

DEMENTIA NOMENCLATURE INITIATIVE

SUMMARY OF PHASE 1 WORK

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OVERVIEW

Clear, accessible communication is at the heart of promoting public health. Current terminology used to diagnose, study, and communicate about age-related cognitive impairment and dementia lacks clarity. Without a clear language for understanding cognitive health and cognitive impairment, many people ignore or minimize important changes. The results of confusing communication are stigma and isolation;¹ delays in diagnosis and care; and barriers to generating much of the needed public education efforts, helpful policy, and vital research.

For those who do seek clinical input, the information they get about these neurodegenerative diseases can cause confusion. Researchers, clinicians, and advocates struggle to communicate in a common and consistent way. Research is also hampered by the lack of clarity, which in turn challenges development of the evidence base about cognitive disorders. Translation from research to clinical care is likewise impacted.

In 2016 the Advisory Council on Alzheimer's Research, Care and Services for the National Plan to Address Alzheimer's Disease recommended that these limitations in terminology be addressed. In 2019 Angela Taylor of the Lewy Body Dementia Association and Ronald C. Petersen, MD, PhD, of Mayo Clinic convened a committee to launch the Dementia Nomenclature Initiative. The Initiative was soon charged by the Advisory Council to recommend improvements in terminology that address interoperability of terminology for researchers, clinicians, and the public.

The Initiative formed a Steering Committee and working groups for each of these three constituencies. Funding for the work of the Initiative was provided by a consortium of nonprofit funders. The RAND Corporation was contracted to provide support for the work both in terms of content and process. Following review of the literature in dementia and in other disorders with terminology challenges, consultation with a range of stakeholders, multiple convenings and deliberation, and collection of input from persons living with dementia and family members, the Initiative has developed a new approach to explain the full spectrum of cognitive impairment and the diseases that cause it. Initiative members have taken the most common types of neurodegenerative diseases and integrated their basic elements into a clear Communications Framework (referred to here as the Framework), with the goal of creating greater clarity and consistency in communication about these conditions. The intended impact of the Framework and related work of the Initiative is increased awareness, expanded access to care and research, and wider dissemination of research results to the public, press, and policymakers.

A review of the work of the Initiative is provided here, beginning with the reason for convening the Initiative and the Initiative's structure. Work from Phase 1 is summarized as well, beginning

with the literature reviews conducted to inform the Initiative, the major output of Initiative Working Groups through their deliverables, a brief summary of the two Workshops held in 2021 and the ways in which those Workshops informed the work, and a summary of the external stakeholder input that RAND and Strategic Communications & Planning staff obtained.

FORMATION OF THE DEMENTIA NOMENCLATURE INITIATIVE

Dementia and other age-related cognitive impairments are widespread public health challenges, affecting approximately 50 million people globally, with an estimated 6 million people living with dementia in the United States.² The burden is expected to grow, with nearly 14 million people (3.3 percent of the U.S. population) affected by 2060.

The National Alzheimer's Project Act (NAPA) is federal legislation designed to address cognitive impairment and dementia among older adults in the United States.³ NAPA led to annual dementia Summits organized by the National Institutes of Health (NIH), in which the harms resulting from inconsistent and unclear terminology were a focus of the 2016 Summit. Among those harms are inadequate clinician communication with patients and lack of clarity in communication among researchers. The problematic terminology contributes to stigma, further impeding access to care and services.⁴ Those working in the field recognize the imperative to improve terminology, including increasing public awareness and understanding, minimizing associated stigma, improving clinician communication with patients, and improving research participation, particularly among underrepresented minority groups.⁵⁻⁷

A recommendation emerged from the 2016 Summit to work toward consensus on nomenclature standards for the diseases addressed by the legislation, specifically Alzheimer's disease (AD), frontotemporal degeneration (FTD), Lewy body dementias (LBD), and vascular contributions to cognitive impairment and dementia (VCID).⁴

To begin the work toward the goal of nomenclature consensus, the Advisory Council on Alzheimer's Research, Care and Services, which oversees the National Plan for NAPA, charged a Steering Committee for the Dementia Nomenclature Initiative to establish cross-cutting stakeholder discussions on barriers, opportunities, and strategies to develop consistent, accurate, and meaningful language for cognitive impairment and dementia that is usable or, at a minimum, interoperable among scientists, providers, and the public. Angela Taylor of the Lewy Body Dementia Association and Ronald C. Petersen, MD, PhD, of Mayo Clinic took on the role of Initiative Co-Chairs. The members of the Initiative are listed on Page 1.

