



# The Alzheimer's Disease Centers Program

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Presented at Directors Meeting, April 21, 2018, Los Angeles, CA





# Topics to cover

- ADC RFA
- Update on recommendations for ADC program (Greenberg)
- Workgroup updates
- GUID update
- [EAC guidelines](#)
- Down Syndrome neuropath
- Other neuropath updates – NBB, catalog
- Genetic Disclosure working group
- VA – TBI
- Recruitment Repository
- NIA ADC webpage
- Morris U13 – Workshop addressing African American participation in AD research






# New RFA

- RFA AG-19-001
- P30 – Alzheimer’s Disease Research Center
- Biomarker core requirement
- REC
- Projects/Pilots now “Developmental Projects”
- Can and should apply for R01s and other grants to utilize resources at your center



# Recommendations for ADC program



HEALTH INFORMATION	RESEARCH & FUNDING	NEWS & EVENT
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[Home](#) / [News & Events](#) / [Expert panel offers transformative recommendations for NIH Alzheimer's research centers](#)

DIVISION ANNOUNCEMENTS

## Expert panel offers transformative recommendations for NIH Alzheimer's research centers

June 29, 2017

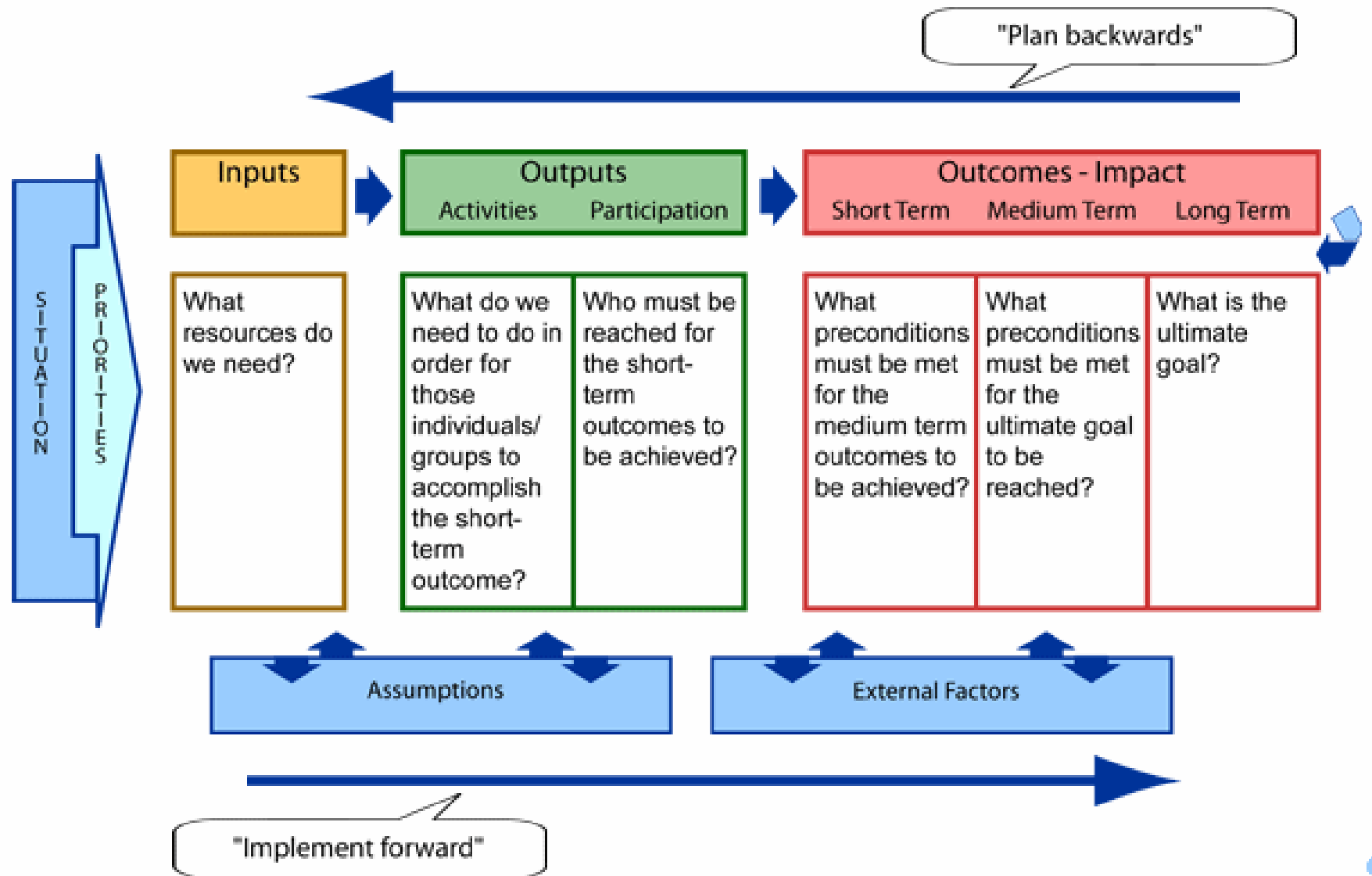
The National Institutes on Aging engaged leading experts from academia, industry and non-profit foundations, working in Alzheimer's and other complex diseases, in a strategic planning process to help ensure that the next generation of AD Centers is poised to accomplish the goals of the [National Alzheimer's Plan](#). The primary focus of this planning effort has been to develop recommendations for how the network of Alzheimer's Disease Centers can best support the implementation of the new integrated translational research agenda put forward at the [2012](#) and [2015](#) Alzheimer's Research Summits, as well as the [ADRD summits](#), and outlined in the research implementation [milestones](#). The 166 resulting recommendations

