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

Summit Virtual Meeting Series
July 10, July 21, and August 13, 2020

https://www.nia.nih.gov/2020-dementia-care-summit
2020 Summit Co-Chairs

David B. Reuben, MD
Director, Multicampus Program in Geriatric Medicine and Gerontology
Chief, Division of Geriatrics
Archstone Professor of Medicine
David Geffen School of Medicine at UCLA

Jennifer L. Wolff, PhD
Eugene & Mildred Lipitz Professor, Dept. of Health Policy and Management
Director, Roger C. Lipitz Center for Integrated Health Care, Johns Hopkins Bloomberg School of Public Health

#DementiaCareSummit
Portions of this event were made possible by the

with generous support from the following contributors:

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Alzheimer’s Association®

**GOLD SPONSORS:**
Biogen
The Shiley Foundation

**SILVER SPONSORS:**
The Association for Frontotemporal Degeneration
Avanir Pharmaceuticals
Home Instead Senior Care®
Welcome

• Purpose and Structure of Summit

• Organization of Gaps and Opportunities by Themes and Cross-Cutting Themes

• Process for Incorporating Input and Your Participation

• Summit Logistics
The primary anticipated outcome of the 2020 summit is the identification of gaps and opportunities for research priorities to inform federal agencies, foundations, and private sector organizations.

The Summit will also summarize the state of the science, identify gaps in knowledge, and highlight progress that has been made since, and as a result of, the 2017 Summit.
Restructuring to Accomplish Original Objectives

• Planned 2-day, in-person meeting March 24 & 25, 2020

• Due to COVID-19, switched to 3 virtual sessions in July & August 2020
  • Short research presentations
  • Introduction of draft research Gaps and Opportunities
  • Reactor panelists’ perspectives
  • Moderated questions and answers and discussion

• Summit Program with speaker bios: https://go.usa.gov/xfCss
Organization: Six Summit Themes

https://www.nia.nih.gov/2020-dementia-care-summit

• **Theme 1:** Impact of Dementia

• **Theme 2:** Long-Term Services and Supports in Home, Community, and Residential Care Settings for Persons with Dementia and their Caregivers

• **Theme 3:** Services and Supports in Medical Care Settings for Persons with Dementia

  **Integration:** The Present and Future of Integrated Long-Term and Medical Care

• **Theme 4:** Participation of Persons with Dementia and their Caregivers in Research

• **Theme 5:** Intervention Research, Dissemination, and Implementation

• **Theme 6:** Research Resources, Methods, and Data Infrastructure

#DementiaCareSummit
Organization: Cross-Cutting Themes

1. Perspectives from persons with dementia and their caregivers
2. Health disparities
3. Ethics
4. Technology
5. Etiologies
Process: Input from Various Sources Leads to Diverse Perspectives

- Request for Information (RFI) published in the NIH Guide in April 2019
- Summit Steering Committee
Summit Steering Committee

- Jennifer Wolff, Johns Hopkins University, Steering Committee Co-chair
- David Reuben, UCLA, Steering Committee Co-chair
- María Aranda, University of Southern California
- Susan Beane, Healthfirst
- Malaz Boustani, Indiana University School of Medicine
- Katie Brandt, Massachusetts General Hospital
- Chris Callahan, Indiana University School of Medicine
- Elena Fazio, National Institute on Aging
- Lori Frank, RAND
- Jason Karlawish, University of Pennsylvania
- Ian Kremer, LEAD Coalition
- Helen Lamont, Office of the Assistant Secretary for Planning and Evaluation, HHS
- Katie Maslow, Gerontological Society of America
- Michael Monson, Centene Corporation
- Vincent Mor, Brown University
- Joanne Pike, Alzheimer’s Association
- Melanie Schicker, Minnesota State University (Retired)
- Robyn Stone, LeadingAge
- Sheryl Zimmerman, University of North Carolina

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Process: Input from Various Sources Leads to Diverse Perspectives

