RESEARCH SUMMIT ON DEMENTIA CARE

Building Evidence for Services and Supports

OCTOBER 16-17, 2017
NATCHER BUILDING, NIH CAMPUS

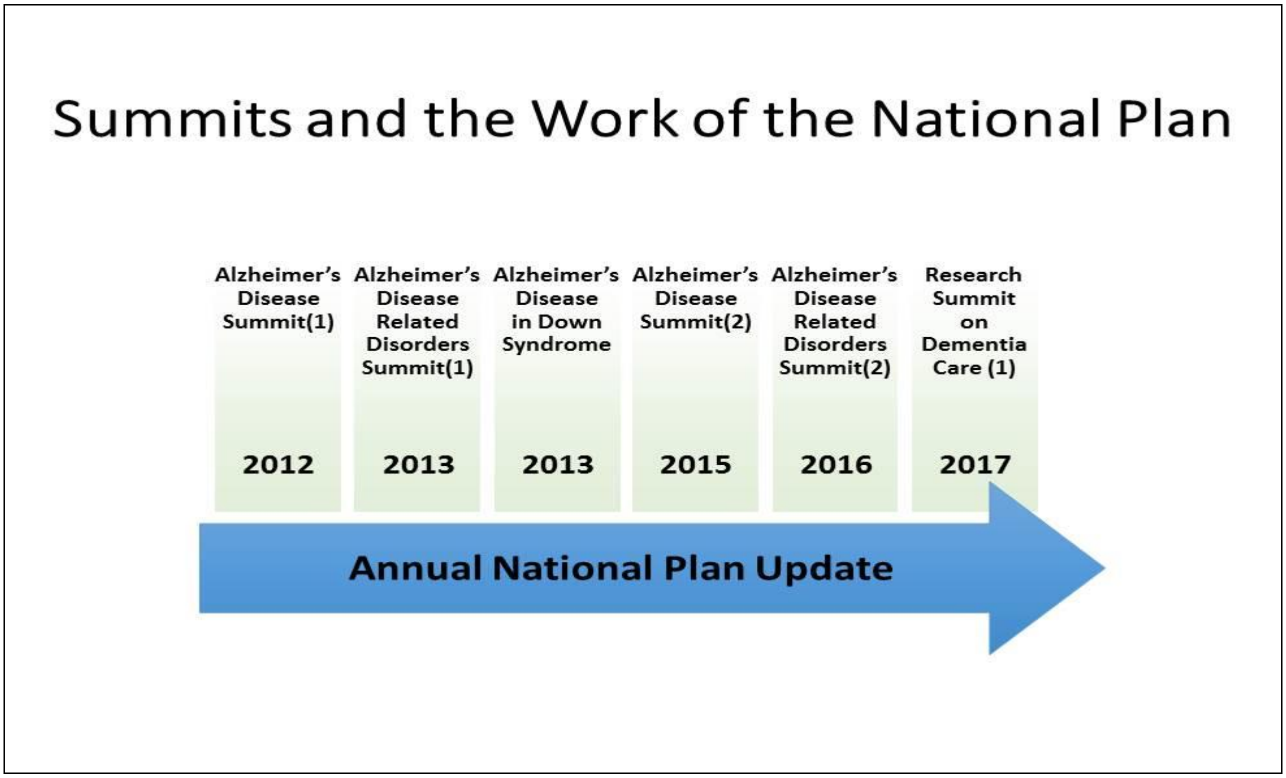
Overview and Recommendations

Laura N. Gitlin and Katie Maslow

Presentation to the Advisory Council on Alzheimer's
Research, Care, and Services
October 27, 2017

Summit Overview

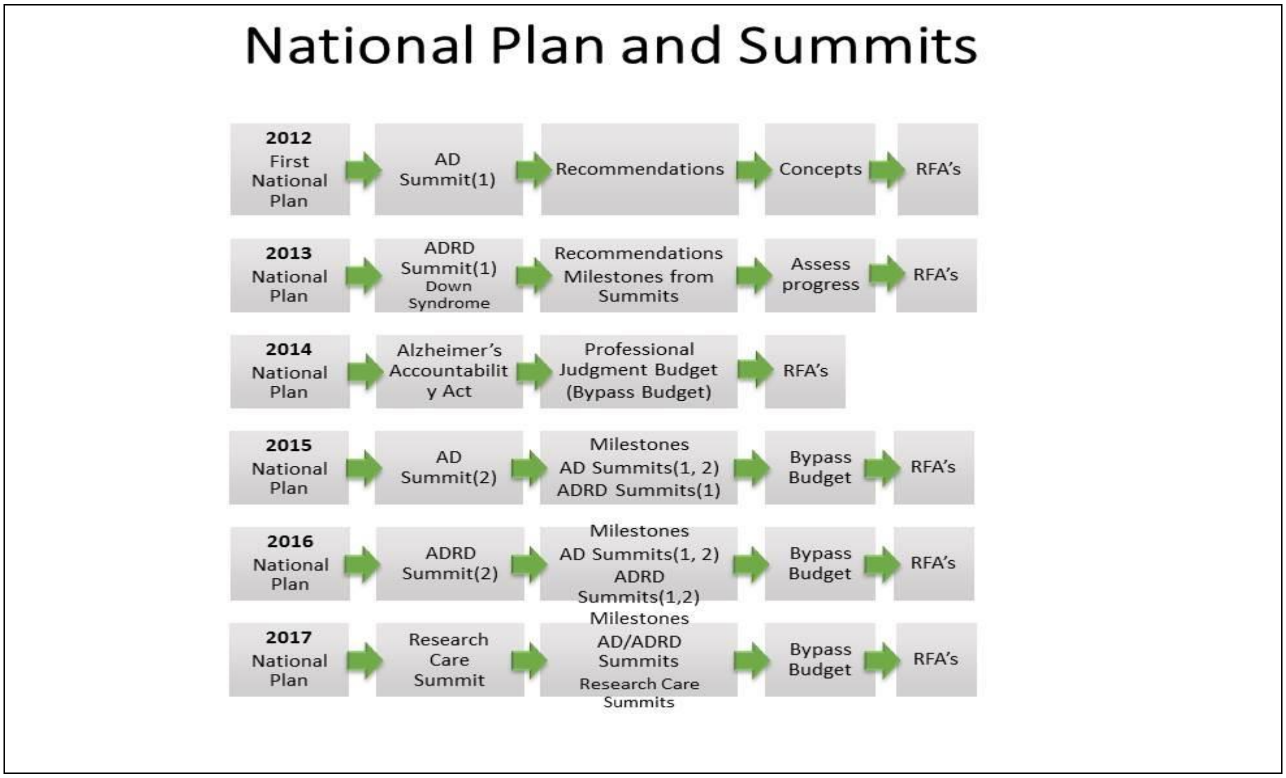
- First National Research Summit on Care, Services and Supports for Individuals Living with Dementia and their Caregivers
- Whereas previous Summits were overseen by NIH, this Summit was sponsored by the Advisory Council:
  - Participation of a Steering Committee with representatives from various federal agencies, member of the Advisory Council and others including persons with dementia
  - Participation of 6 stakeholder groups
  - Research recommendations generated that are relevant to NIH as well as other federal agencies, foundations and industry
    - As research on care, services and supports is complex, and multi-faceted
    - Multiple agencies must be involved
  - Advisory Council will need to have a key role in disseminating recommendations, and monitoring and coordinating efforts to move them forward
- Whereas other National Summits occur every two to three years, frequency and support for this Summit needs to be determined



