Cross-Cutting Recommendations

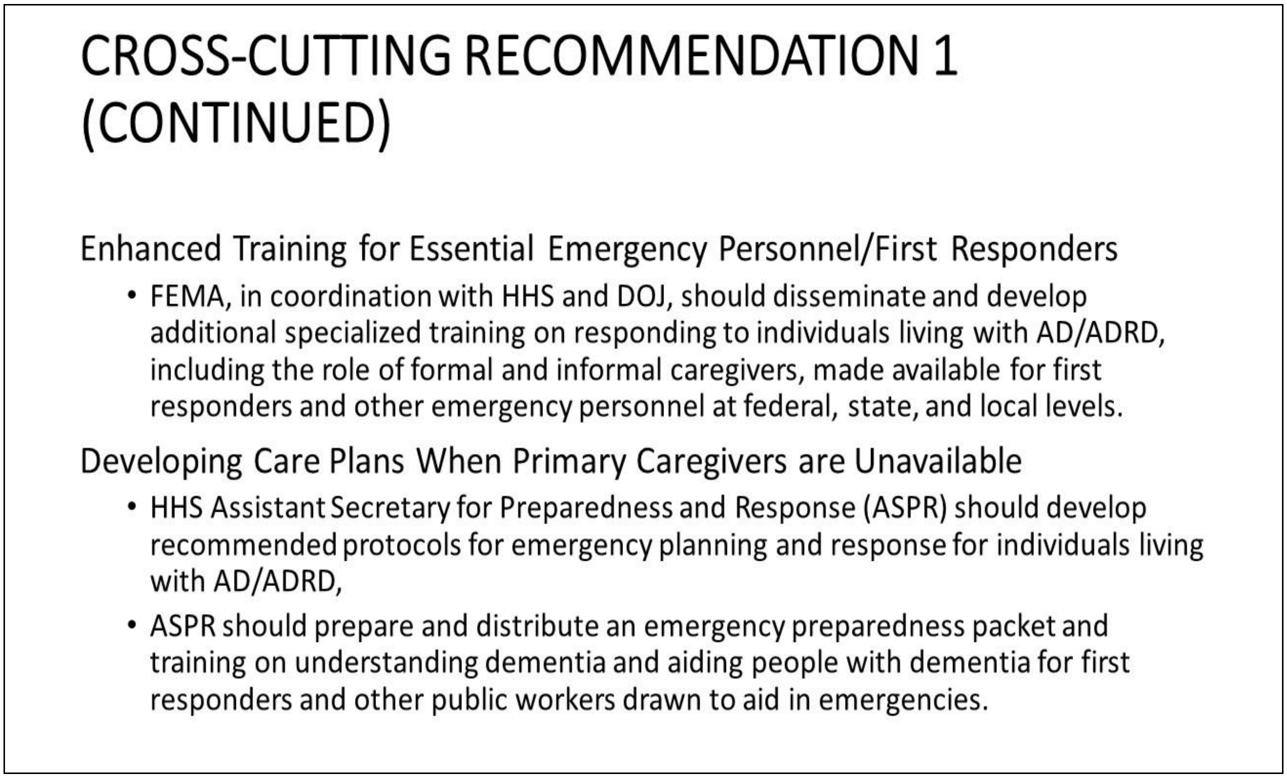
Katie Brandt
Allan Levey
Carrie Molke

CROSS-CUTTING RECOMMENDATION 1

The Department for Health and Human Services (HHS) and federal partners should improve and expand emergency preparedness, response, and recovery with specific consideration of the needs of individuals living with Alzheimer's Disease and Related Dementias and their caregivers.

In recognition of the vulnerabilities of individuals living with AD/ADRD and their caregivers and the potential impact that disasters and emergencies may have on long-term services and supports, clinical care, and research, the Advisory Council recommends the following:

- Advisory Council subcommittees should examine how emergency preparedness, response, and recovery must be tailored to support the domains of research, care and services, and public services for individuals living with AD/ADRD and their caregivers over the next year.
- Subcommittee recommendations should integrate broad input from experts in research, care, and services as well as individuals at risk for or with symptomatic AD/ADRD and caregivers.
- The subcommittees should develop recommendations with specific goals for implementation of emergency preparedness, response and recovery plans that reflect unique needs in the areas of LTSS, clinical care and research.



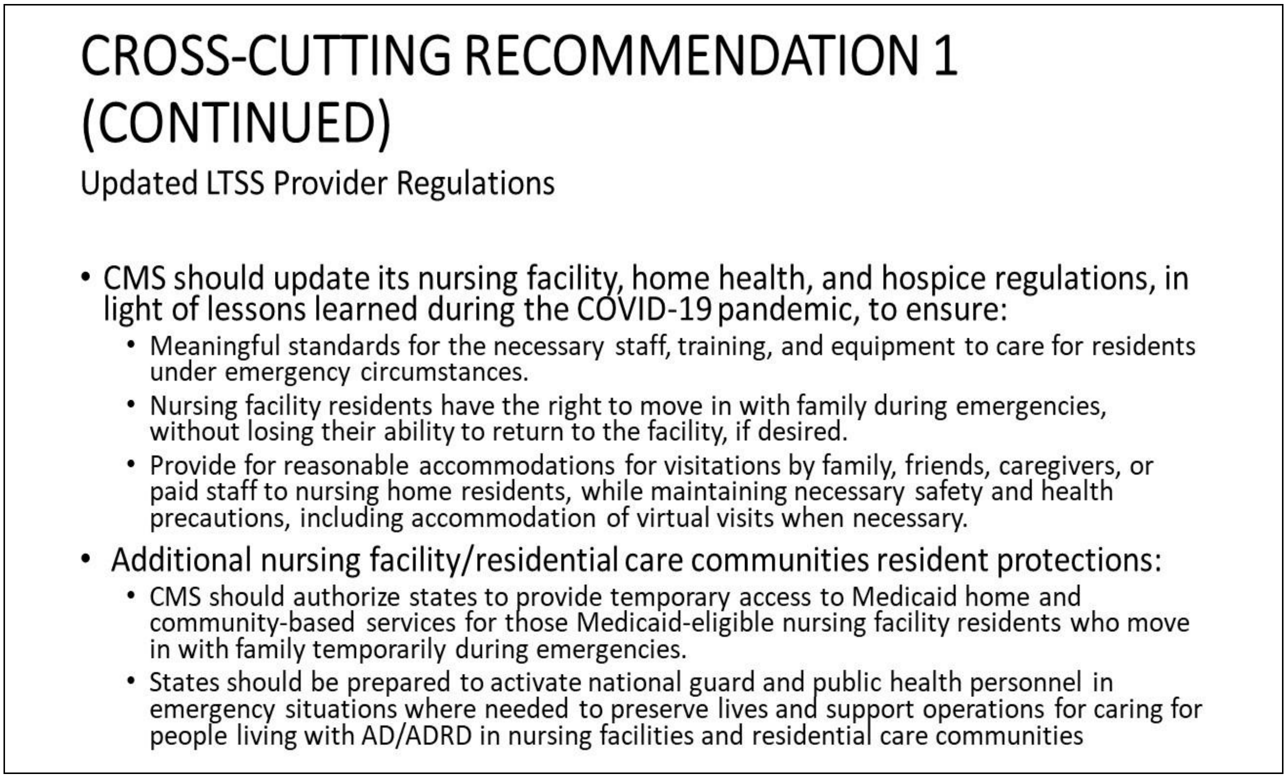
CROSS-CUTTING RECOMMENDATION 1 (CONTINUED)

Enhanced Training for Essential Emergency Personnel/First Responders

- FEMA, in coordination with HHS and DOJ, should disseminate and develop additional specialized training on responding to individuals living with AD/ADRD, including the role of formal and informal caregivers, made available for first responders and other emergency personnel at federal, state, and local levels.

Developing Care Plans When Primary Caregivers are Unavailable

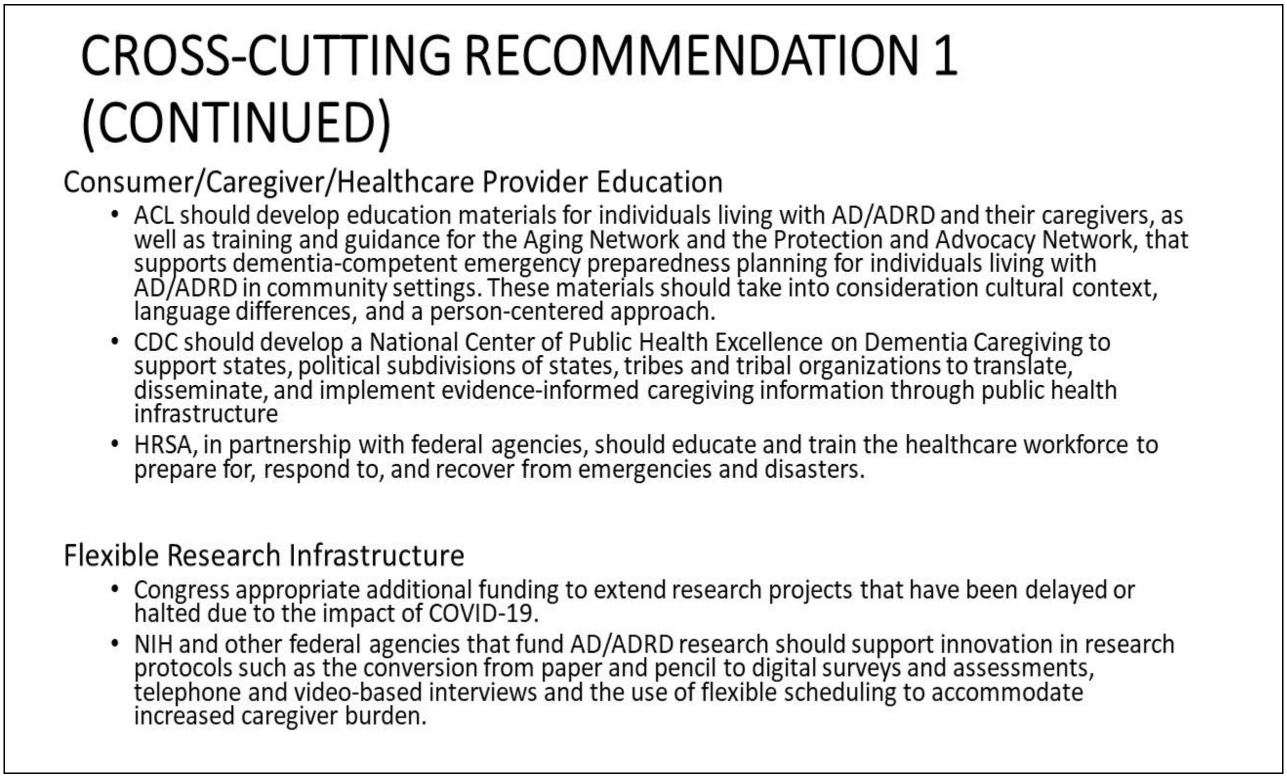
- HHS Assistant Secretary for Preparedness and Response (ASPR) should develop recommended protocols for emergency planning and response for individuals living with AD/ADRD,
- ASPR should prepare and distribute an emergency preparedness packet and training on understanding dementia and aiding people with dementia for first responders and other public workers drawn to aid in emergencies.



CROSS-CUTTING RECOMMENDATION 1 (CONTINUED)

Updated LTSS Provider Regulations

- CMS should update its nursing facility, home health, and hospice regulations, in light of lessons learned during the COVID-19 pandemic, to ensure:
  - Meaningful standards for the necessary staff, training, and equipment to care for residents under emergency circumstances.
  - Nursing facility residents have the right to move in with family during emergencies, without losing their ability to return to the facility, if desired.
  - Provide for reasonable accommodations for visitations by family, friends, caregivers, or paid staff to nursing home residents, while maintaining necessary safety and health precautions, including accommodation of virtual visits when necessary.
- Additional nursing facility/residential care communities resident protections:
  - CMS should authorize states to provide temporary access to Medicaid home and community-based services for those Medicaid-eligible nursing facility residents who move in with family temporarily during emergencies.
  - States should be prepared to activate national guard and public health personnel in emergency situations where needed to preserve lives and support operations for caring for people living with AD/ADRD in nursing facilities and residential care communities



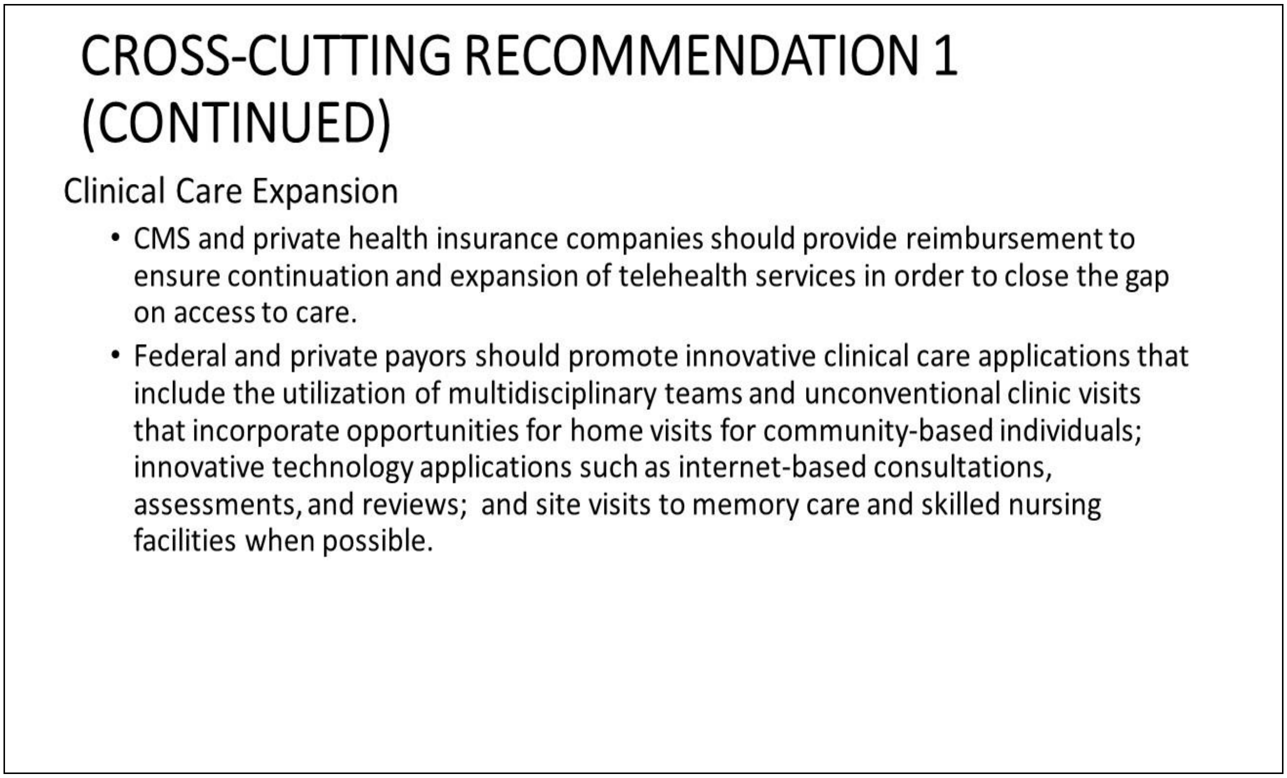
CROSS-CUTTING RECOMMENDATION 1 (CONTINUED)

Consumer/Caregiver/Healthcare Provider Education

- ACL should develop education materials for individuals living with AD/ADRD and their caregivers, as well as training and guidance for the Aging Network and the Protection and Advocacy Network, that supports dementia-competent emergency preparedness planning for individuals living with AD/ADRD in community settings. These materials should take into consideration cultural context, language differences, and a person-centered approach.
- CDC should develop a National Center of Public Health Excellence on Dementia Caregiving to support states, political subdivisions of states, tribes and tribal organizations to translate, disseminate, and implement evidence-informed caregiving information through public health infrastructure
- HRSA, in partnership with federal agencies, should educate and train the healthcare workforce to prepare for, respond to, and recover from emergencies and disasters.

