

PUBLIC MEMBERS OF THE ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE AND SERVICES: 2019 Recommendations

Clinical Care Subcommittee

Clinical Care 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.

The research findings presented at the 2017 and 2020 National Research Summits on Care, Services and Supports for Persons with Dementia and their Caregivers and the final sets of research themes and recommendations should be considered for federal agencies' and others' current plans to improve care for AD/ADRD; gaps in evidence should be addressed by appropriate funders; and, the 2019 National Plan should be updated based on current data and Summits' themes and findings.

- a. 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>).
- b. 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.

- c. Federal agencies and non-governmental organizations should allocate funding and issue requests for applications to address research recommendations stemming from the National Research Summits.
- d. 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.
- e. 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.

Education about the availability of early detection and diagnosis of AD/ADRD is important because people living with cognitive symptoms are better able to participate in person-centered planning when symptoms are in an early stage. General education and information about local/regional resources, including resources and information on recruiting and enrolling persons with cognitive impairment or dementia into research, should be easily accessible and should support the decision-making of persons at-risk for and living with AD/ADRD and their caregivers. Further research on the predictions of early diagnostic testing in terms of prognosis is a critical need.

- a. 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.
 - Promotion of educational materials, such as those available through the NIA (<https://www.nia.nih.gov/health/alzheimers>), should continue including increased linkage of this information to educational resources maintained by advocacy groups and state/local healthcare systems.
 - States and community-based providers should be encouraged to advance coordinated materials for practical use by persons at risk for and living with AD/ADRD and their caregivers through single entry points (“No Wrong Door” <https://nwd.acl.gov/>) such as Area Agencies on Aging, Aging and Disability Resource Centers, and Community Independent Living Programs.

- States and community-based providers should be encouraged to use new educational information about care planning for persons living with AD/ADRD, such as materials available through the National Center on Advancing Person-Centered Practices and Systems (NCAPPS) <https://ncapps.acl.gov/about-ncapps.html>.
- b. 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. Examples of resources include:
- CDC’s Healthy Brain Initiative Road Map for Public Health and other resources (<https://www.cdc.gov/aging/index.html>).
 - ACL’s issue brief Dementia-capable States and Communities: the Basics and other National Alzheimer’s and Dementia Resource Center (NADRC) resources (<https://nadrc.acl.gov>).
 - ACL’s Brain Health: You Can Make a Difference! resources (<https://www.acl.gov/index.php/node/293>).
 - HRSA training materials that include early detection and diagnosis of AD/ADRD. (<https://bhw.hrsa.gov/grants/geriatrics>).
 - NIA’s What is Brain Health initiative (<https://brainhealth.nia.nih.gov/>).
- c. 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 through education to better address the needs of persons living with AD/ADRD and their caregivers.

Federal agencies and others should continue to offer and support current and future workforce education to improve workforce members’ abilities to work with persons living with AD/ADRD, including recognizing early signs and symptoms, addressing early detection and diagnosis, offering and providing counselling to persons living with AD/ADRD and their family members and caregivers, and connecting them to local services and resources.

- a. Federal agencies and others should develop specific new training models to advance workforce readiness nationally in the areas of:
- Disaster Preparedness -- to train health care workers, first-responders and individuals to recognize and better protect the health and safety of persons living with AD/ADR and their family members and caregivers who experience a disaster or hazard.
 - Acute Care -- to train individuals, first-responders and health care workers caring for persons living with AD/ADR in urgent care, emergency room and hospital settings to recognize and better identify and address needs of persons living with AD/ADR.
 - Behavioral Health -- to train health care workers, first-responders and individuals to recognize and better address needs of persons living with AD/ADR and other mental health disorders such as substance use disorder, and mood disorders including depression or suicidal ideation.
 - Comorbid Medical and Mental Health Conditions -- to train health care workers to recognize and better identify, distinguish, and appropriately manage symptoms of AD/ADR when they occur concurrently with signs and symptoms of acute and chronic medical conditions and multifactorial conditions such as pain and reduced communication abilities.
 - Recruitment into Research -- to train health care workers and individuals on the importance of and options for recruiting persons with AD/ADR into research. Recruiting participants into research from typical care settings is important because new research is needed on models of care that meet the needs of people living with AD/ADR, including how to best manage complex medical and mental health conditions.
 - Continuing Education Modules for Health Professionals about Brain Health based -- to train health professionals on: the importance of early detection; the importance of risk reduction; and, culturally appropriate content and materials.
- Available resources to address this recommendation include:
- <https://www.nia.nih.gov/health/now-what-next-steps-after-alzheimers-diagnosis>
 - <https://www.nia.nih.gov/health/managing-older-patients-cognitive-impairment>
 - <https://www.nia.nih.gov/health/talking-older-patients-about-cognitive-problems>
 - <https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients>
- b. One or more working group(s) of health professional associations should be convened to define skills needed by persons delivering evidence-based AD/ADR care across care settings, and determine strategies for incorporation of the needed skills into educational materials and training in clinical and other practices.
- The working groups should address how to train workforce members on the benefits and risks of pharmacotherapy, including the integration of medication