Summits and the Work of the National Plan

Alzheimer's Disease Summit(1)	Alzheimer's Disease Related Disorders Summit(1)	Alzheimer's Disease in Down Syndrome	Alzheimer's Disease Summit(2)	Alzheimer's Disease Related Disorders Summit(2)	Research Summit on Dementia Care (1)
2012	2013	2013	2015	2016	2017

Annual National Plan Update

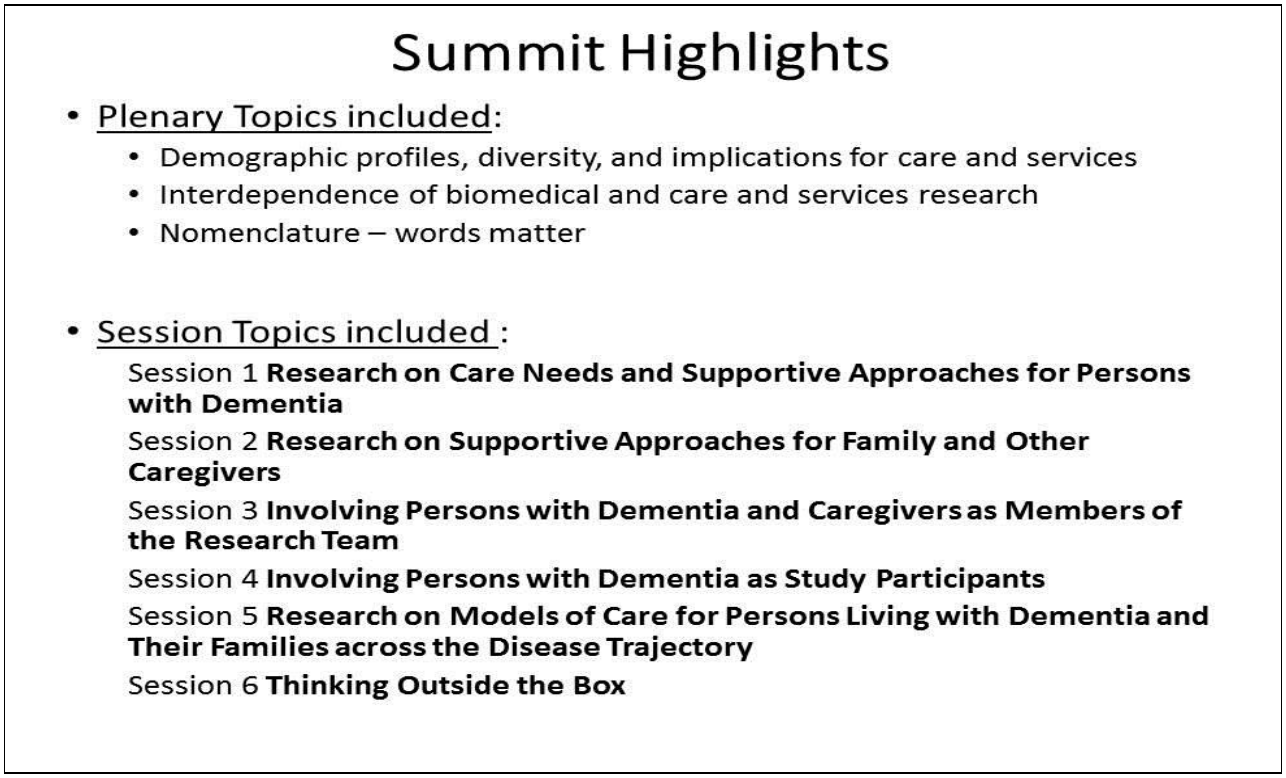


National Plan and Summits

2012 First National Plan	AD Summit(1)	Recommendations	Concepts	RFA's
2013 National Plan	ADRD Summit(1) Down Syndrome	Recommendations Milestones from Summits	Assess progress	RFA's
2014 National Plan	Alzheimer's Accountability Act	Professional Judgment Budget (Bypass Budget)	RFA's	
2015 National Plan	AD Summit(2)	Milestones AD Summits(1, 2) ADRD Summits(1)	Bypass Budget	RFA's
2016 National Plan	ADRD Summit(2)	Milestones AD Summits(1, 2) ADRD Summits(1,2)	Bypass Budget	RFA's
2017 National Plan	Research Care Summit	Milestones AD/ADRD Summits Research Care Summits	Bypass Budget	RFA's

Summit Highlights

- 500 participants registered for in-person attendance
- 787 participants on webcast Day 1; 591 on Day 2
  - 132+ have watched the posted video of Day 1
  - 42+ have watched the posted video of Day 2
- 77 Speakers



Summit Highlights

- Plenary Topics included:
  - Demographic profiles, diversity, and implications for care and services
  - Interdependence of biomedical and care and services research
  - Nomenclature – words matter

- Session Topics included :

  Session 1 **Research on Care Needs and Supportive Approaches for Persons with Dementia**

  Session 2 **Research on Supportive Approaches for Family and Other Caregivers**

  Session 3 **Involving Persons with Dementia and Caregivers as Members of the Research Team**

  Session 4 **Involving Persons with Dementia as Study Participants**

  Session 5 **Research on Models of Care for Persons Living with Dementia and Their Families across the Disease Trajectory**

  Session 6 **Thinking Outside the Box**

Sources of Research Recommendations

Recommendations submitted before Summit

Pre-summit conferences/activities

Stakeholder groups

[RTI research briefs identify research limitations]