► Available on NIA web page:

<https://www.nia.nih.gov/news/expert-panel-offers-transformative-recommendations-nih-alzheimers-research-centers>



# Logic Model







# Imaging workgroup

## Led by Bill Jagust

- Duane Beekly (UW/NACC)
- Tammie Benzinger (Wash U)
- Charlie DeCarli (Davis)
- Brad Dickerson (Harvard/MGH)
- Cliff Jack (Mayo)
- Bill Jagust (Berkeley)
- Sterling Johnson (Wisconsin)
- Bud Kukull (UW/NACC)
- Beth Mormino (Stanford)
- Gil Rabinovici (UCSF)
- Emily Rogalski (Northwestern)
- Andy Saykin (Indiana)
- Nina Silverberg (NIA)
- Cerise Elliott (NIA)
- John Hsiao (NIA)





# Biomarker Workgroup

- Thank you to Doug Galasko and Donna Wilcock
- And to Kaj Blennow, Eric Reiman and Tatiana Foroud
- No workgroup yet





## Genetic and Biomarker Disclosure Working Group

**Scope:** Genetic and Biomarker measures are increasingly being investigated to inform about potential risk for cognitive decline or dementia, identify “high” risk persons to enroll in clinical trials, and provide greater diagnostic specificity in those experiencing cognitive change or decline.

**Expectation:** There is an increased interest from individuals to obtain and learn about their genetic and biomarker results and have an explanation of what these tests and results mean by the members of the clinical and research teams.

**Goal:** Provide recommendations on when and how genetic and biomarker information should be obtained and disclosed in both research and clinical settings and best practices for disclosing this information



# Genetic and Biomarker Disclosure Working Group

## Progress to date:

- Initial WG call noted that group should be inclusive with diverse group of stakeholders, including geneticists, genetic counselors, clinical trial team members, researchers, patients, professional organizations and advocacy groups
- NHGRI interested in partnering with our WG
- In process of reaching out to NCI, NHLBI

## Future plans:

- Conduct Listening Tours and Calls to discuss what the gaps are regarding Genetics and Biomarker Disclosures
- Development of specific Workstreams for Genetics and Biomarkers with specific Deliverables for each group