- use and “deprescribing” into comprehensive non-pharmacological approaches to care.
- The working groups should address measures of success including how to assess that trained workforce members are incorporating learning into current practice.
- c. 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. Examples of such recommendations include:
- The Alzheimer’s Association’s 2018 Dementia Care Practice Recommendations (https://www.alz.org/professionals/professional-providers/dementia_care_practice_recommendations)
 - HRSA Alzheimer’s Disease and Related Dementias Core curriculum and the HRSA Caregiving Curriculum (<https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum>)
 - Brain health education about AD/ADRD and caregiving in curricula for students of public health available through CDC and the Alzheimer’s Association (<https://www.cdc.gov/aging/aginginfo/alzheimers.htm#Curriculum>)
 - Recommendations from the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers (<https://aspe.hhs.gov/basic-report/research-summit-dementia-care-main-summit-recommendations>)
 - Guidance on Inappropriate Use of Antipsychotics: Older Adults with Intellectual and Developmental Disabilities in Community Settings (<https://store.samhsa.gov/product/Inappropriate%20Use%20of%20Antipsychotics%20Brief%20Guidance%3A%20Older%20Adults%20and%20People%20Living%20with%20Intellectual%20Disabilities%20in%20Community%20Settings/PEP19-INAPPUSE-BR>)
- d. 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.

There should be current best practices for comprehensive care of AD/ADRD at all disease stages, informed by evidence, so that persons living with AD/ADRD, caregivers, health systems and payers have similar understanding regarding diagnosis, treatment and/or services and supports; and the Advisory Council should identify an approach for outlining practices for such comprehensive care.

- a. 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>
- b. The work group should consider factors such as the following:
- Elements of care and services that are based on level of function.
 - Health disparities and cultural competencies to advance best practices.
 - Financial concerns and options counselling for health insurance coverage and other benefits
 - Data elements to be potentially included in a person-centered care plan for AD/ADRD and best practices for care plan facilitation and use.
 - Use of electronic health records to enhance person-centered planning.
 - Development and evaluation of technologies to link persons living with AD/ADRD and family members (defined broadly to include fictive kin, neighbors, friends, non-blood relatives), and other caregivers to care providers, share information more efficiently, deliver care interventions, monitor health and symptom status, and promote health and safety.
 - Risks related to quality of life that are either perceived or actual in response to disclosure of a diagnosis of a cognitive disorder; including, for example, loss of employment or insurance in response to knowledge of a diagnosis.
 - The potential of person-centered planning to function continuously over time and to transcend setting; specifically, best practices for use of a person-centered plan that can function well under a range of circumstances, for example when a person with AD/ADRD lives alone, does or does not have an identified family member or caregiver, and/or transitions to a hospital or residential care setting.
 - Definitions of “dementia capability” in a health system or community, including adaptability of the processes based on a person’s level of function and the setting in which the person lives.
 - Alignment of services with the principles of “age friendly” health systems (<https://www.johnhartford.org/grants-strategy/current-strategies/age-friendly-hospitals/>) and community activities (<http://www.who.int/ageing/age-friendly-world/en/>)
 - Pros and cons, barriers and supports, bioethics of various advances
- c. 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.

