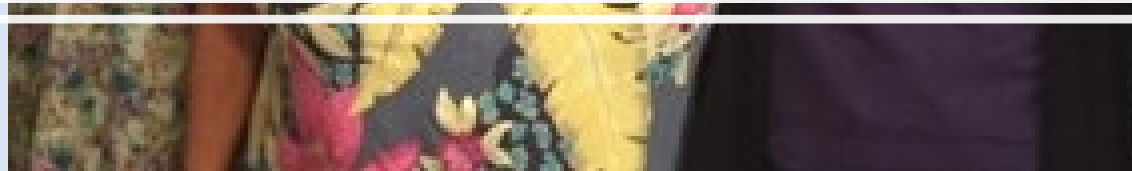# NIA Update: October 12, 2019

- Funding Opportunities

- Designated ADRC Badge

- Coordination Activities

- ADRC Panel Recommendations

- NeuroBioBank

- Global Unique Identifiers

- NIA Research Centers Collaborative Network

- Future ADRC Directors' Meetings

Marcelle Morrison-Bogorad

Survey on Disclosure of Individual Research Results

https://tinyurl.com/adcsurvey2019

- Survey of Clinical Core leaders at all 30+ ADCs
  - Brief (mean = 15 minutes) online survey
- Assessing current disclosure practices within each site's clinical core:
  - What types of results, why, how, to whom, by whom, how often; challenges & facilitators of process
  - Focus on return of genetic / biomarker results
- Results to be shared at future ADC meeting, guide future efforts of Working Group

Follow Up from Participant Presentations

- Background: presentation about what it was like to participate in a clinical trial and what happened when the trial ended

- Working on developing some best practices for clinical trials with the Alzheimer's Association and other outside groups

- If you have suggestions of topic areas, please contact Grayson Donley (grayson.donley@nih.gov)

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 Rela 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 con process to help ensure that the next generation of Alzheimer's Disease Centers (ADCs) is poised to accomplish the goals of the National Alzheime resulting recommendations included several specific ideas centered around collaboration, including developing greater opportunities for collaborati 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 information about the clinical and pathological course of both normal aging and AD/ADRD. Scientists within and outside the ADCs can gain access availability of neuropathological data on thousands of participants) as well as support the collection and integration of new data and samples. This i investigators and a wider participation in the design, analysis and interpretation of studies utilizing these unique resources, further leveraging the e on existing resources and data to answer a broad range of scientific questions. Project data may be used for new grants and/or provide standardiza value to AD and ADRD research goals.

Small Research Grant Program for the Next Generation of Clinical Researchers in AD/ADRD Research

Area of Focus: Archiving and Leveraging Existing Data Sets for Analyses
 PAS-19-391

Area of Focus: Basic Science
PAS-19-392

Area of Focus: Systems Biology
PAS-19-393

Standard Receipt Dates:
February 16
June 16
October 16
Expiration Date:
November 17, 2022

Overall goals:
i. to encourage the next generation of U.S. researchers to pursue research and academic careers in neuroscience, AD/ADRD, and healthy brain aging and
ii. to stimulate established researchers who are not currently doing AD/ADRD research to perform pilot studies developing new, innovative AD/ADRD research programs that leverage and build upon their existing expertise.

NIA Diversity and Re-entry Supplement Program Guidelines

A candidate who is currently receiving support from another PHS funding source (including the parent grant) is not eligible to receive a supplement. Investigators seeking supplement support should inquire about eligibility based on their funding status.

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

Overview

NIA's Diversity and Re-entry Supplement programs support the development of eligible trainee-candidates who seek independent careers in aging and geriatrics research and meet NIA's goal to enhance diversity in the biomedical workforce. Supplement awards provide funds to support a mentor-directed opportunity for a trainee-candidate to develop the critical thinking skills, scientific technical expertise and professional acumen essential for career advancement in the biomedical, behavioral, clinical or social sciences.

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

Approved Concepts

Cleared concepts: A crystal ball for likely future funding initiatives

September 25, 2019

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

Applications | Funding Opportunities | NACA

NIA is excited to unveil our latest collection of cleared concepts for funding opportunity announcements (FOAs). As presented at our final fiscal year 2019 National Advisory Council on Aging meeting, the late-summer crop yielded 15 intriguing ideas to share with the research community to help spark innovation and advances in the field.

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

September 2019 Council

Approved concepts in this round:

- Aging Research Dissertation Awards to Increase Diversity
- The Alzheimer's Disease Sequencing Project (ADSP) Functional Genomics Program (FGP)
- Artificial Intelligence and Technology Centers for Aging Research
- Central and Peripheral Control of Balance in Older Adults
- Emotional Well-Being: High Priority Research Networks
- Glial Plasticity in the Aging Brain
- Harmonization of Alzheimer's Disease and Related Dementias (ADRD) Genetic, Epidemiologic, and Clinical Data to Enhance Therapeutic Target Discovery
- Mechanisms of Rejuvenation and Accelerated Aging in Heterochronic Blood Exchange
- National Longitudinal Study of Adolescent to Adult Health (Add Health) Wave 6
- New/Unconventional Animal Models of Alzheimer's Disease
- Oligomer Seed Bank Initiative
- Planning Projects for Clinical Trials on Effects of Sustained Reductions in Caloric Intake and Related Dietary Practices in Younger and Older Persons
- Prodromal α-Synucleinopathies Consortium
- Research Education Resources to Foster Development of Geriatrics-Related Translational and Clinical Scientists
- Stem Cell Aging and Oncogenic Transformation

Exploratory Alzheimer's Disease Research Centers (P20 Clinical Trial Not Allowed)

RFA-AG-20-023

Section I. Funding Opportunity Description

Purpose

This Funding Opportunity Announcement (FOA) invites applications to establish NIA Exploratory Alzheimer's Disease Centers. NIA's primary goal in offering this P20 funding opportunity is to incentivize innovative ideas and opportunities in Alzheimer's disease and Alzheimer's disease related dementias (AD/ADRD) research.

