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

2016 ADRD Summit

2017 Care and Services Summit

Recurring Recommendations by Advisory Council

2019 ADRD Summit: Process Rec’s on Dementia Nomenclature
Structure

NAPA Advisory Council

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Public Stakeholders Working Group

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AFTD The Association for Frontotemporal Degeneration

FIND HELP-SHARE HOPE

LBDA LEWY BODY DEMENTIA ASSOCIATION

Alzheimer's Drug Discovery Foundation

Bluefield Foundation

Rainwater Clinically Relevant

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
What do we call this continuum and these diseases collectively?

Our Approach: Deconstructing AD/ADRDs

- Heterogeneous clinical presentations
- Distinct and overlapping clinical syndromes
- Commonly mixed pathophysiology
Proposal on Terminology

Domains
Memory
Language
Attention/Executive
Visuospatial Skills
Social/Behavioral
Combinations
**Pathophysiology**

- Amyloid
- Tau
- Alpha-synuclein
- TDP-43
- Vascular disease

**UMBRELLA TERM**

<table>
<thead>
<tr>
<th>Clinical Presentation</th>
<th>Possible Disease Processes</th>
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<tbody>
<tr>
<td><strong>Clinical Features</strong></td>
<td>Amyloid</td>
</tr>
<tr>
<td>Cognitive – Memory, Language, Visuospatial, Executive, Attention</td>
<td>Tau</td>
</tr>
<tr>
<td>Behavioral/Psychiatric – Social Skills, Mood, Apathy, Hallucinations, Delusions</td>
<td>Alpha-synuclein</td>
</tr>
<tr>
<td>Motor – Slowness, Tremor, Rigidity, Gait Change</td>
<td>TDP-43</td>
</tr>
<tr>
<td>Other Neurologic Symptoms: Autonomic: constipation, dizziness on standing, Sleep Disorders: REM sleep behavior</td>
<td>Vascular</td>
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<tr>
<td></td>
<td>Multiple</td>
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<tr>
<td></td>
<td>Other</td>
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</tbody>
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**Clinical Feature Severity Ranges**

- **Cognitive**: None, Minimal, Mild, Moderate, Severe
- **Behavioral**: None, Minimal, Mild, Moderate, Severe
- **Motor**: None, Minimal, Mild, Moderate, Severe

**Other Neurologic Symptoms**: None, Minimal, Mild, Moderate, Severe

**Overall Functional Impact Severity Ranges**

- None, Minimal, Mild, Moderate, Severe

**Evidence**

- Biomarkers
- Genetic Mutations
- Autopsy Confirmation

**Age of Onset**

- Young Adult, Mid Life, Late Life
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
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?