- d. 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>
- e. 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 care¹ 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.

- a. 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>).
- b. 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.
- c. 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 such as:
 - Cognitive Impairment and Assessment Care Planning Codes.
 - Quality Payment Program measures relevant to AD/ADRD.
 - Use of Medicare's Annual Wellness Visit.

¹ Value-Based Healthcare: “a healthcare delivery model in which providers, including hospitals and physicians, are paid based on patient health outcomes” (<https://catalyst.nejm.org/what-is-value-based-healthcare>).

- d. 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.
- e. 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.

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) should apply relevant metrics to the key drivers in the logic model (driver diagram) as a means of assessing progress and should use those metrics to report annually on the progress towards the goals of the National Plan.

- a. ASPE should request information from federal agencies and others regarding metrics to assess progress.
- b. ASPE, in collaboration with the Advisory Council, should identify and select key drivers that can be followed by one or more metrics.
- c. 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.
- d. 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.
- e. ASPE should include metric reporting in annual updates of the National Plan.

Long-Term Services and Supports (LTSS) Subcommittee

Goal 3: Expand Supports for People Living with AD/ADRD and Their Caregivers²

LTSS Themes:

- Improve 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 family/friend caregivers by health care systems.
- Provide high quality, person- and family-centered LTSS, that address behavioral and psychiatric symptoms of AD/ADRD across care settings.

Recommendation 1. Improve Access to Affordable LTSS

Background: Impoverishment can be an issue for individuals and caregiving families who may be forced stop working or to spend down their personal savings trying to purchase or furnish care for a relative with AD/ADRD. Unpaid caregivers providing substantial HCBS may be less able to be productive members of the workforce. For the most part, LTSS are not covered by Medicare. And, while Medicaid covers some LTSS costs for low-income beneficiaries who qualify, for many individuals and families, out-of-pocket LTSS costs drain their personal savings. According to AARP’s Family Caregiving Cost Study (2015), the average out-of-pocket cost caring for a person with dementia is \$10,697 annually and full-time in-home care or assisted living residential care can cost \$4,000 a month or more. This is prohibitive for most middle to lower income individuals and families. The recommendations below focus on non-means-tested programs that can expand the availability of LTSS, especially in home and community-based settings

To help assure that people living with AD/ADRD and their families can access the LTSS they need, including HCBS, it is recommended that:

- a. By 2025, programs beyond Medicaid that provide LTSS (e.g., OAA, state and non-profit programs) should be expanded to support individuals and families with unmet needs, including under-served, diverse populations.
 - Congress should expand covered populations to include people under the age of 60 with a diagnosis of young onset AD/ADRD in the reauthorization of the Older Americans Act.
 - Congress should increase funding for the ACL Alzheimer’s Disease Program Initiative from \$23.5M to \$50M to increase the number of individuals benefitting from tailored education and supports; target the program to under-served and high-risk populations; and evaluate the program’s reach and impact.

² All references to “caregivers” apply to care partners, families and friends providing assistance to people living with AD/ADRD.