**Working Group Primary  
Lead: Neelum T. Aggarwal,  
MD (Rush)**

**Interested in participating?**  
Contact Dr. Cristan Smith  
[cristan.smith@nih.gov](mailto:cristan.smith@nih.gov)





# UDS Workgroup – Background

- NIA Division of Neuroscience Review explicitly recommended an evaluation of the UDS. Some concerns raised were:
  - Measures are not the most current
  - Measures were not selected in order to support hypothesis driven research
  - Length of UDS might inhibit other affiliated research
  - Other measures might be better for capturing other dementias/mixed dementia
- The Recommendations for the future of the centers program included a focus on critically evaluating the UDS.
- Multiple center directors have requested changes, including annual visit requirement
- Compelled to review
- Charge to the workgroup: consider all aspects, aim to improve scientific utility of UDS while addressing site and participant burden.





# UDS Workgroup update

- ✓ Group formed: Led by R. Petersen; A Saykin, C Carlsson, J Schneider, S Hendrix, J Galvin, J Manly, O Lopez, J Hassenstab
- ✓ Survey developed
- ❑ Sorting through results
- ❑ Next steps
  - ❑ **Considerations:** Data/Recommendations from NACC and others on utilization and utility, survey results, expert opinion from workgroup members
  - **Important value:** Weigh existing longitudinal data collection, importance of having uniform data from all ADCs, effort involved in changes, translations into Spanish and Chinese, other studies using UDS
  - ❑ Propose any changes, discuss implications
  - ❑ Implement



# NIA GLOBAL UNIQUE IDENTIFIER (GUID) PORTAL

Progress to Date & Next Steps



Biomedical Research Informatics Computing System (BRICS)

National Institutes of Health (NIH)  
National Institute of Aging (NIA)  
Website: <https://www.nia.nih.gov>

NIH... Turning Discovery Into Health

Contact Us | Policies & Notices | FOIA | National Institutes of Health | USA.gov

Build Version: 3.3.0.711

- Product of a collaboration between NIH Center for Information Technology (CIT) and NINDS, NIA GUID Portal is in beta testing mode;
- Portal allows users to:
  - *create actual and pseudo GUIDS;*
  - *Upload batch information to generate multiple GUIDS*
- Account access and set-up is managed by NIA BRICS Operations Team





## GUID (Global Unique Identifier)

### GUID Tool

GUID Overview

Create GUIDs

My GUIDs

GUID Admin

### GUID Client

Functions About

#### Required Fields

1. Complete legal given (first) name of subject at birth
2. Does the subject have a middle name?
3. Complete additional (middle) name or names at birth
4. Complete legal family (last) name of subject at birth
5. Day of birth [1-31]
6. Month of birth
7. Year of birth [####]
8. Name of city/municipality in which subject was born
9. Country of birth

#### Optional Fields

10. Physical sex of subject at birth [M/F]
11. Government Issued or National ID
12. Country issuing Government-Issued or National ID

GUID

#### Please enter subject's information (PII):

1.
2. ☐ Yes ☐ No
3.
4.
5.
6.
7.
8.
9.

#### Please confirm (re-enter) the subject's information

1.
2. ☐ Yes ☐ No
3.
4.
5.
6.
7.
8.
9.