FORMATION OF THE WORKING GROUPS

The Steering Committee convened in the spring of 2019 to establish a structure for the Initiative and a work plan. The Steering Committee translated the charge from the Advisory Council into 12 discrete deliverables and established three distinct Working Groups (WGs) to complete those deliverables: the Research WG, the Clinical Care WG, and the Public

Stakeholder WG. The Public Stakeholder WG included people living with dementia (PLWD) and family caregivers, along with representatives from advocacy organizations. The Research WG also included a person living with dementia. Each WG was charged with developing an umbrella term deliverable; Research WG had three additional deliverables, and Clinical Care WG and Public Stakeholder WG each had four additional deliverables. See Table 2.

All WGs shared a deliverable of recommending an “umbrella term(s),” and these suggested terms were the basis for final umbrella term recommendation by the full Initiative. See Table 1 for a list of the deliverables.

The Research WG was chaired by Sandra Weintraub, PhD, of Northwestern University. The 17 members of this group met from the spring of 2020 to February 2022. They began with consideration of the ways to accurately communicate the continuum of severity of cognitive impairment. The group also pursued a terminology mapping exercise to provide a repository of all terms associated with the target disease areas of AD, FTD, LBD, and VCID, useful for exploring terminology overlap and differences. This document provided the foundation for development of a standard Communications Framework to improve communications. Multiple iterations of the initial Framework were discussed, and then an early draft was shared with the other WGs for input.

Table 1. Initiative Deliverables, by Working Group

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 of terminology
- 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

The Research WG was also charged with addressing implications of terminology changes for industry and regulatory groups. To meet this need, RAND staff convened multiple discussion groups through the summer of 2021 with a total of 14 individuals representing drug developers, payers, electronic health record consultants, researchers, and clinicians, including within the Department of Veterans Affairs (VA). See the External Stakeholder Input section, below.

The Clinical Care WG convened from September 2020 to January 2022 and was chaired by Marwan Sabbagh, MD, FAAN, of the Barrow Neurological Institute. The 13 members of this group addressed the terminology needs in clinical care and implications of terminology changes for patient/clinician communication and for payers and health systems.

The Public Stakeholder WG convened from November 2020 to April 2022 and was chaired by Jason Karlawish, MD, of the Perelman School of Medicine at the University of Pennsylvania. The ten members of this group addressed the implications of the Framework for addressing stigma, and they addressed cultural and public health aspects of terminology changes.

A schedule was established to ensure that deliverables from each WG were reviewed and discussed by the other WGs before finalizing content. This ensured cross-Initiative input on all deliverables. The Steering Committee provided final review, revision, and approval of all Initiative deliverables.

Throughout the course of the Initiative's work, subgroups formed to meet specific needs. For example, an Umbrella Term Subcommittee formed to review the recommendations from each WG and synthesize recommendations from the three WGs in the final umbrella term deliverable. They established criteria for the umbrella term and then reviewed options for terms. The criteria were that the umbrella term 1) must address coverage of the desired concepts, 2) must address exclusion of extraneous concepts, 3) must be agnostic to type of dementia/cognitive impairment and degree of functional impairment, 4) must be specific enough to suggest that a change in cognitive function is occurring or will occur, 5) must be understandable by the public and have the potential to mitigate stigma, and 6) must be usable by researchers and clinicians. A subcommittee also formed to review the use of the term "disease" versus "disorder" as part of the umbrella term recommendation.

A Framework subcommittee incorporated input from all three WGs into the final Framework.

LITERATURE REVIEWS

To support the work of the Initiative, RAND researchers provided a narrative literature review that explored dementia nomenclature evolution over the last century and a review of literature

relating to the evolution of nomenclature in related therapeutic areas. The Initiative members worked with RAND researchers to determine which related areas to explore. The final related therapeutic areas for review were cancer, autism spectrum disorder, and intellectual disabilities. The main questions addressed through this review of related therapeutic areas were the following: 1) What can other nomenclature efforts from relevant therapeutic areas contribute to considerations by the dementia nomenclature initiative about process, stigma, and communication about the disease? and 2) What methods have been used in other therapeutic areas for establishing or updating disease nomenclature?

