

Research Subcommittee Recommendations 2019

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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 2018 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.

Recommendation 1 (continued)

- 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.
- 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 all the 2025 goals, across biomedical, clinical, LTSS and public health.

RECOMMENDATION 2 (continued)

- 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.
- 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.

RECOMMENDATION 3 (continued)

- 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.
- 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.

RECOMMENDATION 4 (continued)

- 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 on 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 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.
 - 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.
 - 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 (continued)

- 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.
- 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.

RECOMMENDATION 7 – New for 2019

- 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.
 - 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.

Clinical Care Subcommittee Recommendations 2019

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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.

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.

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.

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.

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.

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.

LTSS Subcommittee Recommendations 2019

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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: Expand supports for people living with AD/ADRD and their caregivers*

- 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.
- B. Federal agencies and states should build workforce capacity to provide dementia capable LTSS.
- C. Health care systems should expand access to HCBS.

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

Recommendation 2: Improve integration of clinical care with home and community-based services (HCBS)

- A. By 2025, 20% of hospitals and primary care practices serving people living with AD/ABRD will have in place procedures to:
1. Identify cognitive impairment and integrate management of cognitive impairment into the Care Plan.
 2. Provide a timely diagnosis for individuals who are found to have impairment, through efficient and well coordinated care pathways and referral processes.
 3. 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.

Recommendation 2: Improve integration of care (continued)

4. Co-design care plans with the individual and care giver or authorized health care proxy (where appropriate), so that plans are concordant with the individuals' goals of care and can be supported in the home environment.
5. For individuals who are receiving care in a facility, discharge planning will include due consideration of the individual's cognitive status and care needs.
6. Assess the caregiver's LTSS needs, provide them with disease education and HCBS, and/or refer them to community-based services.

Recommendation 2: Improve integration of care (continued)

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

Recommendation 3: Individuals with AD/ADRD will not be prescribed antipsychotics unless clinically indicated.

To promote person-centered care and promising nonpharmacological treatments for behavioral and psychiatric symptoms of dementia (BPSD), it is recommended that:

- A. Research should be funded through federal agencies to delineate barriers to adoption of evidence-based interventions and to also identify bright spots where uptake is achieved.
- B. Federal agencies and other organizations should disseminate promising, evidence-supported interventions.
- C. Federal agencies and other organizations should continue to build workforce capacity to deliver person-centered care as well as the use of promising and/or evidence-derived nonpharmacological interventions for BPSD.

Recommendation 3 (continued)

- D. Federal agencies should create care or payment models for use of effective evidence-based interventions.
- E. Federal agencies should encourage measure development for HCBS, including measures that address management of challenging behavioral symptoms.
- F. By 2021, HHS should develop a coordinated process for measuring anti-psychotic medication use that will delineate inappropriate use, can be applied to community as well as facility residents, and can be used to calculate prescribing trends over time.