Generate GUID

Copy GUID

Copy GUID and PII

Clear / New

Exit



# Next Steps

## **LAUNCH NIA GUID PORTAL (late May 2018)**

Release to pilot AD Clinical  
Sites

Provide continuous user  
feedback to developers

## **ADOPTION OF PORTAL ACROSS NIA CLINICAL SITES (May 2019)**

Roll out portal to all AD Clinical  
Sites

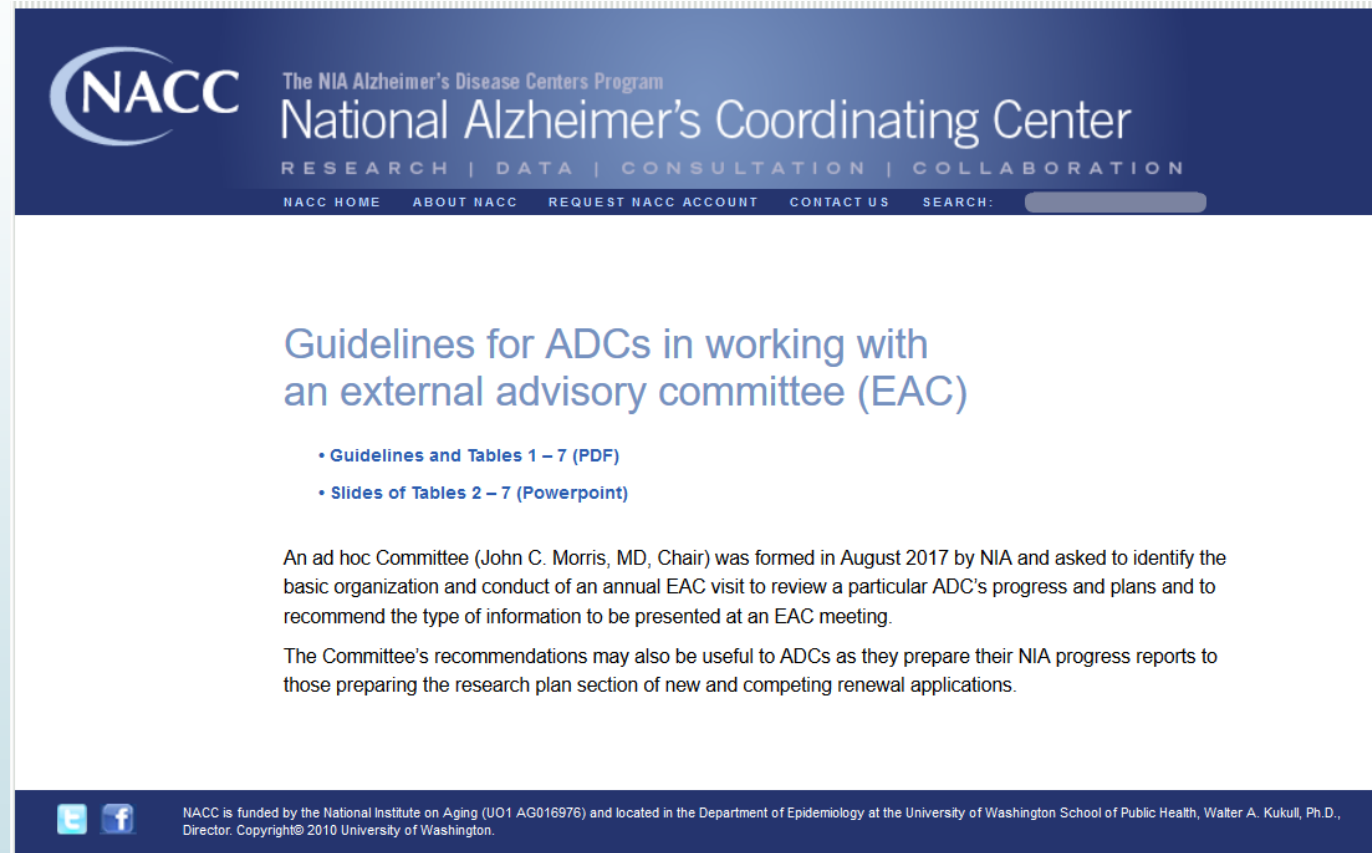
Roll out portal to all NIA Sites

## **CENTRALIZED NIA/NINDS PORTAL (December 2018)**

Alignment of participants enrolled in NIA and NINDS-funded  
clinical studies



# EAC Guidelines – Thank you John Morris



The screenshot shows the NACC (National Alzheimer's Coordinating Center) website. The header is dark blue with the NACC logo and text: "The NIA Alzheimer's Disease Centers Program", "National Alzheimer's Coordinating Center", and "RESEARCH | DATA | CONSULTATION | COLLABORATION". Below the header is a navigation bar with links: "NACC HOME", "ABOUT NACC", "REQUEST NACC ACCOUNT", "CONTACT US", and "SEARCH:". The main content area is white and features the title "Guidelines for ADCs in working with an external advisory committee (EAC)". Below the title are two bullet points: "• Guidelines and Tables 1 – 7 (PDF)" and "• Slides of Tables 2 – 7 (Powerpoint)". The text describes the formation of an ad hoc Committee (John C. Morris, MD, Chair) in August 2017 by NIA to identify the basic organization and conduct of an annual EAC visit. It also mentions that the Committee's recommendations may be useful to ADCs as they prepare their NIA progress reports. The footer is dark blue and contains social media icons for Twitter and Facebook, along with funding information: "NACC is funded by the National Institute on Aging (U01 AG016976) and located in the Department of Epidemiology at the University of Washington School of Public Health, Walter A. Kukull, Ph.D., Director. Copyright© 2010 University of Washington."

