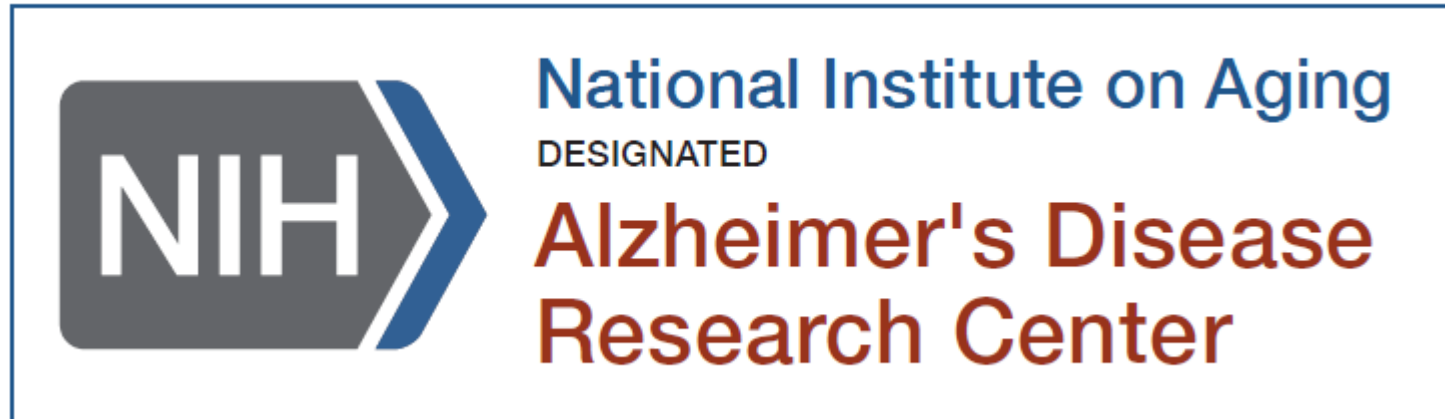


Introducing....
The badge:



Research Supplements to Promote Diversity in Health-Related Research (Admin Supp Clinical Trial Not Allowed)

NIA Diversity and Re-entry Supplement Program Guidelines

- Overview
- Guidelines for Submission
- How to Prepare Your Application
- Review and Funding

<https://www.nia.nih.gov/research/grants-funding/nia-diversity-and-re-entry-supplement-program-guidelines>

Notice to Specify High-Priority Research Topic for PAR-19-070

Notice Number: NOT-AG-18-049

Key Dates

Release Date: November 29, 2018

Related Announcements

[PAR-19-070](#)

Issued by

National Institute on Aging ([NIA](#))

Purpose

This Notice of Information specifies a high-priority topic of interest for PAR-19-070 "Research on Current Topics in Alzheimer's Disease and Its Related Disorders (Optional)".

Collaborative Studies on Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD)

The National Institute on Aging engaged leading experts from academia, industry, and non-profit foundations, working in Alzheimer's and other centers, to help ensure that the next generation of Alzheimer's Disease Centers (ADCs) is poised to accomplish the goals of the National Alzheimer's Coordinating Center (NACC) resulting [recommendations](#) included several specific ideas centered around collaboration, including developing greater opportunities for collaborative interactions with other center programs, and making the resources at the ADCs available to outside investigators.

Building on this notion, this high-priority topic provides the opportunity to facilitate collaborative cross-disciplinary and multi-institutional approaches to study the clinical and pathological course of both normal aging and AD/ADRD. Scientists within and outside the ADCs can gain access to the availability of neuropathological data on thousands of participants) as well as support the collection and integration of new data and samples. This will allow investigators and a wider participation in the design, analysis and interpretation of studies utilizing these unique resources, further leveraging the existing resources and data to answer a broad range of scientific questions. Project data may be used for new grants and/or provide standardized value to AD and ADRD research goals.

Cleared concepts: An early heads-up for savvy scientists seeking funding

February 13, 2019



Marie A. BERNARD,
*Deputy Director,
Office of the Director (OD).*

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

Increasing Competitiveness of Potential Alzheimer's Disease Centers (ADRCs)

ADRCs are poised to play a leading role in many aspects of Alzheimer's disease and related dementias (AD/ADRD) research, including understanding the mechanisms that lead to cognitive and behavioral impairment, and identifying as well as validating novel biomarkers of the disease. In order to meet the goals of the National Alzheimer's Project Act, the program needs to include new areas of focus and provide research participation opportunities to new and more diverse participants across the country.

Enabling Storage, Processing and Sharing of Standardized Alzheimer's and Related Dementia Neuroimaging Biomarkers

Attention, ADCs

Promote your studies and **share** them with researchers around the world

Does your Center have a study that may be a resource for researchers outside your ADC? If so, NIA invites you to promote it on the NACC website.

Just fill out a quick questionnaire, and NACC will post a brief description, along with your logo and a link to the study website.