Flexible Research Infrastructure

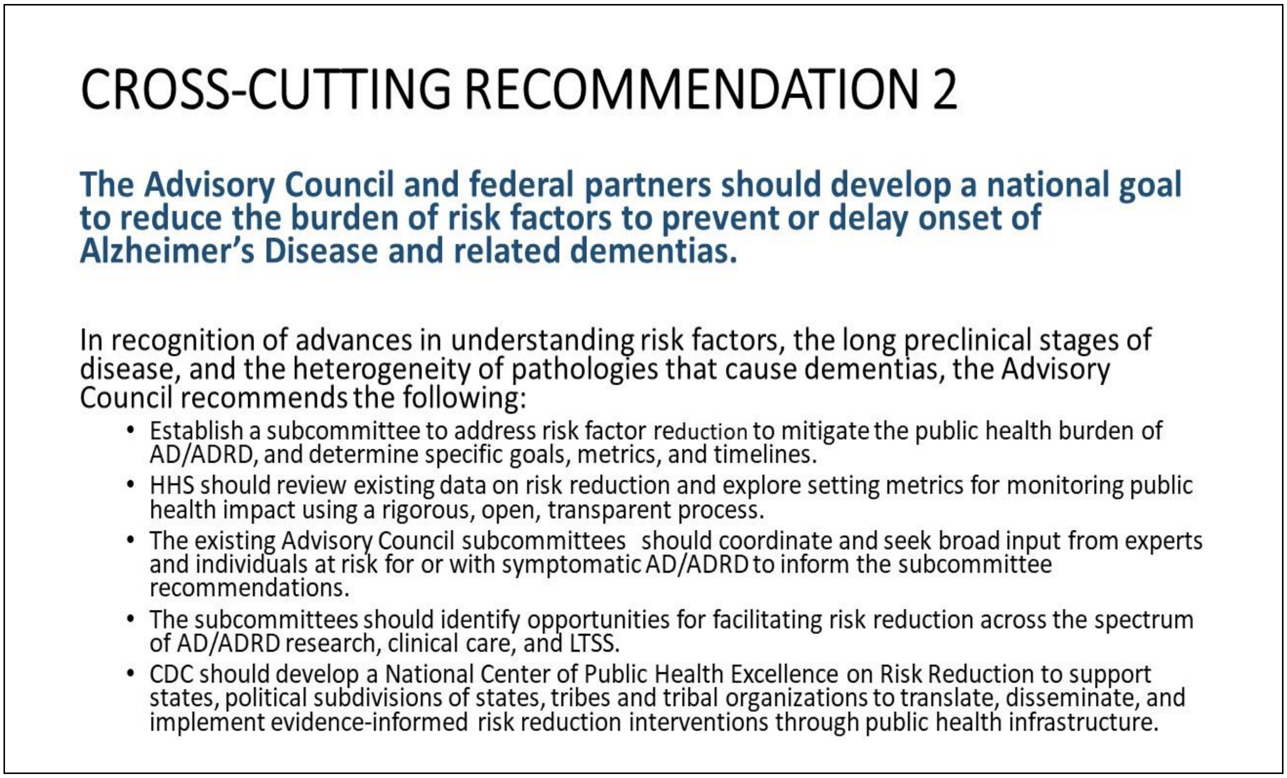
- Congress appropriate additional funding to extend research projects that have been delayed or halted due to the impact of COVID-19.
- NIH and other federal agencies that fund AD/ADRD research should support innovation in research protocols such as the conversion from paper and pencil to digital surveys and assessments, telephone and video-based interviews and the use of flexible scheduling to accommodate increased caregiver burden.



CROSS-CUTTING RECOMMENDATION 1 (CONTINUED)

Clinical Care Expansion

- CMS and private health insurance companies should provide reimbursement to ensure continuation and expansion of telehealth services in order to close the gap on access to care.
- Federal and private payors should promote innovative clinical care applications that include the utilization of multidisciplinary teams and unconventional clinic visits that incorporate opportunities for home visits for community-based individuals; innovative technology applications such as internet-based consultations, assessments, and reviews; and site visits to memory care and skilled nursing facilities when possible.

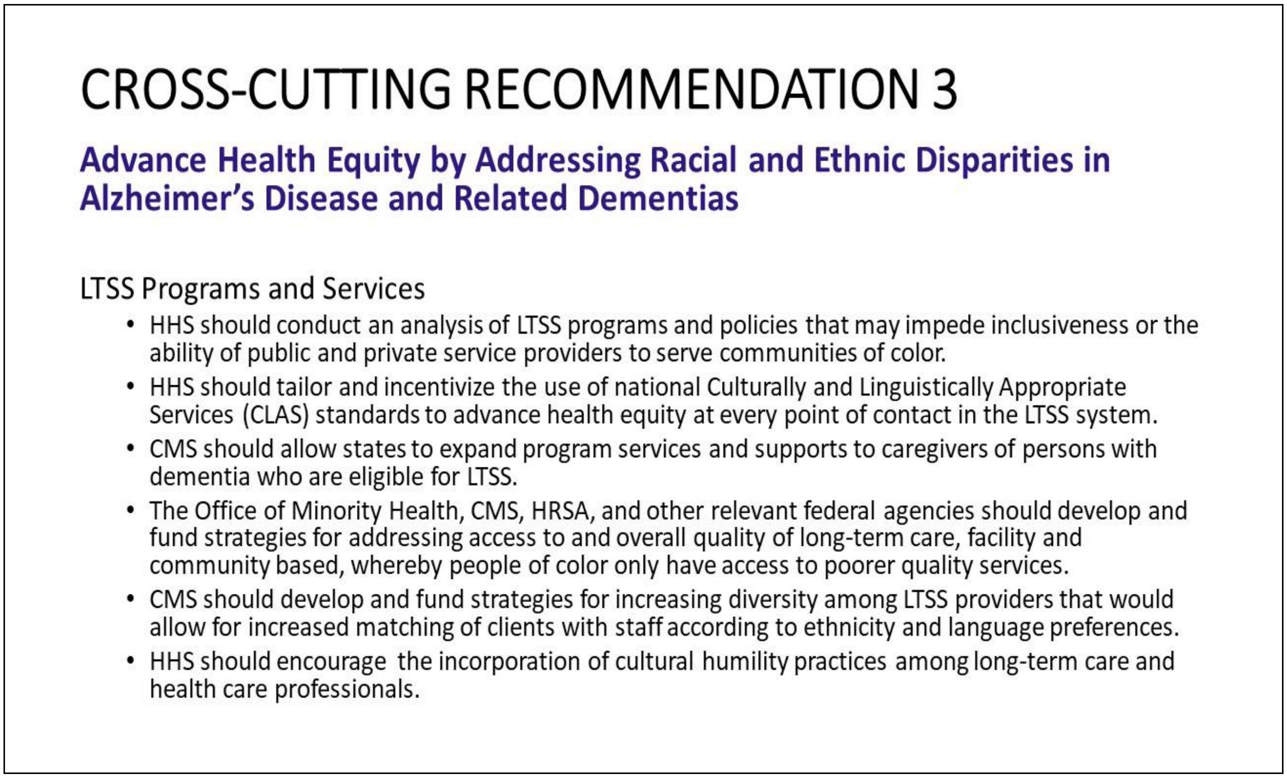


CROSS-CUTTING RECOMMENDATION 2

The Advisory Council and federal partners should develop a national goal to reduce the burden of risk factors to prevent or delay onset of Alzheimer's Disease and related dementias.

In recognition of advances in understanding risk factors, the long preclinical stages of disease, and the heterogeneity of pathologies that cause dementias, the Advisory Council recommends the following:

- Establish a subcommittee to address risk factor reduction to mitigate the public health burden of AD/ADRD, and determine specific goals, metrics, and timelines.
- HHS should review existing data on risk reduction and explore setting metrics for monitoring public health impact using a rigorous, open, transparent process.
- The existing Advisory Council subcommittees should coordinate and seek broad input from experts and individuals at risk for or with symptomatic AD/ADRD to inform the subcommittee recommendations.
- The subcommittees should identify opportunities for facilitating risk reduction across the spectrum of AD/ADRD research, clinical care, and LTSS.
- CDC should develop a National Center of Public Health Excellence on Risk Reduction to support states, political subdivisions of states, tribes and tribal organizations to translate, disseminate, and implement evidence-informed risk reduction interventions through public health infrastructure.

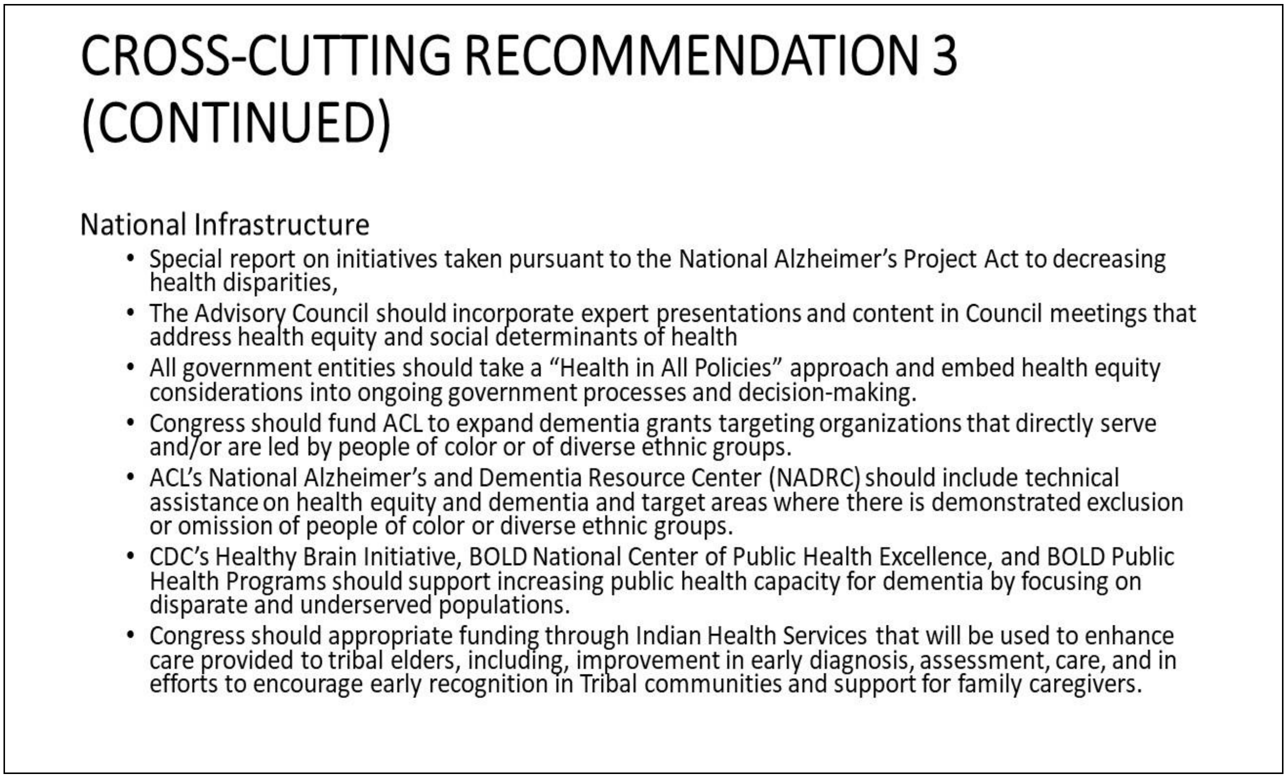


CROSS-CUTTING RECOMMENDATION 3

Advance Health Equity by Addressing Racial and Ethnic Disparities in Alzheimer's Disease and Related Dementias

LTSS Programs and Services

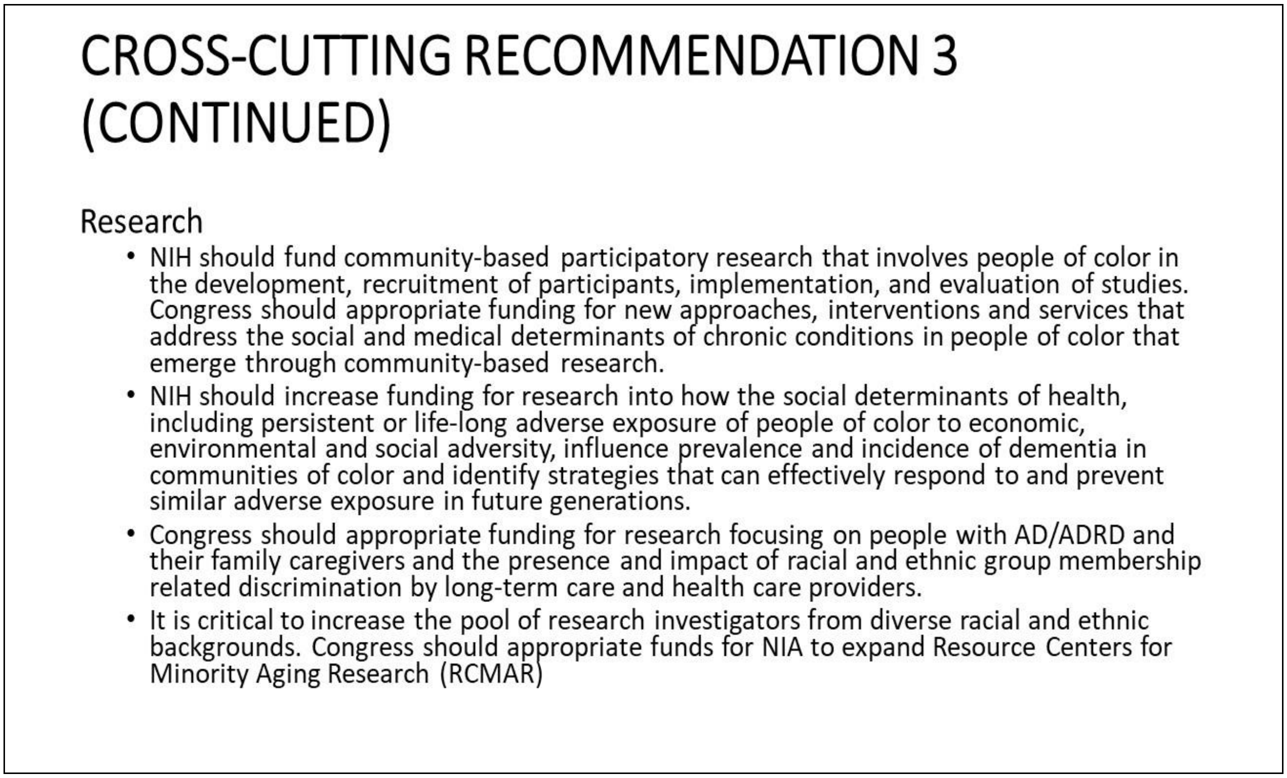
- HHS should conduct an analysis of LTSS programs and policies that may impede inclusiveness or the ability of public and private service providers to serve communities of color.
- HHS should tailor and incentivize the use of national Culturally and Linguistically Appropriate Services (CLAS) standards to advance health equity at every point of contact in the LTSS system.
- CMS should allow states to expand program services and supports to caregivers of persons with dementia who are eligible for LTSS.
- The Office of Minority Health, CMS, HRSA, and other relevant federal agencies should develop and fund strategies for addressing access to and overall quality of long-term care, facility and community based, whereby people of color only have access to poorer quality services.
- CMS should develop and fund strategies for increasing diversity among LTSS providers that would allow for increased matching of clients with staff according to ethnicity and language preferences.
- HHS should encourage the incorporation of cultural humility practices among long-term care and health care professionals.



CROSS-CUTTING RECOMMENDATION 3 (CONTINUED)

National Infrastructure

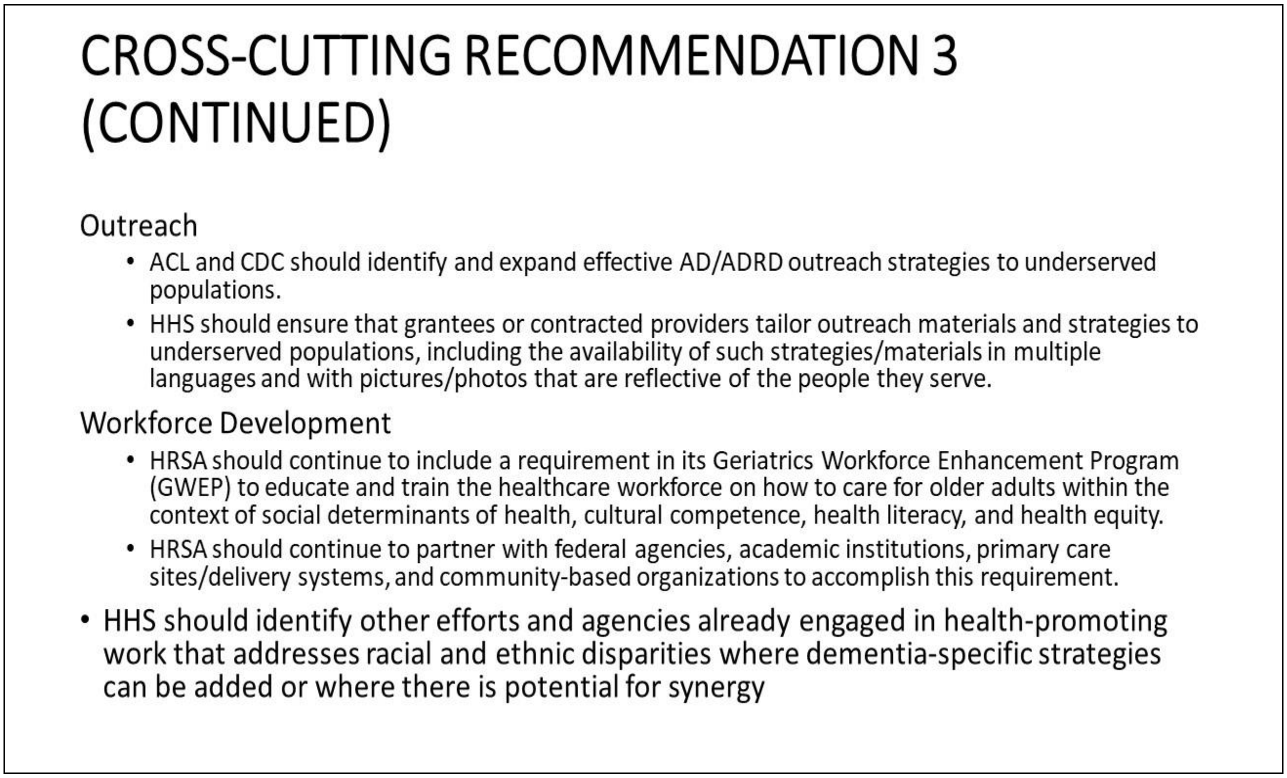
- Special report on initiatives taken pursuant to the National Alzheimer's Project Act to decreasing health disparities,
- The Advisory Council should incorporate expert presentations and content in Council meetings that address health equity and social determinants of health
- All government entities should take a "Health in All Policies" approach and embed health equity considerations into ongoing government processes and decision-making.
- Congress should fund ACL to expand dementia grants targeting organizations that directly serve and/or are led by people of color or of diverse ethnic groups.
- ACL's National Alzheimer's and Dementia Resource Center (NADRC) should include technical assistance on health equity and dementia and target areas where there is demonstrated exclusion or omission of people of color or diverse ethnic groups.
- CDC's Healthy Brain Initiative, BOLD National Center of Public Health Excellence, and BOLD Public Health Programs should support increasing public health capacity for dementia by focusing on disparate and underserved populations.
- Congress should appropriate funding through Indian Health Services that will be used to enhance care provided to tribal elders, including, improvement in early diagnosis, assessment, care, and in efforts to encourage early recognition in Tribal communities and support for family caregivers.