The following dementia nomenclature initiatives from countries outside of the United States were also examined for guidance: recent dementia nomenclature efforts in Canada, Australia, and English-speaking countries in the European Union and English-language reporting on terminology changes in Japan. While each of these other initiatives differed in terms of goals, scope of work, and methods, given their focus on nomenclature they were examined to inform both process and content issues for the Initiative.

FORMATIVE WORKSHOP INPUT

An initial workshop was held in February 2021 to provide multiple audiences with an update on the progress of the Initiative and to obtain formative input into the work. A total of 59 individuals attended that workshop with invitees from the National Institutes of Health (NIH), other federal agencies including the Administration on Community Living, Veteran's Administration (VA), Centers for Disease Control and Prevention (CDC), and the U.S. Department of Health and Human Services, and advocacy groups including AARP, the Alzheimer's Association, and the Gerontological Society of America. Sponsors of the work also attended (see page 17 for a list of sponsors).

The workshop provided the audience with an overview of the rationale for the Initiative and a discussion of the scope of the work. Clarifying that the Initiative members were completing their deliverables based on the diseases called out in the NAPA legislation was a key point of discussion. The pros and cons of including other neurological disorders such as traumatic brain injury were discussed, but presenters emphasized the bounded scope of the work.

The link to NAPA Council and Alzheimer's Disease-Related Dementias (ADRD) Summit recommendations was clarified through the introductory sessions. The NAPA Council's 2016 recommendation was that "Emphasis should be given to the standardization of terminology in dealing with cognitive and dementing disorders" via two activities: "*An integrated conference should be convened to develop consistent language for cognitive disorders among the scientists,*

care providers, and the public, ” and “Engage all of the stakeholders around these issues to reach a consensus for the benefit of persons with dementia, their family members and caregivers, and the scientific and service communities.”

The subsequent March 2019 ADRD Summit resulted in formal process recommendations. The first was to *“Form research, clinical practice, and public stakeholder dementia nomenclature working groups”* with a one- to two-year timeline. The second related to *“Integration and Interoperability of Dementia Nomenclature”* with the goal to *“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”* with a two- to four-year timeline. The 2017 National Institute on Aging (NIA) Dementia Care and Services Research Summit led to a related Milestone: *“Update consensus on AD/ADRD nomenclature necessary to identify target populations for intervention research; clarify role of symptom presentation and presence of biomarkers in new nomenclature. Determine impact on patient/clinician communication about dementia diagnosis and management. Determine impact on public understanding about dementia.”*

The cost of misaligned terminology to research accuracy and efficiency was emphasized through presentation and discussion. The foundational literature reviews completed for the Initiative were presented, demonstrating the work’s reference to relevant historical terminology evolution, to relevant international initiatives, and to terminology evolution in other therapeutic areas. The workshop presentations also provided the audience with an overview of the stakeholder-engaged process developed for the work.

An early version of the Framework was presented and discussed. Relevant NIH initiatives on study recruitment for Black/African American, Hispanic/Latino, and Asian American and Pacific Islander participants was discussed. The Public Stakeholder WG discussed the value of including reference to issues of importance to a wide range of patients and family, including behavior and daily functioning. Participants discussed potential dissemination for the work including sharing with the NIA and the National Institute of Neurological Disorders and Stroke (NINDS) Councils. One major conclusion from this workshop was about the value of collection of input directly from PLWD and caregivers, with attention to views of different race and ethnicity groups. As a result, SCP Communications was asked by the Steering Committee to conduct multiple focus groups in the United States with PLWD and caregivers.

FOCUS GROUP INPUT

The aims of the focus groups were to 1) assess perceptions of current overarching terms, notably Alzheimer’s disease and dementia, used broadly to describe neurodegenerative diseases and conditions; 2) evaluate reactions to umbrella terms recommended by the Initiative and the Framework; 3) examine interpretations of the umbrella term and Communications Framework and how they compare by participants’ race and ethnicity; and 4) elicit information about patient/clinician interactions, particularly related to the language or information presented at diagnosis or in discussions about symptoms.ⁱ

A total of six hour-long focus groups were conducted: two with Latinx/Hispanic participants, one with Black/African American participants, one with Asian American/Pacific Islander participants, one with Native American/American Indian participants, and one with White participants. The groups included 41 participants total, including five PLWD (12.2%).