GET THE QUESTIONNAIRE: naccmail@uw.edu



The NIA Alzheimer's Disease Centers
National Alzheimer's
RESEARCH | DATA CENTER

BIOSPECIMEN BEST PRACTICE GUIDELINES FOR THE ALZHEIMER'S DISEASE CENTERS

VERSION 3.0 (24JUNE 2014)

ADC ADMINISTRATORS

DATA CENTER

Biospecimen best practice guide for the Alzheimer's Disease Centers

- [2014 Best Practice Guidelines in Word](#)
- [Additional 2014 Guidelines in PDF — Induced Pluripotent Stem Cells](#)

Table of Contents

Blood and Urine Guideline.....	2
Cerebrospinal Fluid Guideline.....	6
Brain Guideline	9
DNA / RNA / Protein Guideline.....	12
Induced Pluripotent Stem Cells Guideline.....	15
Metabolomics and Proteomics Guidelines.....	16
Informatics Guideline.....	22
Informed Consent, Confidentiality and Privacy Guideline.....	24
Disseminating and Discarding Guideline.....	27
Cost Recovery Guideline.....	31
Intellectual Property Guideline.....	33
Material Transfer Guideline.....	34

DIVISION ANNOUNCEMENTS

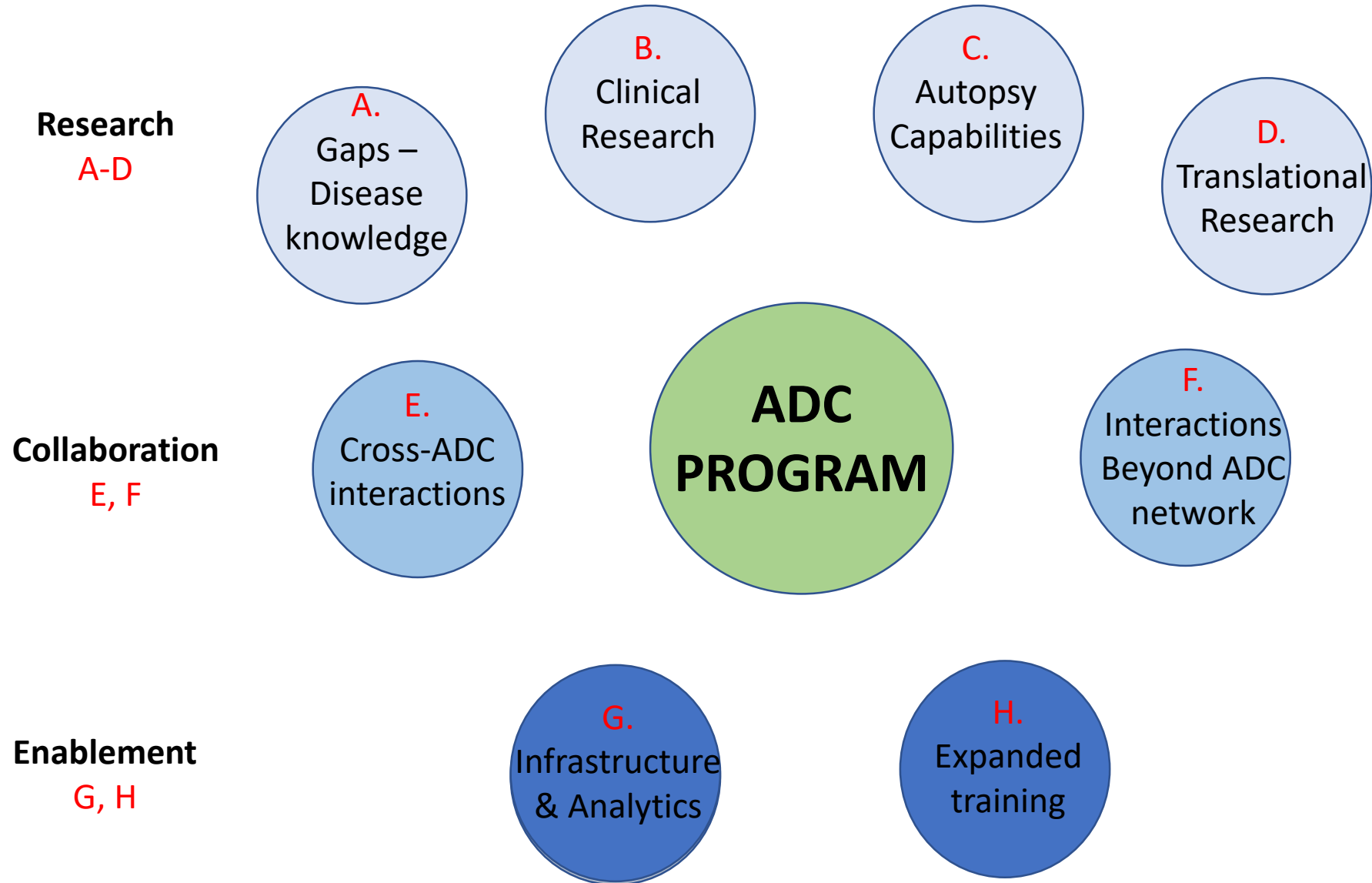
Expert panel offers transformative recommendations for NIH Alzheimer's research centers