CROSS-CUTTING RECOMMENDATION 3 (CONTINUED)

Research

- NIH should fund community-based participatory research that involves people of color in the development, recruitment of participants, implementation, and evaluation of studies. Congress should appropriate funding for new approaches, interventions and services that address the social and medical determinants of chronic conditions in people of color that emerge through community-based research.
- NIH should increase funding for research into how the social determinants of health, including persistent or life-long adverse exposure of people of color to economic, environmental and social adversity, influence prevalence and incidence of dementia in communities of color and identify strategies that can effectively respond to and prevent similar adverse exposure in future generations.
- Congress should appropriate funding for research focusing on people with AD/ADRD and their family caregivers and the presence and impact of racial and ethnic group membership related discrimination by long-term care and health care providers.
- It is critical to increase the pool of research investigators from diverse racial and ethnic backgrounds. Congress should appropriate funds for NIA to expand Resource Centers for Minority Aging Research (RCMAR)



CROSS-CUTTING RECOMMENDATION 3 (CONTINUED)

Outreach

- ACL and CDC should identify and expand effective AD/ADRD outreach strategies to underserved populations.
- HHS should ensure that grantees or contracted providers tailor outreach materials and strategies to underserved populations, including the availability of such strategies/materials in multiple languages and with pictures/photos that are reflective of the people they serve.

Workforce Development

- HRSA should continue to include a requirement in its Geriatrics Workforce Enhancement Program (GWEP) to educate and train the healthcare workforce on how to care for older adults within the context of social determinants of health, cultural competence, health literacy, and health equity.
- HRSA should continue to partner with federal agencies, academic institutions, primary care sites/delivery systems, and community-based organizations to accomplish this requirement.

- HHS should identify other efforts and agencies already engaged in health-promoting work that addresses racial and ethnic disparities where dementia-specific strategies can be added or where there is potential for synergy

LTSS Subcommittee Recommendations 2020

Debra L. Cherry, PhD

Chair, LTSS Subcommittee

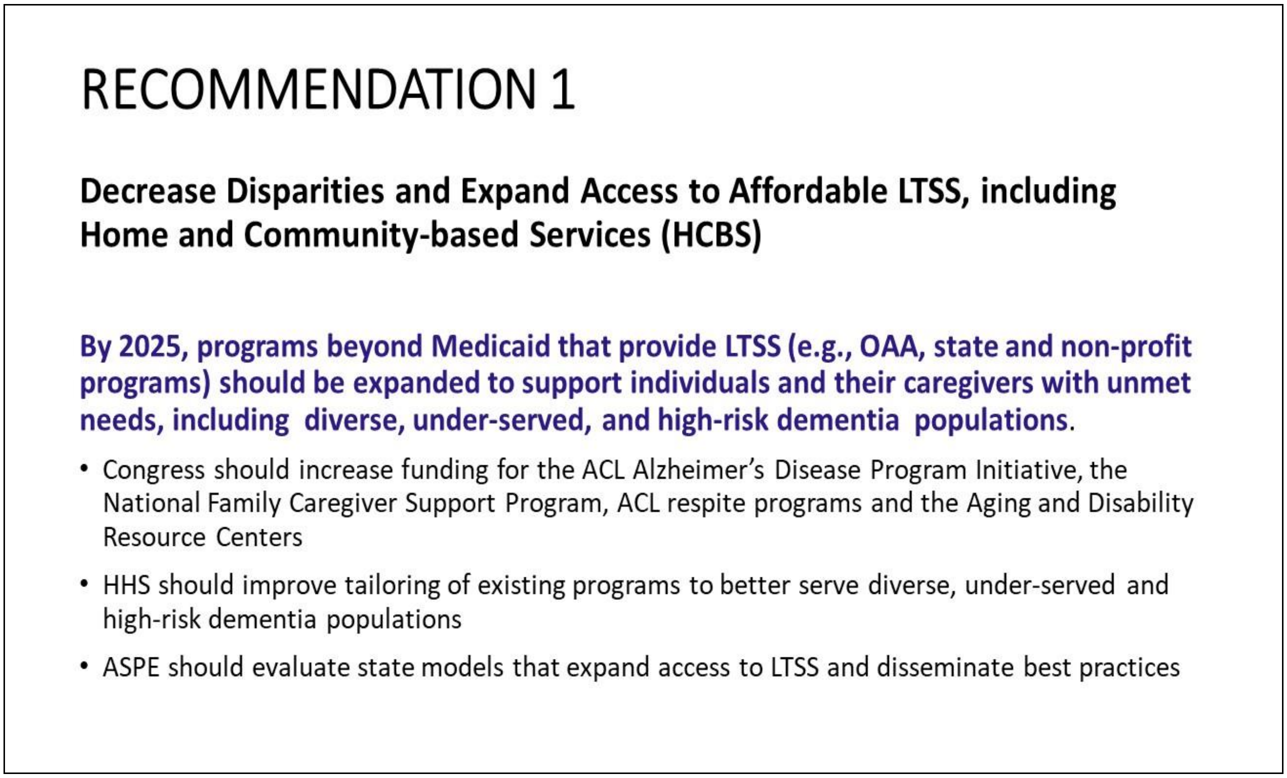
LTSS Subcommittee

Non-federal partners	**Federal partners**
Katie Brandt	Ellen Blackwell - CMS
Debra Cherry (Chair)	Elena Fazio - NIA
Robert Egge	Bruce Finke - IHS
Becky Kurtz	Melinda Kelly – NIA
Carrie Molke	Helen Lamont -- ASPE
Gloria Owens	Erin Long – ACL (Co-Chair)
Venoreen Browne-Boatswain	Lisa McGuire - CDC
María de los Ángeles Ordóñez	Joan Weiss - HRSA
Matthew Janicki	

Themes

- Decrease disparities and expand access to LTSS, including home and community-based services (HCBS)
- Improve integration of clinical care with HCBS including systematic identification, assessment, support, and engagement of persons living with ADRD and their caregivers* by health care systems
- Provide high quality, person- and family-centered LTSS
- Address behavioral and psychological symptoms of ADRD across care settings
- Prepare the nation to reduce risk factors thought to lead to ADRD

*All references to "caregivers" apply to care partners, families, friends, and others with a significant relationship providing assistance to people living with ADRD.

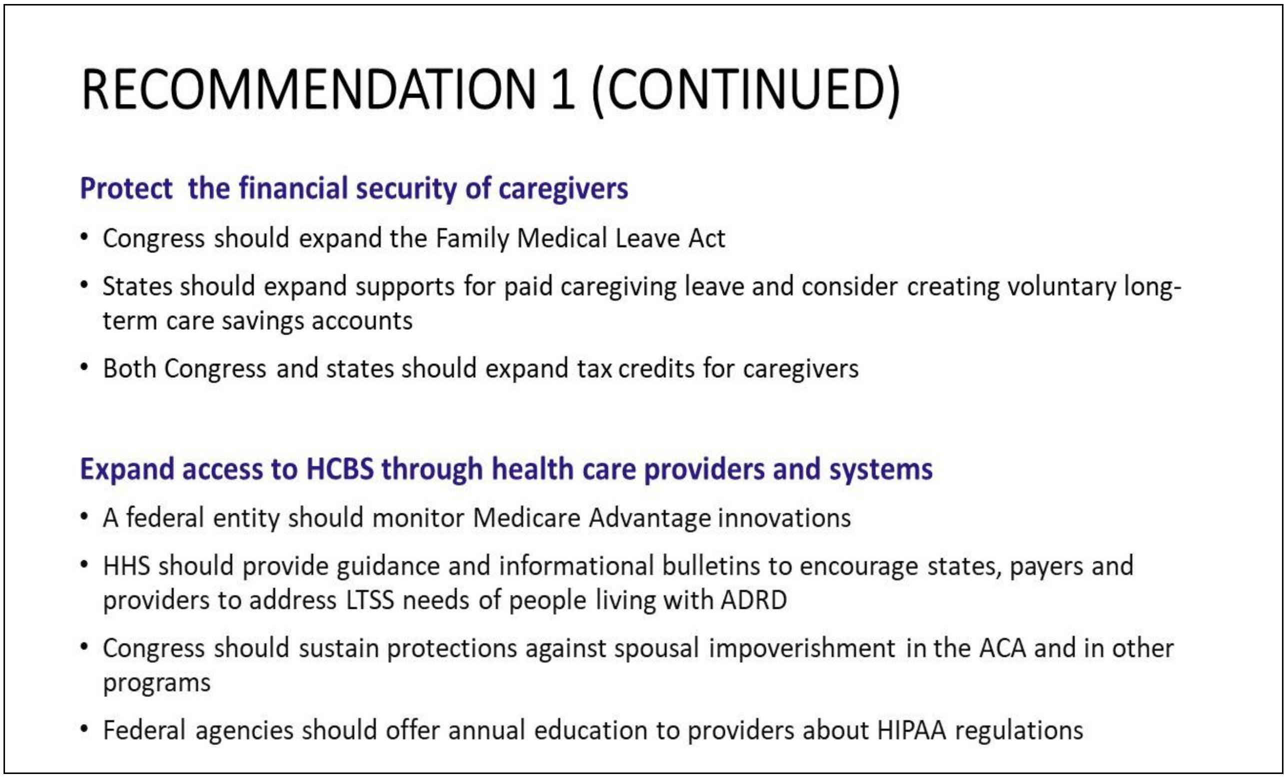


RECOMMENDATION 1

Decrease Disparities and Expand Access to Affordable LTSS, including Home and Community-based Services (HCBS)

By 2025, programs beyond Medicaid that provide LTSS (e.g., OAA, state and non-profit programs) should be expanded to support individuals and their caregivers with unmet needs, including diverse, under-served, and high-risk dementia populations.

- Congress should increase funding for the ACL Alzheimer's Disease Program Initiative, the National Family Caregiver Support Program, ACL respite programs and the Aging and Disability Resource Centers
- HHS should improve tailoring of existing programs to better serve diverse, under-served and high-risk dementia populations
- ASPE should evaluate state models that expand access to LTSS and disseminate best practices



RECOMMENDATION 1 (CONTINUED)

Protect the financial security of caregivers

- Congress should expand the Family Medical Leave Act
- States should expand supports for paid caregiving leave and consider creating voluntary long-term care savings accounts
- Both Congress and states should expand tax credits for caregivers

Expand access to HCBS through health care providers and systems

- A federal entity should monitor Medicare Advantage innovations
- HHS should provide guidance and informational bulletins to encourage states, payers and providers to address LTSS needs of people living with ADRD
- Congress should sustain protections against spousal impoverishment in the ACA and in other programs
- Federal agencies should offer annual education to providers about HIPAA regulations

RECOMMENDATION 2

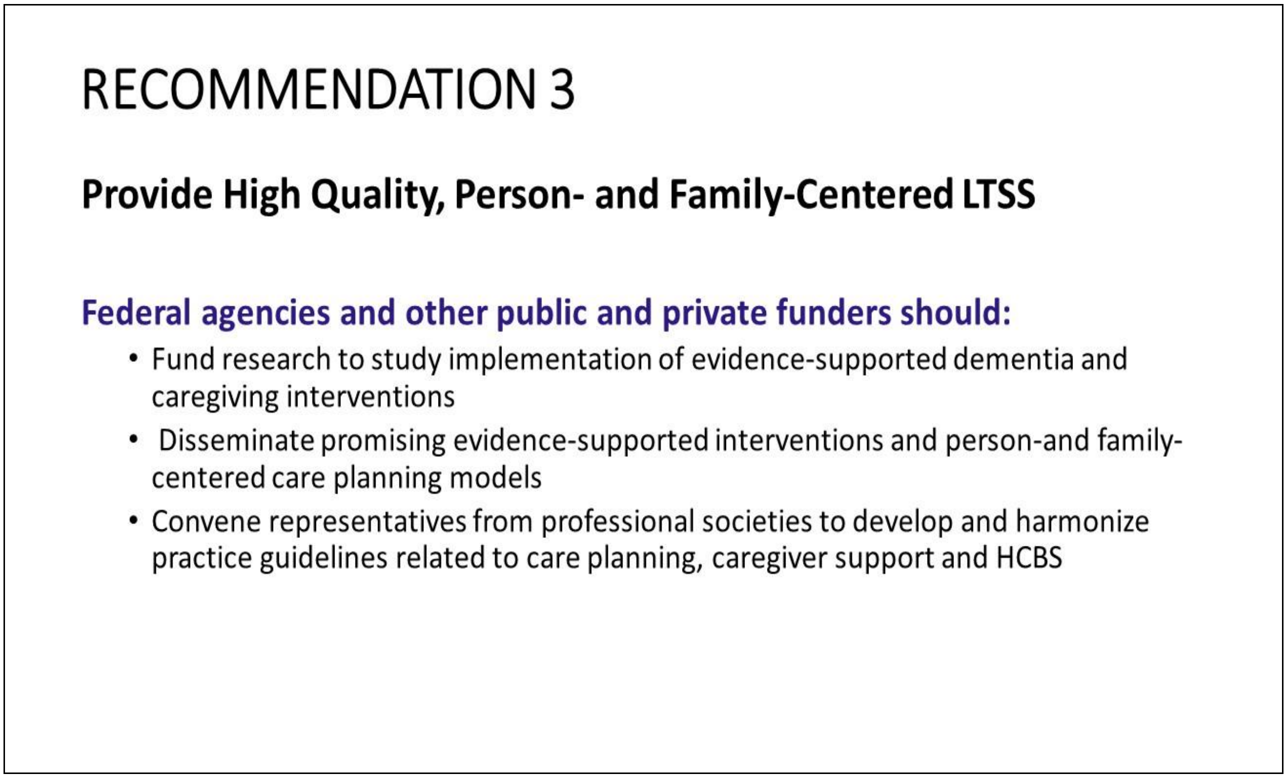
Improve Integration of Clinical Care with HCBS

- **By 2025, 20% of hospitals and primary care practices serving people living with AD/ADRD will have in place procedures to:**
    - Identify cognitive impairment and integrate management of cognitive impairment into the care plan
    - Provide a timely diagnosis for individuals who are found to have impairment, through efficient and well coordinated care pathways and referral processes
    - Identify and document a caregiver or authorized health care proxy, where applicable, to delineate and document the individual's goals of care and better assure goal implementation
    - Co-design person- and family-centered care plans with the individual and caregiver or authorized health care proxy (where appropriate), so that plans are concordant with the individuals' goals of care and can be supported in the community or other LTC setting

RECOMMENDATION 2 (CONTINUED)

- **By 2025, 20% of hospitals and primary care practices serving people living with AD/ADRD will have in place procedures to:**
    - Involve the individual living with ADRD and a caregiver or authorized health care proxy when undertaking discharge planning from a facility so as to lessen risk of re-hospitalization or other adverse events
    - Assess the person living with ADRD and the caregiver's LTSS needs, provide them with disease education, caregiver training and HCBS, and/or refer them to community-based services.

