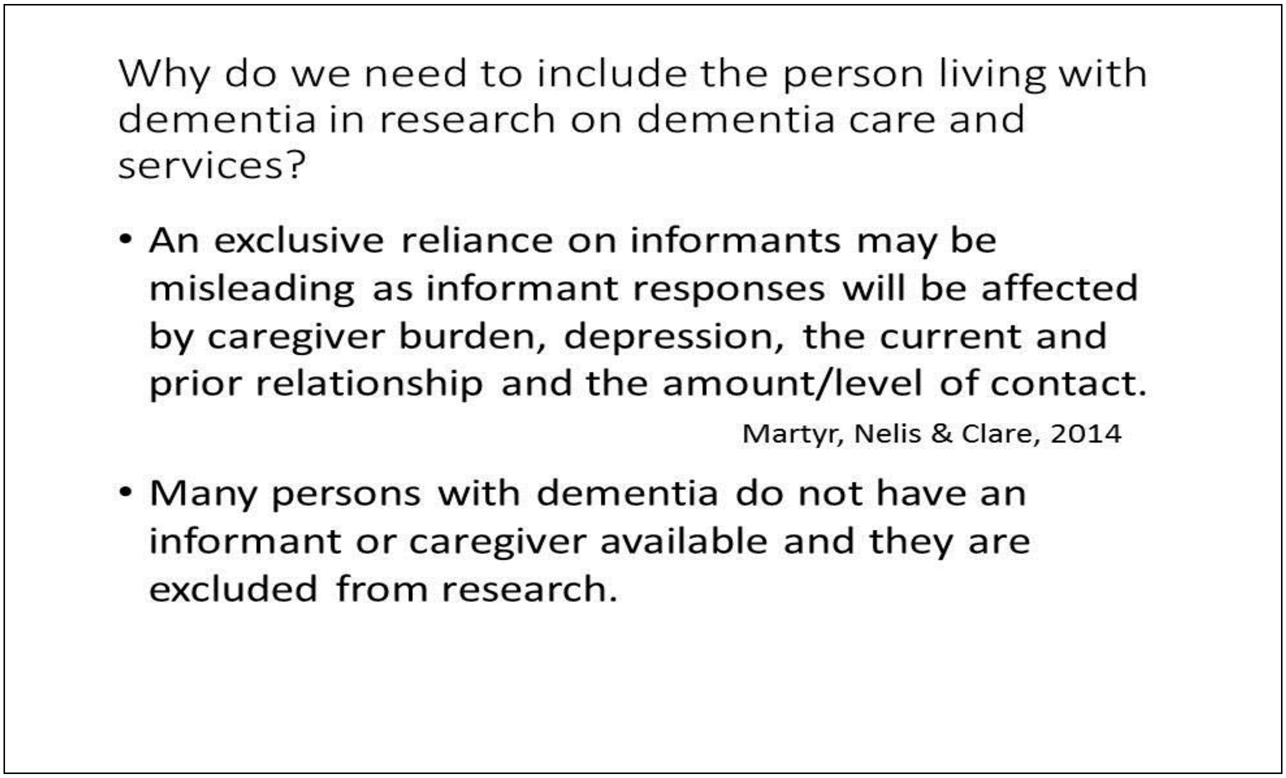


Why do we need to include the person living with dementia in research on dementia care and services?

R. Logsdon, S. Borson, N. Wilson

- Respect for our research partners
  - Make no assumptions: No person living with dementia should be automatically excluded as a source of information about themselves and their experiences without verifying that they cannot provide the necessary information.
- To facilitate participation
- It is the best way to obtain information regarding subjective states, values and beliefs.
  - When we do not include the person with dementia in self-report of their subjective state we run the risk of not addressing key treatable and common conditions. Many family caregivers err on attributing everything to dementia and may not be the best informants about the person's fears and serious anxiety symptoms. Identifying anxiety with the input of the person living with dementia makes it possible to help both members of the dyad learn skills and strategies to address the disabling aspects of dementia.

Bradford et al, 2013; Snow et al, 2012; Stanley et al, 2013



Why do we need to include the person living with dementia in research on dementia care and services?

- An exclusive reliance on informants may be misleading as informant responses will be affected by caregiver burden, depression, the current and prior relationship and the amount/level of contact.

Martyr, Nelis & Clare, 2014

- Many persons with dementia do not have an informant or caregiver available and they are excluded from research.

