

Progress Update: Dementia Nomenclature Initiative

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Examples of Today's Communications Problem

Between Patient and Provider:

- *What's the difference between dementia and Alzheimer's?*

The Public

- *There is varying cultural sensitivity regarding terms like dementia.*

Between Research Stakeholders

- *What specifically do you mean by "Alzheimer's disease."*

Public Health Relies on Good Communication

Promoting public health requires:

- Clear, accessible communication

The Problem:

- Confusing explanations
- Inconsistent use of terminology
- Failure to communicate effectively

Results in:

- Stigma and isolation
- Delays in diagnosis and care
- Barriers to public education, policy, research

Building
Momentum for
Change

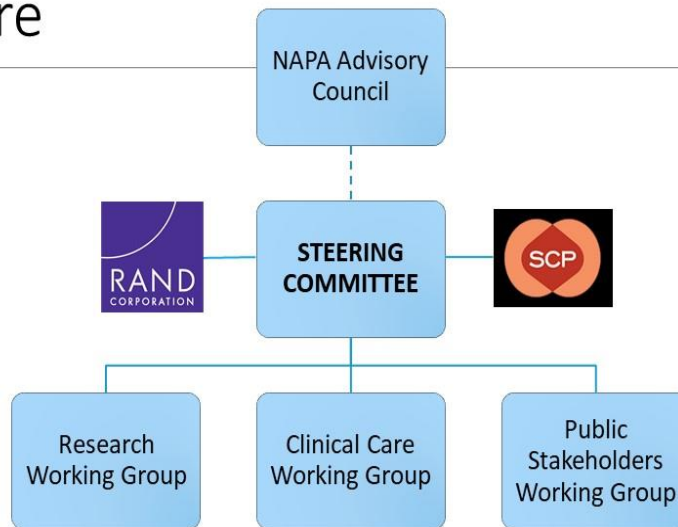
2016 ADRD Summit

2017 Care and Services Summit

Recurring Recommendations by
Advisory Council

2019 ADRD Summit: Process Rec's
on Dementia Nomenclature

Structure



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Deliverables

All Groups:

- What words or terms could be used to describe the full spectrum of cognitive impairment.

Research

- Terms to describe the continuum of severity
- **A standard framework to improve communications**
- Implications for industry and regulatory groups

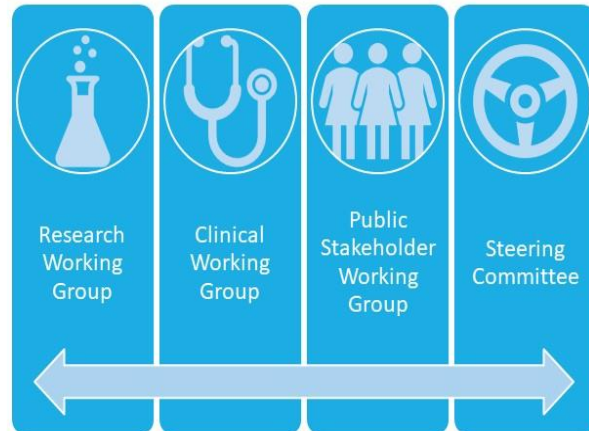
Clinical Care

- **Clinical management needs of terminology**
- Implications of the proposed framework
 - Clinical care
 - Payors, health systems, EMR vendors
 - Public health science and training/education implications

Public Stakeholders

- Current barriers to diagnosis and research participation
- Implications of proposed framework
 - For addressing stigma
 - **Cultural sensitivity of today's terms**