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

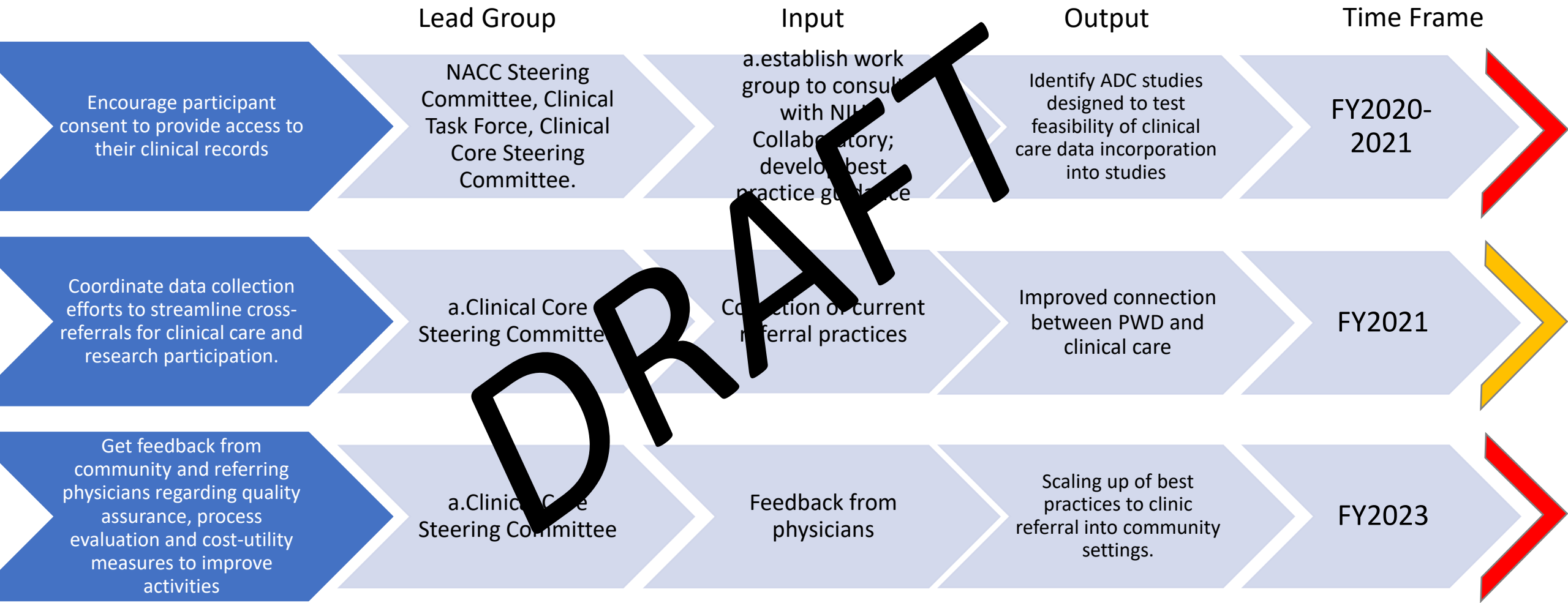
<https://www.nia.nih.gov/news/expert-panel-offers-transformative-recommendations-nih-alzheimers-research-centers>

Panel Recommendations



Clinical research capacities

Strategy B2: Leverage real world clinical data



“B” Recommendations— Progress toward the goals



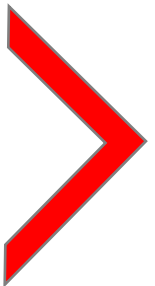
- Goal almost completely met (80%+ work complete)
- 0 of 22 meet this criteria



- Significant progress made (50-80% complete)
- 3 of 22 (13%) are coded



- Work started, but significant amount of work needed. (25-50% complete)
- 11 of 22 (50%) meet this criteria



- Substantial amount of work needed. (<25%)
- 8 of 22 (36%) meet this criteria

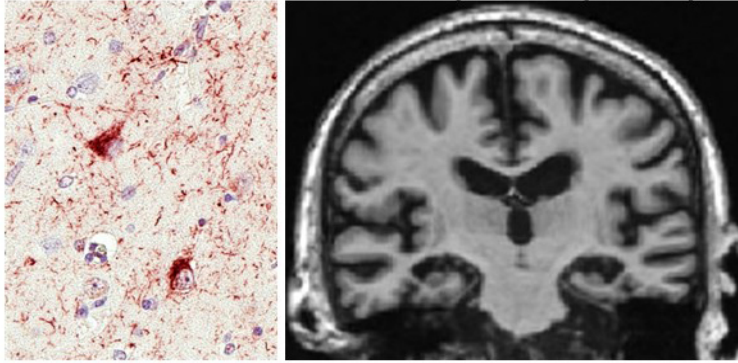
Clinical Core Steering Committee

- 'B1d. Periodically evaluate standardized procedures applicable to clinical practice, including: accepted clinical and psychometric measures, biomarkers (imaging, tissue/fluids), longitudinal observation, innovative assessment tools, methods to acquire brain autopsies, and CLIA certification for sharing of relevant data with research participants and families.
- etc

