

# *Innovating the Next Generation of Dementia and Alzheimer's Disease Care Interventions: Addressing the Needs of Persons Living with Dementia, Caregivers, and Care Providers*

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October 16, 2017



#DementiaCareSummit

## Presentation Overview

- NIA-BSR Presummit Goals
- 4 Categories/Themes for Future Research
- 15 Recommendations

## NIA BSR Presummit Goals

### Primary goals:

- Determine the state of the science of research on evidence-based care interventions for persons with dementia and caregivers
- Articulate a research agenda for caregiving, care, and services for persons with Alzheimer's disease and related dementias (ADRD) and their caregivers
  - i. Aim 1: Classify the various types of care interventions in terms of the populations and outcomes targeted and the settings (e.g., at-home, assisted living, nursing homes, physician's office, community settings) in which they have been studied.
  - ii. Aim 2: Understand some of the barriers that make adoption of evidence-based interventions difficult and the ways in which these barriers can be overcome.
- Frame interventions discussion in terms of the NIH Stage Model

## Categories/Themes for Future Research

- A. Focus intervention research on improving care for persons living with dementia
- B. Coordinate a research agenda to address all phases of intervention development and implementation
- C. Address heterogeneity and disparities
- D. Address measurement issues and multiple outcomes of interest

***A. Focus Intervention Research on Improving Care for Persons Living with Dementia***

1. Support research that tests interventions that improve the quality of life and other outcomes of relevance for persons living with dementia by setting: community home, residential long-term care settings (e.g. assisted living and nursing homes) and in health care systems (ED, clinics, etc.).
2. Support research to test whether technology-based interventions improve the efficiency and effectiveness of evidence based care/service delivery programs for persons living with dementia.

***B. Coordinate a Research Agenda to Address All Stages of Intervention Development and Adoption***

1. Support research to improve our understanding of the basic mechanisms underlying efficacious and effective interventions that improve the quality of life for persons with ADRD and their caregivers.
2. Support research that tests evidence based, efficacious care programs that improve the lives of persons with ADRD and their caregivers as implemented in real-world settings.
3. Support research into the scalability and sustainability of interventions; what aspects of effective interventions are able and unable to be implemented in real world health care system settings.
4. Support interdisciplinary communication regarding optimal approaches to design interventions.
5. Support research into those “leverage points” that can be used to promote the implementation and diffusion of efficacious and effective interventions in real world community and/or health care systems.

### *C. Address Heterogeneity and Disparities*

1. Support research on how well effective intervention programs can be replicated in diverse participant populations as well as in settings oriented toward serving diverse patient populations.
2. Support research on the heterogeneity of response to efficacious interventions; i.e. to characterize persons living with dementia and/or their family caregivers for whom the intervention(s) do and do not achieve the intended effects.
3. Support research on whether and which of the different types of dementia respond and are refractory to interventions shown to be effective, on average.
4. Support research to identify efficacious and effective interventions for persons with mild cognitive impairment and their care partners.
5. Support research designed to identify barriers to access to high-quality dementia care and to develop programs designed to minimize such access barriers

### *D. Address Measurement Issues and Multiple Outcomes of Interest*

1. Support research on the validity and generalizability of measures of outcomes acknowledged to be of importance for persons living with dementia and their caregivers.
2. Support research that constructs longitudinal data systems in order to more efficiently characterize the disease and caregiving need trajectories of those living with dementia (and its identifiable sub-types).
3. Support research on the cost-effectiveness of interventions shown to be effective in improving the quality of life and reducing the unmet needs of persons with dementia and their caregivers