Federal Agency Updates



Alzheimer's Disease and Related Dementias Research Update

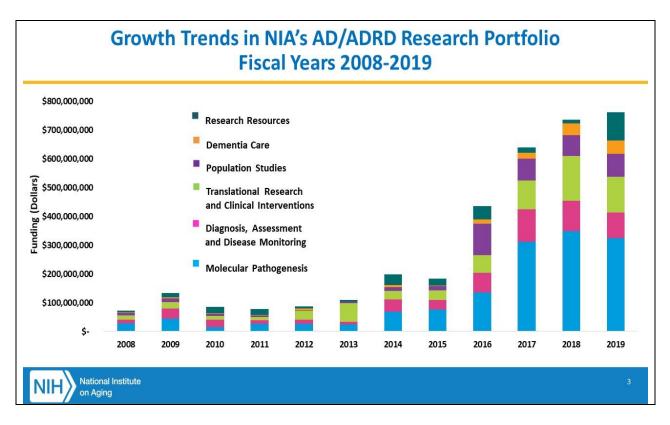
Advisory Council on Alzheimer's Research, Care, and Services Meeting

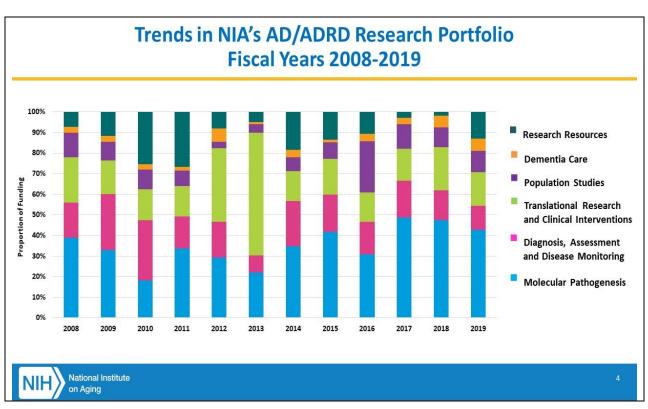
Richard J. Hodes, M.D.

Director, NIA

May 3, 2021







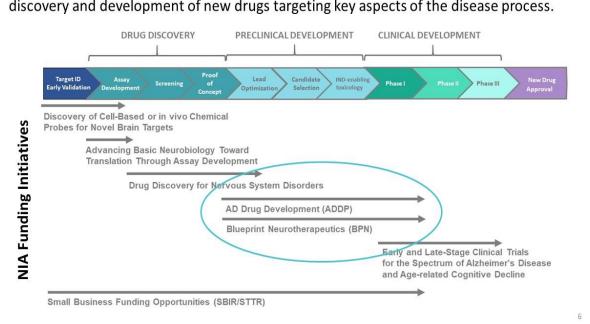
Recruitment of a Growing AD/ADRD Research Workforce

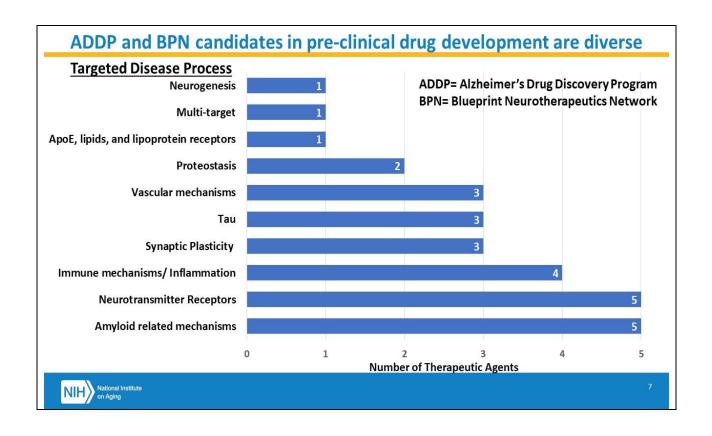
- ~1/3 of NIA's Alzheimer's disease and related dementias awardees from Fiscal Year 2015—2020 were either <u>new or early-</u> <u>stage</u> investigators.
- ~1/4 of NIA's Alzheimer's disease and related dementias awardees were new to the field.