UDS Workgroup update

- Survey completed and analyzed
- Recommendations will be presented to NACC Steering committee
- Final decisions will be made in the next few months
- Not likely to be dramatic changes, but will be some changes that will reduce burden
- Some of the forms, particularly, biomarkers, may become obsolete and information will be collected better (more detailed) and in different ways (more efficient capture) with new biomarker cores

LATE: Limbic-predominant age-related TDP-43 encephalopathy



Nelson et al, *Brain* (2019)



Live Science > Health

A Newly Recognized Brain Disorder Can Mimic Alzheimer's. Here's How It's Different.

By Rachael Rettner, Senior Writer | April 30, 2019 12:00pm ET

The Diagnosis Is Alzheimer's. But That's Probably Not the Only Problem.

Most people with dementia have a number of brain abnormalities, not just Alzheimer's disease. The finding is forcing scientists to rethink the search for treatments.

- Very common (~25% over age 80) pathology
- Clinical features mimic AD-type dementia
- Under-appreciated and under-studied, to date: no prior working group focused on this problem
- Multi-disciplinary, international group of experts
- **Provided a new nomenclature and staging system**

Working group effort to help...

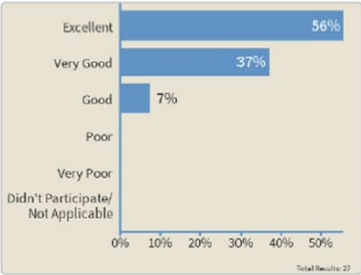
- **Diagnosis at autopsy (“standardize the gold standard”)**
- **Increase public awareness of this condition**
- **Enable a “common language” across disciplines**
- **Catalyze research**
 - **Diagnostic studies – specific biomarkers required**
 - **Important therapeutic target in its own right**
 - **Key consideration in AD clinical trials**
 - **Genetics, risk factors, and many other correlates**



ALZHEIMER'S DISEASE RESEARCH CENTERS RESEARCH EDUCATION COMPONENT (REC) TRAINEES WORKSHOP

- The ADRC REC trainee bootcamp was successfully completed for 30 participants, one from each ADRC, on **March 13, 2019 in Bethesda**
- The participants:
 - 1) prepared and submitted a mock NIH R03 application
 - 2) provided a written review
 - 3) learned the NIH peer review process by interaction with NIA POs and SROs
 - 4) served as primary reviewers in a "Mock study section"
- Each participant received written critiques for their applications from three reviewers: their fellow trainee, an ADRC PI reviewer and an NIA/CSR staff.
- Trainees attended the ADRD Summit on March 14-15 following the workshop.
- We received numerous positive comments from the trainees.
- The success of the workshop was a team effort of
- 16 ADRC PI volunteers and 18 NIA/CSR staff volunteers.

Please rate the overall study section experience.



Response options	Count	Percentage
Excellent	15	56%
Very Good	10	37%
Good	2	7%
Poor	0	0%
Very Poor	0	0%
Didn't Participate/ Not Applicable	0	0%

I found the advice at the beginning helpful and the primary reviewer process useful

Discussion of differences between grant types

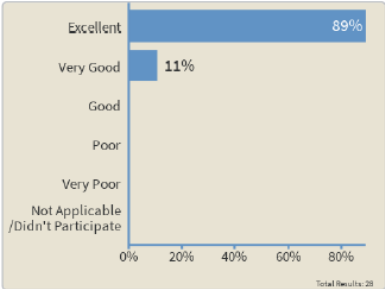
The actual study section and interactions with peers

The networking with colleagues and the participation of the NIH staff in the review process (understanding what they identify as strengths and weakness is helpful).

Hands on mock session. Distinct recommendations for upcoming applications to be successful.

Participating at the section (learning how it works) and the tips for writing successful applications

How was the leadership of the Scientific Review Officer within your session?



Response options	Count	Percentage
Excellent	25	89%
Very Good	3	11%
Good	0	0%
Poor	0	0%
Very Poor	0	0%
Not Applicable / Didn't Participate	0	0%




Renaud La Joie [Ren-no Leh Jwah] @relajoie · Mar 14

Replying to @ManlyEpic @williamhu43 @emoryhealthsci

Some of us (e.g. @mizuelsdorff & @mizuelsdorff) also got sponsored by NIA (@Nina_BSil et al) to attend #adrd19 and a very helpful **mock** study section yesterday.