- Request for Information (RFI) published in the NIH Guide in April 2019
- Summit Steering Committee
- HHS Office of the Assistant Secretary of Planning and Evaluation (ASPE) gathered input from 5 Stakeholder Groups
Stakeholder Groups

- Persons Living with Dementia
  - Co-Chairs: Gary Epstein-Lubow, Monica Moreno
- Family Caregivers of Persons Living with Dementia
  - Co-Chairs: Lisa Gwyther, Ann Cheslaw
- Service Providers, including in-home and community-based services, nursing home, rehabilitation, assisted living and hospice care, public health services, and health care professional groups
  - Co-Chairs: Doug Pace, Sarah Lock
- Workforce Development
  - Co-Chairs: Joan Weiss, Nina Tumosa, Robert Espinoza
- Payers
  - Co-Chairs: Elizabeth Goodman, Alice Bonner
Process: Input from Various Sources Leads to Diverse Perspectives

- Request for Information (RFI) published in the NIH Guide in April 2019
- Summit Steering Committee
- HHS Office of the Assistant Secretary of Planning and Evaluation (ASPE) gathered input from 5 Stakeholder Groups
- Input from federal partners
- Input from the NAPA Advisory Council
- Providing opportunities before, during, and after the Summit meetings for audience participation and engagement
Process: Producing Research Gaps and Opportunities

- Research Gaps and Opportunities are organized by Summit theme
- Stakeholder groups shared draft recommendations from their perspective with the Steering Committee during the planning process, for consideration
- Preliminary recommendations will be unveiled by theme/session
Your participation:

**During the session:** Zoom Q&A
- Submit a comment during the session using the Zoom Q&A. All will be read though time will not permit all to be discussed.

**During or after the session:** Respond to RFI
- Navigate to [https://www.nia.nih.gov/2020-dementia-care-summit#RFI](https://www.nia.nih.gov/2020-dementia-care-summit#RFI) to suggest a modification to a draft gap and opportunity OR suggest a new gap/opportunity.
- All suggestions will be reviewed after the session and before the finalized list is generated.

**After the Summit’s final Gaps and Opportunities are released:**
- Stay engaged and work towards implementing research that improves the lives of persons living with dementia and their caregivers.
Summit Virtual Meeting Series

Today’s Event: Virtual Meeting 1

• Welcome
• Setting the Stage
• Theme 1: Impact of Dementia
• Theme 4: Participation of Persons with Dementia and their Caregivers in Research
Setting the Stage

Richard Hodes, M.D., Director of the National Institute on Aging

Lonni Schicker, EdD, RN, Summit Steering Committee member, person living with dementia

Katie Brandt, MM, Summit Steering Committee member, Director of Caregiver Support Services and Public Relations for the Frontotemporal Disorders Unit at Massachusetts General Hospital, Co-Chair of the National Alzheimer’s Project Act Advisory Council on Alzheimer’s Research, Care, and Services

Arne Owens, Deputy Assistant Secretary, Office of Disability, Aging, and Long-Term Care Policy, ASPE

Laura Gitlin, PhD, FGSA, FAAN, 2017 Summit Co-Chair, Distinguished Professor and Dean of College of Nursing and Health Professions, Drexel University

#DementiaCareSummit
2020 National Research Summit on Care, Services, and Supports for People Living with Dementia and their Caregivers

Richard J. Hodes, M.D.
Director
National Institute on Aging

#DementiaCareSummit
NIA’s Commitment

• Promote health equity
• Eliminate health disparities
• Enhance the diversity of the scientific workforce
NIA AD/ADRD Appropriations

<table>
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</tr>
</thead>
<tbody>
<tr>
<td>NAPA</td>
<td>National Alzheimer’s Project Act (NAPA)</td>
<td>$50 M* redirected within NIH budget</td>
<td>$40 M* redirected within NIH budget</td>
<td>$100 M additional approp.</td>
<td>$25 M additional approp.</td>
<td>$350 M additional approp.</td>
<td>$400 M additional approp.</td>
<td>$414 M additional approp.</td>
<td>$425 M additional approp.</td>
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</tbody>
</table>