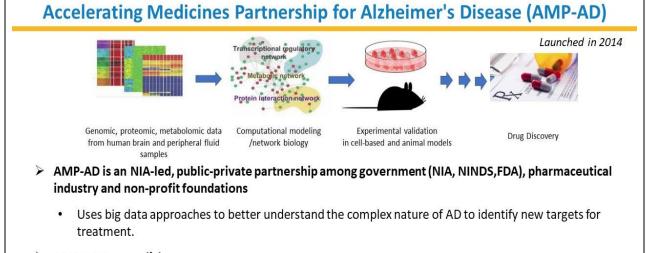


5

<u>NIA's Alzheimer's Translational Research Program</u> provides a pipeline of funding opportunities for academic institutions and biotech companies. These programs support the discovery and development of new drugs targeting key aspects of the disease process.







- AMP-AD Accomplishments
- <u>Centralized data resources</u> for sharing data, analytical results and target nominations, over 2500 AD and control cases
- Rich, <u>high quality data</u> and network models of disease pathways and targets
- Datasets being widely used: ~3000 users to date 60% academia, 40% biotech/pharma
- Over 500 novel candidate targets identified

AMP AD 2.0: Enabling a Precision Medicine Approach to Target and Biomarker Discovery

- Expand multi-omic profiling in samples (brain, CSF, blood) from diverse cohorts (African American and Latino American)
- Generate longitudinal immunologic profiling data across diverse cohorts (Caucasian, African American and Latino American)
- Expand the existing sn/sc molecular profiling efforts to multiple brain regions, and in samples from diverse cohorts



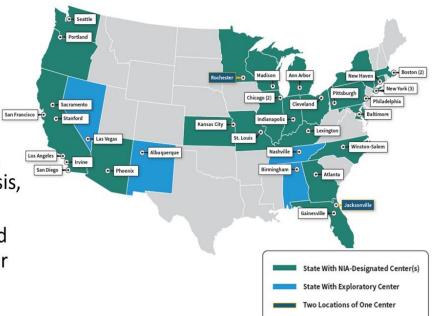
AMP AD 2.0 Partners



AMP AD 2.0 brings together 8 research teams from over 20 academic institutions and 9 public-private partner organizations.

• 31 ADRCs

- 4 new exploratory centers
- Clinical,
 neuropathology,
 imaging, biomarkers,
 genetics, pathogenesis,
 therapeutics
- Provide diagnosis and education services for patients and families



Active NIA AD/ADRD and Related Intervention and Prevention Trials (~270)

45 Early-Stage Clinical Drug Development (Phase I and Phase II Clinical Trials)

Amyloid (11)
Receptors (2)
Sleep (1)
Growth factors and Hormones (2)
Inflammation (3)
Metabolism and Bioenergetics (2)
Multi-target (2)
Neurogenesis (2)
Oxidative stress (3)
Synaptic Plasticity/
Neuroprotection (6)
Vasculature (2)
Other (9)

11 Late-Stage Clinical Drug Development (Phase II/III and Phase III Clinical Trials)

Amyloid (7) Synaptic Plasticity/ Neuroprotection (2) Tau (1) Vasculature (1) 123 Non-Pharmacological Interventions

Assistive Tech/Device (13)
Cognitive Training (18)
Combination Therapy (11)
Decision-Supportive (5)
Diagnostic Tools (8)
Diet/Supplements (7)
Exercise (27)
Light Therapy (1)
Neurostimulation (14)
Sleep (6)
Other (13)

7 Clinical Therapy Development for Neuropsychiatric Symptoms of AD/ADRD

Pharmacological (5) Non-Pharmacological (2) 84 Care and Caregiver Interventions

Improving Care for PWD (43) Improving Family or Informal Caregivers (41)



https://www.nia.nih.gov/research/ongoing-AD-trials

1:

Clinical Trials Pivot During Pandemic to Keep Studies Going

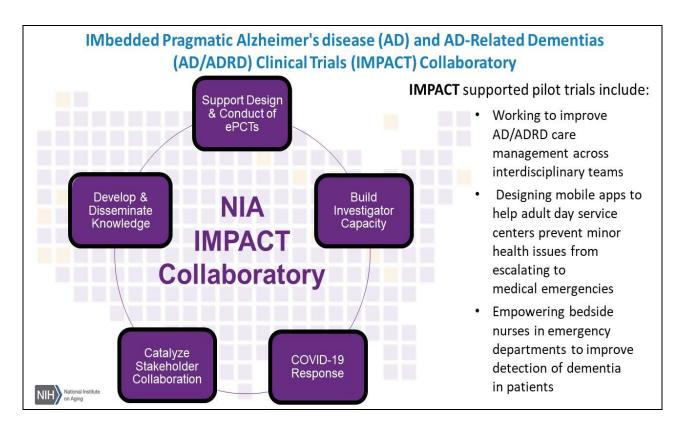
Examples of Shifts to Clinical Trial Protocols in response to COVID-19

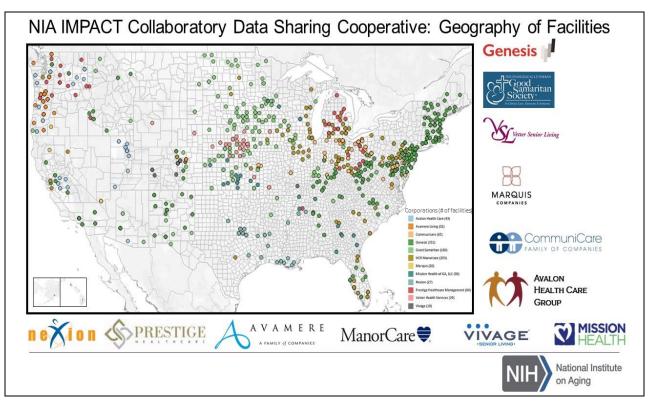
- Exercise trials are now using virtual coaching and fitness training
- Trials with intravenous infusions of medication are moving to in-home infusions
- Trials have shifted to remote monitoring and screening of participants



A number of these flexibilities will remain even after trial sites re-open as they present greater options and reduce barriers for participants





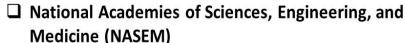


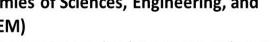
AHRQ-National Academies Study on Dementia Care & Caregiving

Two parts:

■ Agency for Healthcare Research & Quality (AHRQ) Conduct a rigorous systematic review of the evidence on care and caregiving interventions for people living with dementia (PLWD) and their caregivers - released in July 2020









Establish an expert committee to develop a report outlining a set of recommendations on the readiness of these interventions for broad dissemination and implementation, and research gaps in the field released in February 2021



National Academies Recommendations on **Dementia Care & Caregiving**

Key Messages from NASEM Synthesis:

- Most caregiving interventions were not assessed in the study because they had small sample sizes, were pilots, or had high risk of bias
- Two types of interventions demonstrated low-strength evidence of benefit in clinical trials:
 - **Collaborative Care**
 - Resources for Enhancing Alzheimer's Caregiver Health (REACH) II
- The report recommends broader implementation of these programs in real-world settings that allow for continual monitoring, evaluation, and quality improvement

CARING FOR PERSONS LIVING WITH DEMENTIA AND THEIR CARE PARTNERS AND CAREGIVERS A WAY FORWARD

https://www.ncbi.nlm.nih.gov/books/NBK567818

2021 Alzheimer's Disease Research Summit



Archived presentations found at:

https://www.nia.nih.gov/2021-alzheimers-summit





Ways to Stay Informed and Connected



Search all active NIA funding opportunities: https://www.nia.nih.gov/research/funding



Review the latest approved concepts: https://www.nia.nih.gov/approved-concepts



Subscribe to our blog and stay up to date on the latest NIA news: https://www.nia.nih.gov/research/blog





National Alzheimer's Project Act Advisory Council on Alzheimer's Research, Care, and Services