1

6




Dr. Beth Shaaban @PopNeurosci · Mar 16

This was a lot of work, but I learned so much including how to write a winning application and what the funding mechanisms are directly from #NIA staff. Plus, I met the coolest postdocs (1 from each ADRC) who are the next generation of AD researchers.

2

4

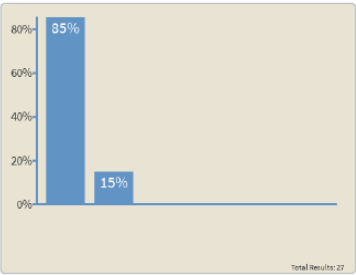


Dr. Beth Shaaban @PopNeurosci · Mar 16

Then we attended the ADRD Summit 2019. This summit is part of the National Plan to Address Alzheimer's Disease and updates research recommendations.

3

How useful was this workshop for your future NIH applications?



Response options	Count	Percentage
Extremely useful	23	85%
Very useful	4	15%
Useful	0	0%
Not Useful	0	0%
Not Very Useful	0	0%
Not Applicable/ Didn't Participate	0	0%

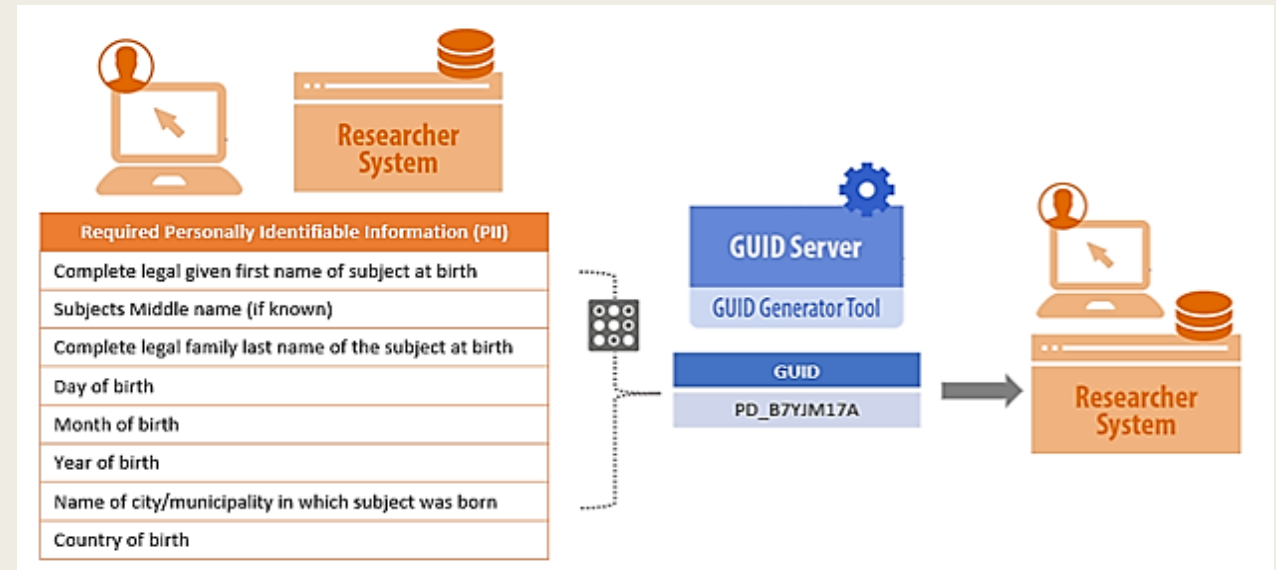
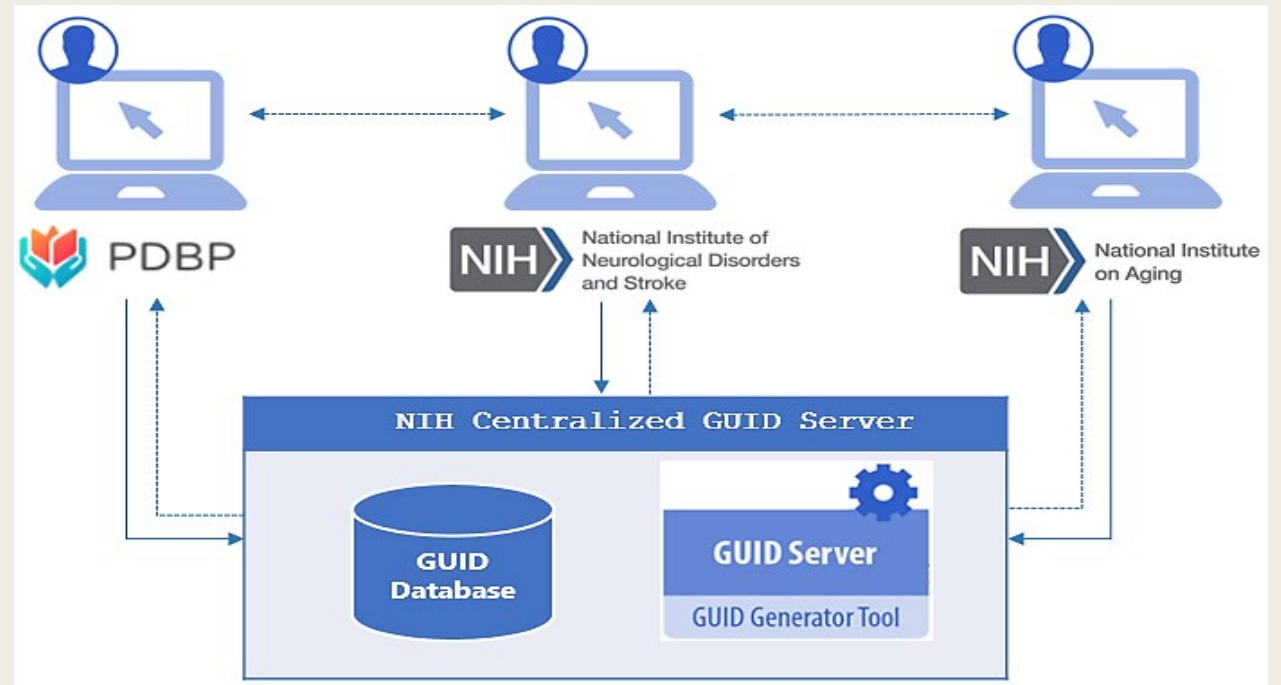
- attendance, commitment and dedication of all NIH members to explain the whole process and address our questions