*One-year money
Years displayed are fiscal years

$350M in additional appropriations as of 12/20/19
# Growth of AD/ADRD Research Spending at NIH

## NIH Funding for AD/ADRD Research – *in millions*

From NIH’s Research, Condition, and Disease Categories (RCDC) System

<table>
<thead>
<tr>
<th>Research/Disease Areas (Dollars in millions and rounded)</th>
<th>FY 2015</th>
<th>FY 2016</th>
<th>FY 2017</th>
<th>FY 2018</th>
<th>FY 2019</th>
<th>Difference – FY15 to FY19</th>
</tr>
</thead>
<tbody>
<tr>
<td>AD/ADRD</td>
<td>$631</td>
<td>$986</td>
<td>$1,423</td>
<td>$1,911</td>
<td>$2,398</td>
<td>3.8-fold increase</td>
</tr>
<tr>
<td>Alzheimer's Disease</td>
<td>$589</td>
<td>$929</td>
<td>$1,361</td>
<td>$1,789</td>
<td>$2,240</td>
<td>3.8-fold increase</td>
</tr>
<tr>
<td>Alzheimer’s Disease Related Dementias¹</td>
<td>$120</td>
<td>$175</td>
<td>$249</td>
<td>$387</td>
<td>$515</td>
<td>4.3-fold increase</td>
</tr>
<tr>
<td>Lewy Body Dementia</td>
<td>$15</td>
<td>$22</td>
<td>$31</td>
<td>$38</td>
<td>$66</td>
<td>4.4-fold increase</td>
</tr>
<tr>
<td>Frontotemporal Dementia</td>
<td>$36</td>
<td>$65</td>
<td>$91</td>
<td>$94</td>
<td>$158</td>
<td>4.4-fold increase</td>
</tr>
<tr>
<td>Vascular Cognitive Impairment/Dementia</td>
<td>$72</td>
<td>$89</td>
<td>$130</td>
<td>$259</td>
<td>$299</td>
<td>4.2-fold increase</td>
</tr>
</tbody>
</table>

¹ The ADRD row reflects the sum of the three existing RCDC categories: Frontotemporal Dementia, Lewy Body Dementia, and Vascular Cognitive Impairment/Dementia—where duplicates are removed.

AHRQ-National Academies Study on Dementia Care & Caregiving

• Status:
  - Agency for Healthcare Research & Quality (AHRQ)
    AHRQ’s Minnesota Evidence Based Practice Center released a draft evidence review on March 24, 2020 and will release a final version soon
  - National Academies of Sciences, Engineering, and Medicine (NASEM)
    NASEM Committee held a public workshop on April 15, 2020 and will reconvene to draft their report, expected to be released in early 2021
NASEM Decadal Survey of Behavioral and Social Science Research on AD/ADRD

www.nas.edu/AlzheimersDecadal

Project Overview
The National Academies’ Division of Behavioral and Social Sciences and Education will appoint a committee to conduct a decadal survey focusing on developing a research agenda for the next decade in the behavioral and social sciences as it relates to Alzheimer’s disease (AD) and Alzheimer’s disease-related dementias (ADRD). For this Decadal Survey, drawing on extensive input from the scientific community, the committee will address the following questions:

CALL #1 FOR WHITE PAPERS
We are seeking input from researchers and stakeholder communities for the first phase of this project.

Submit White Papers
Data Sharing Resources for Researchers

There are a variety of data sharing policies, considerations, resources, and guidance available to support researchers in safely and efficiently sharing data from their studies. NIA also provides data resources to the Alzheimer’s and aging research community.