**NACC** The NIA Alzheimer's Disease Centers Program  
National Alzheimer's Coordinating Center  
RESEARCH | DATA | CONSULTATION | COLLABORATION  
NACC HOME ABOUT NACC REQUEST NACC ACCOUNT CONTACT US SEARCH:

## Guidelines for ADCs in working with an external advisory committee (EAC)

- Guidelines and Tables 1 – 7 (PDF)
- Slides of Tables 2 – 7 (Powerpoint)

An ad hoc Committee (John C. Morris, MD, Chair) was formed in August 2017 by NIA and asked to identify the basic organization and conduct of an annual EAC visit to review a particular ADC's progress and plans and to recommend the type of information to be presented at an EAC meeting.

The Committee's recommendations may also be useful to ADCs as they prepare their NIA progress reports to those preparing the research plan section of new and competing renewal applications.

NACC is funded by the National Institute on Aging (U01 AG016976) and located in the Department of Epidemiology at the University of Washington School of Public Health, Walter A. Kukull, Ph.D., Director. Copyright© 2010 University of Washington.

Available on the NACC website:

[https://www.alz.washington.edu/WEB/eac\\_guidelines.html](https://www.alz.washington.edu/WEB/eac_guidelines.html)



# Neuropath Steering Committee update

- Steering committees generally starting to do more. This one has been very active!
- Planning meeting at NIH on transmissibility risk – May 2

The Newsweek logo, featuring the word "Newsweek" in white, bold, sans-serif font on a red rectangular background.

**ALZHEIMER'S DISEASE PROTEINS MAY BE CONTAGIOUS AND SPREAD THROUGH DIRTY MEDICAL TOOLS**

BY **DANA DOVEY** ON 2/17/18 AT 8:05 AM

- Active planning for Down Syndrome Neuropath module to connect with ABC-DS effort
- Discussing pros/cons and prioritization of digital slide scanning
- Following up on career development awards
- Work with Neurobiobank, Brain donation guidelines