NIA GLOBAL UNIQUE IDENTIFIER (GUID) PORTAL

Progress to Date

Why & How

- Three different systems with an overlap of participants
- Server that will be able to track study participant across sites and studies
- Three NIH systems that will be synced and will communicate with each other
 - As of May 1st all systems are synced
 - In order to see records within all 3 instances, user will need to have an account with each instance





GUID (Global Unique Identifier)

GUID Tool

GUID Overview

[Create GUIDs](#)[My GUIDs](#)[GUID Admin](#)

GUID Overview

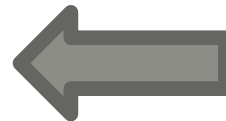
The GUID Tool is a customized software application that generates a Global Unique Identifier for each study participant. A GUID is a subject ID that allows researchers to share data specific to a study participant without exposing personally identifiable information (PII). A GUID is made up of random alpha-numeric characters and is NOT generated from PII/PHI. By using GUIDs in your research data, the system can associate a single research participant's genetic, imaging, clinical assessment data even if the data was collected at different locations or through different studies.

In order to submit data to the system, the system expects all prospective studies to include a GUID in the data submission. For retrospective studies, the team understands that the participant data needed to generate a GUID may not be available. To account for this, the capability to generate pseudo-GUIDs is provided. However submitting data with pseudo-GUIDs, silos the associated research data from the other data associated with valid GUIDs.

Fields required to generate a GUID

In order to generate a GUID, the following PII is required:

- Complete legal given (first) name of subject at birth
- If the subject has a middle name
- Complete legal family (last) name of subject at birth
- Day of birth
- Month of birth
- Year of birth
- Name of city/municipality in which subject was born
- Country of birth



If you do not have all of the required information, you can create a pseudo GUID

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



My GUIDs : NIA GUID : National | x

https://bricsguid.nia.nih.gov/portal/guid/guidActionlist.action

Apps Log In : NIA GUID ... Dashboard | ADSP Onboarding Checkli... BENEFEDS | Federal... Reports List- NIH E...

GUID Tool

GUID Overview

Create GUIDs

My GUIDs

GUID Admin

The table below displays a list of all GUIDs that you have registered from the one-way hashed PII information as well as PseudoGUIDs your organization has registered.

Download Show All All Search:

ID	TYPE	ENTITY	ORGANIZATION REGISTERED BY	USER REGISTERED BY	DATE REGISTERED	LINKED TO
NIHZY980ZPYL2	GUID	NIA	NCRAD	Horner, Kelly	2019-03-22	
NIHZW746NLWXR	GUID	NIA	Washington University in St. Louis	Norton, Joanne	2019-03-28	
NIHZH557WHWVT	GUID	NIA	University of Washington	McDougall, Jessica	2019-02-25	
NIHZC527ZKJZL ⓘ	GUID	NIA	University of Washington	Caso, Christina	2019-03-05	
NIHZC527ZKJZL ⓘ	GUID	NIA	University of Washington	McDougall, Jessica	2019-03-14	
NIHZB409ZHZKB	GUID	NIA	indiana university	herring, scott	2019-01-25	
NIHZA926CGKZ1	GUID	NIA	Washington University in St. Louis	Gentsch, Jennifer	2019-01-29	
NIHYY862UBAZE	GUID	NIA	indiana university	herring, scott	2019-02-08	
NIHXY839TVGLK	GUID	NIA	Northwestern University	Muse, Brittanie	2019-03-28	
NIHXY635JHZF0	GUID	NIA	Massachusetts General Hospital	Flaherty, Ryn	2019-02-28	
NIHYN961VXXFY	GUID	NIA	Washington University in St. Louis	Gentsch, Jennifer	2019-01-31	
NIHYN364LUJF6	GUID	NIA	Washington University in St. Louis	Norton, Joanne	2019-03-26	
NIHYJ695EVELQ	GUID	NIA	Washington University in St. Louis	Gentsch, Jennifer	2019-01-29	
NIHYJ088EWTN7	GUID	NIA	University of Washington	McDougall, Jessica	2019-03-14	