Iterative Input Process



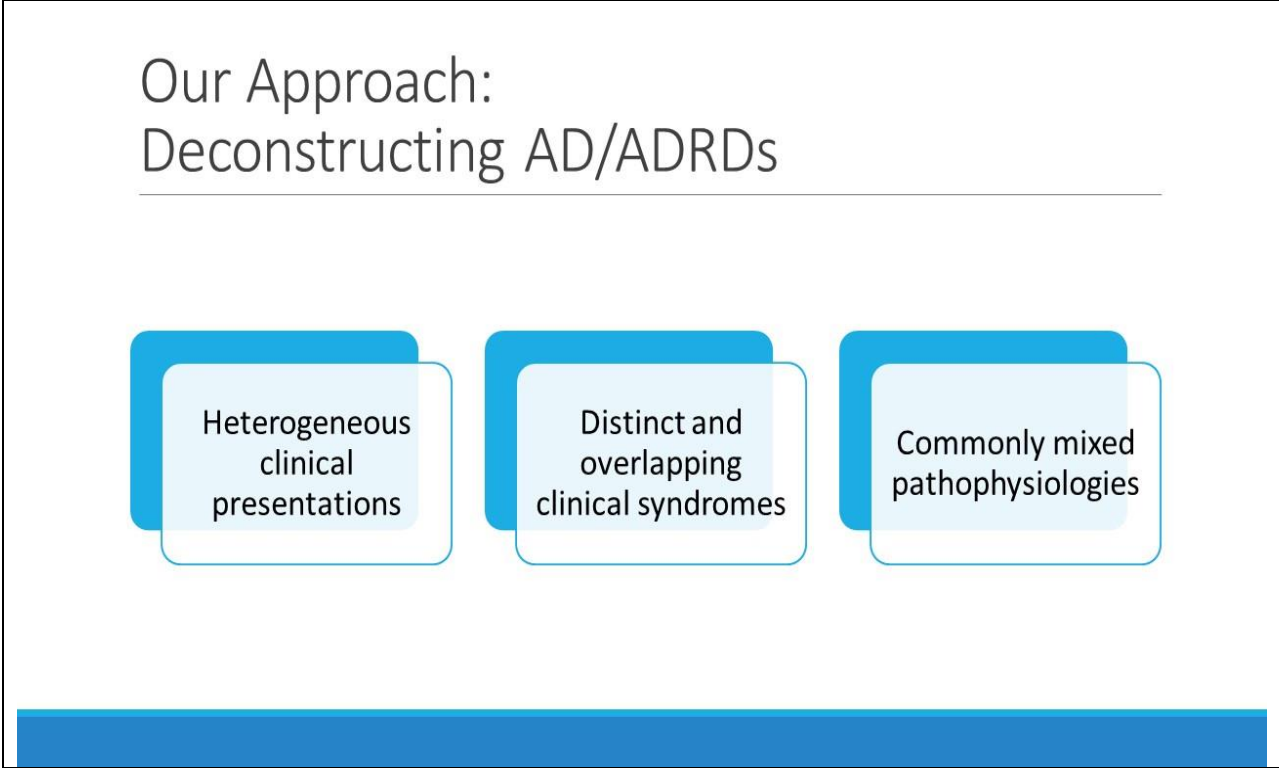