Across the groups there was convergence on the point that commonly used terms to describe the range of neurodegenerative diseases, particularly dementia and Alzheimer’s, were poorly understood or viewed as stigmatizing or unhelpful. Group participants generally endorsed the Framework as a communication tool and agreed with the inclusion of information about symptoms, severity, and possible causes. The groups converged on suggestions to more specifically address ways to help people understand diagnoses and implications for the future, including planning. Reaction to the potential umbrella terms was less convergent. More participants responded neutrally or negatively to the recommended umbrella terms of “adult cognitive disorders/diseases.”

There were few differences between the groups. The few points that did differ by group were the following:

- The Hispanic/Latinx groups had suggestions for family education, early screening to identify symptoms sooner and give patients more time to prepare, the effect of COVID-19, patient rights, and providing patients and caregivers with a “path to discovery” to continue learning about dementia.
- The Black/African American group wanted to hear about how dementia can present differently in different people.
- The issue of genetics and heritability was raised in the Asian American/Pacific Islander group, along with the issue of cultural avoidance of dementia issues.

ⁱ All materials were approved by the Institutional Review Board of University of Pennsylvania.

- Participants in the Native American/American Indian group said that they were looking for more information on the differences between dementia and Alzheimer’s, expectations for the future, possible treatments, and caregiver self-care.
- Several people in the White group emphasized the importance of retaining the humanity of the person with the diagnosis—referring to patients as people living with the condition—and “making sure that the people who are living with these illnesses have a primary input as much as possible, because we’re talking about how people self-identify.”

Participants emphasized the emotional challenge of interactions with others about the diagnosis, including with clinicians and with friends and family. The focus group input suggests that public education related to recommendations from the Initiative will need to incorporate awareness of the charged emotional and even traumatic context in which dementia communications can occur.

EXTERNAL STAKEHOLDER INPUT

To aid the Research WG and Clinical Care WG with their deliverables addressing impact of terminology changes, 14 external stakeholders were recruited to join separate 90-minute discussions held through the summer of 2021. Participants were drawn from the Centers for Medicare & Medicaid Services, the Department of Health and Human Services/Administration for Community Living, health information technology experts, clinicians and researchers from the VA and another health system, pharmaceutical companies with a portfolio in neurodegenerative diseases, and representatives from the NIH.

Participants were asked to review and comment on the Communications Framework (draft version as of the summer of 2021) and the draft umbrella terms. They were asked about their interpretation of the role of terminology and nomenclature in dementia, their reactions to the goals of the initiative and its progress to date, and participant suggestions and recommendations regarding dissemination of the Framework and umbrella terms.

There was consensus in each group that the current state of terminology in the field impedes communication within and between constituencies and can hamper research by limiting comparability across studies. The multi-stakeholder and multidisciplinary process was appreciated by the participants, and many participants noted that the specific individuals working on the Initiative strengthened credibility of the results of the work. Participants shared their view of challenges to achieving Initiative goals including challenges to acceptance by clinicians and the research community. A few noted the impact of terminology changes on the

NIH Research, Condition, and Disease Categorization (RCDC) process, which classifies research funding, potentially affecting funding opportunity announcements as well as tracking of funding investments used to communicate with the public and Congress.

Input from participants suggested that the rationale for the Initiative needed to be clearly expressed, given related efforts such as the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria development and the National Institute on Aging-Alzheimer's Association (NIA-AA) Research Framework. Participants suggested that the Initiative clarify the relationship of Initiative recommendations to existing terminology, and what if any of commonly used terms will be recommended to be replaced. New terminology will affect coding of medical encounters, posing pragmatic challenges for some sectors but also potentially leading to resistance from some stakeholders. Some suggested that the Initiative consider incremental changes to improve wide uptake. The Framework's use of qualitative severity ratings was endorsed as aiding with referral to appropriate long-term services and supports.

Participants from pharmaceutical companies provided practical input about coordinating with requirements of the U.S. Food and Drug Administration (FDA) Office of Prescription Drug Promotion in terms of product label language. Another consideration for the Initiative is impact on the link between clinical development activities (including patient recruitment) and the product label. Participants noted that some clinicians may not want the specificity that new nomenclature might provide, since ambiguity can be easier for clinicians to express than definitive information, given the challenges to treatment of cognitive disorders. Groups discussed the potential benefit of an umbrella term to limit specificity while providing consistent communication across disease types. Finally, participants provided input useful for planning future work finalizing terminology and disseminating and implementing proposed changes.