Recommendations generated during Summit

Plenary Summit Speakers

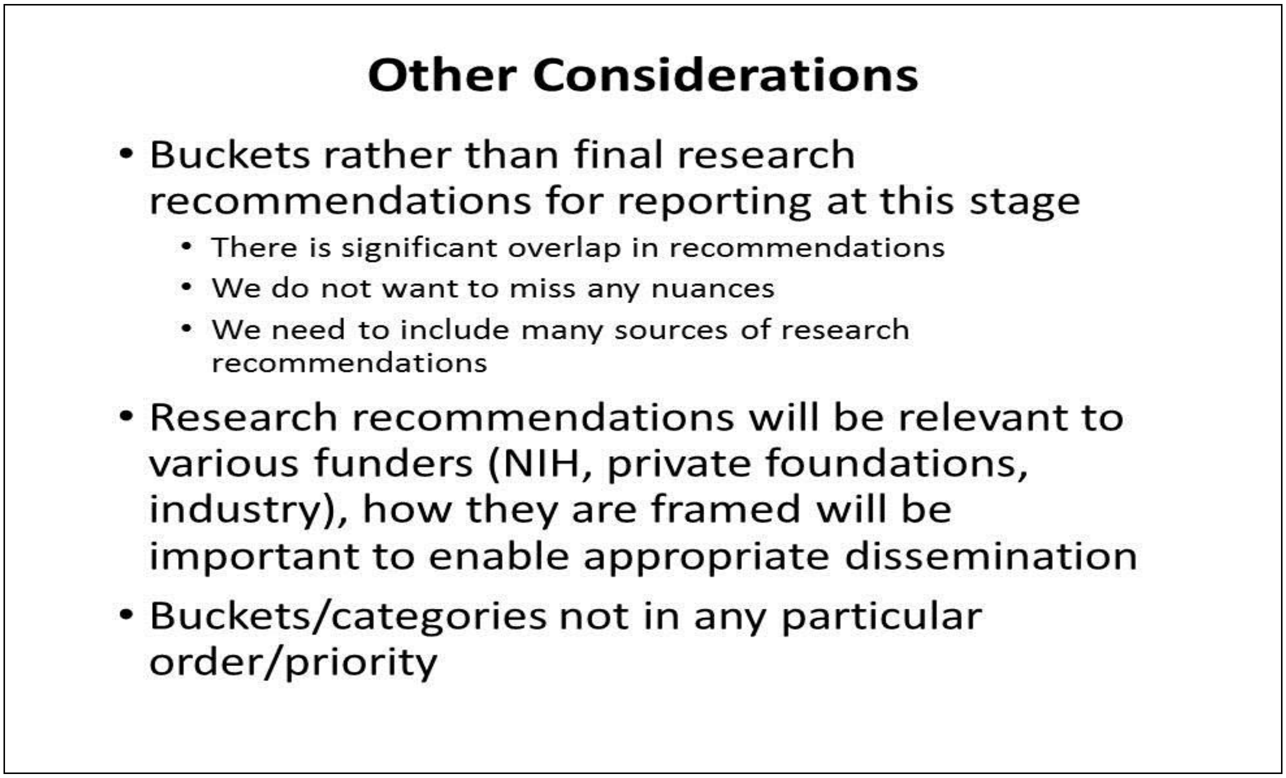
Session chairs/speakers/panelists (up to top 10)

Cross-cutting Chairs

Audience in-person and on-line submission (up to 8 pm Tuesday 17th)

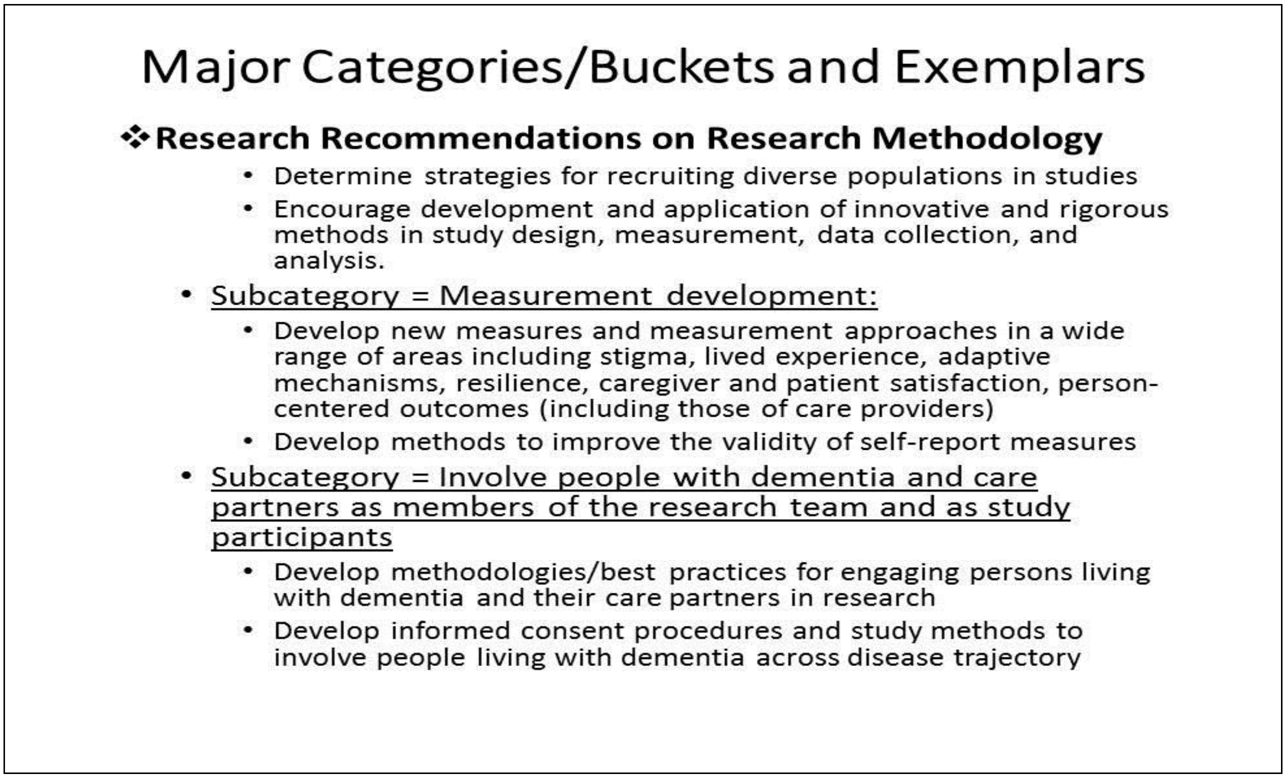
Process of Organizing Research Recommendations