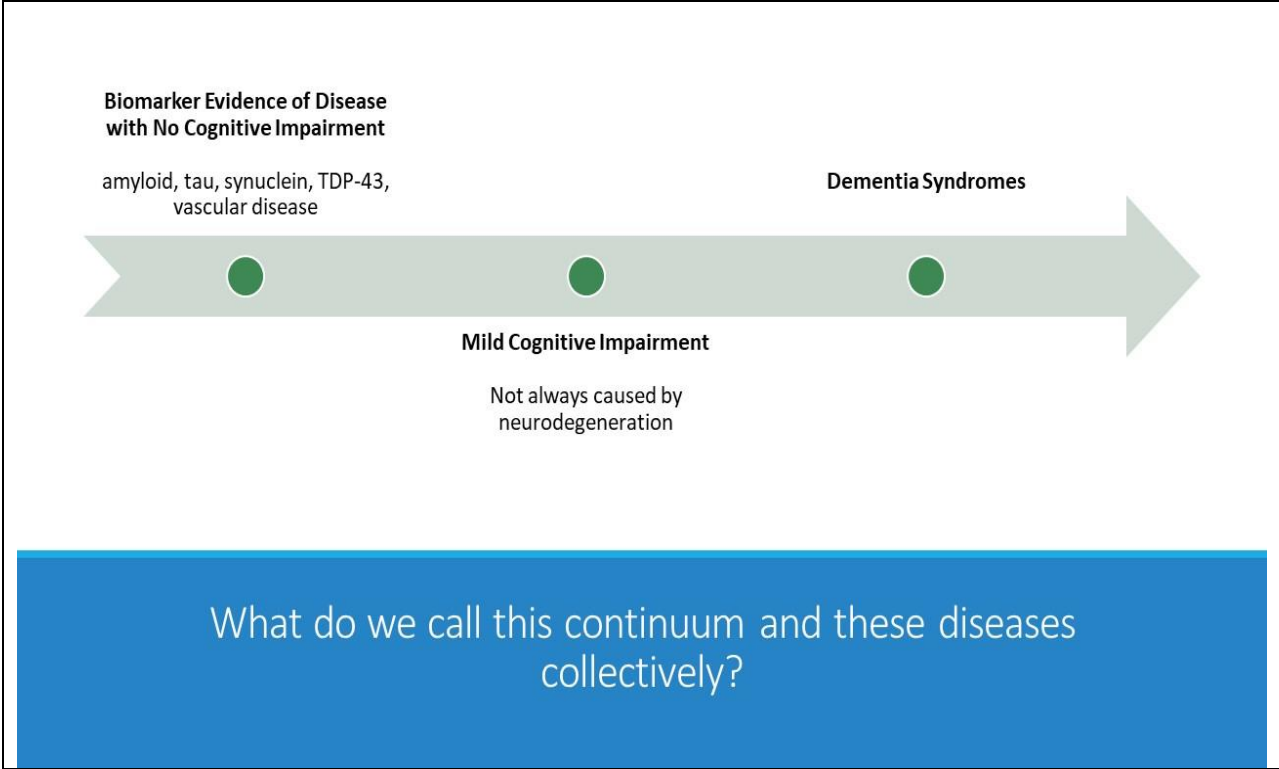
Scope of Work