Long-Term Services and Supports Federal Update

May 3, 2021

Administration for Community Living

FUNDING OPPORTUNITY ANNOUNCEMENT

Alzheimer's Disease Programs Initiative - Grants to States and Communities

HHS-2021-ACL-AOA-ADPI-0083

Estimated Total Funding: \$11,053,915

Expected Number of Awards: 14

Award Ceiling: \$1,000,000 Per Project Period

Award Floor: \$550,000 Per Project Period

Applications due: MAY 10, 2021

NAPA Goals 2, 3, 4

Administration for Community Living

UPCOMING FUNDING OPPORTUNITY ANNOUNCEMENT

Alzheimer's Disease Programs Initiative - Dementia Capability in Indian Country

HHS-2021-ACL-AOA-ADPI-0087

<u>Alzheimer's Disease Programs Initiative - Grants to States and Communities -</u>
Round Two

HHS-2021-ACL-AOA-ADPI-0083

NAPA Goals 2, 3, 4

Administration for Community Living

National Alzheimer's and Dementia Resource Center 2021 WEBINAR Series

- January 13, 2021- Reaching Socially Isolated People Living with Dementia with Carol Manning and Mike Splaine- 727 participants
- February 9, 2021- Exploring Male Caregiving for People Living with Dementia with Molly Perdue and Bob O'Brien, male caregiver- 505 participants
- March 11, 2021- Complex Care Management for People Living with Dementia with Sarah Dulaney and Lori Resnick- 586 participants
- April 27, 2021- Community Health Workers: A key support for people living with dementia and their caregivers with Constantina Mizis and Alicia Nielson 346 participants

Recordings and presentation PowerPoints are posted on the NADRC webpage

NAPA Goals 2, 3, 4

Administration for Community Living

National Alzheimer's and Dementia Resource Center

https://nadrc.acl.gov/
UPCOMING WEBINARS

Person Centered Goal Discovery for People Living With Dementia Tuesday, May 18, 2021 1:00-2:00 PM ET Webinar Registration

Supports for people living with dementia and their families are most effective when they are person-centered and the result of a thoughtful planning process that considers what is important to them. When guiding providers on how to deliver high quality support, it is important to use a clear and engaging approach to discover and address people's priorities as dementia progresses. This webinar will present foundational person-centered principles, and

- June 23, 2021- Elder Abuse and Dementia with Dr. Laura Mosqueda and Charlie Sabatino
- August 24, 2021- Building and Maintaining Relationships after a Dementia Diagnosis (Matt Estrade and Care Partner)

provide examples of how to plan for people who are living with dementia in the community and other settings.

NAPA Goals 2, 3, 4

Administration for Community Living

ACL Brain Health Webpage New Content Focus on Resources for Community Based Organizations

Brain Health Resources for Community Based Organizations: Perspectives From the Field

Community-based organizations play an important role in providing support and services in the home and community. The resources below provide examples of how area agencies on aging and other organizations are boosting awareness, providing education, and conducting services and supports on the topic of brain health.

- A <u>recorded webinar</u> highlights findings from a report assessing how area agencies on aging
 across the country are providing service and supports to individuals with dementia and their
 caregivers and developing initiatives related to brain health. A digital version of the report can be
 found <u>here</u>.
- A <u>companion research paper</u> to the report provides further insights and touches on how services and supports have been adapted during the COVID-19 Pandemic.
- A <u>briefing paper</u> on Promoting Brain Health in States and Communities: Nationwide examples from ACL's Alzheimer's Disease Program Grantees by Vijeth Iyengar, PhD and Erin Long, MSW.

Administration for Community Living

<u>Issue Brief</u> Cataloguing ACL-Funded Support of Brain Health in States and Communities Over Many Years



Figure 1: ACL has supported brain health services or activities from 23 unique organizations (shaded triangles) spanning 15 states (shaded in dark blue) between the years 2014-2020.

Sources: https://acl.gov/sites/default/files/common/lyengar Long BrainHealth IssueBrief ACLAlzheimersDiseasePrograms 0.pdf.

Brain Health Services or Activities Include:

- Psychoeducational programs for family caregivers of persons with dementia.
- Educational series covering basics of brain function, types of dementia, and living with dementia.
- Community presentations covering topics on healthy lifestyle choices and signs of cognitive impairment.

