



Dementia Nomenclature: Launching a National Discussion

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Decades of Evolution

- Age-associated memory loss, mild cognitive impairment, minor neurocognitive impairment
- Dementia, memory disorder, major neurocognitive impairment
 - Alzheimer's disease, dementia due to Alzheimer's disease
 - Dementia with Lewy bodies, Lewy body dementias
 - Lewy body disease, Lewy body disorders
 - Frontotemporal dementia, degeneration
 - behavioral variant FTD, Pick's disease, primary progressive aphasia
 - progressive supranuclear palsy, corticobasal syndrome
 - motor neuron disease, amyotrophic lateral sclerosis
 - Vascular dementia, vascular contributions to cognitive impairment and dementia
 - Mixed dementia, mixed etiology dementia

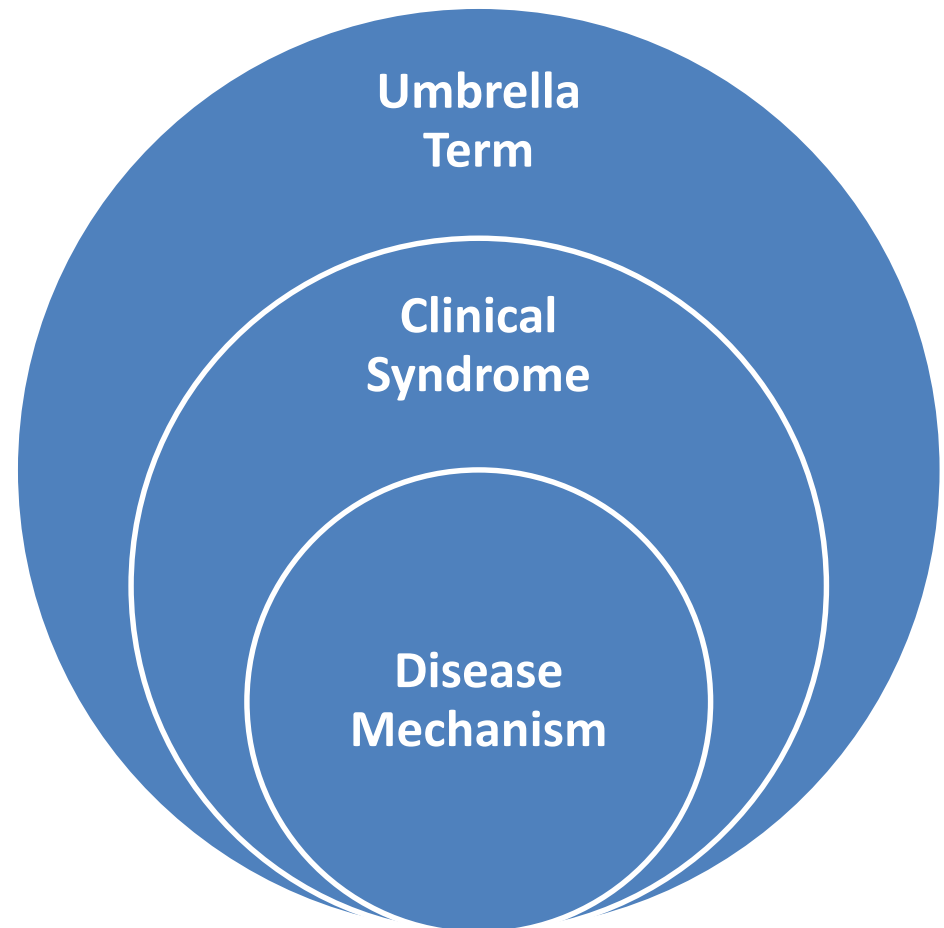


2016 ADRD Summit Hot Topic

Is it time to...

Create a
standardized bulls-
eye model for
public education
and clinical care?

(While respecting
the new DSM-V)



An Expanding Focus on Nomenclature

2016 ADRD Summit

- Hot Topic Session: Conceptual recommendations

2016 NAPA Advisory Council

- Recommendation by non-federal members

2017 Dementia Care & Services Summit

- Echoed by care experts and those living with dementia

2018 Working Group Formed

- NAPA Advisory Council charge

2019 ADRD Summit

- Draft procedural recommendations presented

Can Nomenclature be Improved?

- **Any change = wide-ranging impact**
 - Research, regulatory issues, clinical care, reimbursement issues and public health efforts
- **Charge by the Advisory Council on Alzheimer's Research, Care and Services to:**
 - Design a transparent and inclusive process
 - Implement the process
 - Report on the results
 - May or may not include recommended changes to terminology