- Congress should increase funding for the ACL National Family Caregiver Support Program (NFCSP) from \$180M to \$360M, target the program to families of people with AD/ADRD, and evaluate the reach and dementia capability of the program.
 - Congress should establish new funding for ACL respite programs, target the funding to under-served and high-risk populations and evaluate the programs' reach and impact.
 - Operating divisions within the US Department of Health and Human Services such as CMS, ACL, CDC and HRSA, as well as the VA, should tailor programs to address the HCBS needs of a heterogeneous population living with AD/ADRD and their families and caregivers.
 - Disbursement of resources should consider communities and populations with the greatest need, using objective data sources (like U.S. Census data) for determinations.
 - State models for expanding the availability of LTSS and/or supporting unpaid caregivers through 1115 waivers and other strategies should be evaluated and, if warranted, disseminated broadly to encourage adoption by other states See the Medicaid LTSS toolkit for examples:
https://www.chcs.org/media/Strengthening-LTSS-Toolkit_032019.pdf.
- b. Federal agencies and states should build workforce capacity to provide dementia capable LTSS.
- To address the shortage of a dementia-knowledgeable workforce:
 - Congress should allocate an additional \$25 million in funding for HRSA to support geriatric workforce training in AD/ADRD across the educational continuum.
 - HRSA should continue to allocate a portion of GWEP funding uniquely toward workforce training in AD/ADRD (Currently a minimum of \$100,000 for each of 48 grant recipients).
 - Increase education for paid and unpaid caregivers through ACL and HRSA grant funding (i.e., ADPI, NFCSP & GWEP) including funding for implementation of evidence-based or evidence-informed interventions.
- c. Health care systems should expand access to HCBS:
- CMS should monitor Medicare Advantage (MA) Plans for HCBS supplemental benefits aimed at people living with AD/ADRD and their caregivers.
 - HHS should provide technical assistance, informational bulletins, webinars or other guidance on LTSS needs of people living with AD/ADRD to states, insurers and medical and LTSS providers and develop plans for monitoring implementation.
 - Congress should sustain Section 2404 protections against spousal impoverishment in the Affordable Care Act (ACA), and the section 1915(i) HCBS state plan option, Community First Choice (CFC) attendant care services and supports, and individuals eligible through a medically needy spend down to HCBS waivers.

- Federal agencies (HRSA, CMS, ACL, IHS, VA, CDC) should offer annual education to providers about HIPAA regulations and circumstances for appropriate communication about patient protected personal health information to unpaid caregivers to address the perception by health providers that HIPAA prevents such communication.

(Measurement: Establish a baseline and count # of trainings, # of attendees reached with this information annually. Ask for annual report outs to the Council).

Research Subcommittee

Research Themes:

- Robust biomedical and holistic strategy.
- Sufficient resources.
- Silos minimized.
- Optimal infrastructure and research climate.
- An inclusive role for the dementia community.
- Global leadership role.
- Broad dissemination.
- Commitment to quality.
- Continuous and objective process improvement.

RECOMMENDATION 1: The 2019 National Plan should continue to provide 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.

- a. 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.
 - Cross-agency collaboration between federal agencies on the annual summits is essential to advance progress. Representatives of all federal agencies involved in the NAPA plan should attend the summits and coordinate efforts.
 - Federal agencies should support global efforts to address issues of research, care and services, and workforce development in order to facilitate international collaboration and minimize silos of knowledge.
- b. 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.
- c. 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 all the 2025 goals, across biomedical, clinical, LTSS and public health.

- a. 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 goals of the plan.

- This investment would be applied to AD/ADRD research initiatives spanning basic, translational, clinical, care and services research.
- b. 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.

- a. 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.
- As any change to dementia nomenclature can have wide-ranging impact across research, regulatory issues, clinical care, reimbursement issues and public health efforts, Dementia stakeholder organizations should assist this initiative through administrative and meeting planning support and funding.
- b. 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.
- c. 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.

- a. 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.

- b. NIH should advance innovative recruitment efforts to increase recruitment and retention in randomized controlled clinical trials. (see recommendation on clinical care)
- c. 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, with a continued emphasis on ethics, in collaboration with academia, 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 sharing practices and policies, data harmonization and interoperability, and the training of data scientists in AD/ADRD research.

- a. 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 6: All federal and non-governmental agencies funding AD/ADRD research, along with 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 services and support research.

- a. 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.
- b. 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.
- c. 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.
- d. Enhance methodologies to effectively engage persons living with AD/ADRD, families and caregivers in research on decision making and care planning.

- e. 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.

RECOMMENDATION 7: 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 the NIH NeuroBioBank and Alzheimer’s Disease Research Centers (ADRCs) to Fill these gaps. NIH should consider the value of widening outreach to accept brain donations from clinically well-characterized individuals, such as those receiving clinical care at dementia research sites like ADRCs and Udall Centers.

- a. Collaborations should be considered that leverage existing NIH-funded brain banks and AD/ADRD research programs, with continuing attention on consent issues, harmonizing protocols and data sharing practices.