- All research recommendations (approximately 464) reviewed independently by 3 coders (Katie, Laura, Rohini) to derive higher order categories:
- Through meetings, we obtained agreement for a draft of a core set of categories ("big buckets")
- Independent review conducted of all recommendations and their placement into categories using raw statements
- This yielded agreement concerning:
  - 11 "Big Buckets" or categories of research recommendations
  - Identification of considerations/principles for doing research differently
  - Topics for "post-summit" work
  - Additional comments (policy)



Other Considerations

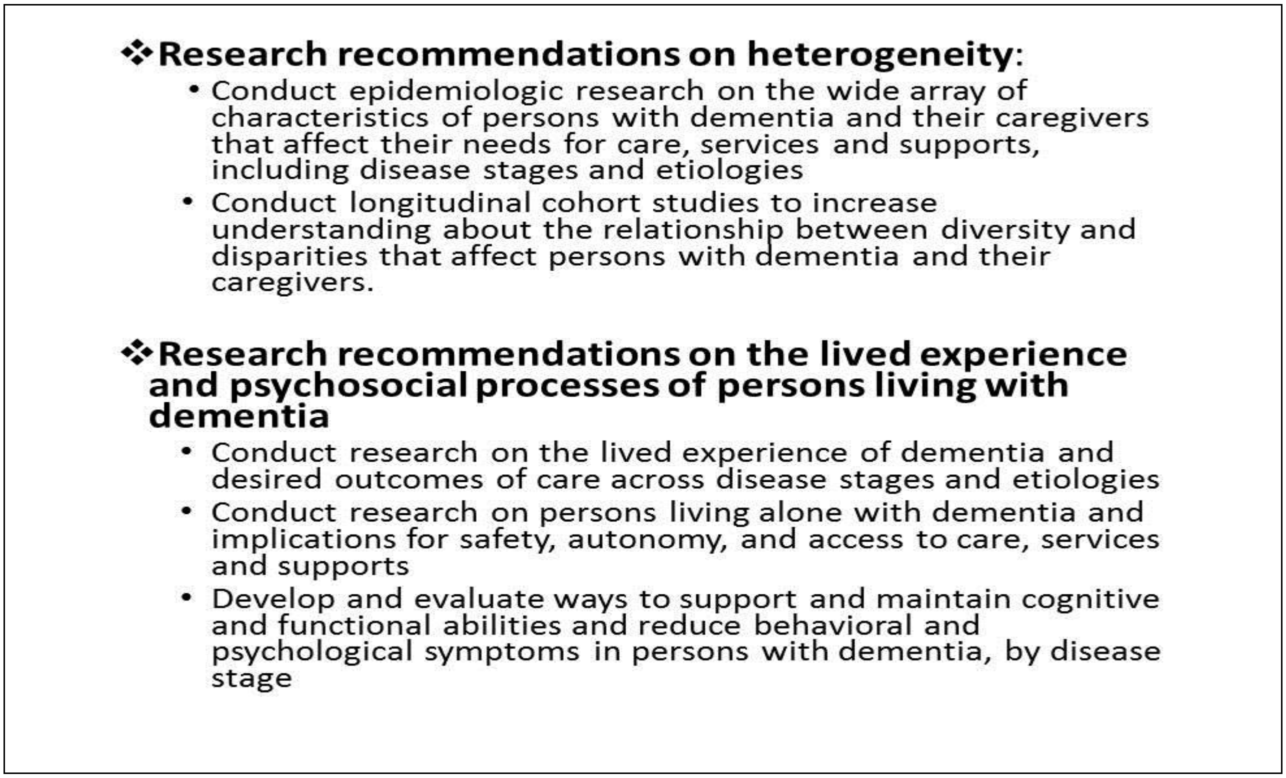
- Buckets rather than final research recommendations for reporting at this stage
  - There is significant overlap in recommendations
  - We do not want to miss any nuances
  - We need to include many sources of research recommendations
- Research recommendations will be relevant to various funders (NIH, private foundations, industry), how they are framed will be important to enable appropriate dissemination
- Buckets/categories not in any particular order/priority



Major Categories/Buckets and Exemplars

❖ **Research Recommendations on Research Methodology**

- Determine strategies for recruiting diverse populations in studies
- Encourage development and application of innovative and rigorous methods in study design, measurement, data collection, and analysis.
- Subcategory = Measurement development:
  - Develop new measures and measurement approaches in a wide range of areas including stigma, lived experience, adaptive mechanisms, resilience, caregiver and patient satisfaction, person-centered outcomes (including those of care providers)
  - Develop methods to improve the validity of self-report measures
- Subcategory = Involve people with dementia and care partners as members of the research team and as study participants
  - Develop methodologies/best practices for engaging persons living with dementia and their care partners in research
  - Develop informed consent procedures and study methods to involve people living with dementia across disease trajectory

