School of Medicine and Public Health
UNIVERSITY OF WISCONSIN–MADISON

Wisconsin Alzheimer's Disease Research Center
Wisconsin Alzheimer's Institute

VA

Addressing Gaps and Opportunities in the Revised Criteria

Fall ADRC Meeting
October 19, 2023

Cindy Carlsson, MD, MS
Professor of Medicine, Division of Geriatrics
Louis A. Holland, Sr., Professor in Alzheimer's Disease
Clinical Core Leader, Wisconsin ADRC
Director, Wisconsin Alzheimer's Institute (WAI)
University of Wisconsin School of Medicine and Public Health

Disclosures

- **Grant Support:**
  - NIH/NIA
  - Department of Veterans Affairs
  - Amarin Corp. (study medications)
  - NIH/Lilly (A4 Study)
  - NIH/Eisai (AHEAD Study)
  - NIH/Cognition Therapeutics (START Trial)
  - Wisconsin Department of Health Services
  - Louis A. Holland, Sr. family
- **AGS member**
- **Clinical Task Force (CTF) member**

Three Additional Perspectives:

- Dementia Nomenclature Initiative
- American Geriatrics Society
- Clinical Task Force

Dementia Nomenclature Initiative

- 2016 NIH ADRD Summit called for consensus and harmonization for AD and ADRD nomenclature
- Should attend to the needs of the range of stakeholders:
  - researchers
  - individuals living with dementia and their families
  - health care practitioners
- NAPA recommended formation of an AD/ADRD nomenclature committee
- 2018: committee formed to address AD, dementia with Lewy bodies, frontotemporal degeneration, and vascular cognitive impairment dementia

Corriveau RA et al. ADRD Summit 2016: national research priorities. *Neurology*. 2017;89(23):2381-2391.
Petersen RC et al. JAMA Neurol. doi:10.1001/jamaneurol.2023.3664 (Published online October 16, 2023).

Dementia Nomenclature Initiative

- Addressed confusion between AD and dementia
- Identified that term “ADRD” is problematic (not all pathologies are related to AD)
- Affirmed importance of differentiating cognitive and behavioral syndromes from underlying pathophysiology
- Sought input from 6 diverse focus groups (n=41 individuals: American Indian or Alaska Native, Asian or Pacific Islander, Black or African American, Hispanic or Latino, and White)
- Discussed issues of stigma

Corriveau RA et al. ADRD Summit 2016: national research priorities. *Neurology*. 2017;89(23):2381-2391.
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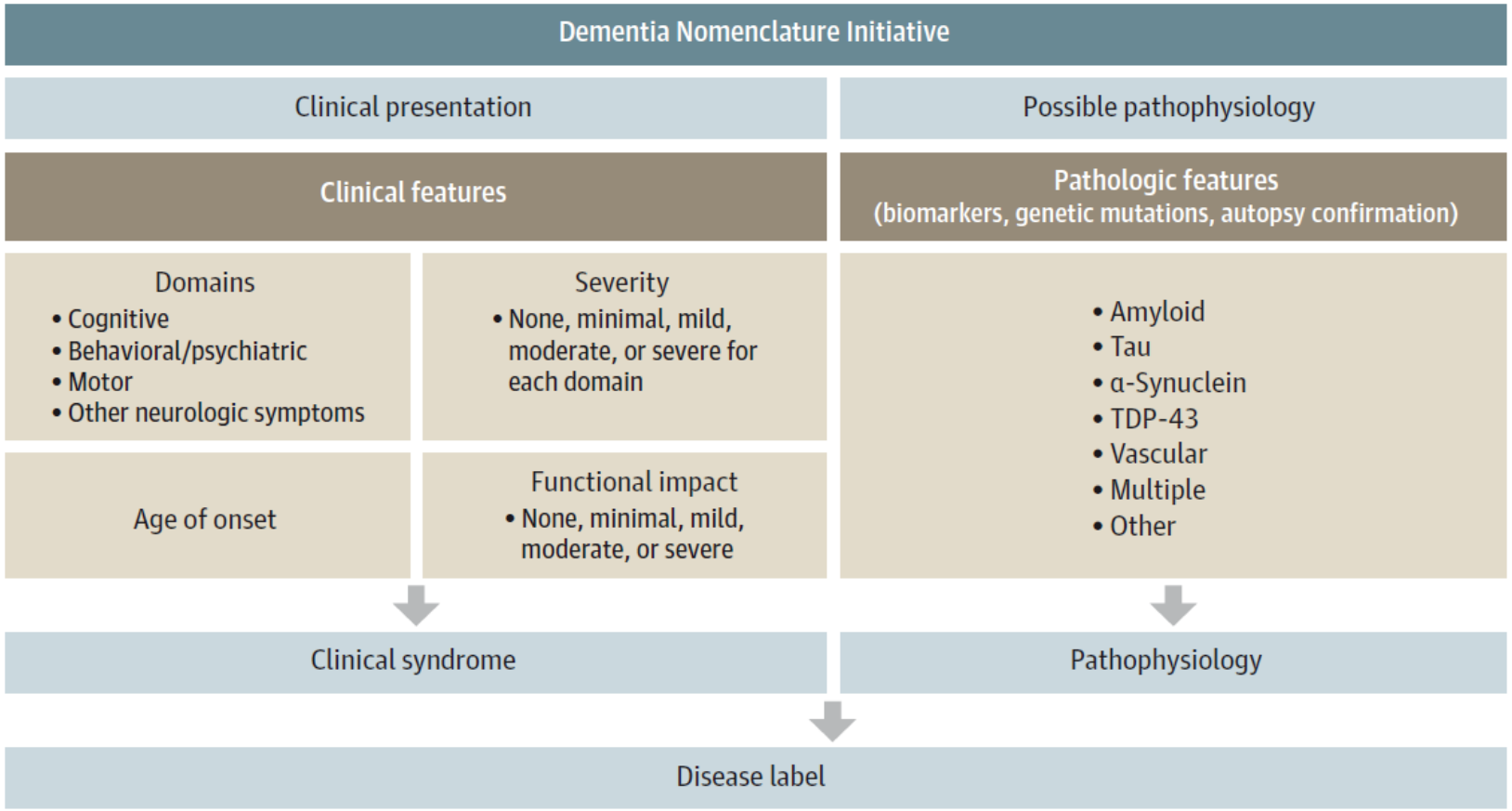
Dementia Nomenclature Initiative: Communications Framework