**NeuroBioBank**  
*Facilitating Research and Creating Awareness*



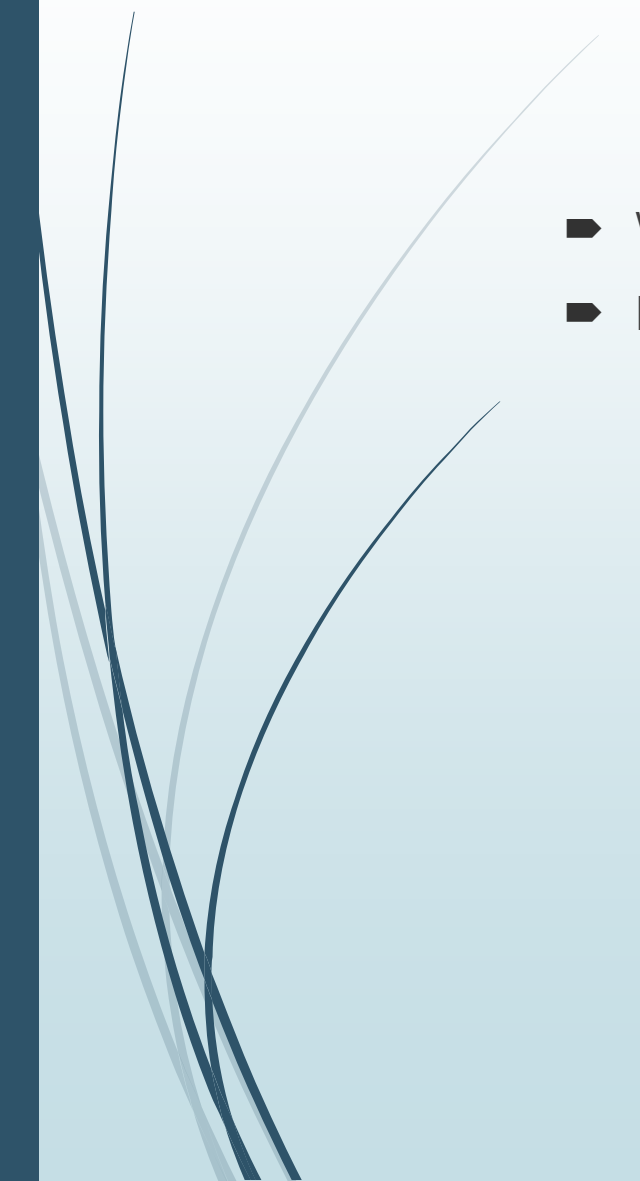
- Will be listed on NACC website
- Will be linked from Neurobiobank

[illegible]





# Your slide here

- What would you like to see and hear about?
  - Poll
- 



# Strategic Partnership to Advance Research and Knowledge (SPARK) – Dementia Research

- Goal - Develop and implement a collaborative framework to facilitate co-funding and support of shared Dementia research priorities between NIH and the VA
- The NIH and VA are the leading federal funders of Dementia research with both supporting dynamic and diverse portfolios
- Opportunity to develop a sustainable process for collaboration and address key barriers or challenges that often hinder communication, sharing of resources and increased coordination between our two organizations.
- The pilot effort will focus on TBI as a risk factor for AD/ADRD
- Develop a workshop to identify gaps in the field and future research priorities



Strategic Partnership for Advancing Research and Knowledge (SPARK):  
TBI as a Risk factor for Dementia

Department of Veteran Affairs and National Institutes of Health  
Dr. Rachel Ramoni, Dr. Richard Hodes and Dr. Eliezer Masliah

Co-Leads –  
Charlene Liggins, Lisa Opanashuk, Nina Silverberg, Alex Chiu

Basic Disease  
Mechanisms  
Work Group

Genetic and  
Population  
Studies Work  
Group

Diagnoses and  
Disease  
Monitoring  
Work Group

Translational  
and Clinical  
Research Work  
Group

Care and  
Caregiving  
Research Work  
Group

Overarching topics - Technology, Recruitment/Retention of Study Participants,  
Health Disparities, Support New & Early Investigators



# NIA Council approved concepts

<https://www.nia.nih.gov/approved-concepts>

## Approved Concepts

Below are concepts approved at the most recent National Advisory Council on Aging (NACA) meetings. We have posted the approved concepts here to give interested researchers maximal lead time to plan projects. Please note that not all concepts will necessarily end up converting to a Funding Opportunity Announcement (FOA), and some of the concepts listed below (particularly from older Council meetings) may have already been converted to FOAs.

- [January 2018](#)
- [September 2017](#)
- [May 2017](#)