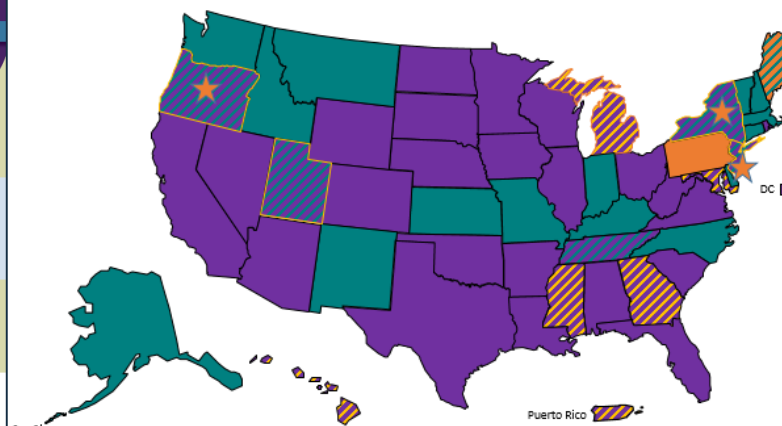
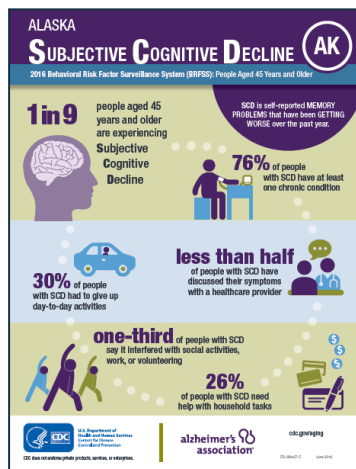
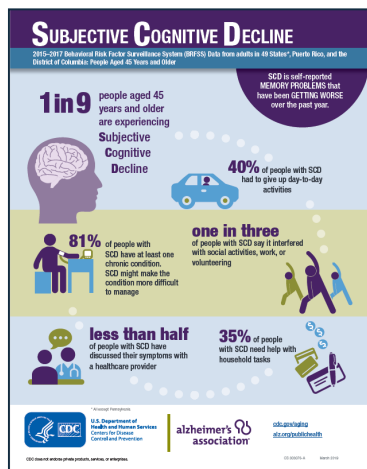
- If there are entries with similar PHI, the system will prompt you that there is a record with similar information and will ask you to confirm
- If multiple users enter the same PHI, then the system will notify you and generate the same GUID

NIA GUID Instance by the Numbers

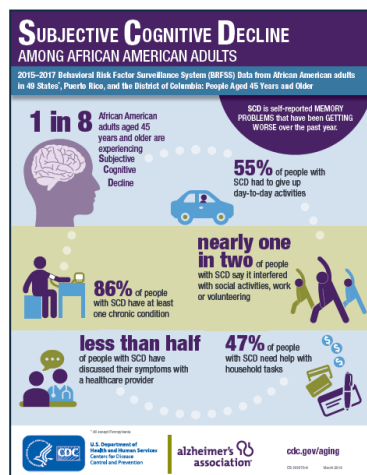
Number of GUIDs in the System	513
Number of Active GUIDs	507
Number of Pseudo GUIDs	6
Number of Clinical Sites Participating	27