- **By 2025, CMS will have quality measures in place that will encourage health care systems (health plans) to implement these recommendations.**

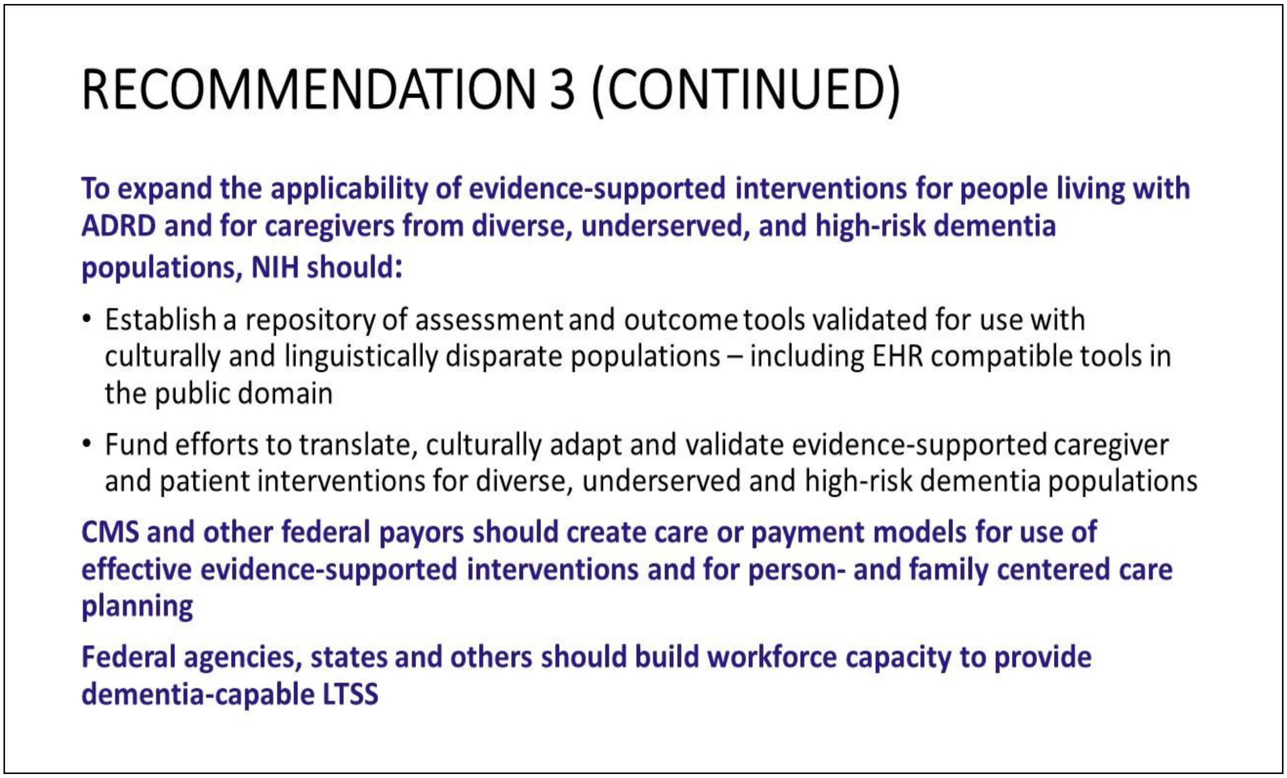


RECOMMENDATION 3

Provide High Quality, Person- and Family-Centered LTSS

Federal agencies and other public and private funders should:

- Fund research to study implementation of evidence-supported dementia and caregiving interventions
- Disseminate promising evidence-supported interventions and person-and family-centered care planning models
- Convene representatives from professional societies to develop and harmonize practice guidelines related to care planning, caregiver support and HCBS



RECOMMENDATION 3 (CONTINUED)

To expand the applicability of evidence-supported interventions for people living with ADRD and for caregivers from diverse, underserved, and high-risk dementia populations, NIH should:

- Establish a repository of assessment and outcome tools validated for use with culturally and linguistically disparate populations – including EHR compatible tools in the public domain
- Fund efforts to translate, culturally adapt and validate evidence-supported caregiver and patient interventions for diverse, underserved and high-risk dementia populations

CMS and other federal payors should create care or payment models for use of effective evidence-supported interventions and for person- and family centered care planning

Federal agencies, states and others should build workforce capacity to provide dementia-capable LTSS

RECOMMENDATION 4

Address Behavioral and Psychological Symptoms of ADRD Across Care Settings

Federal agencies and other organizations should build workforce capacity to:

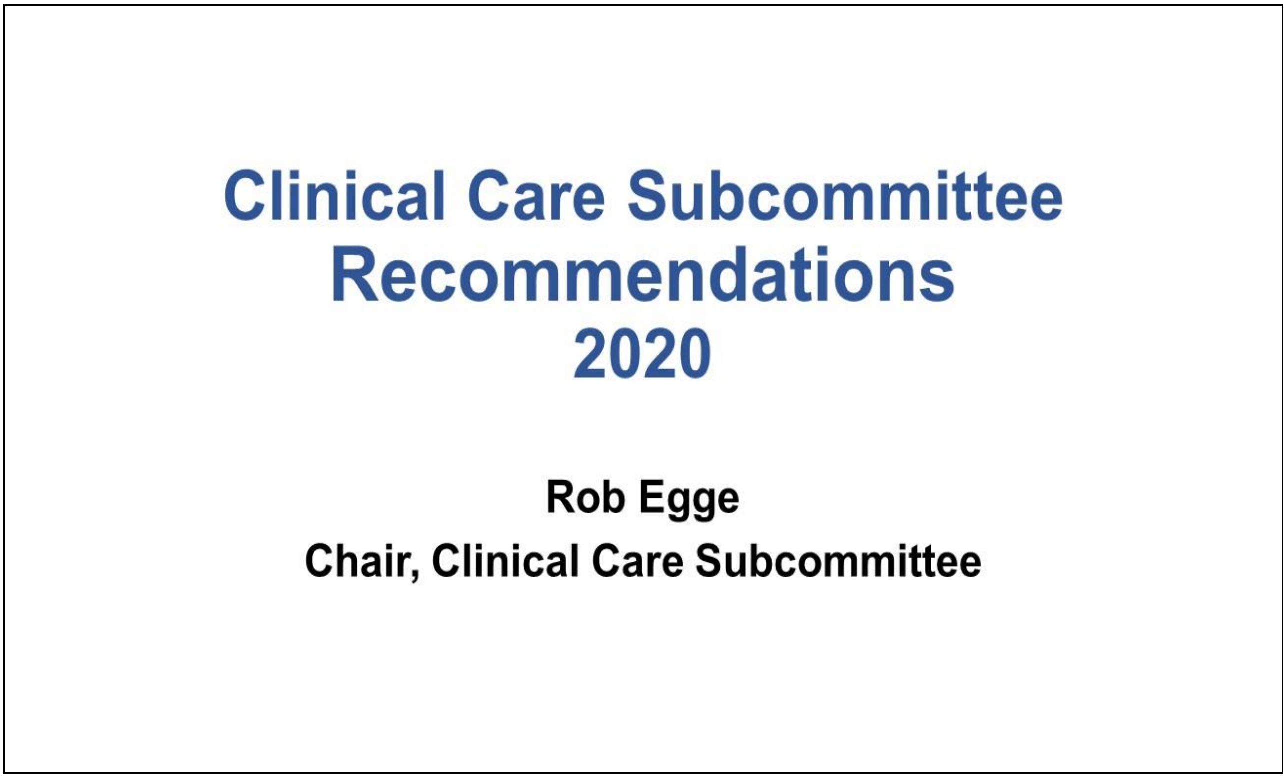
- **deliver person-centered care**
- **use promising and/or evidence-informed, non-pharmacological interventions for BPSD**

RECOMMENDATION 5

Advance Brain Health through Development and Enhancement of the Public Health and Health Care Workforces

To help reduce the prevalence of ADRD, it is recommended that Federal agencies and other organizations educate the general public, people living with ADRD, their caregivers and the workforce about evidence informed strategies for potentially reducing risk for cognitive impairment

- Increase awareness of the general public about brain health
- Educate workforces about ways to reduce risk for cognitive impairment



Clinical Care Subcommittee Recommendations

2020

Rob Egge

Chair, Clinical Care Subcommittee

Clinical Care Sub-Committee

<u>Non-federal partners</u>

Katie Brandt
Cynthia Carlsson
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Brad Hyman
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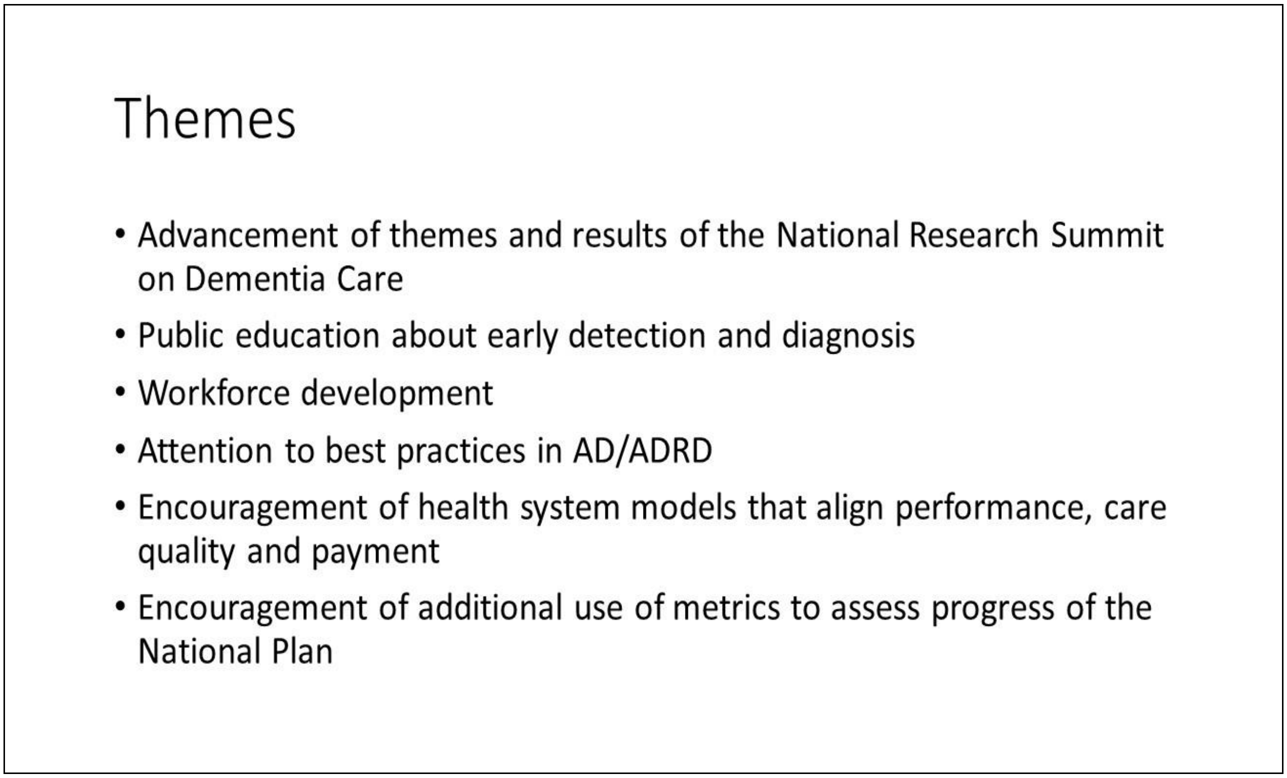
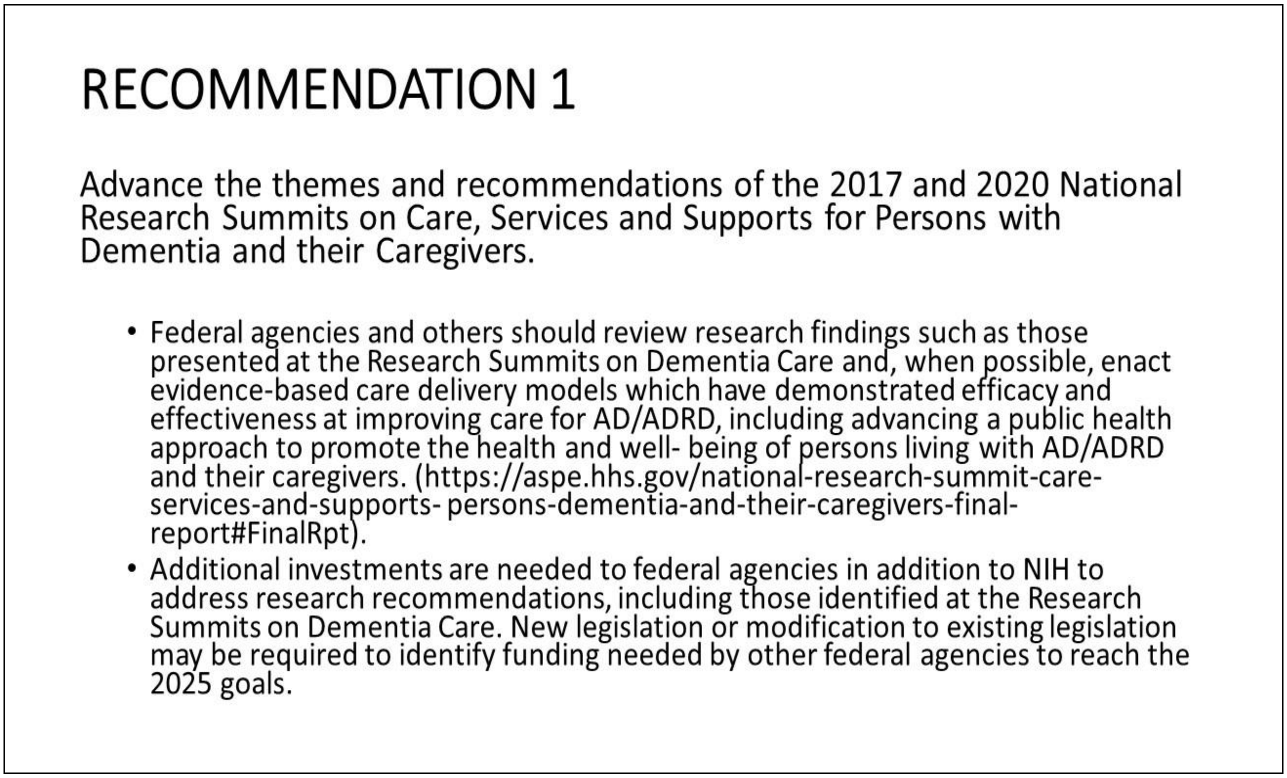
Arlene Bierman - AHRQ
Ellen Blackwell - CMS
Bruce Finke – IHS
Melinda Kelly – NIA
Shari Ling - CMS
Joan Weiss – HRSA



Themes

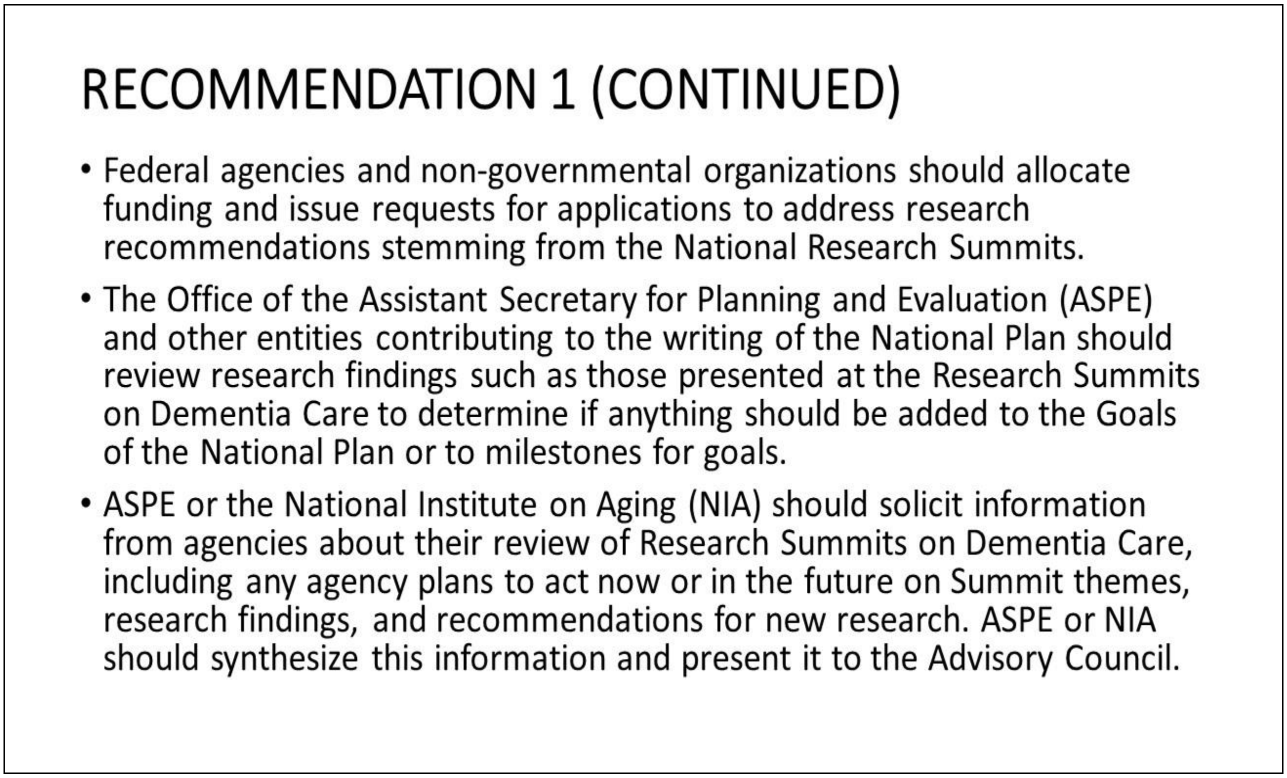
- Advancement of themes and results of the National Research Summit on Dementia Care
- Public education about early detection and diagnosis
- Workforce development
- Attention to best practices in AD/ADRD
- Encouragement of health system models that align performance, care quality and payment
- Encouragement of additional use of metrics to assess progress of the National Plan



RECOMMENDATION 1

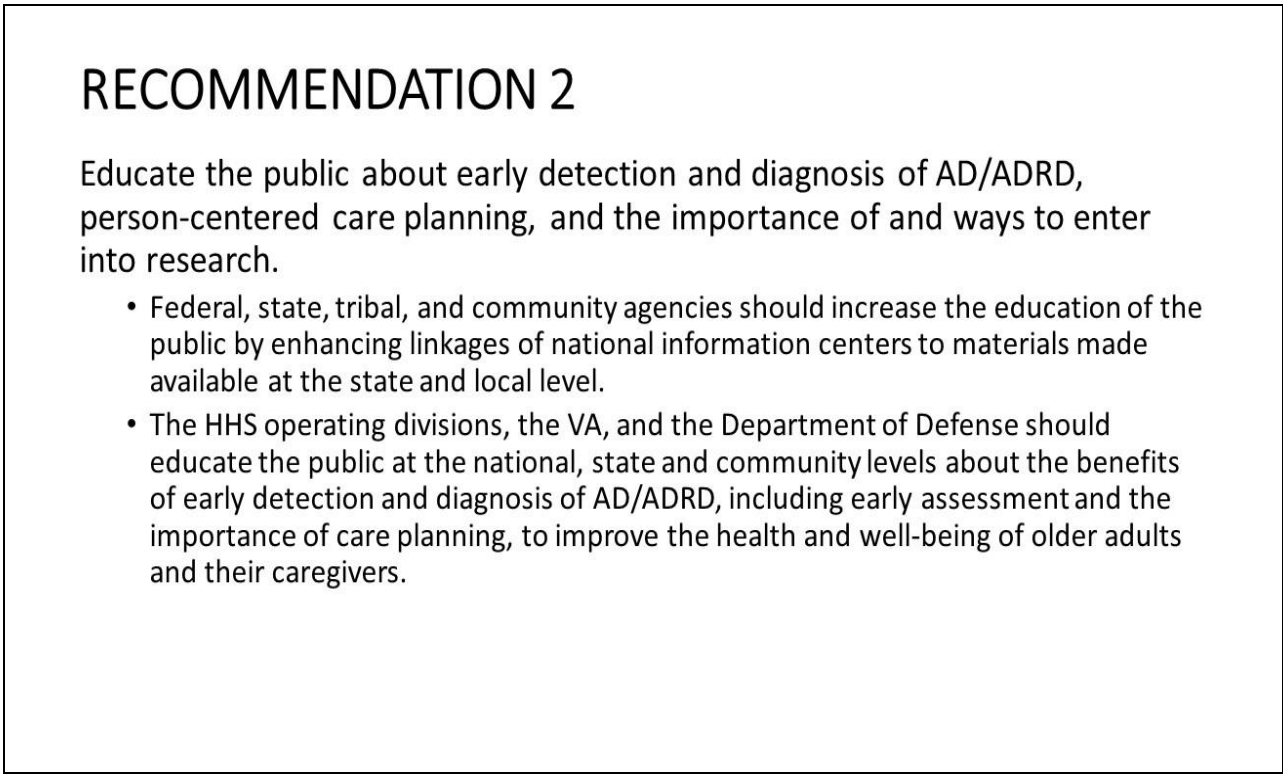
Advance the themes and recommendations of the 2017 and 2020 National Research Summits on Care, Services and Supports for Persons with Dementia and their Caregivers.

