

Engaging individuals living with a cognitive impairment as active research team members

Teresa Webb, RN, BSN

Co-Chair, Stakeholder Group for Persons
Living with Dementia



#DementiaCareSummit

Are You Ready?

I am ready, but are you ready for me?



Puzzle Pieces

Areas of focus to improve outcomes:

- Clinical
- Services
- Caregiver, care partner and family
- Educating the public



Outcomes That Matter

- Psychosocial care practices and behavioral strategies to address neuropsychiatric symptoms including hallucinations, emotional issues (depression, anger), and information processing challenges (i.e. noisy environments) as well as other problematic symptoms such as incontinence and impaired motor control affecting balance and risk for falls.
- Person-centered approaches to assessment and care planning that thoroughly address the individual preferences and quality of life needs of a person living with dementia.
- Resources and models of coordinated care after a diagnosis that are tailored to the person's culture and language, and accessible regardless of geographic location.

Outcomes That Matter

- Implications for use of the term “cognitive impairment” or “cognitive disorder” instead of “dementia” for persons living with illness, family members and public health.
- Implications on advocacy, stigma and reported prevalence rates as a result of consolidating the disease names of all memory disorders under one general term such as “dementia” or “Alzheimer’s.”
- Implications of financial burden on diagnosis, treatment and research participation.

Hear My Voice

Reach out to the experts:

- A seat at the table
- Stakeholder Group for Individuals Living with Dementia

Look here, ask us, learn from us as we learn from you