



# Research Recommendations: Top 6 Outcomes that Matter

## Stakeholder Group Paper

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**Stakeholder Group of  
Persons Living with Dementia**

Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.



## Research Recommendations: “Top 6 Outcomes that Matter” Stakeholder Group of Persons Living with Dementia

October 1, 2017

The Stakeholder Group of Persons Living with Dementia includes 12 retired professionals from diverse backgrounds who are each committed to advocacy about dementia care, services and research. All members experience mild or moderate symptoms of a cognitive disorder. The group is co-chaired by two persons living with dementia and the leadership also includes a geriatric psychiatrist and a project coordinator experienced in leading groups of people in the early stages of a cognitive disorder. To prepare these research recommendations, monthly 90-minute meetings were conducted by videoconference, and each meeting included one or more guest senior research leaders. Between monthly meetings, a subgroup met to address logistical concerns regarding the preparation of research recommendations, responses to requests for input about specific research questions, plans for travel to participate in the Summit, and preparations to support persons living with dementia who attend the Summit. Time limitations and the personal experiences of the Group members resulted in an emphasis on research recommendations addressing early stages of illness. The Group produced recommendations categorized into the general areas of research on: new care practices to improve dementia treatment; access to care and services; strategies to promote participation in clinical trials; the experience of living with a cognitive disorder; best practices for working with family members, caregivers and proxy decision-makers; and, use of new terminology and language for public education. After a voting process, the Group decided on the following “Top 6 Outcomes that Matter.”

Many persons who experience cognitive symptoms find it difficult to obtain a diagnosis and begin a person-centered treatment plan in a coordinated manner that is sensitive to the challenges – emotional, cognitive, social and physical – that accompany the early stages of a cognitive disorder. Therefore, this Group’s strongest recommendations are for new research that addresses treatment of neuropsychiatric symptoms, a person-centered approach to assessment and care planning, and accessible culturally-competent care management after diagnosis. Specifically, the Group recommends new research on:

1. 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.
2. 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.
3. 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.

The Group also recommends clarification of milestones to demonstrate advancement in the understanding of treatments for neuropsychiatric symptoms and person-centered approaches to care planning and care management. Milestone measures should show increases in persons with dementia and family members reporting high satisfaction with her/his care team over time.

Additional new research is recommended on language and terminology. Many Group members reported difficult experiences with the term “dementia,” and concerns were raised that it is inaccurate to describe early stages of illness and that reliance on use of the word dementia may impair engagement in treatments. However, there was also strong interest in studying how greater public education about the terms “dementia” and “Alzheimer’s disease” could lead to reduced stigma and increased ease in reporting of symptoms. Therefore, the Group recommends new research on:

4. Implications for use of the term “cognitive impairment” or “cognitive disorder” instead of “dementia” for persons living with illness, family members and public health.
5. 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.”

Finally, there was group consensus that too little is known about socioeconomic and cognitive disorders. Group members raised concerns that impaired work functioning, job loss or forced early retirement, and treatment costs likely have significant impact on the process of engaging in treatment and the choice as to whether one might participate in a clinical trial. Specifically, the Group recommends new research on:

6. Implications of financial burden on diagnosis, treatment and research participation.

Investigators with expertise in these Top 6 Outcomes that Matter are invited to engage with the Stakeholder Group of Persons Living with Dementia to further clarify the language and meaning of each research recommendation and to develop milestones for achievement.

The Stakeholder Group of Persons Living with Dementia also recommends that research recommendations developed from other stakeholders should be available for public comments including input and refinement from persons living with dementia and their family members and care partners.