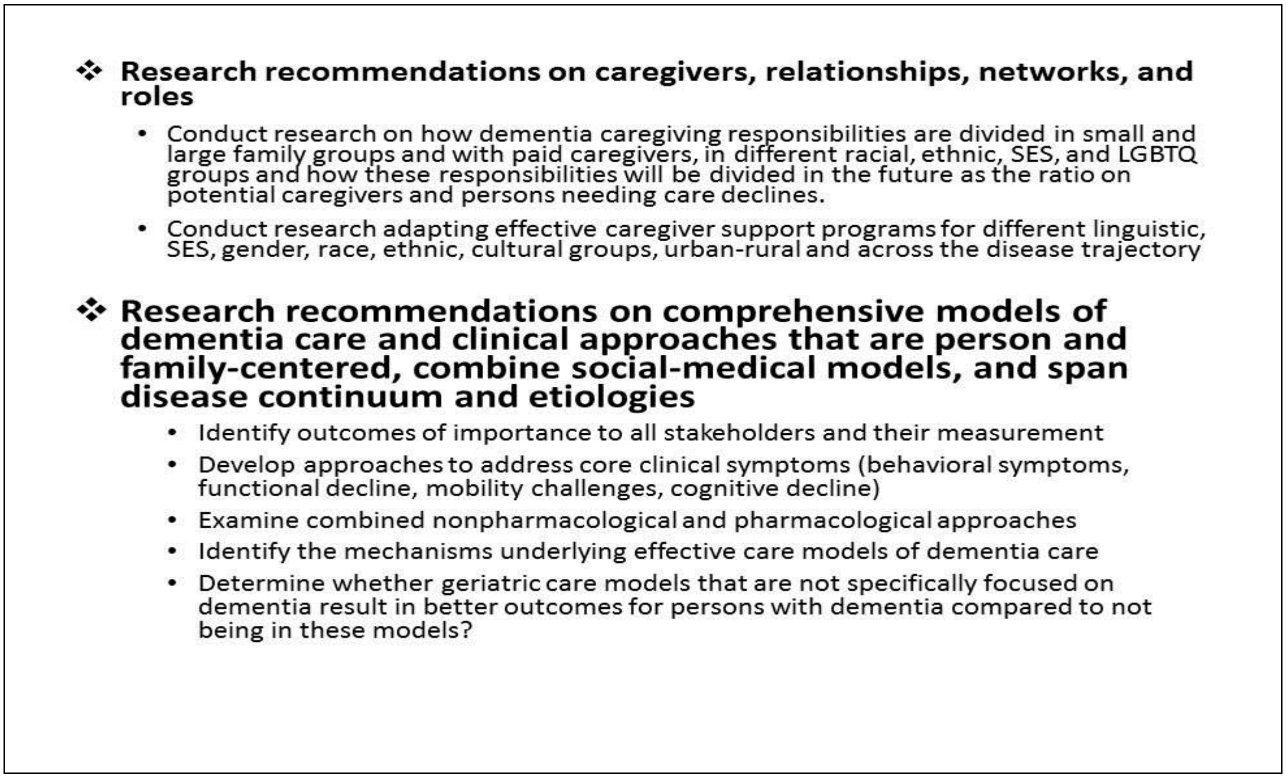


❖ **Research recommendations on heterogeneity**:

- Conduct epidemiologic research on the wide array of characteristics of persons with dementia and their caregivers that affect their needs for care, services and supports, including disease stages and etiologies
- Conduct longitudinal cohort studies to increase understanding about the relationship between diversity and disparities that affect persons with dementia and their caregivers.

❖ **Research recommendations on the lived experience and psychosocial processes of persons living with dementia**

- Conduct research on the lived experience of dementia and desired outcomes of care across disease stages and etiologies
- Conduct research on persons living alone with dementia and implications for safety, autonomy, and access to care, services and supports
- Develop and evaluate ways to support and maintain cognitive and functional abilities and reduce behavioral and psychological symptoms in persons with dementia, by disease stage



❖ **Research recommendations on caregivers, relationships, networks, and roles**

- Conduct research on how dementia caregiving responsibilities are divided in small and large family groups and with paid caregivers, in different racial, ethnic, SES, and LGBTQ groups and how these responsibilities will be divided in the future as the ratio on potential caregivers and persons needing care declines.
- Conduct research adapting effective caregiver support programs for different linguistic, SES, gender, race, ethnic, cultural groups, urban-rural and across the disease trajectory

❖ **Research recommendations on comprehensive models of dementia care and clinical approaches that are person and family-centered, combine social-medical models, and span disease continuum and etiologies**

- Identify outcomes of importance to all stakeholders and their measurement
- Develop approaches to address core clinical symptoms (behavioral symptoms, functional decline, mobility challenges, cognitive decline)
- Examine combined nonpharmacological and pharmacological approaches
- Identify the mechanisms underlying effective care models of dementia care
- Determine whether geriatric care models that are not specifically focused on dementia result in better outcomes for persons with dementia compared to not being in these models?

❖ **Research recommendations on strategies for scaling and disseminating existing evidence, drawing upon implementation science**

- Conduct research that promotes translation, implementation, and dissemination of existing evidence-based programs in real-world settings (such as, private homes, community agencies, congregate care) using existing staffing (professional and nonprofessional)
- Conduct research to study the process of implementation, focusing on large group partnerships including business, engineering, marketing, information technology, and end-user experience expertise and identifying common barriers including financial disincentives, competing priorities, and complexity across individuals.
- Build research infrastructure and consortia similar to VA capacities or to the ADCs (“ADCs for dementia care or ADCCs)”

- **Research recommendations on financial burdens across disease trajectory including loss of income, health insurance and costs of care and services**
  - Determine the impact of, and ways to overcome, financial burden on access to care and services, research participation and quality of life for diverse populations living with dementia.

❖ **Research recommendations on living arrangements, housing, care settings, and environmental design**

- Identify desired housing and living options for persons with dementia, and related outcomes for the person, the family and the staff who serve a care partners
- Conduct research to redesign the American home for persons living with dementia

❖ **Research recommendations on technology**

- Conduct developmental research on technology solutions that are responsive to the needs of different dementia care stakeholders across settings and that build on existing technologies.
- Develop a more solid evidence base on barriers to “meaningful access” as well as strategies that promote technology uptake for diverse user groups.

❖**Research recommendations on nomenclature**

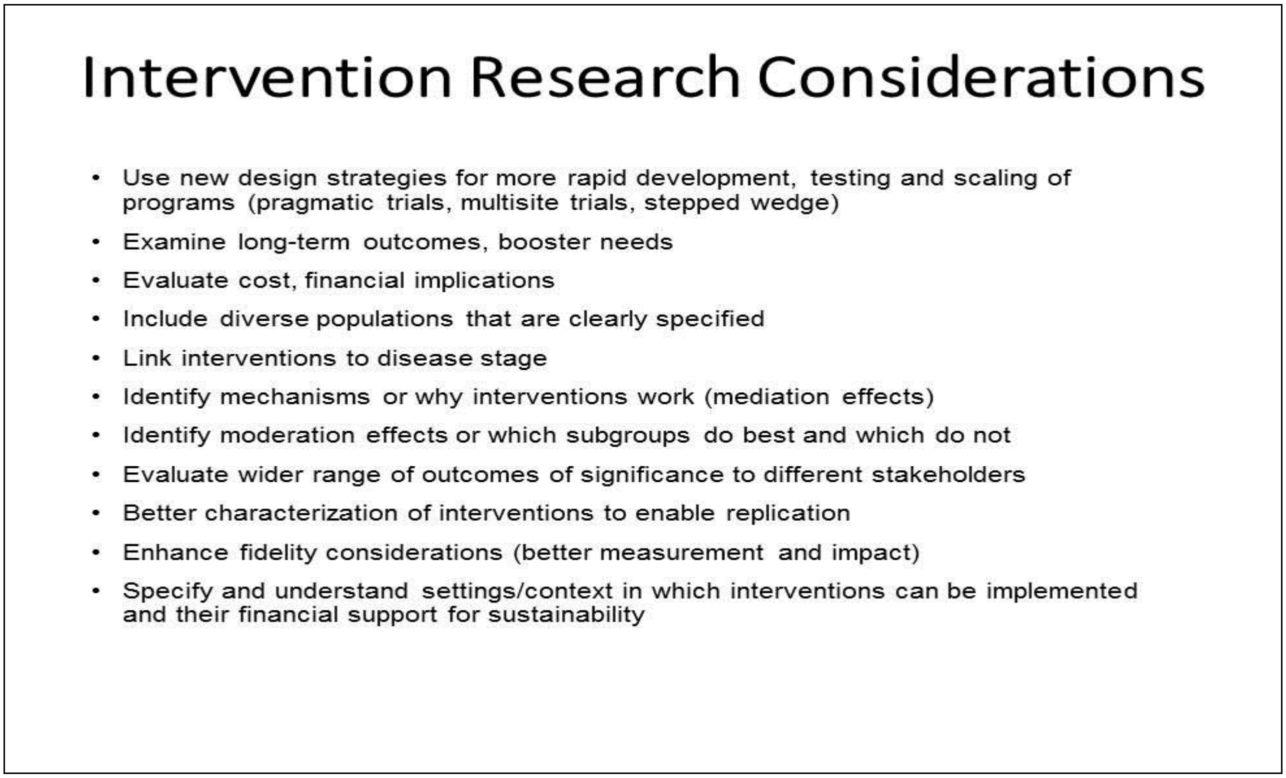
- Identify the best opportunities for early nomenclature changes, what stakeholder groups must be convene to establish proposed changes, what are the top challenges and identify strategies to make incremental progress
- Recommend research needed to further define and address public knowledge gaps perpetuated by confusing terminology, terminology that perpetuate stigma and isolation, and terminology-related barriers to early diagnosis, access to care and services, and research participation

