

Proposed Research Summit on Care and Services for Persons with Dementia and their Family Caregivers

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Jan. 25, 2016

Goal of the Research Summit

The goal of the research summit is to accelerate the design, testing, translation, and scaling up of effective approaches to increase quality of care and services and improve outcomes, including quality of life and the lived experience of Alzheimer's disease and other dementias, for persons with these conditions and their families.

Context for the Research Summit

- Valuable outcomes from three previous Alzheimer's and dementia research summits that focused primarily on biomedical research
- Growing number of evidence-based care practices and services with positive outcomes for persons with dementia and their families, reinforcing awareness that it is possible to improve the quality of life and lived experience of dementia
- Realization that the existing evidence-based care practices and services are not available in most communities across the country
- Growing attention to the heterogeneity of persons with dementia, family caregivers, and caregiving situations and to the need for care practices and services that address individual needs

Building on Previous and Ongoing Work

The research summit is intended to build on, not re-do or replace:

- research funded and conducted by government and private sector organizations and individual research teams
- pilot and demonstration programs that are serving persons with dementia and their families, and
- existing initiatives to identify needs and establish goals, priorities, and milestones for improving care and services for persons with dementia and their families.

Main Topics for the Research Summit

1. Evidence-based care practices and services for persons with dementia and family caregivers
 - What do we know about the effectiveness of existing, evidence-based care practices and services?
 - What additional research is needed:
 - to address research gaps
 - to allow targeting of particular care practices and services to persons with dementia and family caregivers who are most likely to benefit?

Main Topics for the Research Summit

2. Translation studies to test evidence-based care practices and services outside research settings
 - Which evidence-based care practices and services have been tested in translation studies?
 - What real-world outcomes have been found with respect to effectiveness, acceptability, feasibility, costs, and training and skills needed to deliver the care practices and services?
 - What additional translation studies are needed to support scaling up of effective care practices and services?

Topics to be addressed before the Summit

1. Demographics of dementia to describe the heterogenous population we are trying to reach and help
 - Findings to be presented as introductory information at the summit
 - Including the range/array of characteristics of persons with dementia, family and other key caregivers, and caregiving situations
 - Report and graphics (perhaps a data book) to convey the findings

Topics to be addressed before the Summit

2. Methodological issues in research on care and services for persons with dementia and family caregivers
 - Are there promising care practices and services that cannot be studied with RCT methodology? If so, what alternate methodologies can be used to produce findings that will be acknowledged as “evidence based”?
 - How can persons with dementia be routinely engaged (e.g. interviewed) in research on care practices and services?
 - How can persons with dementia and family caregivers be engaged in identifying important research on care practices and services and outcomes that are meaningful to them?

Additional Topics for Consideration (post-summit workshops or the next summit)

- Training. What do we know about training for delivery of evidence-based care practices and services? What additional research is needed?
- Quality. How should quality be measured for care practices and services for persons with dementia and their family caregivers?
- Information dissemination. How can findings from research and translation studies be disseminated to agencies and payers that may want to provide and pay for evidence-based care practices and services?

Summit Outcomes

- Research gaps identified
- Translation study gaps identified, including gaps in information needed to support scaling up
- Priorities for research and translation studies established
- Established priorities considered for funding by government and private sector organizations that support research and translation studies
- Established priorities considered for inclusion in NAPA plan updates
- Established priorities for scaling considered by government and private sector providers and payers

Related NAPA Goals

- Goal 2: Enhance Care Quality and Efficiency
- Goal 3: Expand supports for people with Alzheimer's and their families
- Goal 5: Improve data to track progress

Stakeholder Groups

- Persons with dementia and family and other key caregivers
- Government and private sector organizations that support research on dementia-related issues
- Researchers who conduct studies to test and evaluate approaches to improve dementia care and services
- Organizations and individuals that advocate for improved dementia care and services
- Government and private sector providers and payers

Summit Structure and Logistics

- Public-Private sector steering committee to plan and organize the summit
- Information about some topics prepared and disseminated before the summit (e.g. demographics and research methodology)
- Topic-related “sessions” would include invited presentations, panel discussion, and robust audience participation
- Workgroup(s) designated to draft findings and recommendations

Next Steps

- Establish a diverse, representative, and expert summit steering committee
- Define desired level of coordination between the NAPA Advisory Council and the summit steering committee
- Engage more stakeholders and generate partnership commitments
- Build on experience from previous summits and existing successful work led by government and private sector stakeholders to achieve the summit’s overarching goal (see slide 2) of improving “quality of life and the lived experience of Alzheimer’s disease and other dementias, for persons with these conditions and their families.”

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