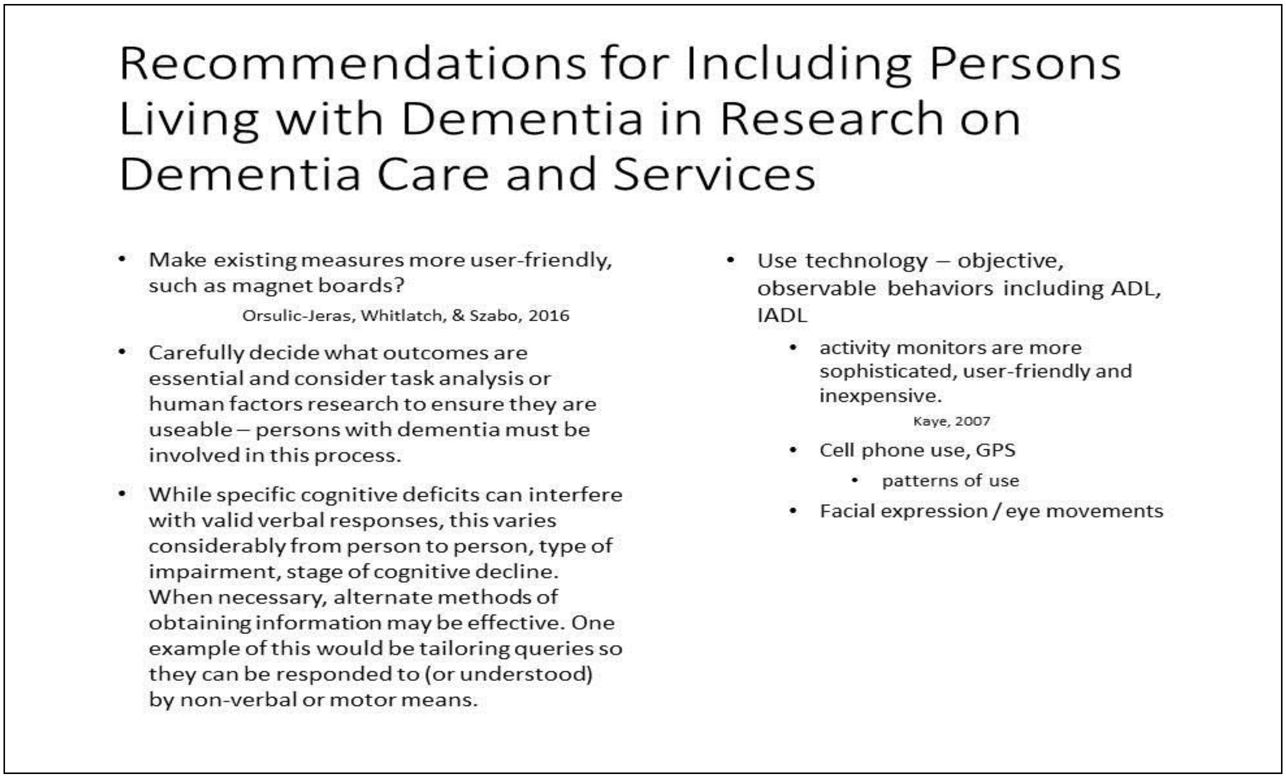
What Influences Self-Report from the Person Living with Dementia?

- Individual characteristics
  - Cognitive-comprehension, language, memory
  - Insight, understanding, acceptance of diagnosis and prognosis
  - Education, health literacy, cultural norms, perceived consequences
  - Disease progression and changes over time support the need for longitudinal studies. The good days/bad days aspects of cognitive decline could strongly affect cross sectional or one point in time self reports.
- Characteristics of measure
  - Design and complexity
  - Support for sensory and cognitive challenges; for example, large print, cues for response options

What Influences Self-Report from the Person Living with Dementia?

- Nature of information
  - Subjective: opinion, value, feeling
    - Make queries personally relevant and anchor them to an individual experience and/or the values of the person living with dementia. (It is difficult to respond to abstractions).
  - Objective: ADL, IADL, specific tasks
  - Memory requirements; e.g., 'in the past week..." vs. right now
  - For the field, create an encyclopedia of tools that have been well validated for use by people with dementia, those for which self- and proxy reports have been compared, and those that have been evaluated across dementia stages.
- How collected
  - Questionnaire, interview, in-person, telephone
    - In the Partners in Dementia Care trial, staff were trained to conduct research interviews by telephone with veterans and caregivers--and approximately 8% of the trial subjects were self-report only due to absence of a caregiver participating. A simple cognitive screen with non-traditional scoring (Blessed) was used.

      Judge et al, 2011
  - Level of detail
    - Multi-step, can it be broken into smaller components; e.g., poor-fair-good-excellent – could be broken into mostly good (good or excellent) or not so good (fair or poor).
    - Expression of emotional/non-verbal and visual rather than verbal responses should be properly classified and standardized for research purposes.