❖**Research recommendations on workforce**

- Determine optimal staff mix, ratios, and models of care to promote health and well-being in different care settings
- How can the workforce be optimized? For example, what are effective training strategies and what factors influence workforce recruitment and retention for dementia care?

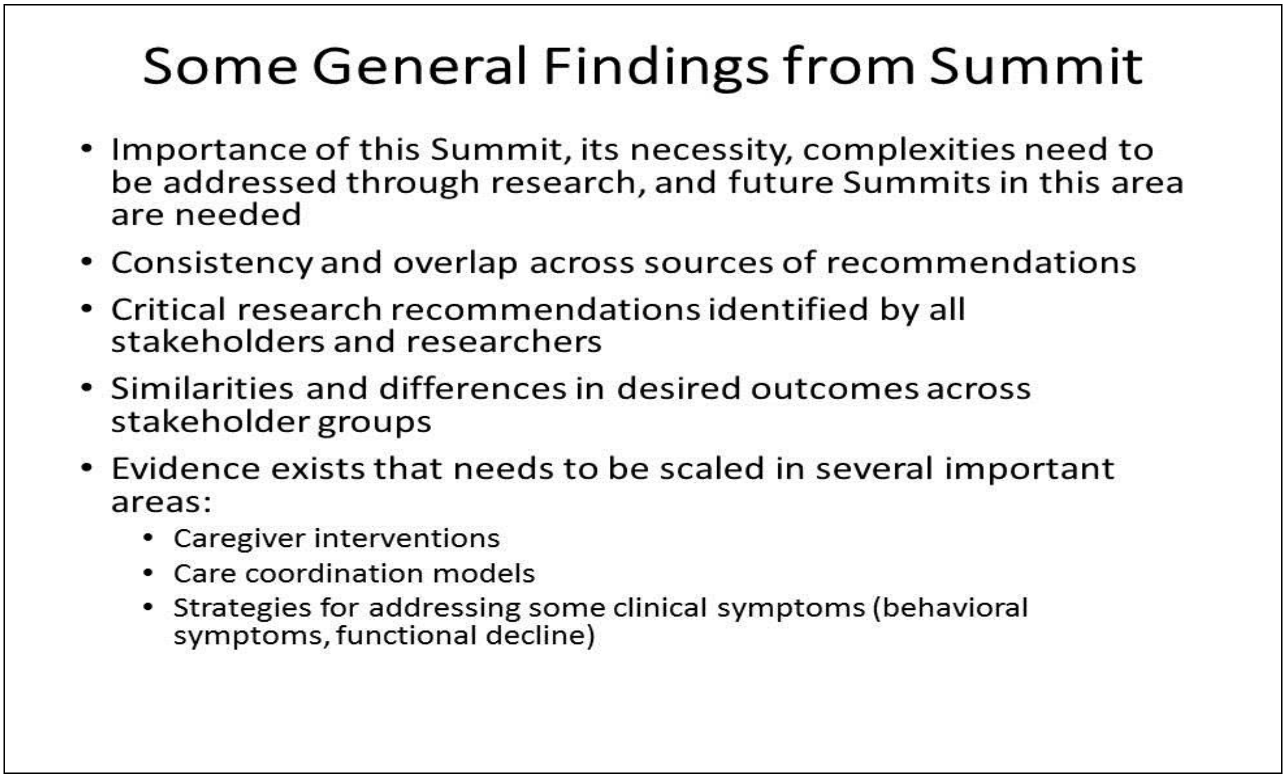
Considerations for Doing Research Differently (Highlights Only)

- Involve stakeholders in all phases of research as members of the research team and specifically individuals living with dementia and caregivers
- Inclusion of more diverse populations and better categorization
- Better characterization of study samples (etiology (when possible), disease stage, race, ethnicity
- Examine broad array of outcomes (objective and subjective) meaningful to different stakeholders
- Examine changes and impacts over time (need longitudinal perspectives)
- Infrastructure development to enable community-based agencies to participate in multi-site trials for rapid identification of research needs and deployment of evidence



Intervention Research Considerations

- Use new design strategies for more rapid development, testing and scaling of programs (pragmatic trials, multisite trials, stepped wedge)
- Examine long-term outcomes, booster needs
- Evaluate cost, financial implications
- Include diverse populations that are clearly specified
- Link interventions to disease stage
- Identify mechanisms or why interventions work (mediation effects)
- Identify moderation effects or which subgroups do best and which do not
- Evaluate wider range of outcomes of significance to different stakeholders
- Better characterization of interventions to enable replication
- Enhance fidelity considerations (better measurement and impact)
- Specify and understand settings/context in which interventions can be implemented and their financial support for sustainability