To obtain early input from the non-U.S. researcher community on the work of the Initiative, a September 2021 meeting was convened with senior researchers from the Netherlands, Sweden, Italy, and Switzerland. Participants were asked to discuss the role of terminology and nomenclature in dementia, challenges with terminology in their respective countries, reactions to the goals of the Initiative and its progress to date, and suggestions and recommendations regarding translatability and cultural adaptation and dissemination of the Framework to potential users.

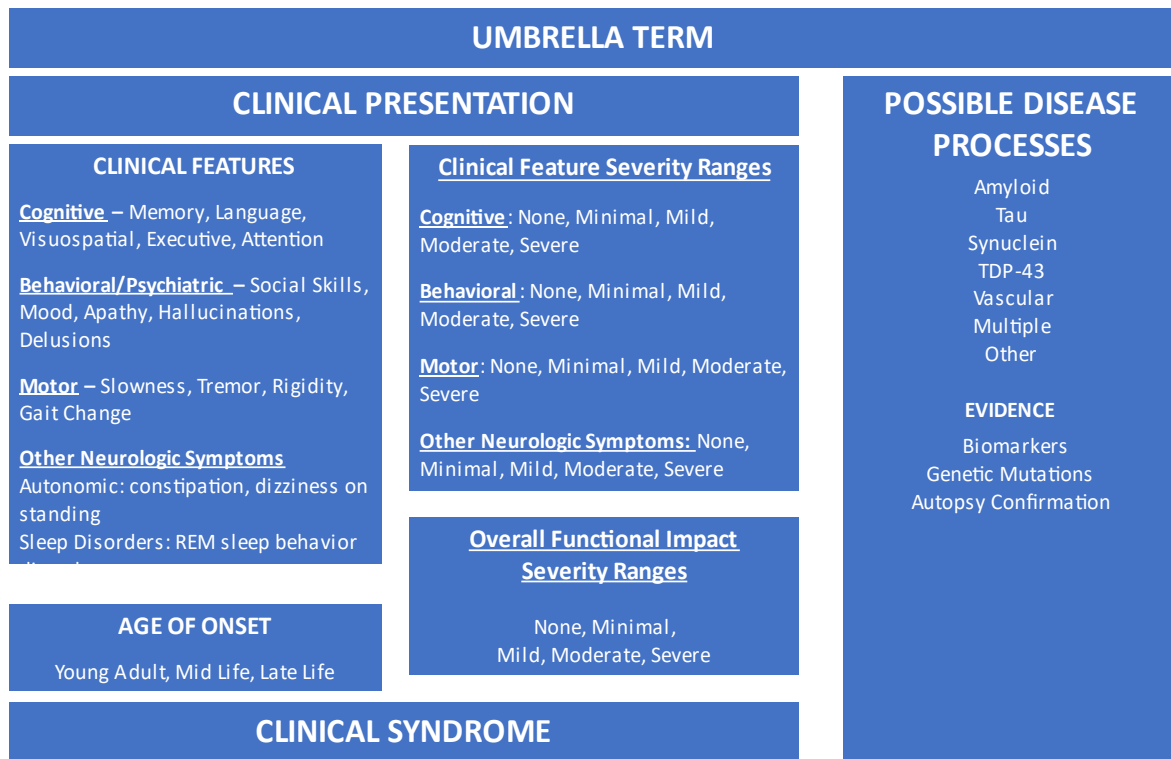
The international participants agreed that the Framework would help the research field and help with communication across stakeholder types, including in clinical interactions with patients. Limited availability of biomarkers for all the underlying diseases was identified as a

challenge for use of the Framework. Participants indicated that the complexity of the Framework might be a challenge to wide uptake with the general population, but also that the research community could benefit from the Framework. Participants noted that the problem of confusing terminology in the field is worth tackling but that efforts to improve terminology have been made in the past, with limited effect. Availability of new treatments and improved biomarkers may improve the success of the effort now.

THE COMMUNICATIONS FRAMEWORK

Ongoing Initiative discussions and external feedback were used to revise the Communications Framework. See Figure 1.

Figure 1. Communications Framework



The Framework structure separates clinical observations from pathophysiologic findings regarding possible disease processes. Among the considerations in developing the Framework were that dementia and mild cognitive impairment are syndromes diagnosed by clinical evaluation and do not connote a specific underlying pathophysiology. The Framework was informed by the distinction in the DSM-5 between syndromic labels of mild and major

neurocognitive disorder and etiology-based descriptions that can incorporate, for example, biomarker data [8] [9]. The Framework was also informed by the National Institute on Aging-Alzheimer's Association (NIA-AA) Research Framework.

