

Clinician Insights on Improving Diagnostic Communication from the Dementia Nomenclature Initiative

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BACKGROUND

The Advisory Council on Research, Care, and Services of the National Plan to Address Alzheimer's Disease authorized the **Dementia Nomenclature Initiative** to improve how dementia diagnoses are communicated to patients and families.

The Initiative developed a **Communications Framework** and **User Guide for clinicians** to improve clarity and consistency in discussions about cognitive impairment.

OBJECTIVE

To capture clinician feedback on the clarity, value, and potential implementation challenges of the Dementia Nomenclature Initiative User Guide in order to refine the Guide, optimize alignment with clinical workflows and support broad uptake.

METHODS

- 20 semi-structured virtual interviews with U.S. clinicians (Fall 2025)
- Neurologists (n=12), geriatricians (n=5), and specialists in psychiatry/internal medicine
- Mean 17 years in practice (range 3–39 years) across 6 states
- Inclusion criteria: diagnose ≥25 older adults with cognitive impairment evaluated annually
- Interviews recorded, transcribed, and analyzed via manual thematic analysis with AI-assisted theme identification
- Duke University IRB approved (Protocol No. 00118387)

20
Clinicians

6
U.S. States

17 yrs
Avg. Experience

RESULTS: GENERAL IMPRESSIONS

Framework Reflects Specialist Practice

- Experienced specialists felt the Framework mirrors their existing diagnostic and communication processes
- Endorsed value for trainees, early-career clinicians, and non-specialists
- Standardizing language across specialties viewed as a benefit

RESULTS: CLINICAL WORKFLOW & COMMUNICATION

Communication & Understanding

- Many endorsed the need for standardized language and a consistent approach to diagnosis and communication
- Framework praised for helping explain symptoms vs. underlying causes
- Many found the severity gradations (minimal/mild/moderate/severe) to be unclear
- Many expressed concern about moving away from term 'dementia' without a clear alternative

Clinical Workflow

- Many said the Framework reflects their existing practice and would not alter their workflow
- Framework noted for potential value for trainees, less-experienced clinicians, and non-specialists
- Time constraints identified as a significant challenge to use given visits of 20 minutes or less

PARTICIPANT DEMOGRAPHICS

- | | |
|-------------------------|------------------------|
| • Female: 65% | • Age range: 45–54 yrs |
| • Neurologists: 60% | • Priv. practice: 25% |
| • Geriatricians: 25% | • VA / community: 30% |
| • Academic centers: 45% | • < 10 yrs exp: 25% |

RESULTS: BARRIERS & FACILITATORS

⚠ Implementation Barriers



Limited appointment time (especially primary care and high-volume clinics)



Training needs for non-specialists unfamiliar with Framework



Resource gaps in rural areas (limited access to biomarkers, imaging)

✓ Implementation Facilitators



Electronic health record (EHR) integration as smart phrase or checklist



Short training resources: webinars, vignettes, quick-reference cards



Patient-facing materials (handouts, videos, take-home summaries)

RESULTS: EQUITY & CULTURAL SENSITIVITY

- Most clinicians use professional interpreters; some rely on family due to resource constraints
- Cultural adaptations needed beyond language (e.g., some families prefer not to disclose dx to pt)
- Materials must meet patients/families 'where they are emotionally, culturally, and educationally'

SPECIFIC SUGGESTIONS FOR USER GUIDE

- Clarify purpose: communication tool, not a diagnostic algorithm
- Reduce jargon; use plain language throughout
- Add case studies across greater range of patient types
- Address mixed etiologies, prognosis, safety (driving), and care planning

CONCLUSIONS

- The User Guide aligns with specialist practice and shows strong potential for non-specialists and trainees
- Clinicians identified specific, actionable opportunities to refine the User Guide: simplify language, clarify purpose, add patient-facing materials, and address prognosis
- Input from non-specialists and pilot testing will further optimize implementation and real-world uptake

RECOMMENDATIONS

Make Content Updates

- Clarify guide purpose, severity definitions, and dementia terminology
- Incorporate more visuals; reduce jargon; expand case studies

Develop Supplemental Materials

- Patient handout/video; clinician quick-reference; cultural/language translations

Conduct Additional Research

- Non-specialist interviews (primary care), clinical pilot testing, patient & care partner input

Review Guide Structure

- Consider stepwise organization; streamline for time-constrained clinical settings

ACKNOWLEDGMENTS

We thank all interview participants for generously sharing their time. Research team contributions: Alain Chang, Alex James, Renee Levery, Sonya Sutton, Gina Uhlenbrauck. Supported by the Dementia Nomenclature Initiative (Lewy Body Dementia Association & Alzheimer's Association). Conducted by the Duke Clinical Research Institute.

Reference: Petersen RC, et al. A New Framework for Dementia Nomenclature. JAMA Neurol. 2023;80(12):1364-1370.