Includes

- Implementing process recommendations from 2019 the ADRD Summit:
 - Identify **barriers**, **opportunities** and **strategies** to improve communication
 - Focus from NAPA legislation: AD, FTD, LBD, VCID and mixed dementias

Does NOT include

- Changing diagnostic criteria
- Recommending replacement terms
- Influencing funding priorities



SEPARATION:

Syndrome

Pathophysiology

Proposal on Terminology

Syndrome

Domains

Memory

Language

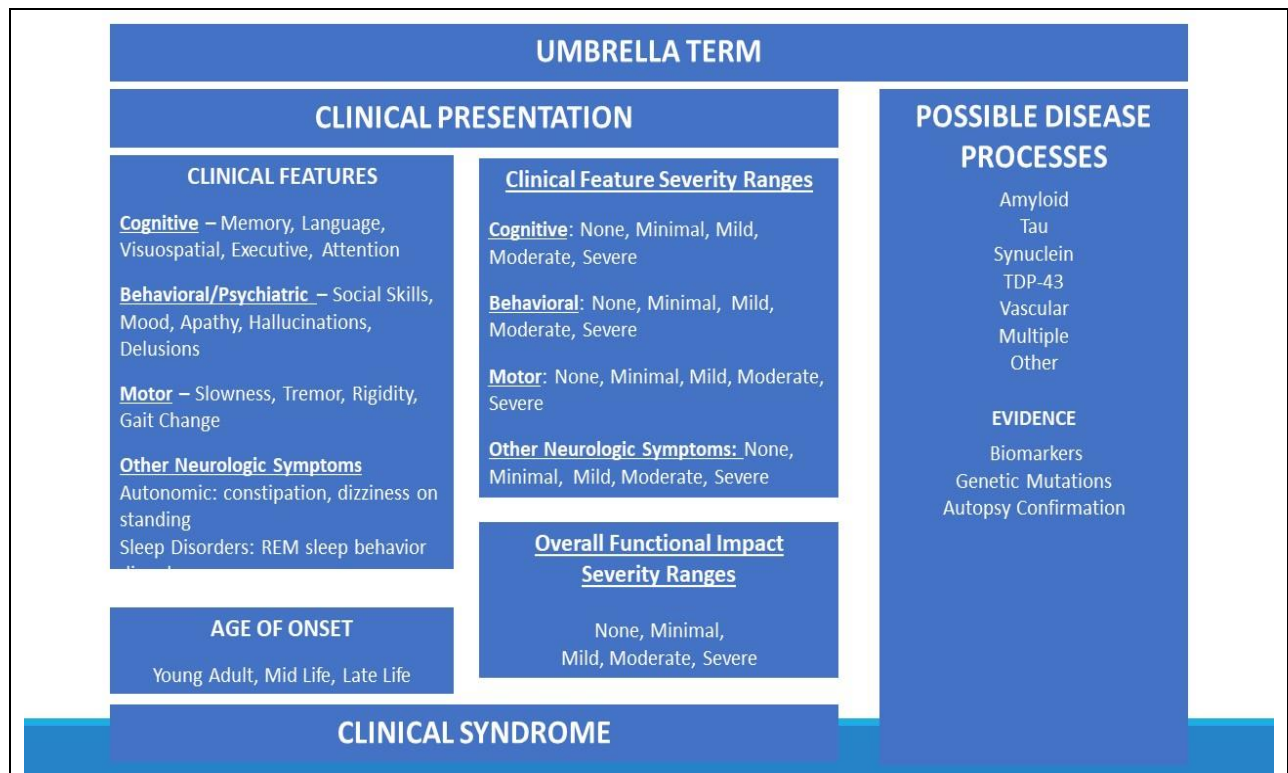
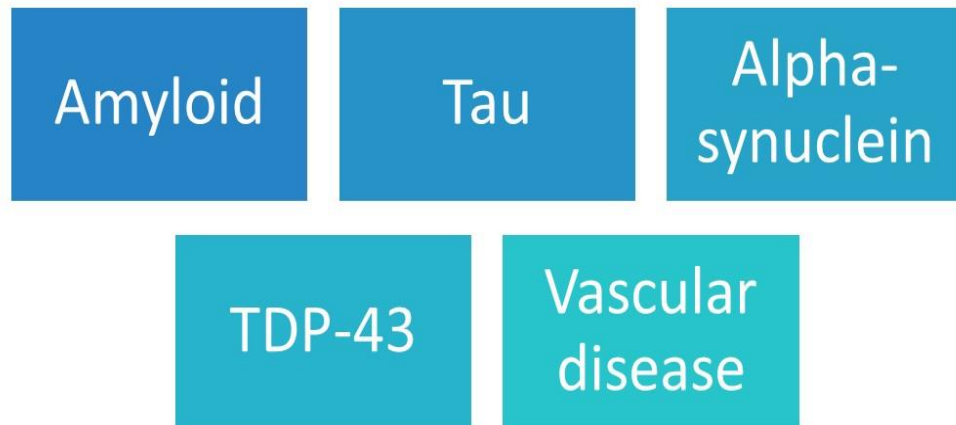
Attention/Executive