To learn more about data sharing at NIH, see the NIH Sharing Policies and Related Guidance on NIH-Funded Research Resources and the NIH Data Sharing FAQs,

https://www.nia.nih.gov/research/data-sharing-resources-researchers

https://www.nia.nih.gov/research/grants-funding/nia-specific-funding-policies#datasharing
Alzheimer’s Semipostal Stamp

Total Raised to Date: $1,061,777
AD/ADRD Summits

- ADRD Summits: 2013, 2016, 2019, 2022
- Dementia Care, Caregiving, & Services: 2017, 2020 (*virtually*)
Ways to Share Your Perspective:

- Participate in live discussions during today’s event and two future virtual meetings
- Respond to NIA’s Request for Information

https://www.nia.nih.gov/2020-dementia-care-summit
Why aren’t we all on the same page?

**My Journey**

1. Diagnosis
2. Communication
3. Planning for the future

*Lonni Schicker, EdD, RN, 2020 Summit Steering Committee member, person living with dementia, and retired registered nurse and professor of health administration*
Caregiver Perspective

Katie Brandt, Caregiver

July 10, 2020
National Institute on Aging

National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers
Love started the story...
Multi-Generational Impact
• Financial Vulnerability
• Employment Disruption
• Barriers to Accessing Services and Supports
• Loss of Community

Unique With Common Needs
• Respite
• Training and Education
• Community Connections
• Specialized Care Providers
Trifecta for Care Planning

Person Living With a Diagnosis, Care Partners, Family & Friends

Medical Community (Diagnosis, treatment options, research opportunities)

Home Community (Adult Day Health, Home Care, Memory Care, SNF, Hospice)

Disease Community (Education, Support Groups, Community Building Events)
Evolving Goals of Care

• Person and Family-Centered
• Incorporating Values and Culture
• Empowerment Through Education
Moving forward with love…
National Alzheimer’s Project Act (NAPA)
Advisory Council on Alzheimer’s Research, Care and Services

Co-Chair, Katie Brandt, MM, Massachusetts General Hospital, Frontotemporal Disorders Unit
Co-Chair, Allan Levey, MD, PhD, Emory University, Alzheimer’s Disease Research Center
Acknowledgement & Gratitude

Amy Almeida, PhD  
Loren Blanchard  
Noah Brandt  
Alicia Calef, MS  
Brad Dickerson, MD  
Albert Galaburda, MD  
Diane Lucente, MS, CGC  
Tom McMullen  
Megan Quimby, MS, CCC-SLP  
Bonnie Wong, PhD/ABPP-CN  
Alzheimer’s Association  
Association for Frontotemporal Degeneration  
Boston-area FTD Support Group  
Massachusetts Biotech Council  
National Alzheimer’s Project Act (NAPA) Advisory Council

Patients, Caregivers & Family Members in our Dementia Community

Given in Loving Memory of Michael Brandt & Diane McMullen
The principal advisor to the Secretary of the U.S. Department of Health and Human Services on policy development, and is responsible for major activities in policy coordination, legislation development, strategic planning, policy research, evaluation, and economic analysis.
National Alzheimer’s Project Act (NAPA)

Enacted January 4, 2011; Requires the Secretary of the U.S. Department of Health and Human Services (HHS) to establish the National Alzheimer’s Project to:

- Create and maintain an integrated national plan to overcome Alzheimer’s;
- Coordinate research and services across all federal agencies;
- Accelerate the development of treatments that would prevent, halt, or reverse the disease;
- Improve early diagnosis and coordination of care and treatment of the disease;
- Improve outcomes for ethnic and racial minority populations at higher risk;
- Coordinate with international bodies to fight Alzheimer’s globally; and
- Create an Advisory Council to review and comment on the national plan and its implementation.
National Plan

1. Prevent and Effectively Treat Alzheimer’s Disease by 2025

2. Optimize Care Quality and Efficiency

3. Expand Supports for People with Alzheimer’s Disease and Their Families

4. Enhance Public Awareness and Engagement

5. Track Progress and Drive Improvement
Advisory Council on Alzheimer’s Research, Care, and Services

12 members representing:
- 2 Patient Advocates, including a person living with dementia
- 2 Caregivers
- 2 Providers
- 2 State and local government reps
- 2 Researchers
- 2 Voluntary health association representatives