2019 ADRD Summit ***Draft Recommendations***

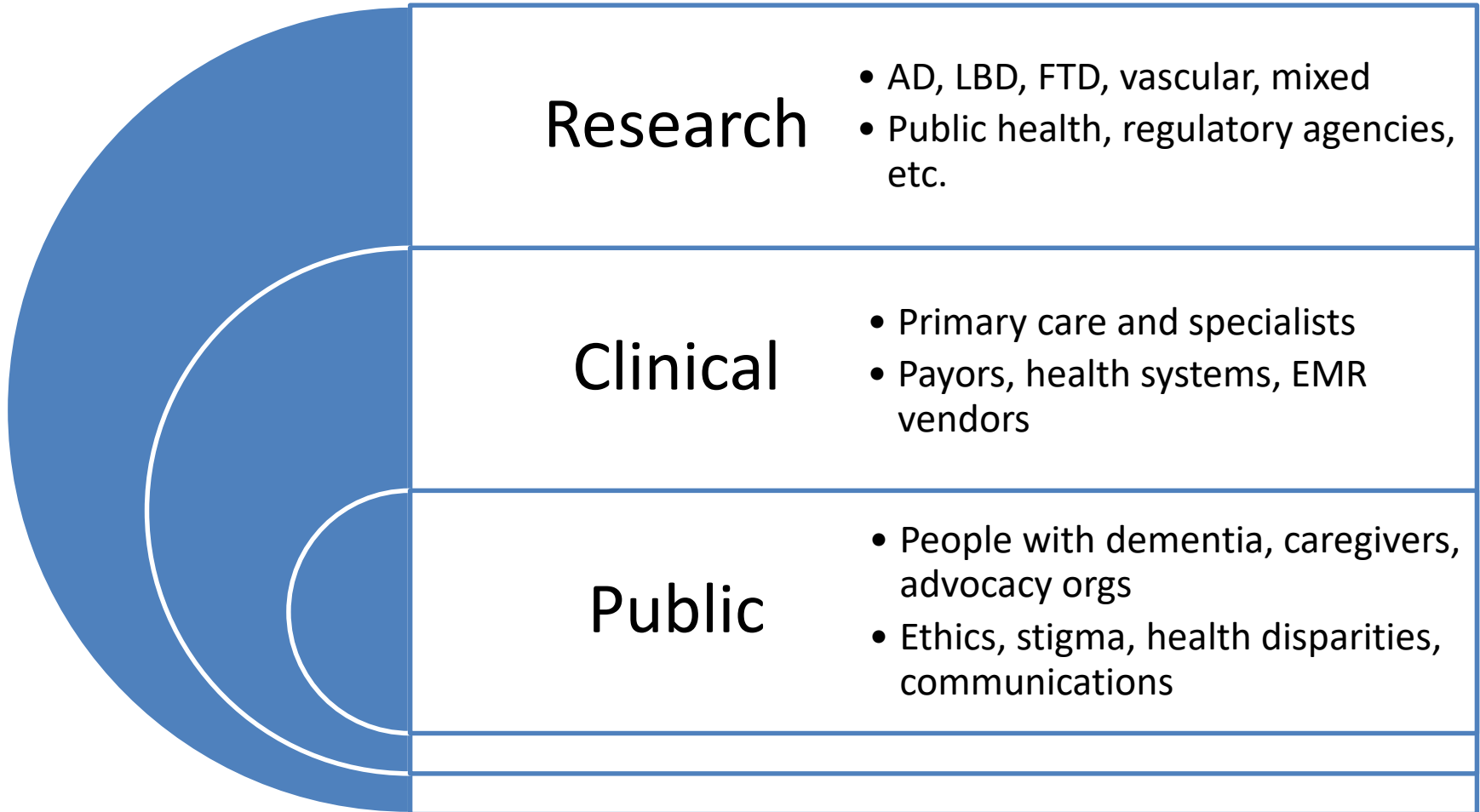
Focus Area 1: Dementia Nomenclature Working Groups

REC 1 – Priority 1. Form research, clinical practice and public stakeholder dementia nomenclature working groups (1-2 y).

Focus Area 2: Integration and Interoperability of Dementia Nomenclature

REC 2 – Priority 1. Integrate and refine recommendations from the Research, Clinical Practice, and Public Stakeholder Working Groups into standardized, acceptable and accurate nomenclature that works across the spectrum of stakeholders (2-4 y).

Working Group Composition (Cross-Talk Required)



Steering Committee

- Co-Chairs
 - Ronald Petersen, MD, PhD, Mayo Clinic
 - Angela Taylor, Lewy Body Dementia Association
- Working Group Chairs
 - Sandra Weintraub, PhD, Northwestern University
 - Research Working Group
 - Marwan Sabbagh, MD, Cleveland Clinic, Las Vegas
 - Clinical Practice Working Group
 - Jason Karlawish, MD, University of Pennsylvania
 - Public Stakeholder Working Group
- Additional Members
 - Charles Adler, MD, PhD, Mayo Clinic, Arizona
 - Paul Applebaum, MD, Columbia University
 - Peggye Dillworth-Anderson, PhD, University of North Carolina
 - Cynthia Huling-Hummel, DMin, Person Living with Dementia

Summary

- Changing terms would have a wide-ranging impact
- The recommendations establish a transparent and inclusive process, not an outcome.
- Stakeholder input and working group cross-talk is essential.
- Working groups will present and discuss recommendations at a nomenclature symposium.
- We will report out on opportunities and challenges to improving dementia nomenclature.