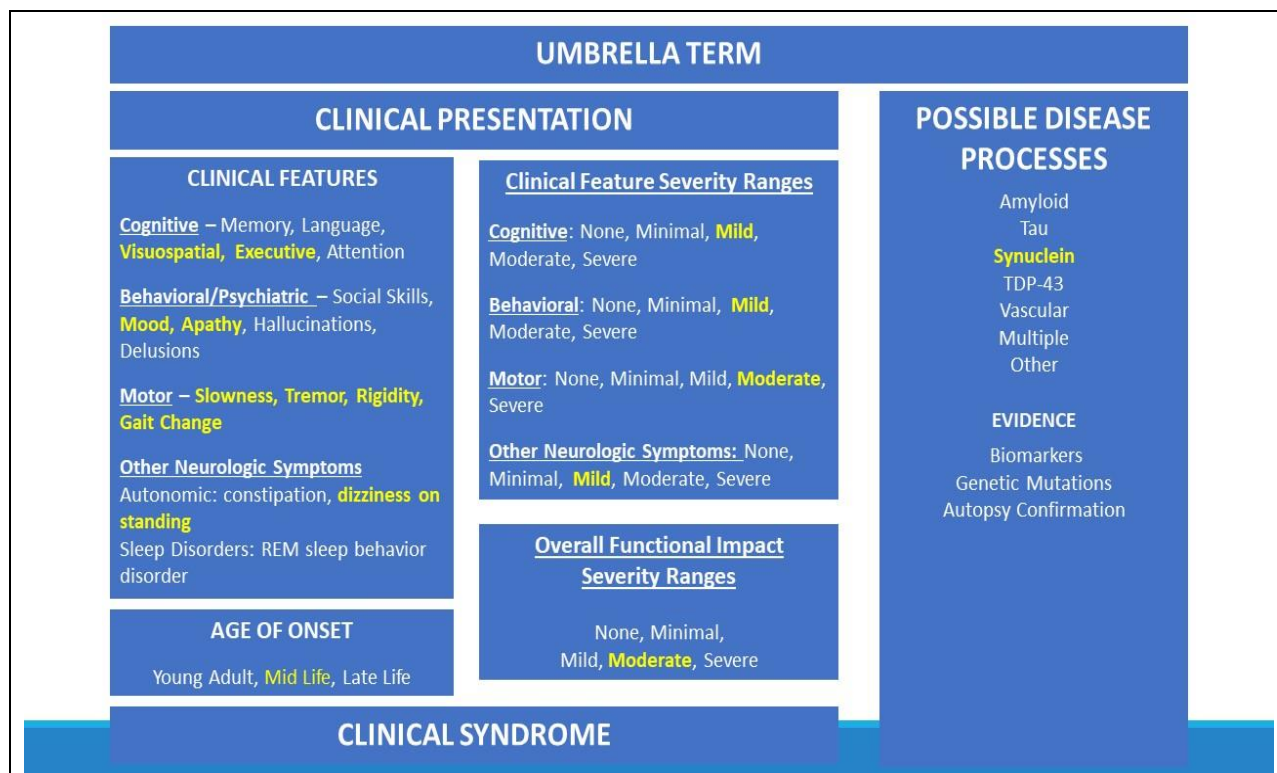
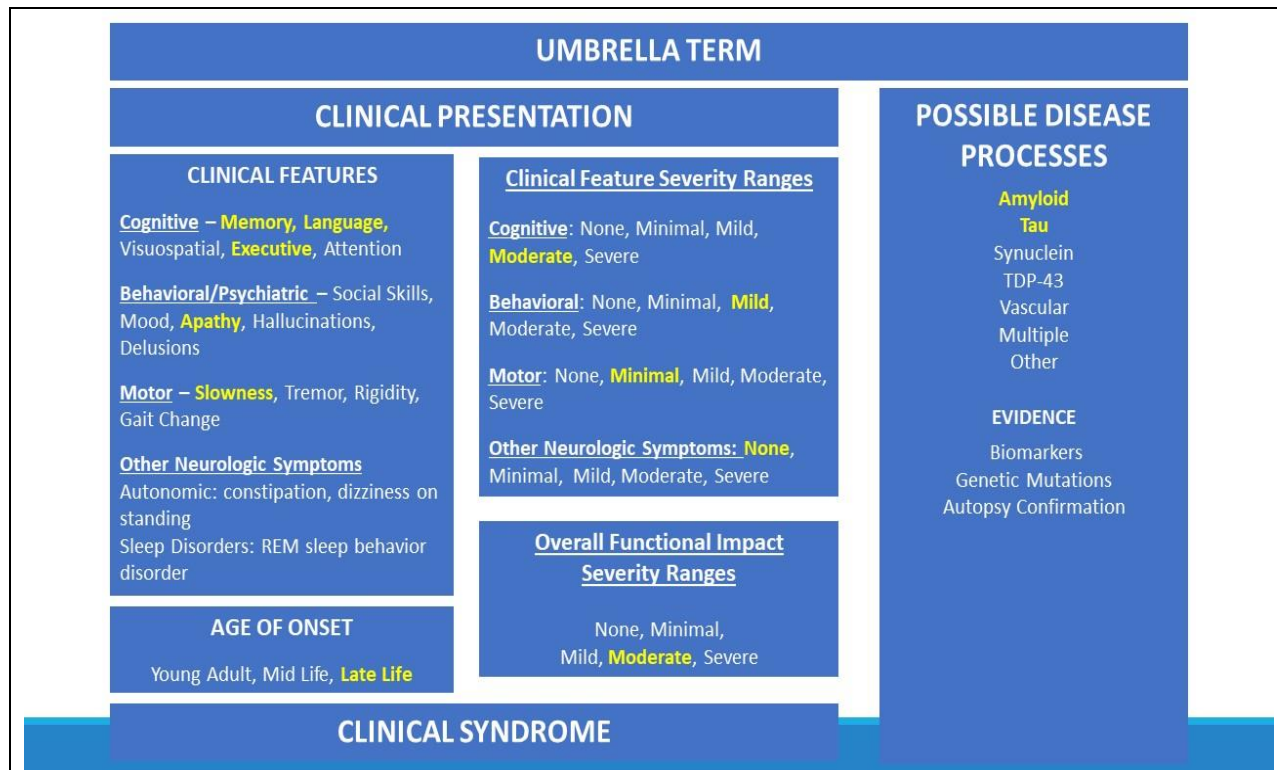
Visuospatial Skills