Public Members

- Meets quarterly
- Annual recommendations to Secretary and Congress on priority actions

Federal Members

Department of Health and Human Services
- ASPE, ACL, NIH, AHRQ, CMS, HRSA, IHS, FDA, CDC
- Department of Veterans Affairs
- Department of Defense
- National Science Foundation

Meets quarterly
Annual recommendations to Secretary and Congress on priority actions
National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers

- First Summit in 2017 - result of a recommendation of the Alzheimer’s Advisory Council

- Gaps and opportunities identified through Summit will inform:
  - NIA research plans
  - Recommendations of the Advisory Council

- Opportunity to take advantage of great minds in the field
Thank You!

For more information, see:

http://aspe.hhs.gov/daltcp/napa
2020 National Research Summit on Care, Services, and Supports for People Living with Dementia and their Caregivers

Progress to Date

Laura N. Gitlin, Ph.D. FGSA, FAAN
Distinguished Professor, Dean, College of Nursing and Health Professions
Drexel University
Adjunct Professor, Johns Hopkins School of Nursing
#DeanDrexelCNHP

#DementiaCareSummit
Funding Sources and Disclosures

Funded by:

- National Institute on Aging
- National Institute on Mental Health
- Veterans Administration
- PA Department of Tobacco
- Alzheimer’s Association
- Administration on Community Living

Disclosures:

Consultant to various community-based agencies concerning dementia care;

Inventor of an online program for an intervention (Tailored Activity Program) for which Johns Hopkins University, Drexel University, and Dr. Gitlin are entitled to fees.
Where We Began:

October 2017

Goals of First Historic Summit

• Identify existing evidence & what we need to know to provide comprehensive dementia care that improves quality of care & outcomes across all care settings and for individuals/families from diverse backgrounds & living situations

• Embrace complexity:
  • Recognize, examine and understand diversity defined broadly as:
    • race, ethnicity, gender, age, etiologies, disease stages, living arrangements, geography, financial status, social and structural determinants of access to care, quality of care received & role of discrimination and racism
Paradigm switch:
• Care is important & matters
• Care can address clinical symptoms, may slow disease progression
• Involving people living with dementia & care partners aligns research questions and measures with what matters
• Need to involve stakeholders throughout research process
• We have evidence we can move to the real world
464 recommendations

12 “Buckets” of recommendations

- Heterogeneity
- Lived experience
- Caregiver relationships, roles networks
- Person/family-centered care models spanning disease continuum and etiologies
- Engaging people living with dementia as research team members
- Financial burdens and cost of care
- Living environments & arrangements
- Nomenclature
- Workforce development
- Research methods (Measurement)
- Scale up/disseminate evidence
- Technology

Since October 2017 Summit
NIA Funding Opportunities

26 funding opportunities and 4 Notices of Special Interest on
dementia care and caregiving topics such as:

- home and community-based services
- lucidity in dementia
- pragmatic dementia care clinical trials
- care and caregiver support interventions
- assistive technology
- dementia care workforce
- interpersonal processes with care partners and health care providers

Slide provided by the NIA.
Since October 2017 Summit: NIA Awards

• Approximately **129 new NIA awards** came out of care-related funding opportunities (does **not include** awards from other NIH Institutes or continuing awards)

• Number of awards **will likely increase as** some opportunities are still accepting applications

• Many **more** awards have been granted to **investigator-initiated research** on dementia care and caregiving topics (i.e., not submitted to a targeted funding opportunity)

• **RFA-AG-18-030** Dementia Care and Caregiver Support Interventions

• **RFA-AG-19-007** Roybal Centers for Translational Research on Dementia Care Provider Support