- Federal agencies and others should review research findings such as those presented at the Research Summits on Dementia Care and, when possible, enact evidence-based care delivery models which have demonstrated efficacy and effectiveness at improving care for AD/ADRD, including advancing a public health approach to promote the health and well- being of persons living with AD/ADRD and their caregivers. (https://aspe.hhs.gov/national-research-summit-care-services-and-supports- persons-dementia-and-their-caregivers-final-report#FinalRpt).
- Additional investments are needed to federal agencies in addition to NIH to address research recommendations, including those identified at the Research Summits on Dementia Care. New legislation or modification to existing legislation may be required to identify funding needed by other federal agencies to reach the 2025 goals.



RECOMMENDATION 1 (CONTINUED)

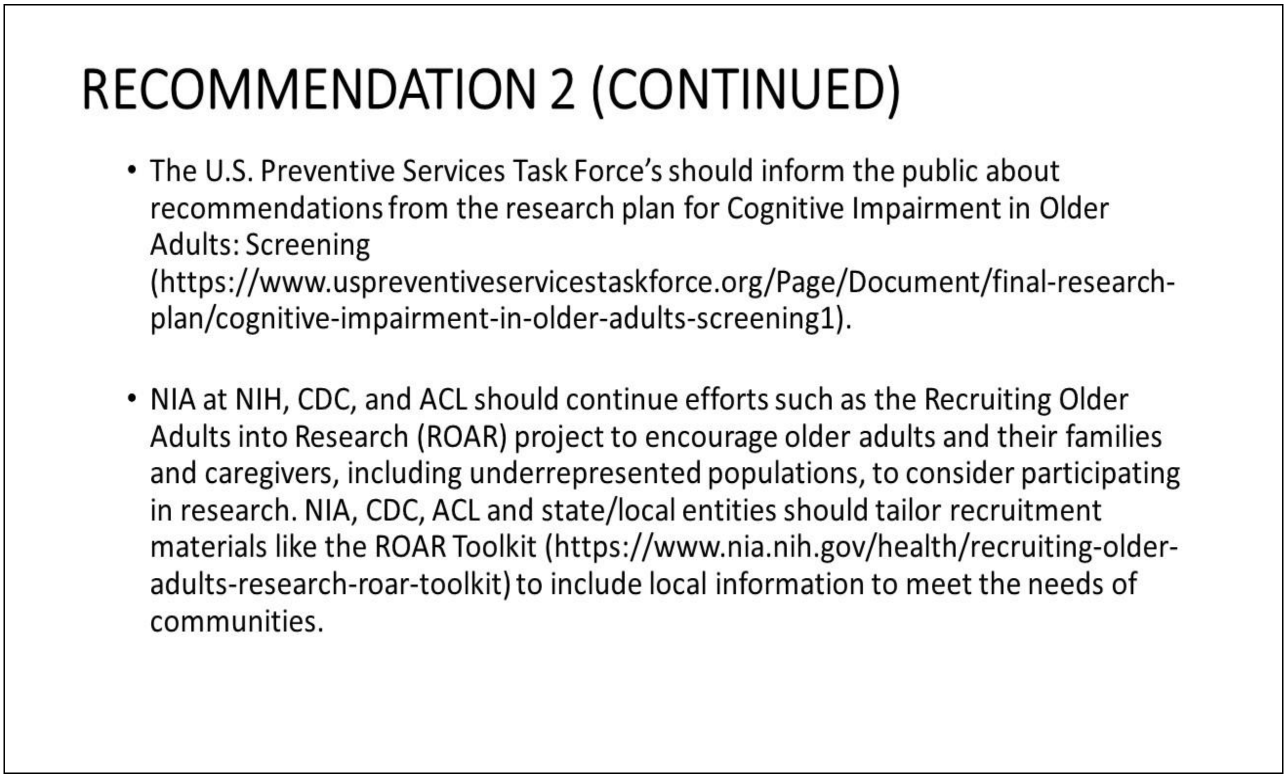
- Federal agencies and non-governmental organizations should allocate funding and issue requests for applications to address research recommendations stemming from the National Research Summits.
- The Office of the Assistant Secretary for Planning and Evaluation (ASPE) and other entities contributing to the writing of the National Plan should review research findings such as those presented at the Research Summits on Dementia Care to determine if anything should be added to the Goals of the National Plan or to milestones for goals.
- ASPE or the National Institute on Aging (NIA) should solicit information from agencies about their review of Research Summits on Dementia Care, including any agency plans to act now or in the future on Summit themes, research findings, and recommendations for new research. ASPE or NIA should synthesize this information and present it to the Advisory Council.



RECOMMENDATION 2

Educate the public about early detection and diagnosis of AD/ADRD, person-centered care planning, and the importance of and ways to enter into research.

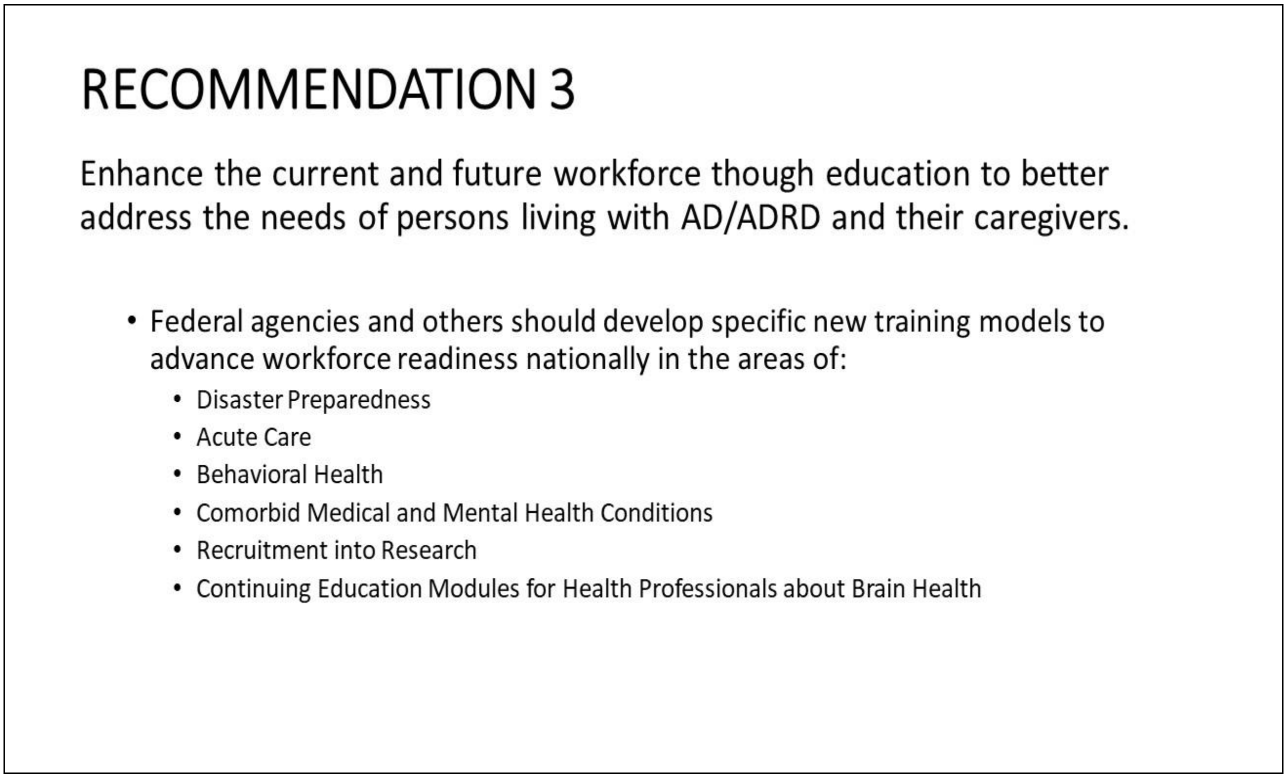
- Federal, state, tribal, and community agencies should increase the education of the public by enhancing linkages of national information centers to materials made available at the state and local level.
- The HHS operating divisions, the VA, and the Department of Defense should educate the public at the national, state and community levels about the benefits of early detection and diagnosis of AD/ADRD, including early assessment and the importance of care planning, to improve the health and well-being of older adults and their caregivers.



RECOMMENDATION 2 (CONTINUED)

- The U.S. Preventive Services Task Force’s should inform the public about recommendations from the research plan for Cognitive Impairment in Older Adults: Screening (https://www.uspreventiveservicestaskforce.org/Page/Document/final-research-plan/cognitive-impairment-in-older-adults-screening1).

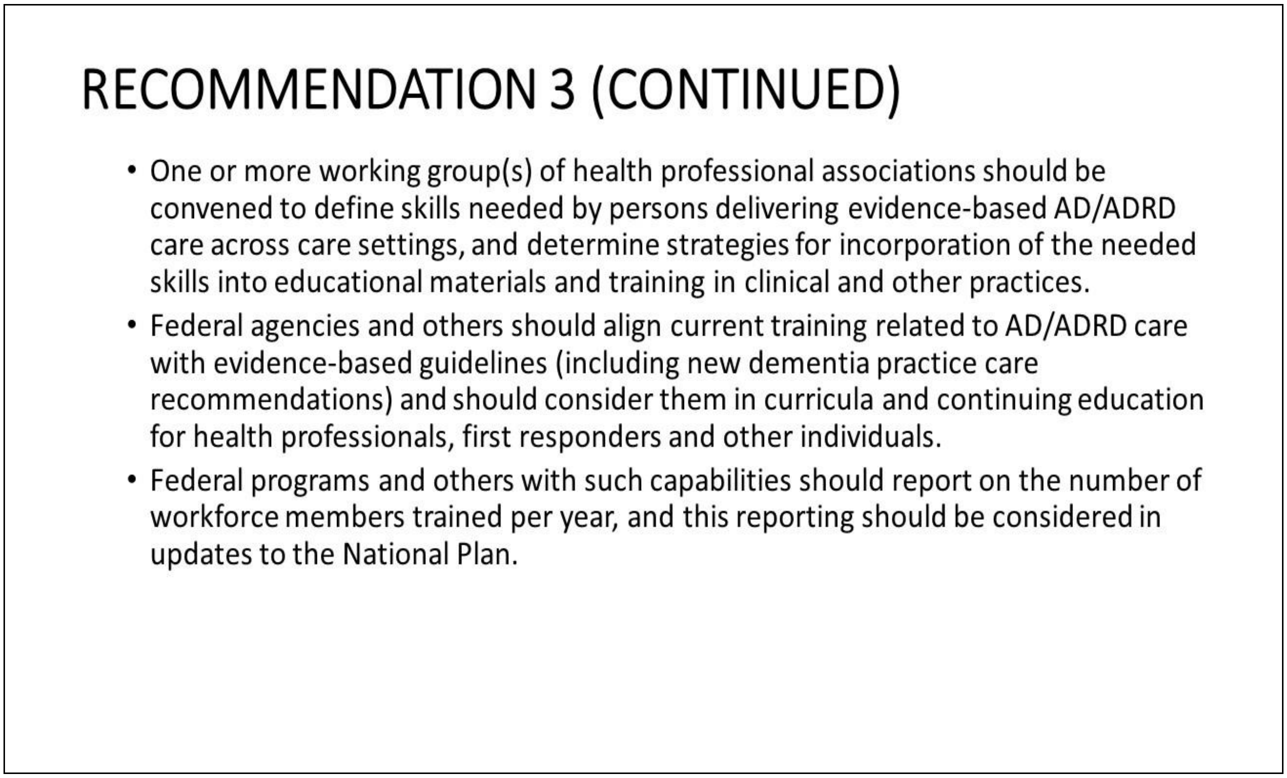
- NIA at NIH, CDC, and ACL should continue efforts such as the Recruiting Older Adults into Research (ROAR) project to encourage older adults and their families and caregivers, including underrepresented populations, to consider participating in research. NIA, CDC, ACL and state/local entities should tailor recruitment materials like the ROAR Toolkit (https://www.nia.nih.gov/health/recruiting-older-adults-research-roar-toolkit) to include local information to meet the needs of communities.



RECOMMENDATION 3

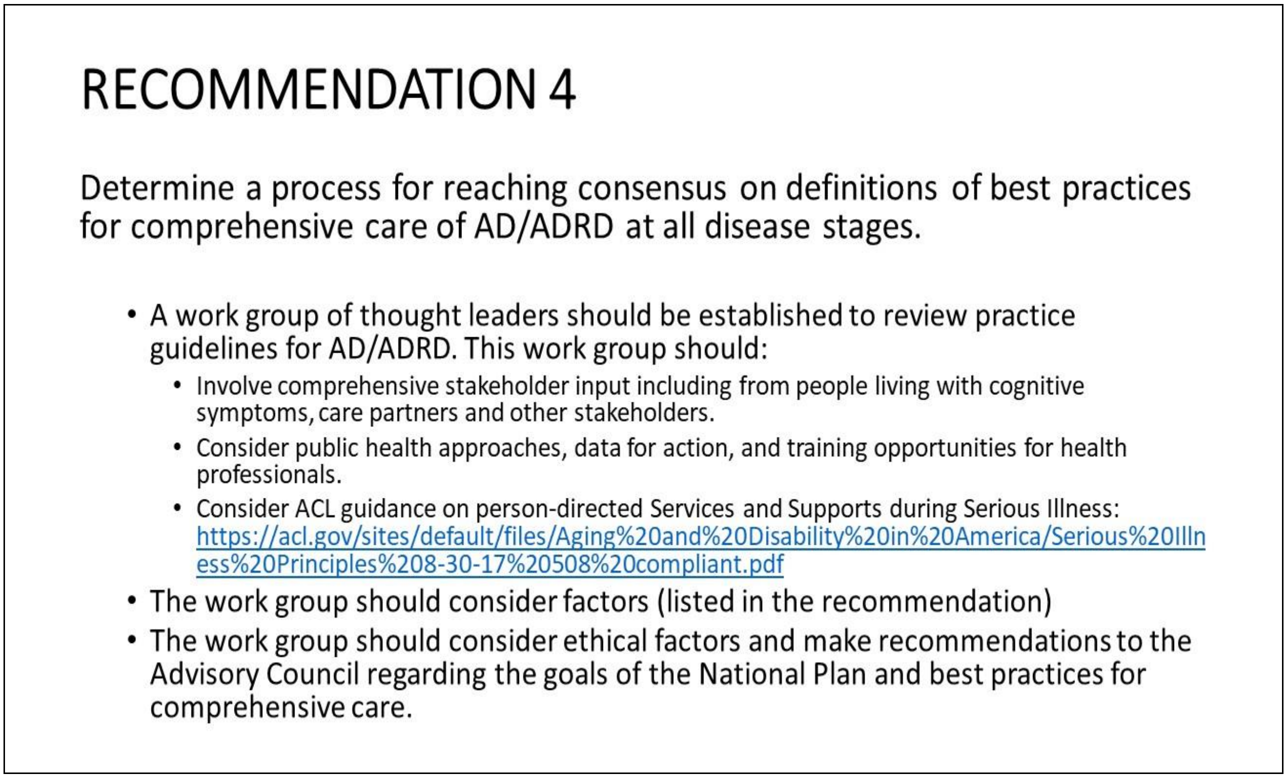
Enhance the current and future workforce though education to better address the needs of persons living with AD/ADRD and their caregivers.

