



Nomenclature, Words Matter Recommendations

Plenary Session Paper

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Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.



National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers

Summit Recommendations from the Plenary Session: Nomenclature, Words Matter

1. Establish a federally-led working group, reporting to the Advisory Council on Alzheimer's Research, Care and Services, comprised of representatives from government, patient advocacy (including people with dementia and caregivers), clinical, scientific, industry and regulatory stakeholder groups, plus communications and public health experts, and leaders from other fields that addressed comparable nomenclature challenges.
2. Identify and review existing market research done by dementia stakeholder organizations on the public's understanding of dementia and its underlying causes.
3. As it pertains to preclinical and prodromal diagnoses of AD and ADRD:
 - a. Research the cost/savings benefits of earlier classifications on the dementia continuum
 - b. Identify potential risks (i.e. psychosocial, emotional and social impact) of delivering these diagnoses, and educational and support needs to maximize well-being.
 - c. Identify policy implications and civil rights issues, including privacy of at-risk status, employment, housing insurance, access to goods, services, healthcare and support.
 - d. Identify professional education implications for the medical and caring workforce.
 - e. Identify unique, age-appropriate services needed by younger adults diagnosed as at-risk.
4. Recommend research needed to further define and/or address public knowledge gaps perpetuated by confusing terminology, terms that perpetuate stigma and isolation and address terminology-related barriers to early diagnosis, access to care and services, and research participation.
5. Identify and test public health education strategies to a) increase public understanding of the syndrome of dementia, b) increase their understanding of the varying underlying causes of dementia, c) destigmatize the concept of dementia and d) reduce social isolation of people with dementia and the family caregiver after the diagnosis.
6. Identify the best opportunities for early nomenclature changes, what stakeholder groups must be convened to establish proposed changes, what are the top challenges, and identify strategies to make incremental progress.