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Measuring What Matters
LINC-AD: Leveraging an Interdisciplinary Consortium to Improve Care and Outcomes for Persons Living with Alzheimer’s and Dementia (R24AG065185)

• Led by Dr. Fazio (Alzheimer’s Association), Dr. Zimmerman (University of North Carolina), and members of Alzheimer’s Association with guidance from 38 Research Steering Committee Members and a Care and Support Advisory Group
  o Critique existing outcome measures and care tools and identify gaps
  o Promote development of new outcome measures and care tools
  o Facilitate dissemination, adoption, implementation, and sustained use of existing and new outcome measures and care tools

Slide adapted from NIA.
# Heat Map of Caregiver Outcomes

(54 Published Efficacy Studies)

## Intervention Setting

<table>
<thead>
<tr>
<th>Intervention Setting</th>
<th>Mental Health</th>
<th>Stress/Strain/Burden</th>
<th>Physical Health</th>
<th>Psychosocial Resources</th>
<th>Quality of Life/Well-being</th>
<th>Social Support</th>
<th>Dyad Relationship</th>
<th>Knowledge</th>
<th>Community Resource Utilization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>6</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Hospital/Medical Center</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Telephone/Web-based</td>
<td>11</td>
<td>13</td>
<td>7</td>
<td>7</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Community Space (Library, School, Adult Day Service</td>
<td>7</td>
<td>7</td>
<td>3</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>1</td>
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## Totals

|                      | 27            | 29                   | 16              | 19                     | 10                        | 9             | 6                | 3         | 6                           |

## # of Interventions

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<th>1-3</th>
<th>4-6</th>
<th>7-9</th>
<th>10+</th>
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Gitlin et al., NIA IMPACT Dissemination and Implementation Core, Manuscript in Progress
LINC-AD

Promote measures that …

• Foster a constructive balance between strength and deficit assessments

• Consider measures from different stakeholder perspectives and a health equity lens

• Provide a practice-based conceptual framework to inform measurement

• Emphasize evidence-based tools to guide structures and processes of care
Implementing Evidence in Healthcare Settings

NIA IMbedded Pragmatic Alzheimer’s Disease (AD) and AD-Related Dementias (AD/ADRD) Clinical Trials (IMPACT) Collaboratory (PIs: Mor and Mitchell)

The Collaboratory aims to:

- Spur innovation to improve dementia care
- Develop and disseminate technical, policy, and best practices for moving evidence to health systems
- Enhance research development and investigator capacity
- Engage a variety of stakeholders
- Provide technical assistance in pragmatic trial design

Slide adapted from NIA.
iCare- AD/ADRD Challenge

- 33 submissions for mobile device applications or web-based methods
- 1st place: MapHabit- mobile app (Dr. Zola)
- 2nd place: Dementia Care Software System (UCLA; Dr. Reuben)
- 3rd place: Caregiver411 (N.C. A&T State)- mobile app (Dr. Naney)

https://nia.nih.gov/challenge-prize
• Peer navigator
• DICE approach
  • WeCareAdvisor Prescription
• Caregiver Survival Guide
• Daily messaging (emails)

Funded by NIA (R01AG061116)
Gitlin, Kales, Lyketsos

Outcomes for caregivers (N=57)

- Decreased distress
- Improved confidence
- Trend in reduction in severity of behavioral symptoms

Gitlin et al., 2017
Kales et al., 2018
• Within 33 months, NIA produced an impressive array of initiatives and awards (with more forthcoming).

• Science of care and services at a critical inflection point:
  • Next three years promises to yield important new understandings of lived experiences, testing of novel care approaches for diverse populations & settings, integration of evidence in different healthcare systems

• While intervention development is slow, new iterative models, technology, implementation science and pragmatic trial designs hold promise of accelerating use of evidence in care settings to address different care needs to improve everyday life.

• We have a lot of work ahead but with recognition of the importance of involving stakeholders and evidence how to do so effectively, the future is promising.