Administration for Community Living

Minority Organizations Technical Assistance & Resource Center (TARC) Program

- ACL funds five national organizations that support diverse older adult populations:
- African American; Hispanic; Asian-Pacific Islander; Native Americans; and Lesbian, Gay, Bisexual, And Transgender (LGBT)

Technical Assistance call

MHP Salud: <u>COVID-19</u>, <u>Social Isolation</u>, and <u>Hispanic Adults with Alzheimer's and other Dementia February 17</u>, 2021.

Blog

MHP Salud: <u>How to Raise Awareness About Dementia in Hispanic/Latino Older Adults</u>, (available in English and Spanish) January 2021.

NAPA Goals 2, 3, 4

Questions? Thank you!

Erin Long, MSW
Team Lead
Alzheimer's Disease Programs Initiative (ADPI)
Office of Supportive and Caregiver Services
Administration on Aging
Administration for Community Living

<u>Erin.Long@acl.hhs.gov</u>
202-795-7389

•

CMS Posts Information on Medicare Cognitive Assessment and Care Plan Services

- In March 2021 CMS updated the web page for beneficiaries that describes covered items, devices, and services to include a description of the Cognitive Assessment and Care Plan Service (CPT code 99483) available to beneficiaries with under Medicare Part B, distinct from the cognitive screening in the Annual Wellness Visit
- The new page links to resources including the Medicare depression screen, Alzheimer's.gov, CDC and NIH resources, ACL's Eldercare locator, and VA benefits
- CMS also plans to include a reference in the 2022 "Medicare & You" handbook
- The new page can be found at: https://www.medicare.gov/coverage/cognitive-assessment-care-plan-services

(Strategy 2.B)



Indian Health Service UPDATES

Dr. Bruce Finke, MD

Indian Health Service

- \$5,000,000 appropriated to the IHS in FY 2021 to address Alzheimer's Disease.
- IHS is currently highly engaged in Tribal Consultation and Urban Confer with Tribal and Urban Indian Program Leadership on the allocation of these resources.
 - Consultation initiated with <u>Dear Tribal Leader Letter</u> on March 31, 2021.
 - April May: Learning Sessions, Tribal Consultation and Urban Confer Sessions, Area Listening Session recorded and available.
 - To submit comments and for the schedule of all sessions: https://www.ihs.gov/dccs/consultationandconf
- Approach aligned with the National Plan to Address Alzheimer's Disease
 - Partnership with Tribes and Urban Indian Health programs.
 - Integrated with other federal efforts.
 - Opportunities for partnership and collaboration with non-federal partners.
- Conclusion of Tribal Consultation / Urban Confer by June, plan for action by July.
- This is the first ever specific appropriations for ADRD in the IHS budget.



ASPE Updates

New Reports on People with Dementia

The Impact of COVID-19 on Medicare Beneficiaries with Dementia

https://aspe.hhs.gov/dementia-medicare-bene-covid

The Risk and Costs of Severe Cognitive Impairment at Older Ages: Literature Review and Projection Analyses

- https://aspe.hhs.gov/basic-report/risk-and-costs-severe-cognitive-impairment-older-ages-literature-review-and-projection-analyses
- Issue Brief: https://aspe.hhs.gov/basic-report/risk-and-costs-severe-cognitive-impairment-older-ages-key-findings-our-literature-review-and-projection-analyses-research-brief

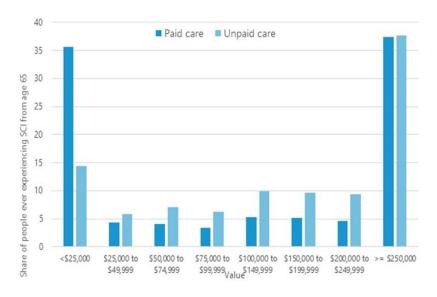


Uses the Dynamic Simulation of Income Model (DYNASIM) to project:

- The risk and costs of severe cognitive impairment at older ages
- Severe cognitive impairment (SCI): "Cognitive impairment that is severe enough to limit function, usually defined as social or occupational function. In its severe forms, a person with dementia/SCI may not be able to recognize people, use language, or execute purposeful movements."