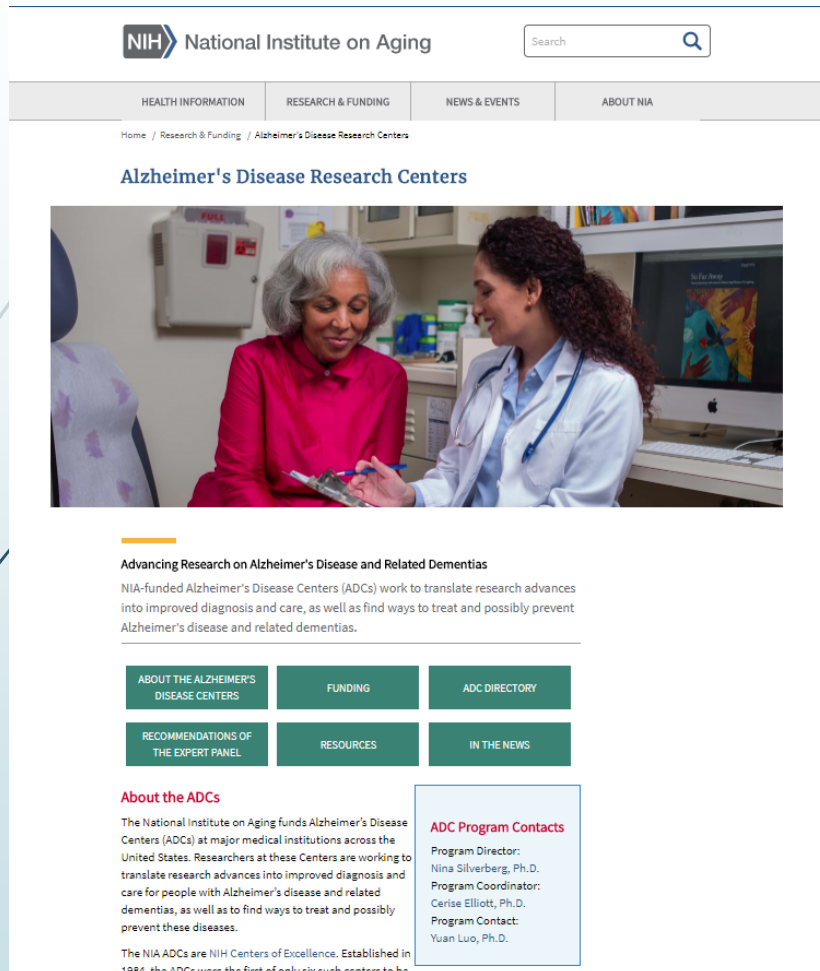
## NIA Small Research Grant Program for Investigators New to Alzheimer's Disease and Alzheimer's Disease-Related Dementias Research

A major goal in the [National Plan to address Alzheimer's disease and Alzheimer's disease-related dementias \(AD/ADRD\)](#) is to accelerate the development of treatments that would prevent, delay or reverse the course of Alzheimer's and improve early diagnosis. However, there is a workforce shortage to conduct the wide variety of innovative and interdisciplinary research, including clinical, translational, prevention, and treatment research in AD/ADRD. This small grant program concept will address [National Alzheimer's Project Act \(NAPA\)](#) Milestone 4.1: "to establish new training programs as well as fellowship and career development programs to develop a new translational and data science workforce" especially targeting recruitment of junior investigators to NIA's AD/ADRD portfolio. A major barrier for non-AD researchers to obtain an R01 grant to conduct AD research is the lack of critical preliminary data. This FOA would help them to overcome this barrier.

The overall goal of this FOA is to support important and innovative research in areas in which more scientific investigation is needed to improve the prevention, diagnosis, treatment, and care for AD/ADRD. The aim is to encourage the next generation of researchers in the United States to pursue research and academic careers in neurosciences, Alzheimer's disease, and healthy brain aging. Another aim is to stimulate novel research ideas from researchers in other fields.



# ADCs In the News – current, future plans




The screenshot shows the NIH National Institute on Aging website. The header includes the NIH logo, the text "National Institute on Aging", and a search bar. Below the header is a navigation bar with links: HEALTH INFORMATION, RESEARCH & FUNDING, NEWS & EVENTS, and ABOUT NIA. The main content area is titled "Alzheimer's Disease Research Centers" and features a photograph of an elderly woman in a red shirt and a healthcare professional in a white lab coat. Below the photo is a section titled "Advancing Research on Alzheimer's Disease and Related Dementias" with a paragraph of text. Underneath this is a grid of six green buttons: ABOUT THE ALZHEIMER'S DISEASE CENTERS, FUNDING, ADC DIRECTORY, RECOMMENDATIONS OF THE EXPERT PANEL, RESOURCES, and IN THE NEWS. At the bottom, there is a section titled "About the ADCs" with a paragraph of text, and a box titled "ADC Program Contacts" listing the Program Director (Nina Silverberg, Ph.D.), Program Coordinator (Cerise Elliott, Ph.D.), and Program Contact (Yuan Luo, Ph.D.).