- Federal agencies and others should develop specific new training models to advance workforce readiness nationally in the areas of:
  - Disaster Preparedness
  - Acute Care
  - Behavioral Health
  - Comorbid Medical and Mental Health Conditions
  - Recruitment into Research
  - Continuing Education Modules for Health Professionals about Brain Health



RECOMMENDATION 3 (CONTINUED)

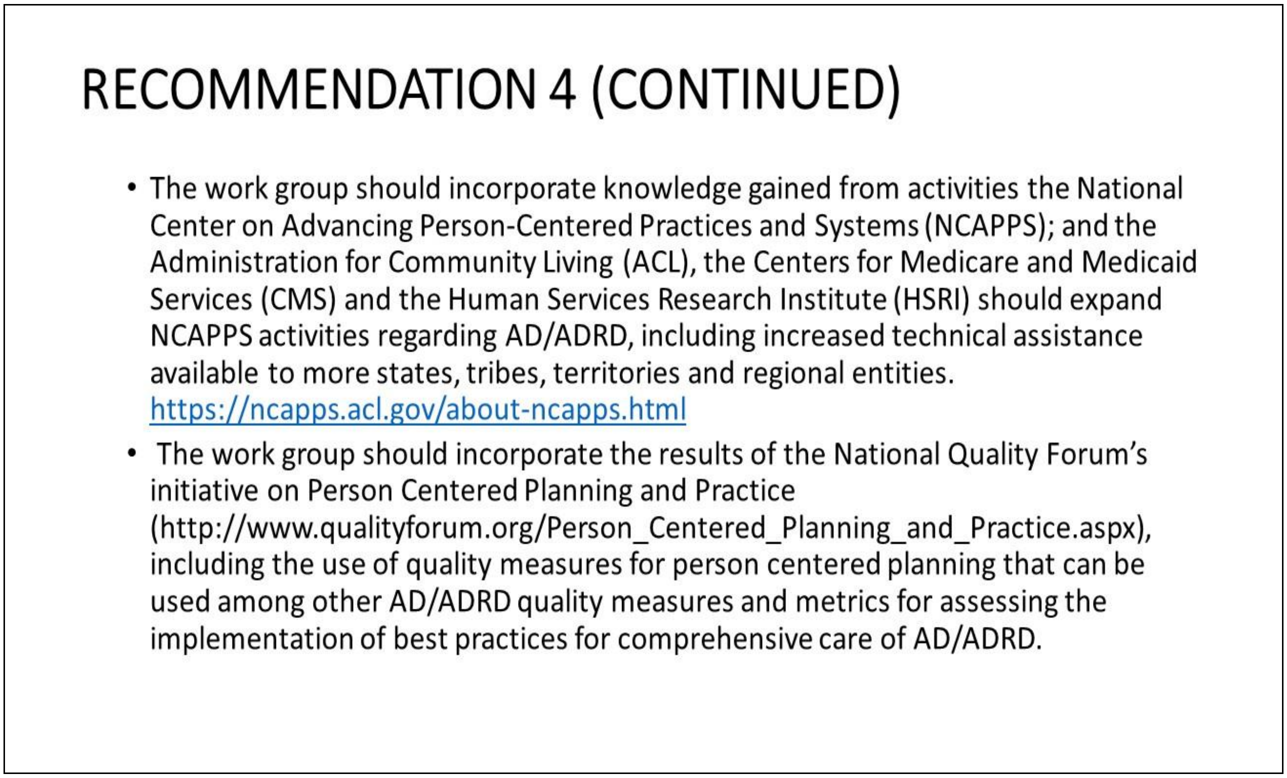
- One or more working group(s) of health professional associations should be convened to define skills needed by persons delivering evidence-based AD/ADRD care across care settings, and determine strategies for incorporation of the needed skills into educational materials and training in clinical and other practices.
- Federal agencies and others should align current training related to AD/ADRD care with evidence-based guidelines (including new dementia practice care recommendations) and should consider them in curricula and continuing education for health professionals, first responders and other individuals.
- Federal programs and others with such capabilities should report on the number of workforce members trained per year, and this reporting should be considered in updates to the National Plan.



RECOMMENDATION 4

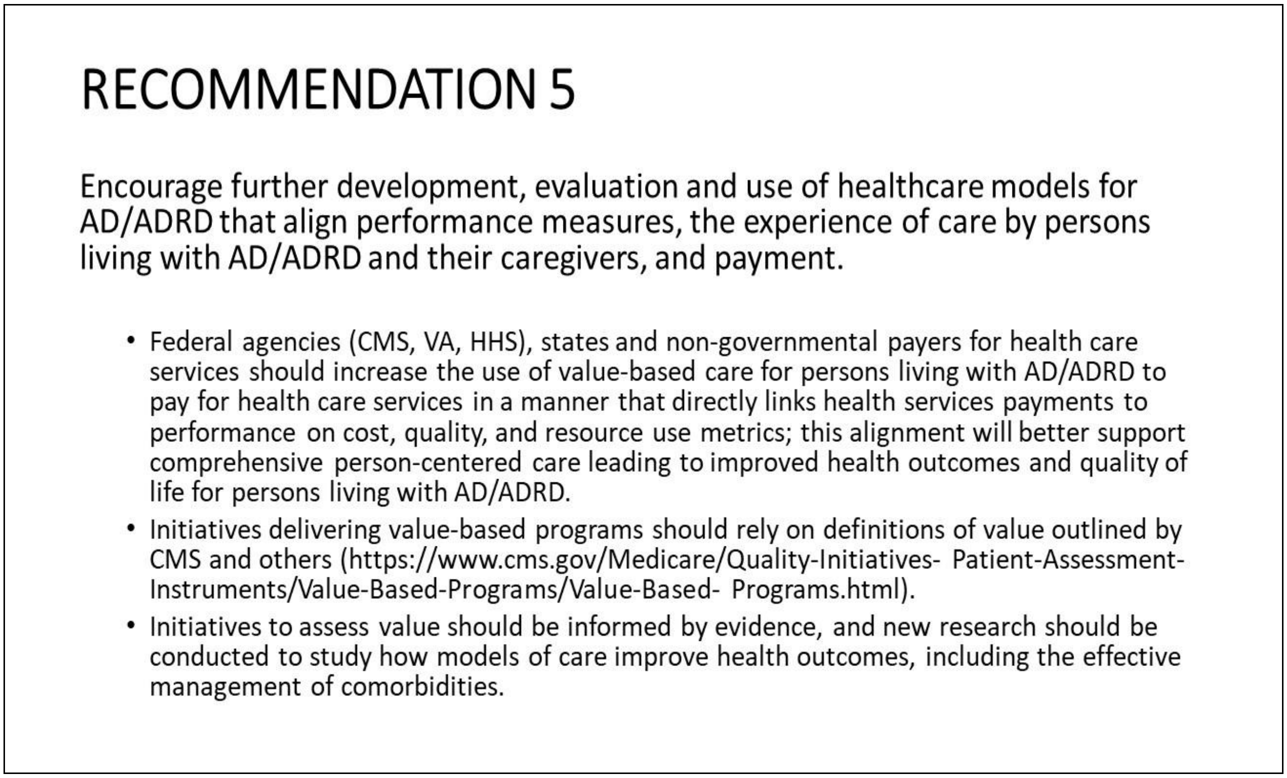
Determine a process for reaching consensus on definitions of best practices for comprehensive care of AD/ADRD at all disease stages.

- A work group of thought leaders should be established to review practice guidelines for AD/ADRD. This work group should:
  - Involve comprehensive stakeholder input including from people living with cognitive symptoms, care partners and other stakeholders.
  - Consider public health approaches, data for action, and training opportunities for health professionals.
  - Consider ACL guidance on person-directed Services and Supports during Serious Illness: https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/Serious%20Illness%20Principles%208-30-17%20508%20compliant.pdf
- The work group should consider factors (listed in the recommendation)
- The work group should consider ethical factors and make recommendations to the Advisory Council regarding the goals of the National Plan and best practices for comprehensive care.



RECOMMENDATION 4 (CONTINUED)

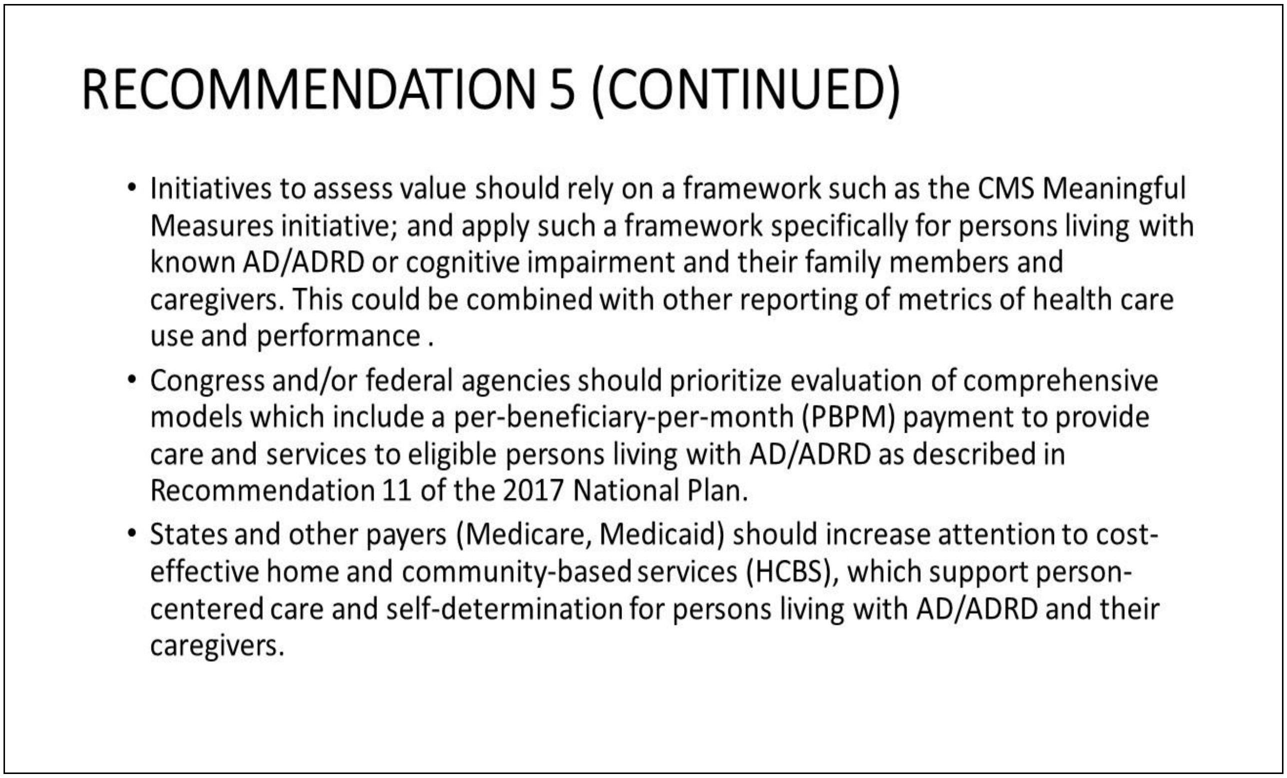
- The work group should incorporate knowledge gained from activities the National Center on Advancing Person-Centered Practices and Systems (NCAPPS); and the Administration for Community Living (ACL), the Centers for Medicare and Medicaid Services (CMS) and the Human Services Research Institute (HSRI) should expand NCAPPS activities regarding AD/ADRD, including increased technical assistance available to more states, tribes, territories and regional entities. https://ncapps.acl.gov/about-ncapps.html
- The work group should incorporate the results of the National Quality Forum's initiative on Person Centered Planning and Practice (http://www.qualityforum.org/Person_Centered_Planning_and_Practice.aspx), including the use of quality measures for person centered planning that can be used among other AD/ADRD quality measures and metrics for assessing the implementation of best practices for comprehensive care of AD/ADRD.



RECOMMENDATION 5

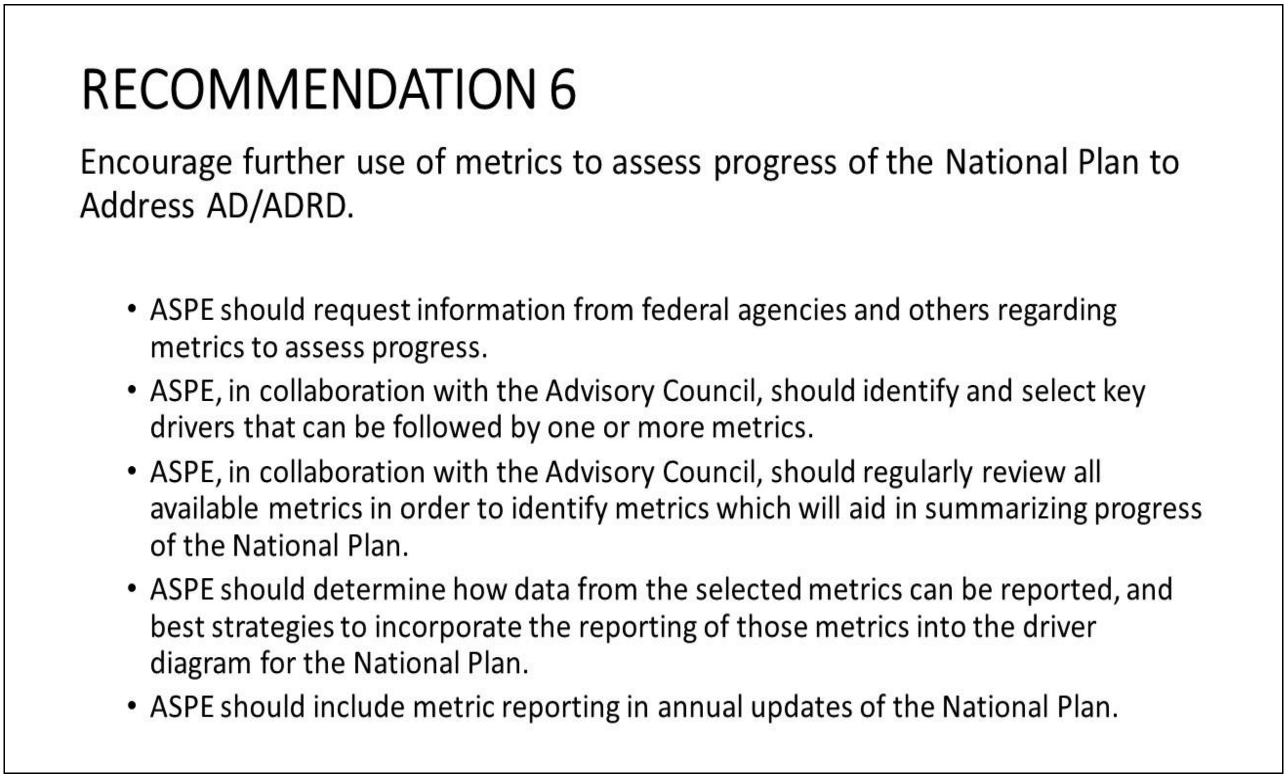
Encourage further development, evaluation and use of healthcare models for AD/ADRD that align performance measures, the experience of care by persons living with AD/ADRD and their caregivers, and payment.

- Federal agencies (CMS, VA, HHS), states and non-governmental payers for health care services should increase the use of value-based care for persons living with AD/ADRD to pay for health care services in a manner that directly links health services payments to performance on cost, quality, and resource use metrics; this alignment will better support comprehensive person-centered care leading to improved health outcomes and quality of life for persons living with AD/ADRD.
- Initiatives delivering value-based programs should rely on definitions of value outlined by CMS and others (https://www.cms.gov/Medicare/Quality-Initiatives- Patient-Assessment-Instruments/Value-Based-Programs/Value-Based- Programs.html).
- Initiatives to assess value should be informed by evidence, and new research should be conducted to study how models of care improve health outcomes, including the effective management of comorbidities.



RECOMMENDATION 5 (CONTINUED)

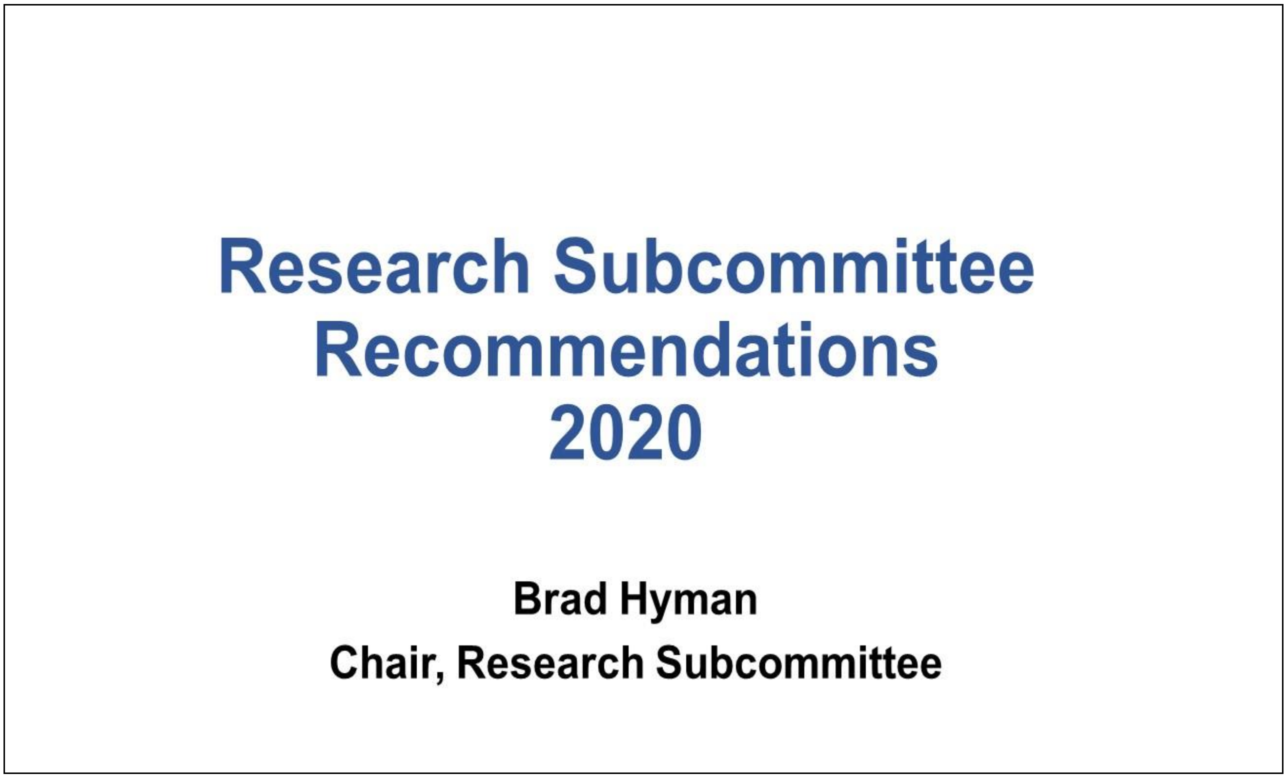
- Initiatives to assess value should rely on a framework such as the CMS Meaningful Measures initiative; and apply such a framework specifically for persons living with known AD/ADRD or cognitive impairment and their family members and caregivers. This could be combined with other reporting of metrics of health care use and performance .
- Congress and/or federal agencies should prioritize evaluation of comprehensive models which include a per-beneficiary-per-month (PBPM) payment to provide care and services to eligible persons living with AD/ADRD as described in Recommendation 11 of the 2017 National Plan.
- States and other payers (Medicare, Medicaid) should increase attention to cost-effective home and community-based services (HCBS), which support person-centered care and self-determination for persons living with AD/ADRD and their caregivers.