Figure. Dementia Nomenclature Initiative



Petersen RC et al. JAMA Neurol. doi:10.1001/jamaneurol.2023.3664 (Published online October 16, 2023).

American Geriatrics Society Response – Draft NIA-AA Revised Clinical Criteria for AD
(Submitted August 16, 2023)

- Proposing guidelines be used in clinical practice is premature
- Concerns about composition of the workgroup (chiefly researchers, potential conflicts and need for more disclosures)
- Concern for need for more studies that include persons from diverse racial/ethnic backgrounds

https://www.slowmedicine.com.br/wp-content/uploads/AGS-Alz.pdf

American Geriatrics Society Response – Draft NIA-AA Revised Clinical Criteria for AD

(Submitted August 16, 2023)

- Lack of recognition of important distinctions across fields of 'clinical practice.' (cognitive neurology is not like clinical practice in geriatrics, family medicine, or internal medicine)
- Clinicians are not prepared to guide person-centered decision-making about appropriate use of biomarker information
- Stigma of diagnosis in medical records
- Uncertainty about how to code for new diagnostic framework

https://www.slowmedicine.com.br/wp-content/uploads/AGS-Alz.pdf

Clinical Task Force

INITIAL VISIT PACKET UNIFORM DATA SET (UDS) VERSION 4.0

Form D1a: Clinical Syndrome

ADRC: _____ PTID: _____ Form date: __ __ / __ __ / __ __ __ __ Visit #: _____ Examiner's initials: _____

Language:	Mode:	Key (remote reason):
☐1 English	☐1 In-person	*1=Too cognitively impaired*
☐2 Spanish	☐2 Remote *(reason):* ___	*2=Too physically impaired*
	☐1 Telephone ☐2 Video	*3=Homebound or nursing home*
		4=Refused in-person visit
		5=Other

INSTRUCTIONS: *This form is to be completed by the clinician. For additional clarification and examples, see the* **UDS Coding Guidebook** *for* **Form D1a.** *Check only one box per question.*

1. Diagnosis method—*responses in this form are based on diagnosis by a:*
   ☐1 Single clinician ☐2 Formal consensus panel ☐3 Other *(e.g., Two or more clinicians or other informal group)*

Section 1 – Level of impairment – ***Unimpaired cognition, SCD, MCI/MBI, or dementia***

INITIAL VISIT PACKET UNIFORM DATA SET (UDS) VERSION 4.0

Form D1b: Biomarkers used to support Etiological Diagnosis

In-person ☐ Remote ☐

ADRC name: _____ Participant ID: _____ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___

Visit #: _____ Examiner's initials: _____ Language: English ☐ Spanish ☐

Clinical Task Force and ADRC Program

UDSv4:

- will allow testing of NIA-AA biology and clinical staging framework
- Still uses CU, MCI, and dementia, but adds SCD, MBI, and parses out elements of “Cognitively impaired, not MCI” – can be matched up with NIA-AA numeric clinical stages
- Form D1b allows for identification of which biomarkers used to support diagnosis, but allows for evolution of biomarker field

ADRC Program:

- Allows testing and refining of how to operationalize clinical and biological staging and best practices for biomarker disclosures

Closing Thoughts

- Roll out NIA-AA framework in research and clinical research setting
- Gather data to refine clinical stages from UDSv4
- Work on integrating communication framework with research framework
- Gather and refine best practices for implementing guidelines from ADRCs to share with clinicians

Thank you!

cmc@medicine.wisc.edu