



# Persons Living with Dementia Recommendations

## Dementia Care Virtual Summit Meeting

July 2020

Prepared by:  
**Persons Living with Dementia Stakeholder Group**

Additional information can be found at the Summit website (<https://www.nia.nih.gov/2020-dementia-care-summit>) 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.

# **National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers**

## **2020 Dementia Care Virtual Summit Meeting: Persons Living with Dementia Stakeholder Group Research Recommendations**

### ***RECOMMENDATIONS: BY THEME***

#### **THEME 1: Impact of Dementia**

##### **Recommendation 1A: Lived Experience and Health Disparities.**

Study known health disparities among demographic groups and how these factors affect the experience of living with dementia. Factors important for study include: race, ethnicity, socioeconomic status, sexual orientation, education, geographic location, living situation, social support, gender identity, veteran status, history of cognitive symptoms before dementia (intellectual and developmental disability), sensory impairments, and medical conditions. These factors should be studied: (1) to improve health outcomes in-general and specifically for members of sociodemographic groups at greater risk for dementia and for negative outcomes related to dementia; (2) to reduce barriers to care and treatment; and, (3) to identify strategies for enhancing quality of life and improving the experience of living with dementia.

##### **Recommendation 1B: Financial Burden.**

Study how economic and financial burdens affect choices about diagnosis, treatment and research participation. This research should lead to strategies for reducing financial burden--particularly for persons living with dementia and care partners who are younger than 65--and to improved access to early diagnosis, treatment, living conditions, and opportunities for research participation among persons living with dementia and care partners who experience financial burden.

##### **Recommendation 1C: End of Life.**

Study the effects of a dementia diagnosis on thoughts about end of life care, including thoughts about the state-by-state laws regarding physician-assisted death or "medical aid in dying" in circumstances of dementia. This should be studied to improve the quality of end of life care for dementia.

## **THEME 2: Long-Term Services and Supports**

### **Recommendation 2A: Workforce.**

Study workforce education and training programs designed to enhance learners' skills in working with persons living with dementia to determine the effectiveness of the education and training for improving: (1) the understanding of experiences of persons living with dementia; and (2) workforce members' competence and confidence. These trainings may target health care providers, other non-licensed service and care providers, and workers (e.g., first responders, bankers) who impact the well-being of people with dementia in the course of their work.

### **Recommendation 2B: Managing Symptoms.**

Study care practices to improve the experience of living with symptoms including: hallucinations, emotional issues (depression, anger, anxiety, traumatic stress), information processing challenges (i.e. noisy environments), and other difficult symptoms such as incontinence and impaired motor control affecting balance and risk for falls.

### **Recommendation 2C: Person-Centered Planning.**

Study person-centered planning approaches for assessment and care to show how thoroughly addressing individual preferences can result in better quality of life, meaningful activities and sense of purpose of a person living with dementia. This should involve planning related to all stages of the disease.

### **Recommendation 2D: Barriers to Person-Centered Care.**

Study if regulatory or procedural aspects of health care services may inhibit elements of person-centered planning or lead people living with cognitive symptoms or their care partners to choose to not seek opportunities for care at relevant times during the illness course. For example, eligibility requirements for home-based services may limit access to such services, or regulatory aspects of residential care may prevent elements of person-centered care from being implemented in the residential setting. This is important to increase access to care and to improve person-centered planning.

## **THEME 3: Services and Supports in Medical Care Settings**

### **Recommendation 3A: Infrastructure and Technology.**

Study strategies--including improved infrastructure and use of new technologies--to enhance communication among care providers (in medical and community settings), family, and support team members, and to support people with dementia to live more independently. This is important to show how better coordination and

communication can improve the experiences of persons living with dementia and their family members and care partners.

**Recommendation 3B: Stigma.**

Study ageism and stigma against persons living with dementia to show how such biases can impact the experiences of persons living with dementia. This would include the study of nomenclature, in particular the use of the term “cognitive impairment” or “cognitive disorder” instead of “Alzheimer’s and other related disorders” or “dementia.” This is important to identify attitudes and misperceptions regarding dementia and set the groundwork to determine how best to educate the general public and businesses on how to improve the experiences of people living with dementia and their care partners. Also, study how the reference to dementia as “an older person’s disease” (with many services and research studies being geared towards an older group) impacts the growing number of people under 65 living with dementia. This is important to improve the experiences of persons living with dementia and their family members and care partners.

**Recommendation 3C: Medical Conditions.**

Study ways to improve treatments of medical conditions for persons living with dementia, including treatments in primary care, emergency rooms, hospitals and other health care settings. This is important to improve health outcomes for persons living with dementia.

**THEME 4: Participation of Persons Living with Dementia and their Caregivers in Research**

Recommendations were made under this theme but were not prioritized by members of the Stakeholder Group of Persons Living with Dementia.

**THEME 5: Intervention Research, Dissemination, and Implementation**

Recommendation 5A: Care Coordination: Study models of care coordination after a diagnosis that are tailored to the person’s culture, race, ethnicity, socioeconomic status, education, geographic location, living situation, social support, sexual orientation, gender identity, veteran status, and history of cognitive symptoms. This research should seek to identify approaches that result in improvements in the care experience of persons living with dementia and their family members and care partners

**THEME 6: Research Resources, Methods, and Data Infrastructure**

Recommendations were made under this theme but were not prioritized by members of the Stakeholder Group of Persons Living with Dementia.

## **AFTERWARDS**

The following recommendations were discussed as important but were not prioritized in the top 11:

1. **“Dementia Friendly:”** Study the elements of “dementia friendly” initiatives to determine which aspects result in improvements in the experiences of persons living with dementia.
2. **Dementia-Related Behaviors:** Study medication and non-medication strategies used to address behavioral and psychological symptoms of dementia. This should be studied to improve the quality of care in residential settings and community-based services.
3. **Research Accessibility:** Study strategies to increase participation in research. Include study of new approaches to support participation in medical or residential settings, and the use of overnight research centers for participants who do not have a study partner. Also study strategies for including persons living with cognitive symptoms as members of research teams. This research should be done to show how participation can be increased and be less burdensome.
4. **Ethics of Participation in Research:** Study the effects of increasing the amount of personal research data information shared and the method for information sharing. This can show potential benefits to participants regarding knowledge about disease severity over time. Include studies of how to assign research staff to participants to show reduced confusion about the nature of research and how the timing of starting and/or ending the research may impact lived experiences of participants.
5. **Clinical Care Accessibility:** Study strategies to increase access to evidence-based clinical services by first increasing education about the services. Include study of new approaches to increase access such as tailoring clinical services to the population’s needs and developing peer networks to improve communication.
6. **Observational Research:** Study research methods which focus on observation of the daily/weekly routine(s) of persons living with dementia and their family members and support team to show how participation in research can be less cumbersome and to learn about the lived experience through such studies.
7. **Core Characteristics:** Study development of a core list of characteristics of persons living with dementia, their families, their support team, and their living environment that should be measured in research on dementia care, services and supports. This is important to know the heterogeneity of situations and to inform the planning of future research and the ability to compare studies of populations.

## **Appendix A: List of Persons Living with Dementia Stakeholder Group Members**

### ***Co-Chairs***

Gary Epstein-Lubow	Brown University
Monica Moreno	Alzheimer's Association

### ***Members***

Arthena Caston	Macon, Georgia
David Elliott	Piedmont, California
Bonnie Erickson	Billings, Montana
Keith Moreland	Anderson, South Carolina
Ed Patterson	Clermont, Florida
Laurie Scherrer	Oley, Pennsylvania
Chris Shwilk	Carlisle, Pennsylvania