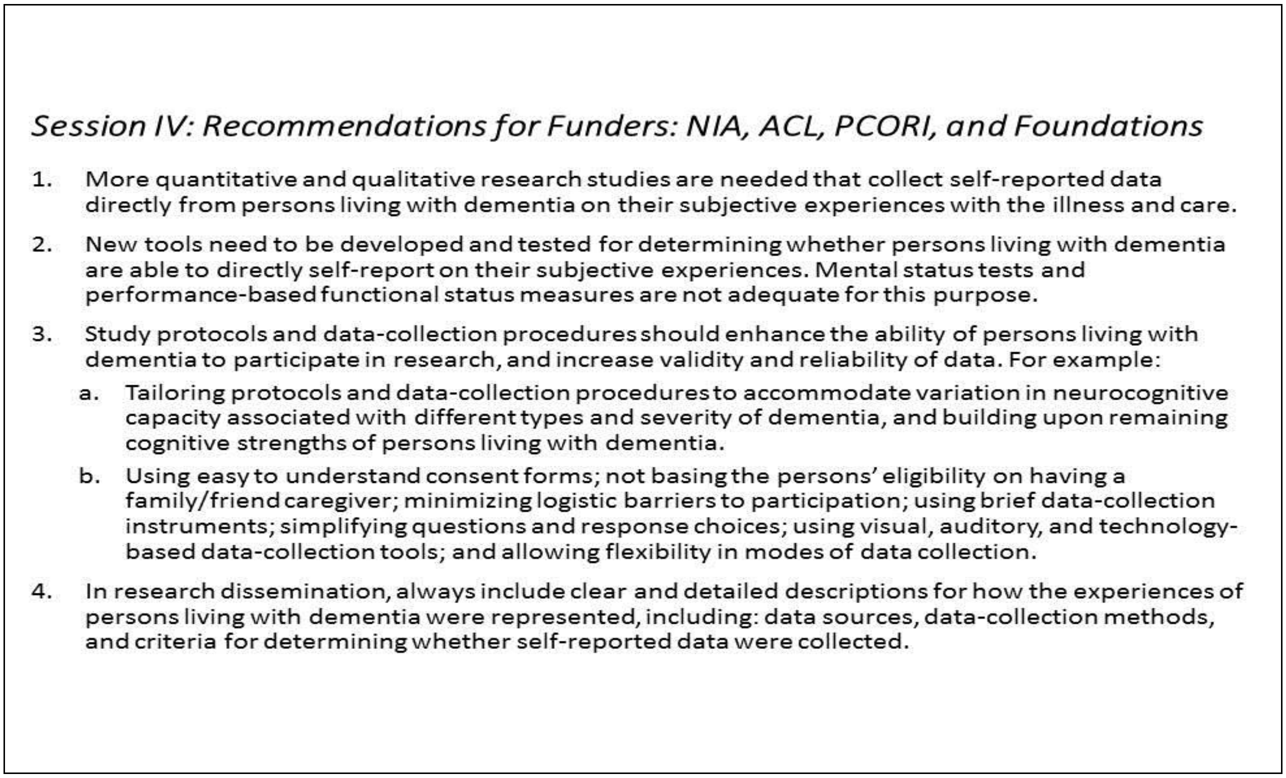


Recommendations for Including Persons Living with Dementia in Research on Dementia Care and Services

- Make existing measures more user-friendly, such as magnet boards?

  Orsulic-Jeras, Whitlatch, & Szabo, 2016
- Carefully decide what outcomes are essential and consider task analysis or human factors research to ensure they are useable – persons with dementia must be involved in this process.
- While specific cognitive deficits can interfere with valid verbal responses, this varies considerably from person to person, type of impairment, stage of cognitive decline. When necessary, alternate methods of obtaining information may be effective. One example of this would be tailoring queries so they can be responded to (or understood) by non-verbal or motor means.
- Use technology – objective, observable behaviors including ADL, IADL
  - activity monitors are more sophisticated, user-friendly and inexpensive.

    Kaye, 2007
  - Cell phone use, GPS
    - patterns of use
  - Facial expression / eye movements



Session IV: Recommendations for Funders: NIA, ACL, PCORI, and Foundations

1. More quantitative and qualitative research studies are needed that collect self-reported data directly from persons living with dementia on their subjective experiences with the illness and care.
2. New tools need to be developed and tested for determining whether persons living with dementia are able to directly self-report on their subjective experiences. Mental status tests and performance-based functional status measures are not adequate for this purpose.
3. Study protocols and data-collection procedures should enhance the ability of persons living with dementia to participate in research, and increase validity and reliability of data. For example:
   a. Tailoring protocols and data-collection procedures to accommodate variation in neurocognitive capacity associated with different types and severity of dementia, and building upon remaining cognitive strengths of persons living with dementia.
   b. Using easy to understand consent forms; not basing the persons' eligibility on having a family/friend caregiver; minimizing logistic barriers to participation; using brief data-collection instruments; simplifying questions and response choices; using visual, auditory, and technology-based data-collection tools; and allowing flexibility in modes of data collection.
4. In research dissemination, always include clear and detailed descriptions for how the experiences of persons living with dementia were represented, including: data sources, data-collection methods, and criteria for determining whether self-reported data were collected.