(Finding consistent with presentations by Judy Dey and Melissa Favreault in October 2019)

Distribution of Projected Costs of Paid LTSS and Value of Unpaid Care for Those Who Ever Experience SCI: DYNASIM 1955-1959 Birth Cohort



The value of informal care --close to \$243,5000 (\$161,000 in present value terms)--just exceeds the formal costs-\$281,000 (\$164,000 in present value terms).

New Reports on Risks & Financing of LTSS

Long-Term Services and Supports for Older Americans: Risks and Financing, 2020 Research Brief

https://aspe.hhs.gov/basic-report/long-term-services-and-supports-older-americans-risks-and-financing-2020-research-brief

Projections of Risk of Needing Long-Term Services and Supports at Ages 65 and Older

- https://aspe.hhs.gov/basic-report/projections-risk-needing-long-term-services-and-supports-ages-65and-older
- Issue Brief: https://aspe.hhs.gov/basic-report/most-older-adults-are-likely-need-and-use-long-term-services-and-supports-issue-brief

New Reports on LTSS and Economic Hardship

Economic Hardship and Medicaid Enrollment in Later Life: Assessing the Impact of Disability, Health, and Marital Status Shocks

 https://aspe.hhs.gov/basic-report/economic-hardship-and-medicaid-enrollment-later-life-assessingimpact-disability-health-and-marital-status-shocks

Extended LTSS Utilization Makes Older Adults More Reliant on Medicaid: Issue Brief

 https://aspe.hhs.gov/basic-report/extended-ltss-utilization-makes-older-adults-more-reliant-medicaidissue-brief

Risk of Economic Hardship Among Older Adults: Issue Brief

• https://aspe.hhs.gov/basic-report/risk-economic-hardship-among-older-adults-issue-brief

CDC UPDATES

LISA C. MCGUIRE, PHD



COVID-19 Information for Older Adults



Older adults and people of any age who have serious underlying medical conditions are at higher risk for developing more serious complication from COVID-19 illness.



COVID-19 Guidance for Older Adults (cdc.gov)

COVID-19 Guidance for Older Adults: ADULT DAY SERVICE CENTERs (ADSCs)



Guidance for ADSC Participants and Caregivers

- Ways to protect yourself and other people
- What to do if you're sick or have been exposed to COVID-19
- What to do if you're worried, stressed, or sad
- Additional resources

Guidance for ADSC Administrators and Staff

- Promotion of vaccines and mitigation behaviors
- Strategies for healthy operations
- Maintenance of healthy environments
- Mental health resources



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COVID-19 Cases Among Nursing Home Residents and Staff Mirror Community Spread



- COVID-19 infection rates increased during June, July, and November 2020 among nursing home residents and staff.
- Trends in reported COVID-19 cases among nursing home residents and staff members resembled trends in COVID-19 incidence in surrounding communities. <u>Morbidity and Mortality Weekly Report, January 9, 2021.</u>



COVID-19 Information for Older Adults Mental Health and Social Isolation Among Older Adults



How Right Now



<u>HowRightNow.org</u> provides inspiration, tips, and resources to help manage and reduce any feelings of <u>stress</u>, <u>loneliness</u>, <u>worry</u>,

or sadness, you might be experiencing.

Social Isolation and COVID-19

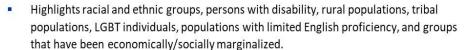


Dr. Craig Thomas discusses growing concerns of social isolation and loneliness among older adults before and during the COVID-19 pandemic.

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COVID-19 Information for Older Adults <u>Maintaining Physical and Mental Well-Being of</u> <u>Older Adults and Their Caregivers During Public</u>

Health Emergencies



- Key needs and concerns of older adults and caregivers during COVID-19 and needed assistance for older adults and caregivers
- Older adults' and caregivers' information-seeking behaviors and resource preferences
- Interventions and strategies focused on social isolation, deferral of medical care, management of chronic conditions, elder abuse and neglect, and deconditioning

The National Foundation of the Centers for Disease Control and Prevention funded this study conducted by NORC at the University of Chicago, with partners TMN Corp and Burness



HEALTHY AGING. HEALTHY BRAIN.



