



Dementia Nomenclature Initiative (DeNomI)

UPDATE TO THE ADVISORY
COUNCIL ON ALZHEIMER'S
RESEARCH CARE AND SERVICES

JULY 20, 2020

Introduction: Today's Terms are Confusing

Researchers and clinicians use different terms in different ways, e.g.

- Alzheimer's disease
 - E.g. syndrome or etiology?
- DSM-5
 - Mild and major neurocognitive disorder

For the general public

- Stigma from the term dementia
- Dementia = Alzheimer's disease?
- Finding services and supports

Changing terms could have implications for healthcare reimbursement, regulatory decisions, training and more.

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

"A cross-cutting stakeholder discussion on barriers, opportunities and strategies to develop consistent, accurate, and meaningful language for cognitive impairment and dementia, that is useable or at minimum interoperable among scientists, care providers and the public."

Dementia
Nomenclature
Initiative

Today's DeNomI Update



STRUCTURE



MILESTONES



TIMELINE



RESOURCES

Structure

STEERING COMMITTEE

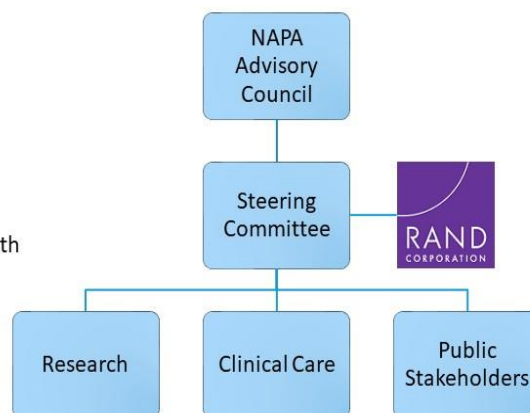
- Strategy, Deliverables, Funding, Workshops

Co-chairs:

- Ronald C. Petersen, MD, PhD, Mayo Clinic
- Angela Taylor, Lewy Body Dementia Association

Members:

- Charles Adler, ME, PhD, Mayo Clinic
- Peggye Dillworth-Anderson, PhD, University of North Carolina
- Cynthia Huling-Hummel, Dmin, person living with dementia
- Jason Karlawish, MD, University of Pennsylvania
- Marwan Sabbagh, MD, Cleveland Clinic
- Sandra Weintraub, PhD, Northwestern University



Working Groups

Research	Clinical Care	Public Stakeholders
<ul style="list-style-type: none"> • Sandy Weintraub, Northwestern (chair) • Brian Appleby, Case Western • Lisa Barnes, Rush U. • Michael Belleville, PwD • Maria Carillo, Alz. Assoc. • Rod Corriveau, NINDS • Sharon Denny, AFTD • Brad Dickerson, Harvard • Elena Fazio, NIA • Elizabeth Gould, RTI Int'l • Dave Knopman, Mayo Clinic • Oscar Lopez, University of Pittsburgh • Lisa McGuire, CDC • Julie Schneider, Rush U. • Dom Sisti, U of Pennsylvania 	<ul style="list-style-type: none"> • Marwan Sabbagh, Cleveland Clinic (chair) • Cindy Cordell, Global Alz. Platform • Judit Illes, Geron. Society of America • Eran Klein, Oregon Health & Science U • Jim Leverenz, Cleveland Clinic • Darby Morhardt, Northwestern • Darina Petrovsky, U of Pennsylvania • Maria Reyez, Salt Lake City VA • Luke Stoekel, NIA • Eric Tangalos, Mayo Clinic (ret'd) 	<ul style="list-style-type: none"> • Jason Karlawish, Upenn, (chair) • Angela Arnott, Livonia Senior Center • Rodney Blough, PwD • Sam Crowe, caregiver • Christian Elliott, My Brain Test • Cara Fallon, U of Pennsylvania • Matt Janicki, U of IL at Chicago • Sara Locke, AARP • Jason Resendez, Latinos Against Alz • Matt Sharp, AFTD



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Facilitate communication and coordinate meetings for the Steering Committee and Working Groups
- 
Data collection, information synthesis, report preparation
- 
Meeting planning
- 
Summarize results in final project report
- 
Disseminate results

Early Milestones



2019

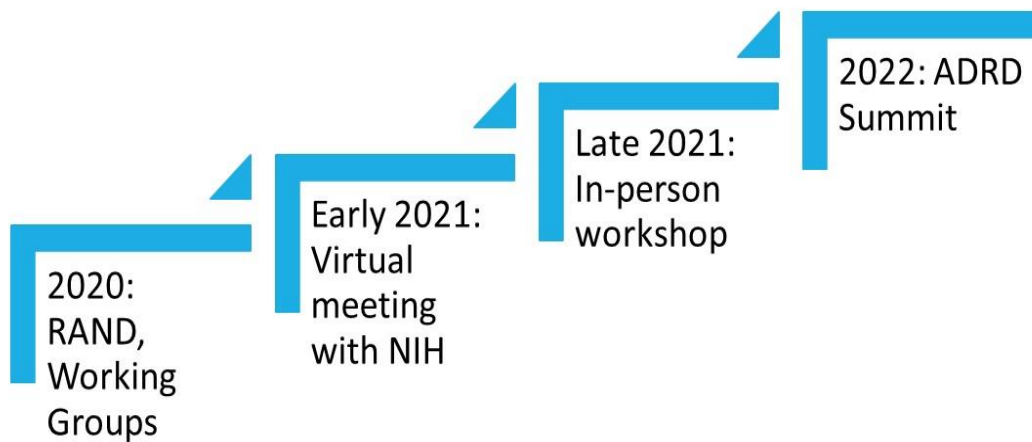
Steering Committee
Strategy and timeline
Working Groups (3)



2020

Research Working Group
Budget and Sponsorships
RAND Corporation

More Milestones



Sponsors



Sponsorship Opportunities Available

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