RECOMMENDATION 6

Encourage further use of metrics to assess progress of the National Plan to Address AD/ADRD.

- ASPE should request information from federal agencies and others regarding metrics to assess progress.
- ASPE, in collaboration with the Advisory Council, should identify and select key drivers that can be followed by one or more metrics.
- ASPE, in collaboration with the Advisory Council, should regularly review all available metrics in order to identify metrics which will aid in summarizing progress of the National Plan.
- ASPE should determine how data from the selected metrics can be reported, and best strategies to incorporate the reporting of those metrics into the driver diagram for the National Plan.
- ASPE should include metric reporting in annual updates of the National Plan.



Research Subcommittee Recommendations
2020

Brad Hyman
Chair, Research Subcommittee

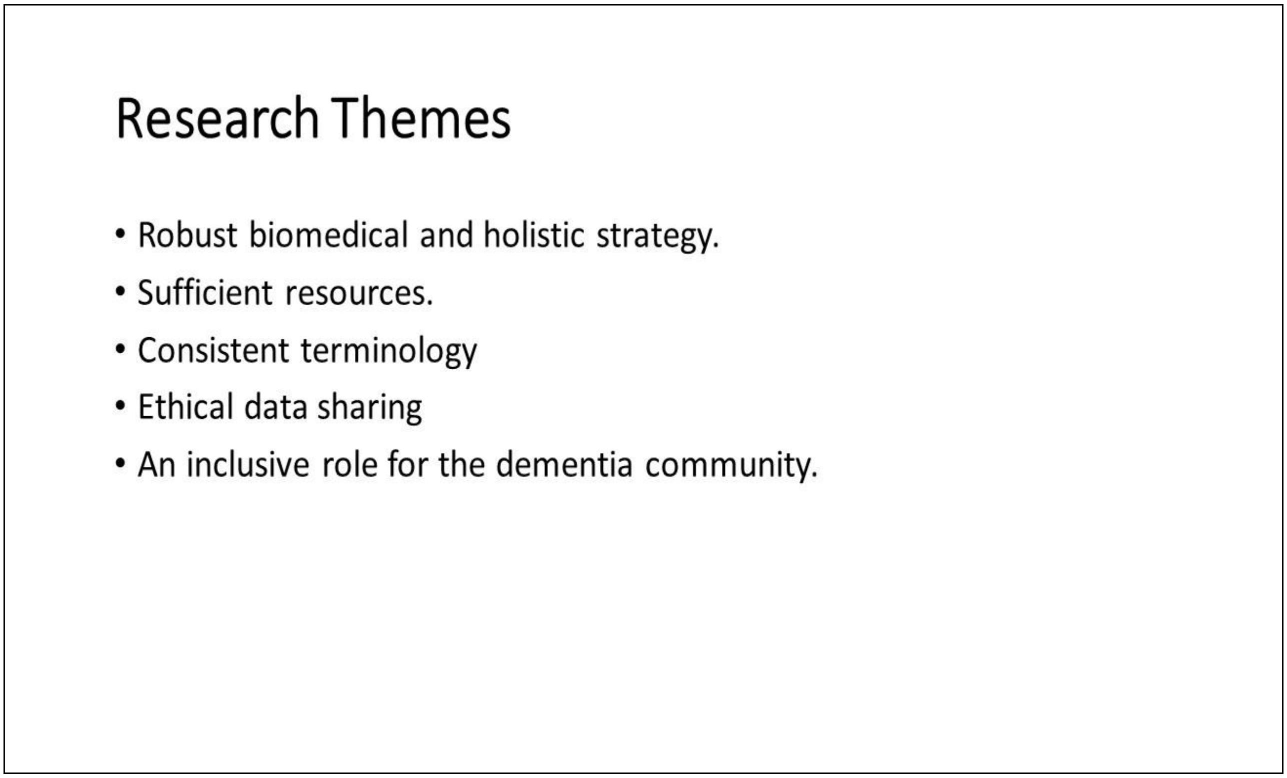
Research Sub-Committee

Non-federal partners

- Cynthia Carlsson
- Robert Egge
- Brad Hyman (Chair)
- Allan Levey
- Maria Ordonez

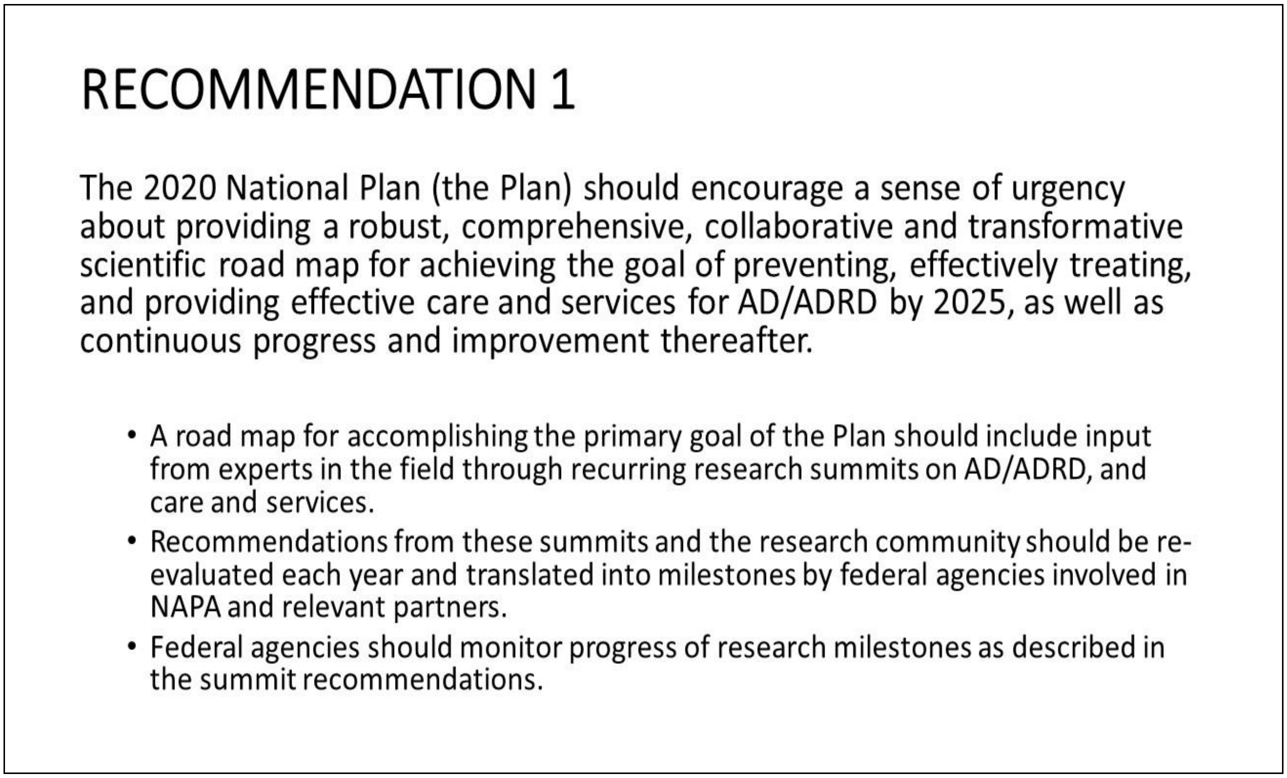
Federal partners

- Marie Bernard - NIA
- Ellen Blackwell - CMS
- Rod Corriveau - NINDS
- Richard Hodes - NIA
- Melinda Kelly – NIA
- Walter Koroshetz - NINDS
- Shari Ling - CMS
- Erin Long - ACL
- Lisa McGuire - CDC



Research Themes

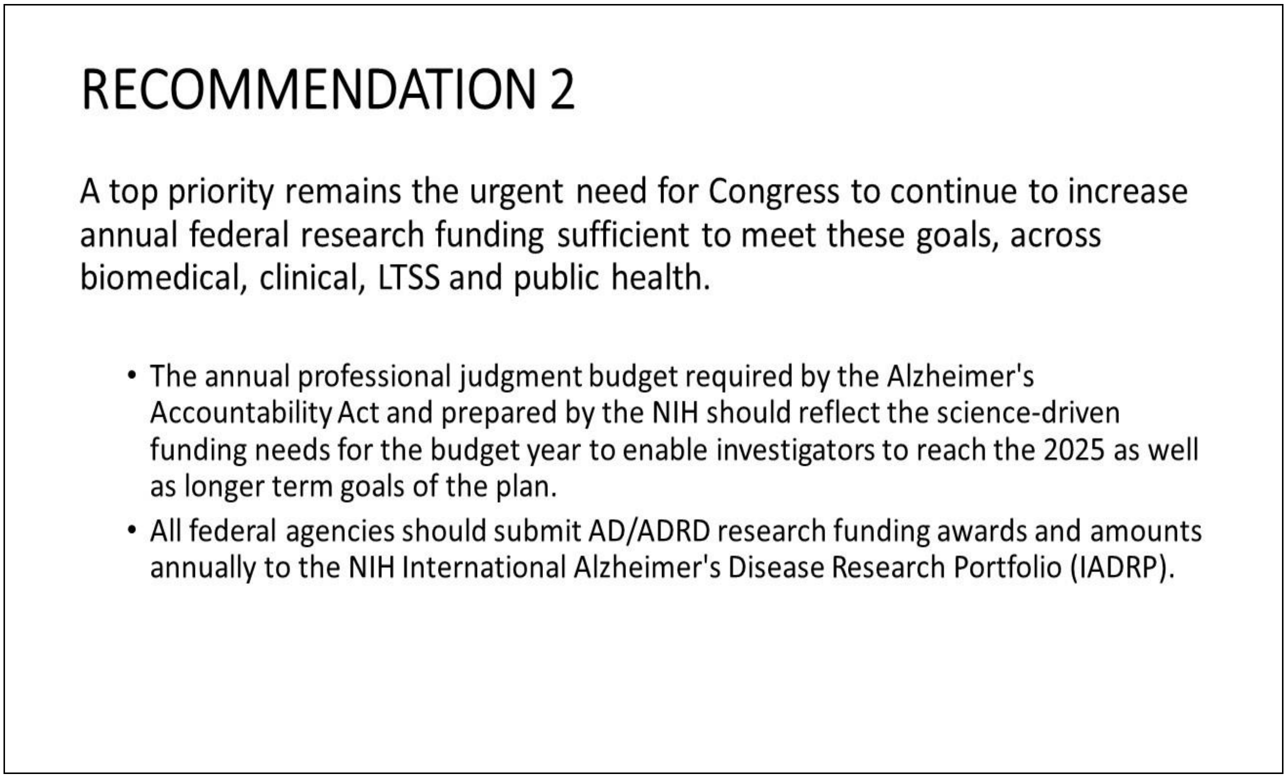
- Robust biomedical and holistic strategy.
- Sufficient resources.
- Consistent terminology
- Ethical data sharing
- An inclusive role for the dementia community.



RECOMMENDATION 1

The 2020 National Plan (the Plan) should encourage a sense of urgency about providing a robust, comprehensive, collaborative and transformative scientific road map for achieving the goal of preventing, effectively treating, and providing effective care and services for AD/ADRD by 2025, as well as continuous progress and improvement thereafter.

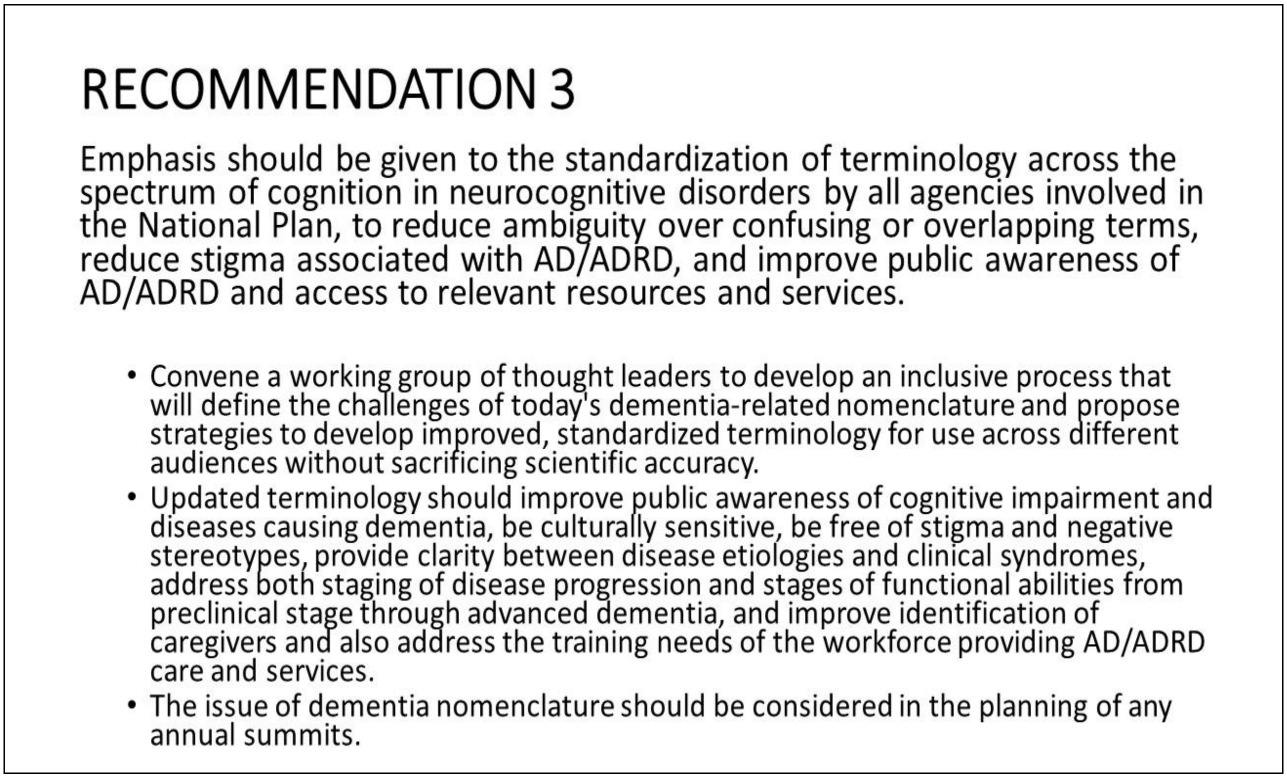
- A road map for accomplishing the primary goal of the Plan should include input from experts in the field through recurring research summits on AD/ADRD, and care and services.
- Recommendations from these summits and the research community should be re-evaluated each year and translated into milestones by federal agencies involved in NAPA and relevant partners.
- Federal agencies should monitor progress of research milestones as described in the summit recommendations.



RECOMMENDATION 2

A top priority remains the urgent need for Congress to continue to increase annual federal research funding sufficient to meet these goals, across biomedical, clinical, LTSS and public health.

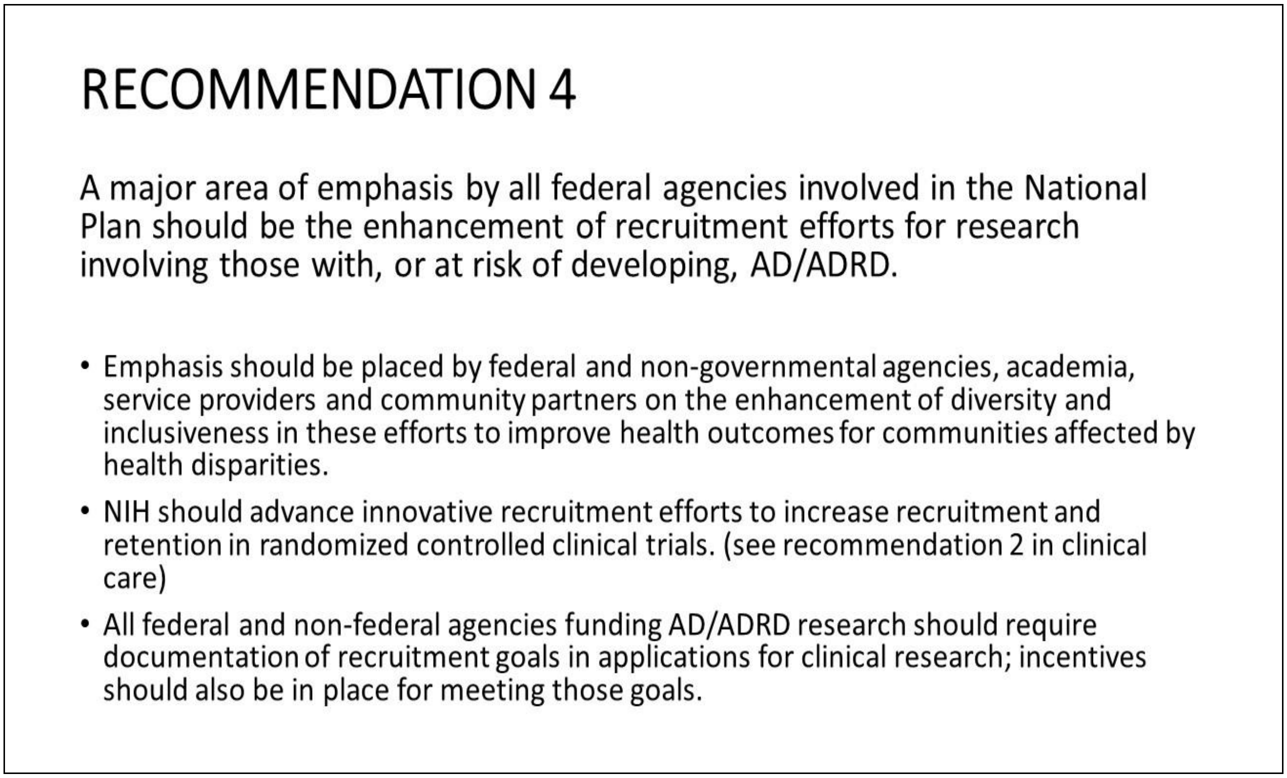
- The annual professional judgment budget required by the Alzheimer's Accountability Act and prepared by the NIH should reflect the science-driven funding needs for the budget year to enable investigators to reach the 2025 as well as longer term goals of the plan.
- All federal agencies should submit AD/ADRD research funding awards and amounts annually to the NIH International Alzheimer's Disease Research Portfolio (IADRP).