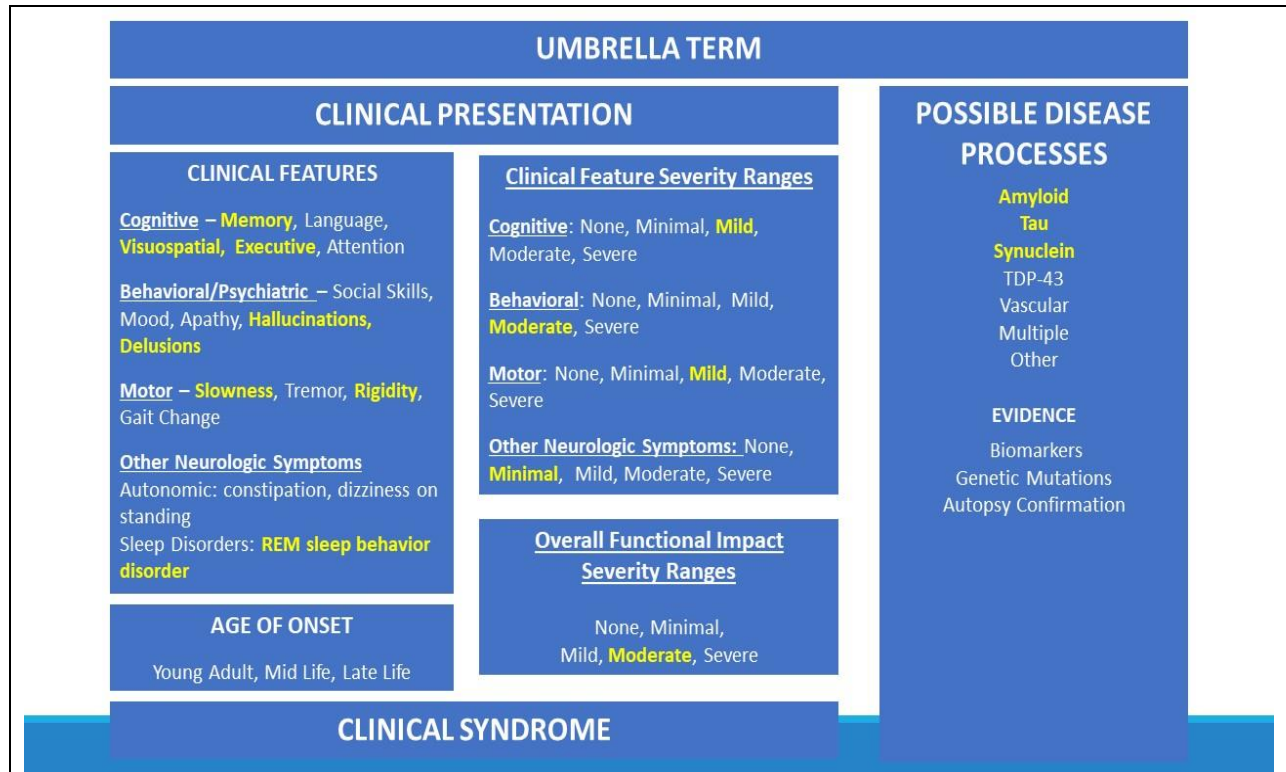
Social/Behavioral

Combinations

Pathophysiology







Umbrella Term Criteria

- 1) **coverage** of the desired concepts
- 2) **exclusion** of extraneous concepts;
- 3) **agnostic** to type of dementia/cognitive impairment and degree of functional impairment;
- 4) **specific enough** to suggest that a change in cognitive function is occurring or will occur;
- 5) **Understandable** by the public **and** have the potential to **mitigate stigma**;
- 6) **Usable** by researchers and clinicians.

Umbrella Term Candidates

Adult Cognitive Diseases

Adult Cognitive Disorders

Phase 1: Early Feedback; Phase 2 Needed

Challenges

- Change management, e.g., electronic health record, RCDC, NAPA
- Service eligibility

Advantages

- Clarifies communication
- Supports workflow
- Streamlines drug development

Phase 2

Expand input on the Framework from dementia community across a range of patient and caregiver types

Build consensus on the Framework with professional societies, other sectors

Cycles of beta testing of the Framework in the clinic

Develop robust communications resources to drive uptake of the Framework

Who else should be involved?

- Professional societies like APA, AAN
- Advocacy organizations
- Multiple types of care and service providers
- Journal editors
- Media
- Federal agencies

Considerations for the Council

- How could clear, consistent nomenclature aid in the implementation of the National Plan?
- How might the uptake of the Framework contribute towards diversity, equity and inclusion in clinical care and research?
- Does the Council endorse the initiative moving forward into a second phase and reporting back our progress?