The Framework is intended to drive inclusion of all types of relevant information. Clinical presentation data include clinical features across cognitive, behavioral/psychiatric, motor, and other symptom domains, severity ranges across those domains, overall functional impact, and age of onset. Together these observations provide information about the clinical syndrome. Information about possible disease processes is incorporated into the Framework, such as location and extent of amyloid, tau, alpha synuclein, and other pathophysiologic indicators, as well as genetic data. The clinical syndrome information along with the disease process information provides the basis for clear and comprehensive communication about specific diseases and is intended to aid with communication among researchers, among clinicians, and between clinicians and patients, and is intended to guide public communication. The umbrella term encompasses all the disease or disorder conclusions from the use of the Framework, with a focus on the target disease areas per the Initiative's charge: AD, FTD, LBD, and VCID.

Input from the Initiative deliberations, external stakeholder input, literature reviews, and participant discussion at the workshops was reviewed and used in finalizing the Framework.

DECEMBER 2021 WORKSHOP: COLLECTING FINAL INPUT

A second workshop was convened in December 2021 to provide an update on the work of the Initiative to relevant stakeholders. Cindy Carlsson, Chair, NAPA Advisory Council, provided opening remarks, followed by an overview of the problem the Initiative was charged to address, the Initiative's approach to resolving the problem, and the Framework, presented by Ron Petersen and Angela Taylor.

The workshop also introduced a concept outline considered for the Initiative's Phase 2, including expanded input from dementia community with emphasis on understanding and meeting needs of a range of communities within the United States, consensus-building among professional societies and other sectors, and more robust communications resources to drive uptake.

The workshop presentations and discussion addressed the sources of stigma and ways in which terminology changes and communication strategies paired with those changes can mitigate stigma and improve public understanding.

Continued use of the term “dementia” was a point of discussion. Many participants acknowledged that the term “AD/ADRD” is used inconsistently and that the scope of its meaning— the diseases included—is not clear to all audiences. Some suggested revising the term AD/ADRD. The Public Stakeholder WG recommended discontinuation of the term “demented,” and, relatedly, they noted that ongoing use of the term dementia requires consideration.

PLWD and caregivers joined a panel to share challenges that they have encountered with current terminology, especially around understanding diagnosis and prognosis, and they provided examples of when current terminology caused difficulty for them with seeking care.

The Clinical Care WG provided an overview of use of the Framework in clinical encounters, with case examples to illustrate.

Members of the Research WG provided insight into how the Framework could be usefully applied to drug development and clinical trials, and to clinical and psychosocial research.

Representatives from federal agencies discussed the Initiative’s work from the perspective of their organizations: the Office of the Assistant Secretary for Planning and Evaluation within the Department of Health and Human Services; representative of the Advisory Council on Alzheimer’s Research, Care, and Services; the interagency group for the National Plan to Address Alzheimer’s Disease; Centers for Disease Control and Prevention; Administration for Community Living; the Health Resources & Services Administration; and the VA.

Panelists acknowledged the nature of the challenge with current dementia terminology, as well as the value of continuing this work. Potential obstacles to proposed terminology changes were discussed, such as retrofitting electronic health record systems and ensuring consistent terminology use across health system departments.

Participants at the workshop were generally enthusiastic about the potential for the Framework to provide a structure for communication that can meet needs of patients and families, clinicians, and researchers. Participants raised the centrality of legislative language, including that contemplated for future legislation related to NAPA, for driving terminology changes.

In discussion of next steps, participants indicated that ongoing wide stakeholder inclusion is warranted along with collection of more input from PLWD and stakeholders. Broadening the range of individuals and organizations involved in the work will help encompass the range of cultural considerations informing the work and will pave the way for dissemination and uptake of recommendations. Many agreed on the value of tailoring the Framework for different audiences and the need to establish a systematic communication plan.

FINALIZING RECOMMENDATIONS

The WGs reconvened following the December 2021 workshop to incorporate input into their deliverables. The Steering Committee convened to finalize all deliverables. A subcommittee convened to formulate recommendations for the next phase of work, based on input obtained throughout the course of the Initiative's work.

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