Resources: <u>The National Association of Chronic</u> <u>Disease Directors (NACDD) Rack Cards</u>

The NACDD partnered with CDC developed a series of visual information products to provide information about reducing risk for cognitive decline. The cards focus on areas such as healthy diet, adequate physical activity, and blood pressure management.









45

Resources: <u>Healthy Heart, Healthy</u> <u>Brain Editable Messaging</u>



- The Healthy Brain Initiative Road Map Series calls on public health to educate the public about steps to take to reduce risk of cognitive decline.
- The new editable templates provide ways people can work with their health care providers and independently to protect cognitive and heart health.



Resources: Managing Hypertension to Protect Heart and Brain Health



 Hypertension is a major risk factor for numerous health and chronic conditions, including cognitive impairment. The public health community can help reduce the risk of cognitive decline in populations by preventing and managing high blood pressure.



"[B]rain health should be as much on people's minds as heart health, breast cancer, and the war on smoking have been for decades."

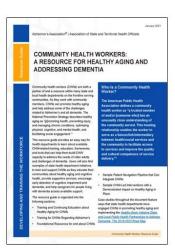
Former U.S. Surgeons General, Drs. Richard Carmona, Joycelyn Elders, Antonia Novello and David Satcher,

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Resources: Community Health Workers (CHW) Guide



The **new** <u>Community Health Workers (CHW):</u> <u>A Resource for Healthy Aging and Addressing Dementia</u> guide features how CHW can promote healthy aging and address dementia challenges.



RISK REDUCTION GOAL UPDATES

LISA C. MCGUIRE, PHD



Risk Reduction Goal

Rationale

- Advances in science of risk factors: Science continues to evolve in the
 prevention, identification, treatment, and management of Alzheimer's disease
 and related dementias (ADRD). The most current scientific information will be
 utilized to drive the development of this goal.
- <u>Preclinical stages of the disease</u>: The preclinical states of ADRD are ripe for
 primary prevention. Intervening during this portion of the life course will not
 only reduce or delay the onset on ADRD but also will help to maintain the
 health, well-being, and independence of older adults by improving the health of
 the nation.
- Heterogeneity of pathologies that cause dementias: Dementia symptomology is
 caused by multiple pathologies and combinations of pathologies. The
 intervention of risk factors known to prevent or delay onset of ADRD,
 regardless of pathology, is the key.

Objective

To develop a national goal to reduce the burden of risk factors in order to prevent or delay onset of Alzheimer's Disease and related dementias (ADRD)

Steering Committee



Matthew Baumgart

Vice President of Health Policy at Alzheimer's Association



Lisa C. McGuire, Ph.D.

Lead, Alzheimer's Disease Program

National Center for Chronic Disease Prevention and Health Promotion Division of Population Health



Kelly O'Brien

Executive Director of the Brain Health Ecosystem project at UsAgainstAlzheimer's

Process and Timeline

Process

- 1. Steering Committee Initial Meetings:
 - ➤ Establish Subcommittee Members
 - ➤ Develop initial recommendations
 - Form Workgroups (subset of risk factors)
 - Science, clinical intervention, and public health action
 - > Technical guidance for national risk reduction goal
- 2. Subcommittees revise recommendations
- 3. Steering Committee reviews and revises recommendations
- 4. Recommendations sent to broader review and then revised
- 5. Recommendations presented to NAPA Advisory Council

How to get involved as a reviewer: aging@cdc.gov

SUBCOMMITTEE MEMBERSHIP

Steering and Subcommittee Advisor: Alan Levey, NAPA co-chair

Expertise Categories:

- ➤ Public Health
- ➤ Clinical Care
- ►Innovation Industry
- **≻**Research

Selection Criteria/Consideration: Will include two members who fall into one of the categories above to serve as subcommittee members.