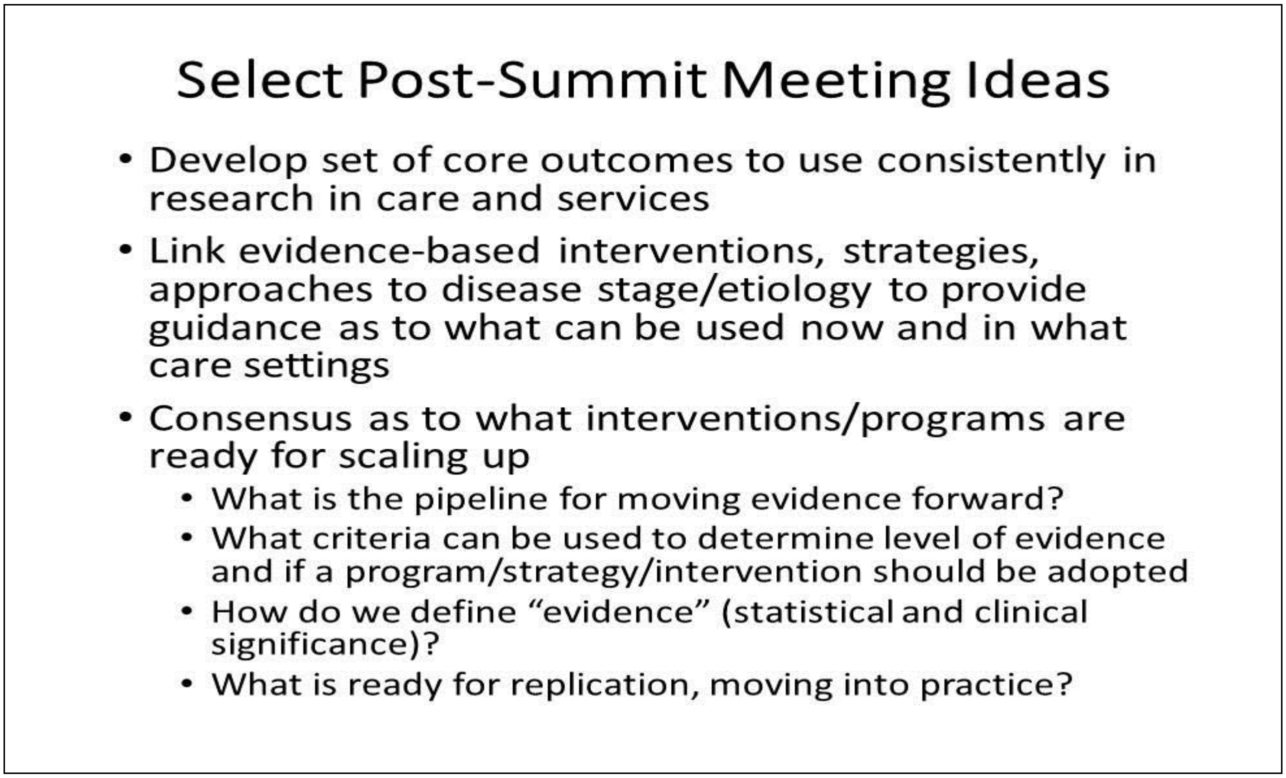


Some General Findings from Summit

- Importance of this Summit, its necessity, complexities need to be addressed through research, and future Summits in this area are needed
- Consistency and overlap across sources of recommendations
- Critical research recommendations identified by all stakeholders and researchers
- Similarities and differences in desired outcomes across stakeholder groups
- Evidence exists that needs to be scaled in several important areas:
  - Caregiver interventions
  - Care coordination models
  - Strategies for addressing some clinical symptoms (behavioral symptoms, functional decline)

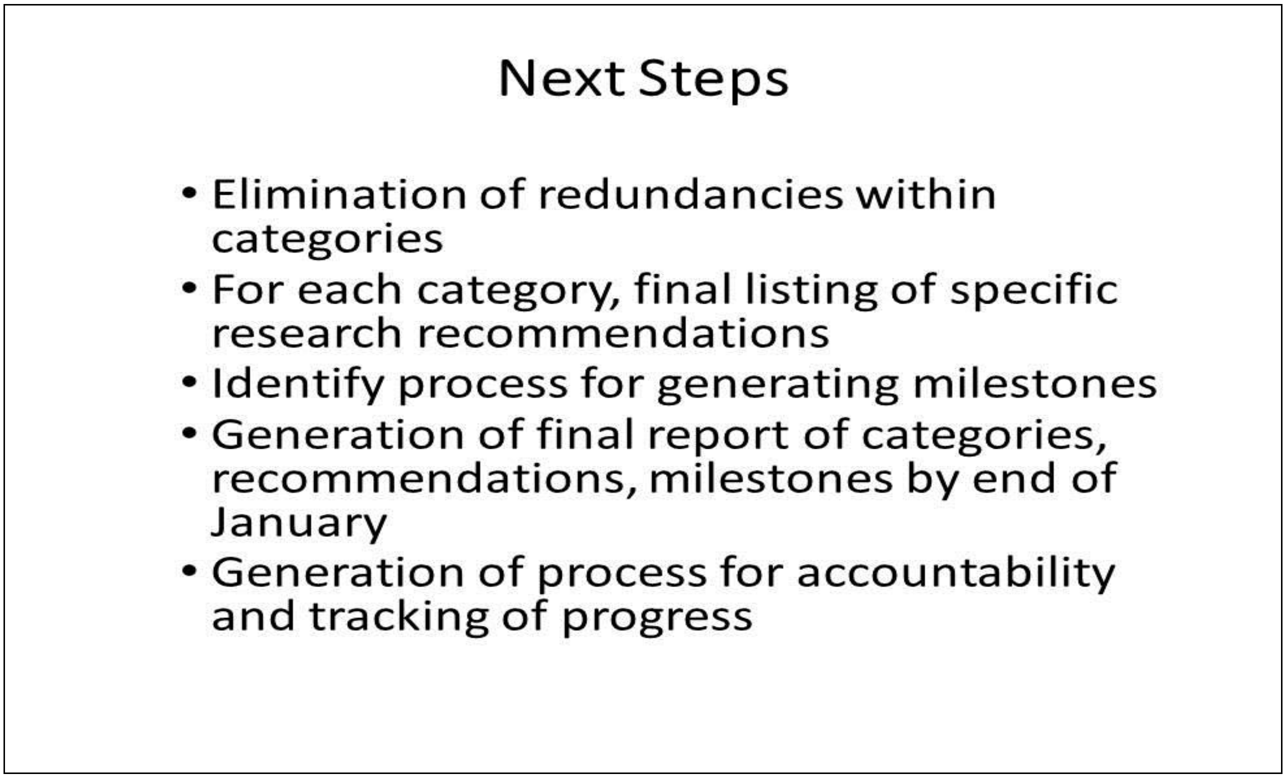
Big Gaps in Knowledge

- Big gaps in knowledge identified concerning:
  - How to involve people living with dementia as members of the research team
  - The lived experience of dementia including psychosocial processes, adaptive mechanisms, stigma and impact by gender, race, disease stage
  - Financial burdens across disease trajectory for individuals and caregivers
  - Disparities and impact on access to and delivery of care and services
  - Perceived and structural stigma throughout disease trajectory