RECOMMENDATION 3

Emphasis should be given to the standardization of terminology across the spectrum of cognition in neurocognitive disorders by all agencies involved in the National Plan, to reduce ambiguity over confusing or overlapping terms, reduce stigma associated with AD/ADRD, and improve public awareness of AD/ADRD and access to relevant resources and services.

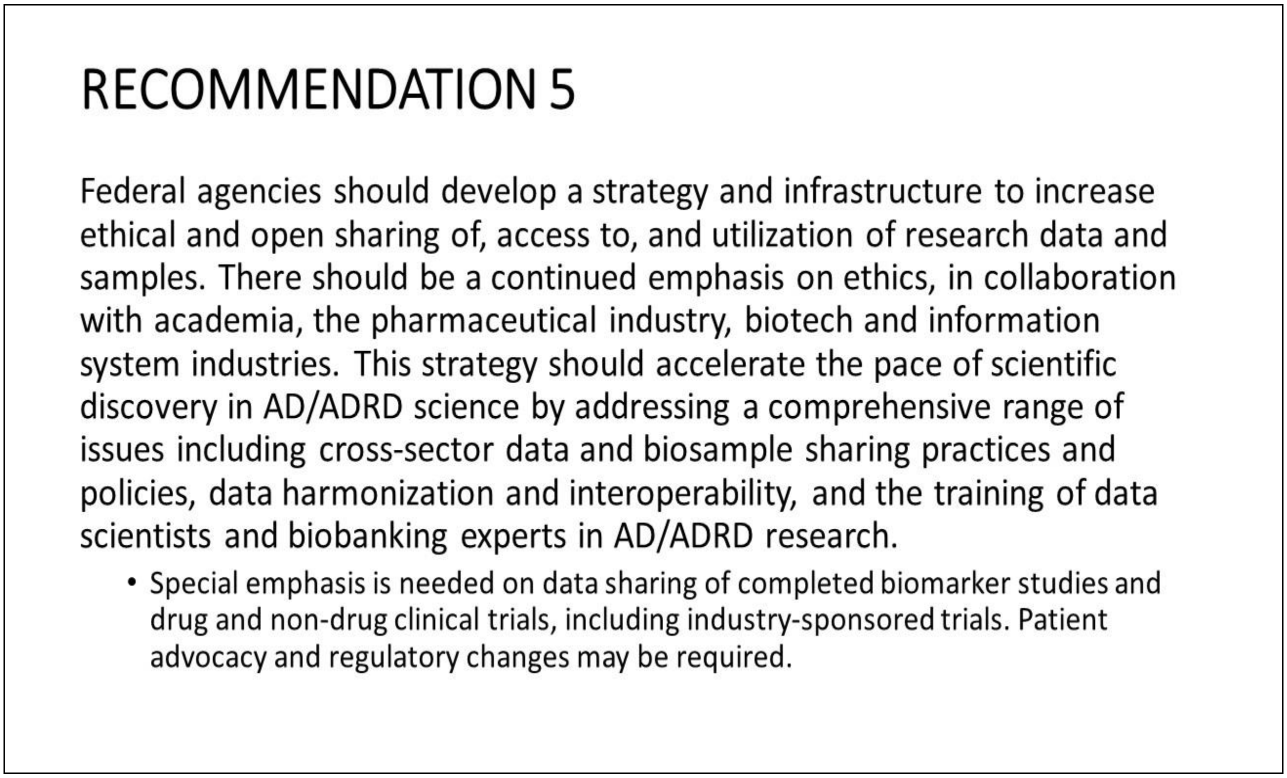
- Convene a working group of thought leaders to develop an inclusive process that will define the challenges of today's dementia-related nomenclature and propose strategies to develop improved, standardized terminology for use across different audiences without sacrificing scientific accuracy.
- Updated terminology should improve public awareness of cognitive impairment and diseases causing dementia, be culturally sensitive, be free of stigma and negative stereotypes, provide clarity between disease etiologies and clinical syndromes, address both staging of disease progression and stages of functional abilities from preclinical stage through advanced dementia, and improve identification of caregivers and also address the training needs of the workforce providing AD/ADRD care and services.
- The issue of dementia nomenclature should be considered in the planning of any annual summits.



RECOMMENDATION 4

A major area of emphasis by all federal agencies involved in the National Plan should be the enhancement of recruitment efforts for research involving those with, or at risk of developing, AD/ADRD.

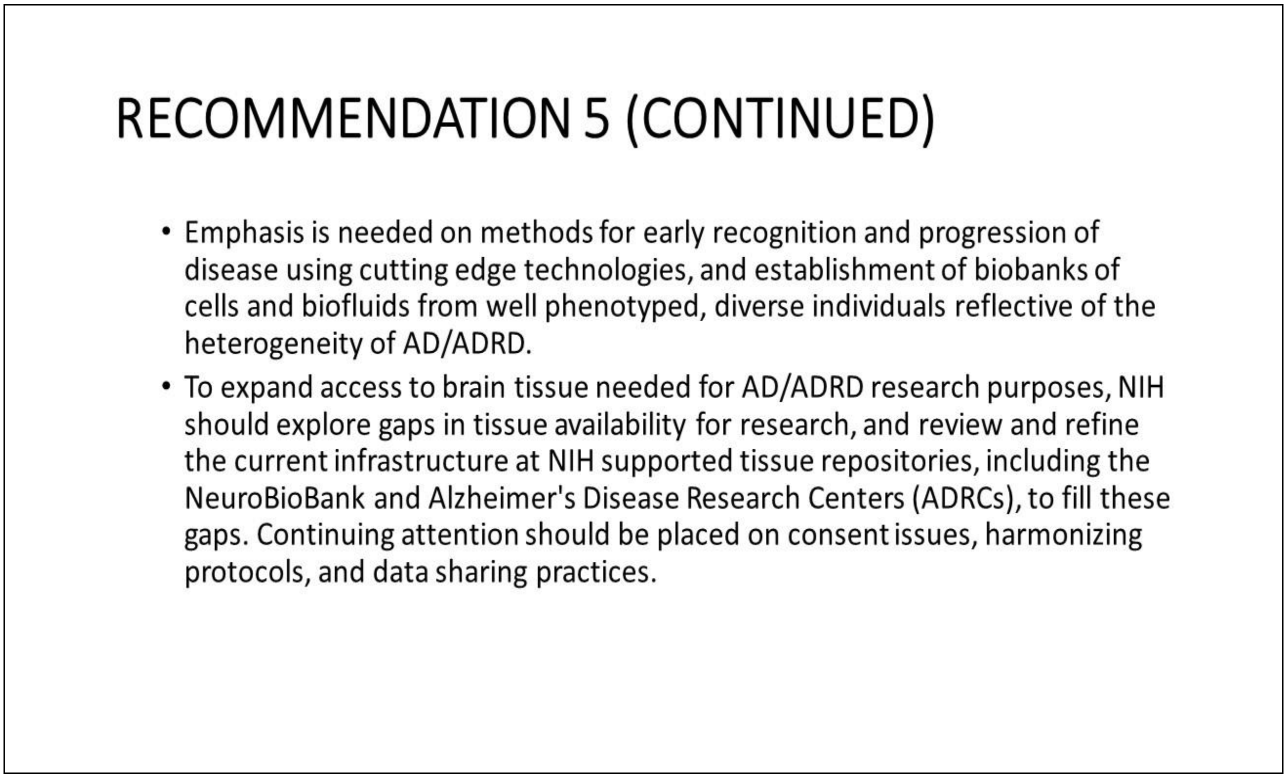
- Emphasis should be placed by federal and non-governmental agencies, academia, service providers and community partners on the enhancement of diversity and inclusiveness in these efforts to improve health outcomes for communities affected by health disparities.
- NIH should advance innovative recruitment efforts to increase recruitment and retention in randomized controlled clinical trials. (see recommendation 2 in clinical care)
- All federal and non-federal agencies funding AD/ADRD research should require documentation of recruitment goals in applications for clinical research; incentives should also be in place for meeting those goals.



RECOMMENDATION 5

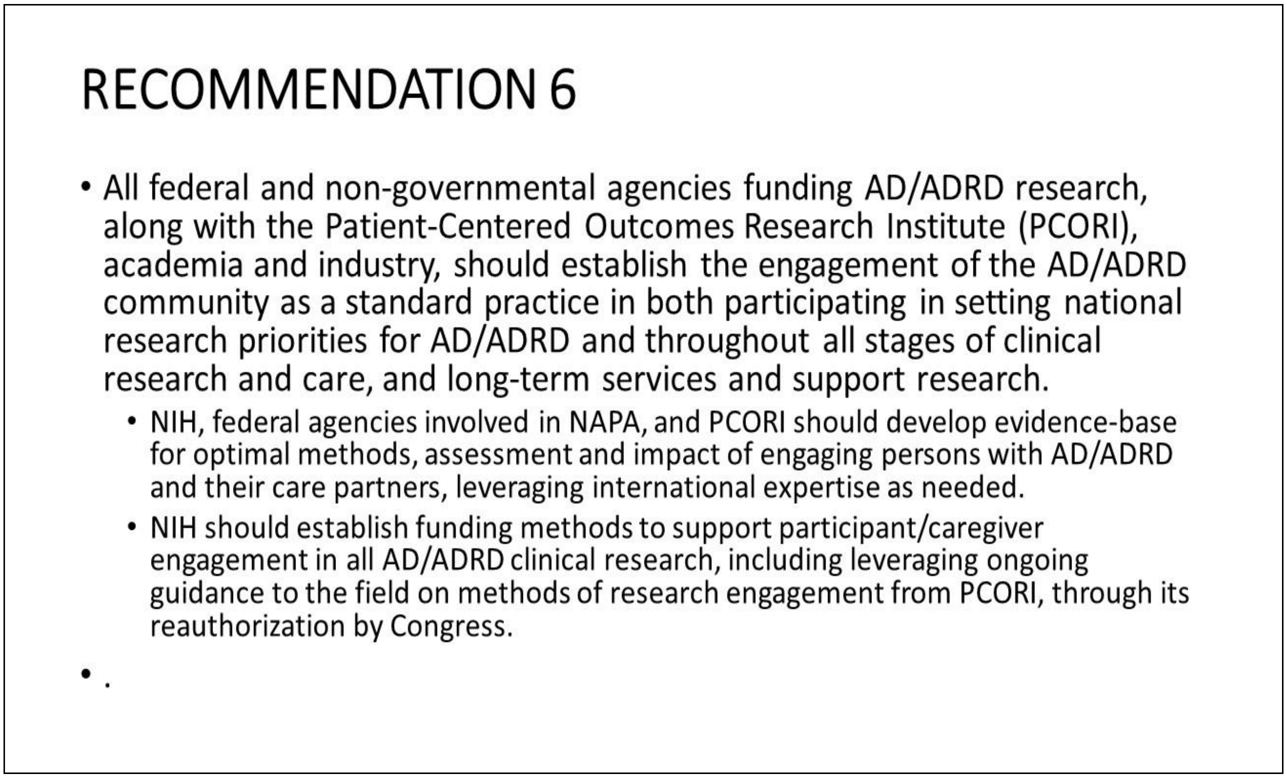
Federal agencies should develop a strategy and infrastructure to increase ethical and open sharing of, access to, and utilization of research data and samples. There should be a continued emphasis on ethics, in collaboration with academia, the pharmaceutical industry, biotech and information system industries. This strategy should accelerate the pace of scientific discovery in AD/ADRD science by addressing a comprehensive range of issues including cross-sector data and biosample sharing practices and policies, data harmonization and interoperability, and the training of data scientists and biobanking experts in AD/ADRD research.

  - Special emphasis is needed on data sharing of completed biomarker studies and drug and non-drug clinical trials, including industry-sponsored trials. Patient advocacy and regulatory changes may be required.



RECOMMENDATION 5 (CONTINUED)

- Emphasis is needed on methods for early recognition and progression of disease using cutting edge technologies, and establishment of biobanks of cells and biofluids from well phenotyped, diverse individuals reflective of the heterogeneity of AD/ADRD.
- To expand access to brain tissue needed for AD/ADRD research purposes, NIH should explore gaps in tissue availability for research, and review and refine the current infrastructure at NIH supported tissue repositories, including the NeuroBioBank and Alzheimer's Disease Research Centers (ADRCs), to fill these gaps. Continuing attention should be placed on consent issues, harmonizing protocols, and data sharing practices.



RECOMMENDATION 6

- All federal and non-governmental agencies funding AD/ADRD research, along with the Patient-Centered Outcomes Research Institute (PCORI), academia and industry, should establish the engagement of the AD/ADRD community as a standard practice in both participating in setting national research priorities for AD/ADRD and throughout all stages of clinical research and care, and long-term services and support research.
  - NIH, federal agencies involved in NAPA, and PCORI should develop evidence-base for optimal methods, assessment and impact of engaging persons with AD/ADRD and their care partners, leveraging international expertise as needed.
  - NIH should establish funding methods to support participant/caregiver engagement in all AD/ADRD clinical research, including leveraging ongoing guidance to the field on methods of research engagement from PCORI, through its reauthorization by Congress.
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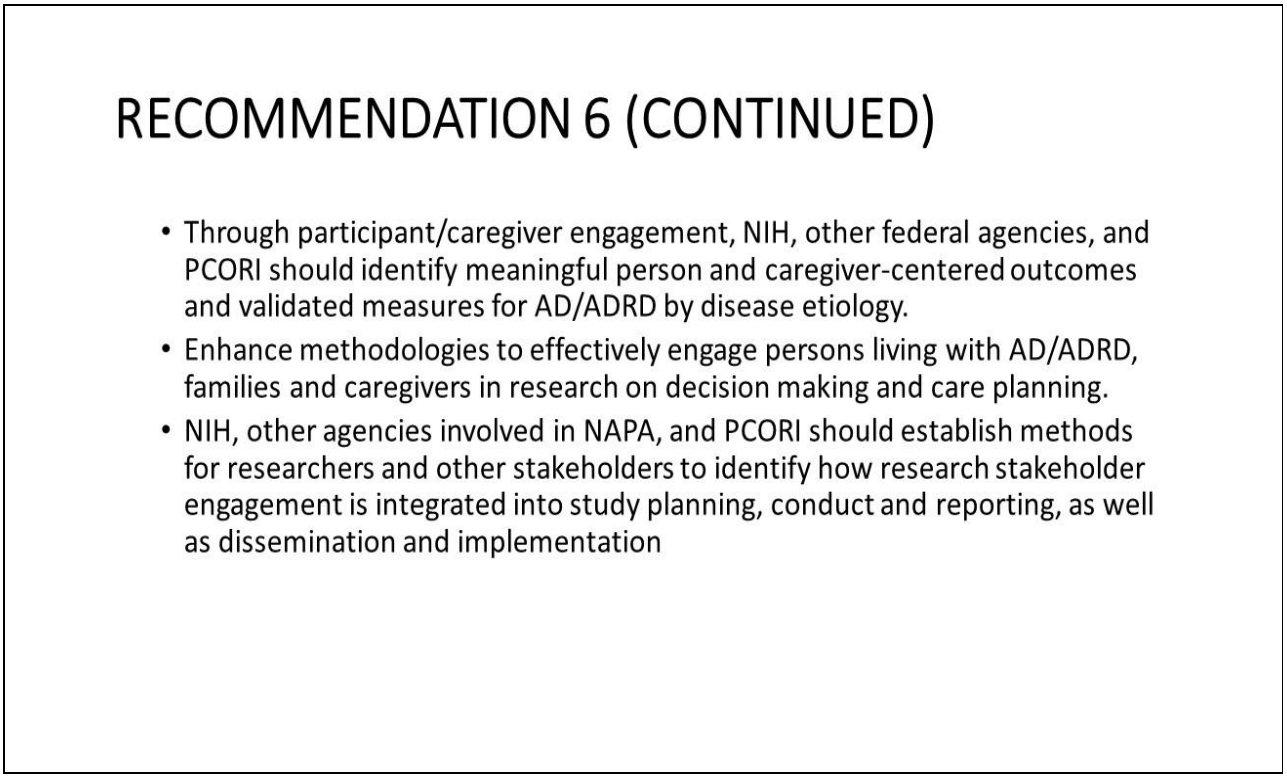

RECOMMENDATION 6 (CONTINUED)

- Through participant/caregiver engagement, NIH, other federal agencies, and PCORI should identify meaningful person and caregiver-centered outcomes and validated measures for AD/ADRD by disease etiology.
- Enhance methodologies to effectively engage persons living with AD/ADRD, families and caregivers in research on decision making and care planning.
- NIH, other agencies involved in NAPA, and PCORI should establish methods for researchers and other stakeholders to identify how research stakeholder engagement is integrated into study planning, conduct and reporting, as well as dissemination and implementation