NIH National Institute on Aging

HEALTH INFORMATION RESEARCH & FUNDING NEWS & EVENTS ABOUT NIA

Home / Research & Funding / Alzheimer's Disease Research Centers

## Alzheimer's Disease Research Centers



**Advancing Research on Alzheimer's Disease and Related Dementias**

NIA-funded Alzheimer's Disease Centers (ADCs) work to translate research advances into improved diagnosis and care, as well as find ways to treat and possibly prevent Alzheimer's disease and related dementias.

ABOUT THE ALZHEIMER'S DISEASE CENTERS FUNDING ADC DIRECTORY

RECOMMENDATIONS OF THE EXPERT PANEL RESOURCES IN THE NEWS

**About the ADCs**

The National Institute on Aging funds Alzheimer's Disease Centers (ADCs) at major medical institutions across the United States. Researchers at these Centers are working to translate research advances into improved diagnosis and care for people with Alzheimer's disease and related dementias, as well as to find ways to treat and possibly prevent these diseases.

The NIA ADCs are NIH Centers of Excellence. Established in 1984, the ADCs were the first of only six such centers to be

**ADC Program Contacts**

Program Director:  
Nina Silverberg, Ph.D.  
Program Coordinator:  
Cerise Elliott, Ph.D.  
Program Contact:  
Yuan Luo, Ph.D.

## Featured Content:

- Spotlight on Scientists
  - Awards
  - Community Outreach
  - Highlights from your newsletters
  - Findings from recent publications
- 
- Updated quarterly
  - Email your submissions to Nina Silverberg and Cerise Elliott

<https://www.nia.nih.gov/research/adc>

## In the News

Read the latest news from the ADCs.

- My Grandmother Is Donating Her Brain to Science® (Article in *The Atlantic*)
- Disrupted sleep-wake cycle might be measure for preclinical Alzheimer's
- Complexities, combinations of age-related brain conditions are challenge to combating cognitive decline
- Decade after menopause poses highest risk of Alzheimer's for women with ApoE4 gene
- First-ever atomic look at tau fibril structure in Alzheimer's reveals detailed pathways
- Moderate physical activity linked to increases in metabolism across brain regions



# Alzheimer's Disease and Related Dementias Recruitment Repository

## Provide a Repository for investigators

Recruitment happens at the local level, where investigators and study sites must find resources to get potential participants in the door. To facilitate those efforts, we are developing a **Recruitment Repository** (a central online portal) which will feature and make widely available a collection of materials related to planning, budgeting, and implementing recruitment efforts for trials and studies.

### Goal:

Serve as comprehensive, web-based resource of materials, tools, and best practices to support recruitment and retention efforts in clinical studies

**Please email your  
resources to  
[NIAADRR@mail.nih.gov](mailto:NIAADRR@mail.nih.gov)**

Boston University	University of Kansas
Indiana University	University of Kentucky
Oregon Health & Science University	University of Michigan
Rush University	University of Pennsylvania
Stanford University	University of Pittsburgh
UC Davis	University of Wisconsin
UC Irvine	Washington University
UC San Francisco	Wake Forest University



# AFRICAN AMERICAN PARTICIPATION IN ALZHEIMER RESEARCH: EFFECTIVE STRATEGIES



**October 9-10, 2018**

**Washington University School of Medicine in St. Louis**

**★ ★ Travel costs for two leaders from each ADC will be covered ★ ★**

**Learn more: [phillipsj@wustl.edu](mailto:phillipsj@wustl.edu) / 314.286.2882**