

Outline for Summit Final Report

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

Report to the National Advisory Council on Alzheimer's Research, Care, and Services

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- **Abstract:**
- **Introduction:**
- **Advance Preparation:**
 - Steering Committee:
 - Stakeholder Groups:
 - Pre-Summit Activities:
- **Organizing Participants and Sponsors**
- **Summit Overview:**
- **Session Highlights:** brief overview of what occurred at each session
 - **Plenary Sessions:** Diversity, Nomenclature, and Thinking Outside the Box
 - **Session I: Research On Care Needs And Supportive Approaches For Persons With Dementia** (Session Co-Chairs: Richard H. Fortinsky, Phd And Ann Kolanowski, Phd, RN, FGSA, FAAN)
 - **Session II: Research On Supportive Approaches For Family And Other Caregivers** (Session Co-Chairs: Linda Teri, Phd And Lisa Fredman, Phd)
 - **Session III: Involving Persons With Dementia And Caregivers As Members Of The Research Team** (Session Co-Chairs: Mark Snowden, MD, MPH And Lee Jennings, MD, MSHS)
 - **Session IV: Involving Persons With Dementia As Study Participants** (Session Co-Chairs Darby Morhardt, Phd, LCSW And David M. Bass, Phd)
 - **Session V: Research On Models Of Care For Persons Living With Dementia And Their Families Across The Disease Trajectory** (Session Co-Chairs Vincent Mor, Phd And David B. Reuben, MD)
 - **Session VI: Thinking Outside The Box** (Session Co-Chairs: Christopher Callahan, MD And Alan B. Stevens, Phd)
 - **Cross-cutting Themes:** Heterogeneity, Technology, Differential Impact on Women
- **Recommendations:** how many and process to consolidate and organize
- **Priority Recommendations:** We consolidated to 11 themes and the following recommendations under each.
 - **Heterogeneity**
 - Focus Area 1
 - Rec 1

- Rec 2
 - Rec 3
 - Focus Area 2
 - Rec 1
 - Rec 2
 - Rec 3
- **Clinical Approaches and the Lived Experience of Persons with Dementia**
- **Caregiver Relationships, Roles, and Networks**
- **Comprehensive Models of Care Across Trajectories and Care Settings**
- **Strategies for Scaling and Disseminating Existing Evidence, Drawing Upon Implementation Science**
- **Dementia-Related Terminology and Stigma: Words Matter**
- **Financial Burden and Costs**
- **Living Arrangements, Care Settings, and Persons with Dementia who Live Alone**
- **Technology**
- **Workforce**
- **Research Methodology**
- **Post-Summit Follow-Up:**
 - Anticipated outcomes:
 - Post-Summits:
 - Publications:

Appendixes:

- Steering Committee Members
- Stakeholder Groups
- Writing Committee (3rd Day participants)