- > Multi-disciplinary, action-oriented, and diverse candidates
- Those with a history of working within the field (e.g., clinician, academic)
- ➤ Range of experiences and representation from fields of aging, cardiovascular disease, and other primary risk factor areas of AD/ADRD

Subcommittee Members



Jewel Mullen Dell Medical School



Joshua Chodosh New York University Langone Health



Laurie Whitsel American Heart Association, American Stroke Association



Caraline Coats Humana



Joe Chung Kinto Care, Redstar Ventures



Marilyn Albert Johns Hopkins Medicine



Karthik Sivashanker American Medical Association



Rebecca Gottesman Johns Hopkins University

Workgroup Leaders

Group A		Group B		Group C		Group D	
Joshua Chodosh	Jewell Mullen	Laurie Whitsel	Caraline Coats	Marilyn Albert	Joe Chung	Rebecca Gottesman	Karthik Sivashanker
Obesity		Physical Activity		Social Isolation		Hypertension	
Diet		Smoking/Tobacco		Depression		Hyperlipidemia	
Sleep		Alcohol		Hearing Loss		Diabetes	
Traumatic Brain Injury				Cognitive Activity			

Risk & Protective Factors Selected

- Alcohol
- Cognitive Activity
- Depression
- Diabetes
- Diet
- Hearing Loss
- Hyperlipidemia
- Hypertension

- Obesity
- Physical Activity
- Sleep
- Smoking/Tobacco
- Social Isolation
- Traumatic Brain Injury

Workgroup Members

Group A: Joshua Chodosh and Jewell Mullen	
Obesity, Diet, Sleep, Traumatic Brain Injury	
Jeannette Beasley	
Jennifer Martin	
Temitayo Oyegbile-Chidi	
Kristine Yaffe	
Alice Lichtenstein	

Group B: Laurie Whitsel and Caraline Coats						
Physical Activity, Tobacco Use, Alcohol						
Ross Arena	Aruni Bhatnagar					
Cedric Bryant	Jordan Endicott					
Hadiya Green Gerraro	James Galloway					
Mark Stoutenberg	Monica Rivera-Mindt					
Amy Bantham	Melinda Kelley					
Monica Cornelius	Alison Moore					
John Omura/ Kathy Watson						

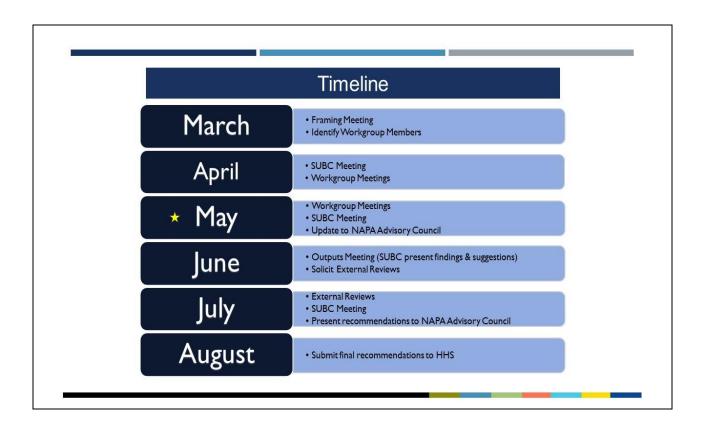
Workgroup Members

Group C: Marilyn Albert and Joe Chung
Social Isolation, Depression, Hearing Loss and Cognitive Activity
Carla Perissinotto
Ipsit Vahia
Meryl Butters
Frank Lin
Michael Marsiske

Group D: Rebecca Gottesman and Karthik Sivashanker						
Hypertension, Hyperlipidimia, Diabetes						
Heather Hodge						
David Hoffman						
Laura Baker						
Judy Hannan						

Framing Questions

- I. To what extent does the potential dementia risk and protective factor have strong evidence from a population-based perspective?
- 2. To what extent is the potential dementia risk and protective factor ripe for public health action (i.e., Does it have promising [strong evidence-based] community-level interventions)?
- 3. To what extent would the potential dementia risk and protective factor, if addressed by the public health community, have strong public health impact (including in diverse communities)?
- 4. Does the potential dementia risk and protective factor have interventions or actions that individual health care providers/teams can recommend to their individual patients?
- 5. Can the potential dementia risk and protective factor be addressed through policy and payment (systemic) changes, either at the federal, state, or private sector level?



WANT TO BE A REVIEWER?

Email: aging@cdc.gov