As of April 30, 2019

SUBJECTIVE COGNITIVE DECLINE (SCD) SURVEILLANCE

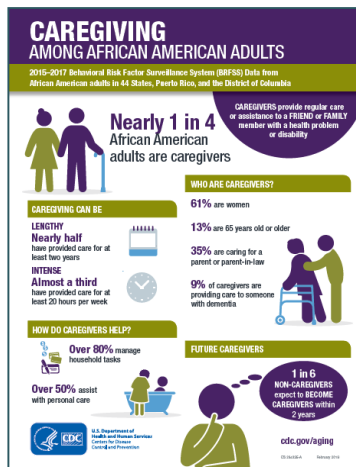
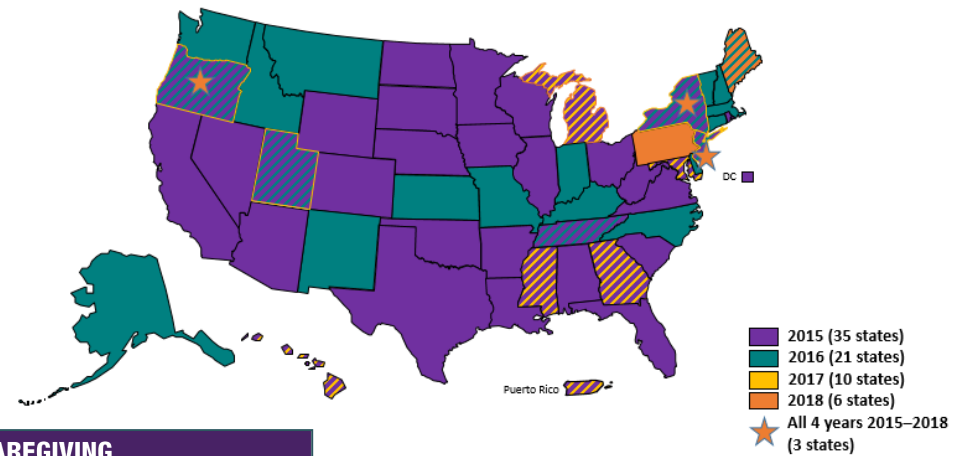
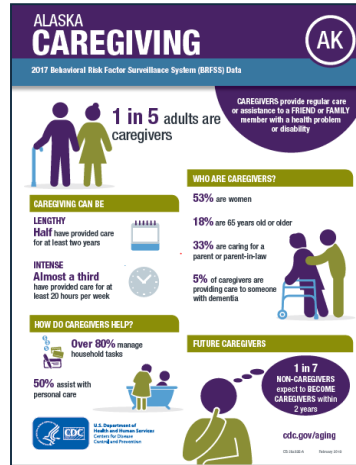
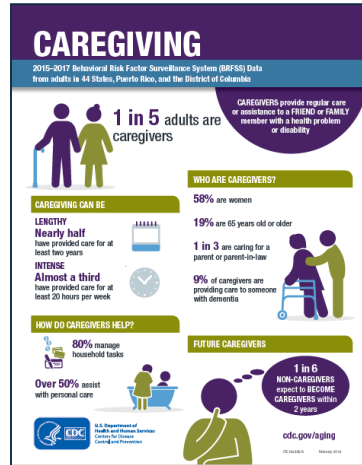


■ 2015 (35 states)
 ■ 2016 (21 states)
 ■ 2017 (10 states)
 ■ 2018 (6 states)
 ★ All 4 years 2015–2018 (3 states)



<https://www.cdc.gov/aging/index.html>

CAREGIVING SURVEILLANCE



<https://www.cdc.gov/aging/index.html>

NEW NHANES: COGNITIVE DATA

- Administered during 2019-2020 and 2021-2022 (revised MEC)
- Interview questions
 - *During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?*
- Mobile exam center (MEC)
 - *Montreal Cognitive Assessment (MOCA)*



**MONITOR &
EVALUATE**

NHANES: COGNITIVE DATA

- Administered during 2011-12 and 2013-14 cycles
- Interview questions
 - *During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?*
 - *During the past 7 days, how often have you had trouble remembering where you put things, like your keys or your wallet?*
- Mobile exam center (MEC)
 - *CERAD word recall*
 - *Categorical verbal fluency (Animal naming)*
 - *WAIS Digit symbol*
- 2500 persons aged 60+ years completed the modules
- Publicly available Spring 2017



MONITOR &
EVALUATE

NIA Research Centers Collaborative Network (RCCN)

RCCN-AGING.ORG

Twitter: @RCCNaging



RCCN Goals

- Foster Collaborations across NIA Centers Programs
- Prepare Emerging Investigators for Interdisciplinary and Inter-Institutional Research



RCCN Activities



Activity	Examples	For Early Career Investigators
Workshops convening researchers from multiple NIA center programs around a common problem.	<ol style="list-style-type: none"> 1. Behavior Change for Older Adults (Dec 6 – 7, 2018)* 2. Sex and Gender in Aging (June 6-7, 2019) 3. Resilience (Nov 11 -12, 2019) 	<ul style="list-style-type: none"> -Travel Awards for Early Career Faculty (<u>Workshop 2 applications due April 1</u>) -Special Didactic Program Focused on Early Career Faculty Concerns -Participation in Preparing Workshop Proceedings
Cross Center Pilot Awards	Two \$40K pilots on the theme of each workshop. RFA issued following each workshop.	<ul style="list-style-type: none"> -Early Career Faculty are encouraged to apply. -Participation of junior investigators is a review criteria.
Webinar Series Directed at Interdisciplinary Research Skills	<ol style="list-style-type: none"> 1. Building Cross-Disciplinary Collaborations in Aging Research* 2. Jumpstart Your Research Team* 	Announced through Center Programs' Coordinating Centers and RCCN's twitter feed (@RCCNaging).

*Slides and recordings of presentations available at RCCN-AGING.Org