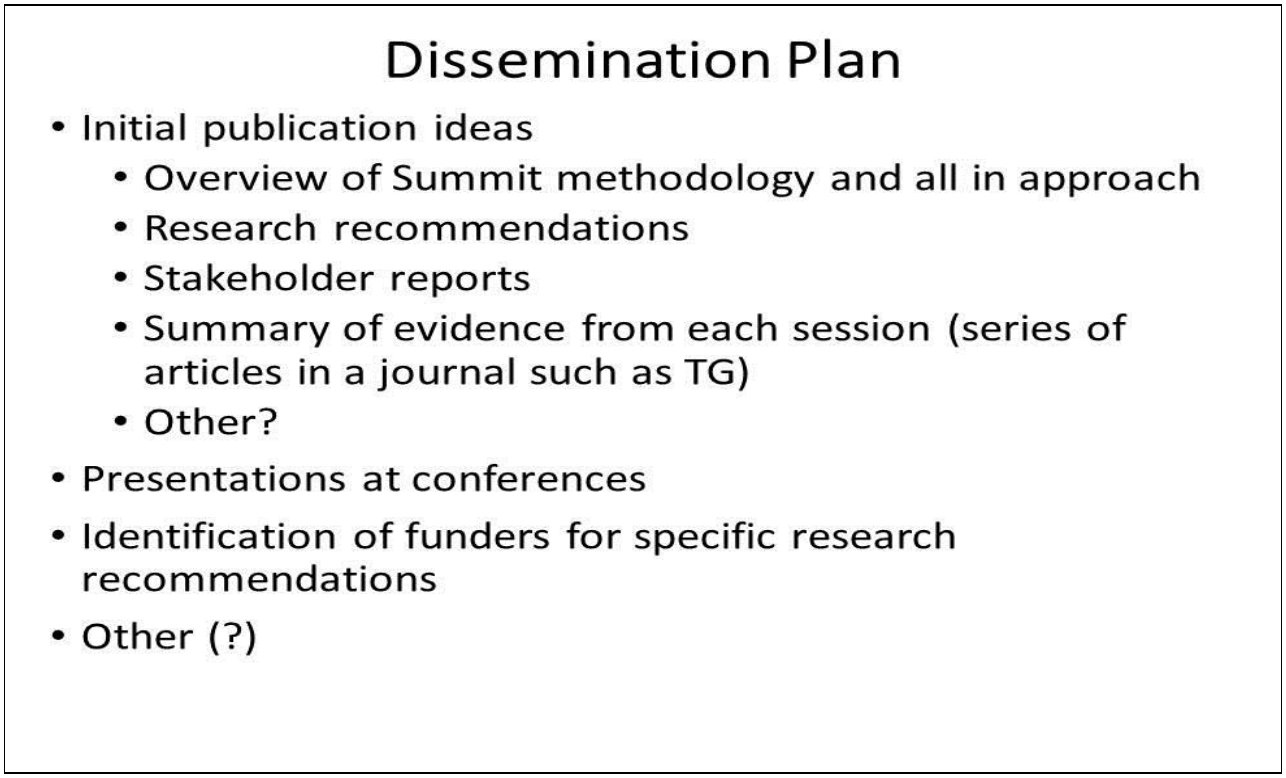
Select Post-Summit Meeting Ideas

- Develop set of core outcomes to use consistently in research in care and services
- Link evidence-based interventions, strategies, approaches to disease stage/etiology to provide guidance as to what can be used now and in what care settings
- Consensus as to what interventions/programs are ready for scaling up
  - What is the pipeline for moving evidence forward?
  - What criteria can be used to determine level of evidence and if a program/strategy/intervention should be adopted
  - How do we define “evidence” (statistical and clinical significance)?
  - What is ready for replication, moving into practice?



Next Steps

- Elimination of redundancies within categories
- For each category, final listing of specific research recommendations
- Identify process for generating milestones
- Generation of final report of categories, recommendations, milestones by end of January
- Generation of process for accountability and tracking of progress



Dissemination Plan

- Initial publication ideas
  - Overview of Summit methodology and all in approach
  - Research recommendations
  - Stakeholder reports
  - Summary of evidence from each session (series of articles in a journal such as TG)
  - Other?
- Presentations at conferences
- Identification of funders for specific research recommendations
- Other (?)

October 27, 2017 -- Advisory Council Meeting #26

The meeting was held on Friday, October 27, 2017, in Washington, DC. The Advisory Council welcomed its new members and invited them to share their experiences and where they see the Council going over the length of their terms. The Advisory Council also spent some time discussing the process of developing recommendations and how those recommendations relate to the National Plan. The Council then spent much of the meeting discussing the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers, held on October 16-17. Material available from this meeting is listed below and is also available at https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Oct2017.

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

General Information

Agenda	[HTML Version] [PDF Version]
Meeting Announcement	[HTML Version] [PDF Version]
Meeting Summary	[HTML Version] [PDF Version]
Public Comments	[HTML Version]

Handouts

National Plan to Address Alzheimer's Disease: 2017 Update	[HTML Version] [PDF Version]
Public Members of the Advisory Council on Alzheimer's Research, Care and Services: 2017 Recommendations	[HTML Version] [PDF Version]

Presentation Slides

2017 National Plan	[HTML Version] [PDF Version]
Before NAPA: IADRP	[HTML Version] [PDF Version]
Clinical Care Subcommittee Update	[HTML Version] [PDF Version]
Clinical Subcommittee Update	[HTML Version] [PDF Version]
Developing, Sustaining and Taking Innovations to Scale	[HTML Version] [PDF Version]
Discussion of Future Meetings	[HTML Version] [PDF Version]

Long-Term Services and Supports Committee Update	[HTML Version] [PDF Version]
Overview of the NAPA Legislation and the Charge to the Council	[HTML Version] [PDF Version]
Overview of the National Plan and the Process for Recommendations	[HTML Version] [PDF Version]
Research Progress for Alzheimer's Disease and Related Dementias	[HTML Version] [PDF Version]
Research Summit on Dementia Care Overview and Recommendations	[HTML Version] [PDF Version]

Videos

Welcome through Overviews	[Video]
Subcommittees and Fed Workgroups and Future Meeting Discussion	[Video]
Care Summit Overview and Presentation of Recommendations	[Video]
Discussion through lunch	[Video]
Public Comments	[Video]
Marie Schall Presentation and 2017 National Plan Discussion	[Video]
Federal Workgroup Updates through adjourn	[Video]

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