As part of a network, Centers are expected to participate in collaborative efforts on a national scale. Applicants must agree to collect a standard clinical data set (the Uniform Data Set, or UDS) that is common to all Centers and to transmit that data to the National Alzheimer's Coordinating Center (NACC). Applicants should contact NACC to learn more about NACC procedures, the structure of the UDS, and the regular updates to the datasets required from all Centers at http://www.alz.washington.edu/.

To support the unique research needs of the NACC, most Centers collect additional data to supplement those required by the UDS. These should also be made readily available to qualified investigators. Similarly, Centers should demonstrate a readiness to provide biological samples and data, with proper consent from well-characterized populations, to enable participation in large-scale, collaborative, national, or international research projects. Sample sharing may be done either locally or centrally through the National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD). Centers are a local, regional, national, and international resource.

Exploratory Alzheimer's Disease Centers are required to include the following three cores:

- Administrative - Manage and coordinate interactions among the Director, the core leaders, the principal investigators of research projects using the resources of the Center, other researchers at the applicant institution as well as outside institutions, appropriate institutional administrative personnel, the staff of the awarding agency, and the members of the community in which the Center is located.
- Clinical - Establish and maintain a clinical enterprise that provides valuable, well-documented resources for cutting-edge clinical research for both Center personnel and the wider scientific community.
- Additional - Propose an additional core that contributes to the overall focus of the planned Center that is scientifically justified, develops resources that support other research affiliated with the Center, and fits within the budget guidelines outlined in Section II: Award Information of the FOA.

National Alzheimer's Project Act Advisory Council

Dr. Cynthia Carlsson
Wisconsin ADRC

Designated ADRC Badge

Attention, ADRCs

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

Promote your studies and share them with researchers around the world

NACC Steering Committee Overview

ADRC Listservs and Interest Groups

Listservs for ADC interest groups and cores

To support collaboration across Centers, NIA has worked with NACC to create the following listservs geared toward various interest groups and cores. These groups are open to interested persons within and, in some cases, outside of the ADCs.

Also available to support collaboration are the **umbrella listservs** for each of the ADC required cores. The umbrella listservs include the relevant core leaders, along with others who have expressed an interest in getting messages on topics of interest to the group.

To subscribe to any of these groups, please write to naccmail@uw.edu, using the subject line "Subscribe: *name of interest group*" and indicate your role in the ADC (or other organization). To unsubscribe from any group, use the subject line "Unsubscribe: *name of interest group.*"

Please note that you must be listed in the ADC Personnel Directory in order to be automatically subscribed upon request to any of the listservs below. If you are not listed in the ADC Personnel Directory, NACC will first request authorization from the Administrator of your ADC.

ADC interest groups

ADC African American Interest Group	*ADC_AfrAm@uw.edu*
ADC Latinx Interest Group	*ADC_Latino@uw.edu*
ADC Vascular Interest Group	*ADC_Vascular@uw.edu*
ADC Native American Interest Group	*ADC_NatAm@uw.edu*
ADC Down Syndrome Interest Group	*ADC_DownSyn@uw.edu*
ADGC and NCRAD Interest Group	*ADC_Genetics@uw.edu*

ADC core-focused listservs

CORE	FOR USE OF CORE LEADERS ONLY	UMBRELLA LISTSERV (Includes core leaders, others)
Directors	*ADC_Director@uw.edu*	*ADC_Dir@uw.edu*
Administrators	*ADC_Administrator@uw.edu*	*ADC_Admin@uw.edu*
Clinical Core	*ADC_Clin_Leader@uw.edu*	*ADC_Clin@uw.edu*
Neuropathology Core	*ADC_NP_Leader@uw.edu*	*ADC_NP@uw.edu*
ORE Core	*ADC_ORE_Leader@uw.edu*	*ADC_ORE@uw.edu*
Data Core	*ADC_Data_Leader@uw.edu*	*datamngrs@uw.edu*
REC	*ADC_REC_Leader@uw.edu*	*ADC_REC@uw.edu*
Biomarkers Core	*N/A at this time*	*ADC_Biom@uw.edu*
Imaging Core	*ADC_Image_Leader@uw.edu*	*ADC_Image@uw.edu*

Jobs listserv

PLEASE NOTE: The jobs listserv is intended for ADC-related job postings. It is, however, a public listserv whose membership is not limited to ADC personnel. To subscribe or unsubscribe, please visit the list information page.

ADC-related job postings	*ADC_jobs@uw.edu*

ADRC Clinical Task Force

Reinstating the ADRC Clinical Task Force (CTF)

NIA Appointed Members
- Allan Levey, Chair
- Rhoda Au
- Lisa Barnes
- Brad Boeve
- Suzanne Craft
- Teresa Gomez-Isla
- Andy Saykin
- Suzanne Schindler
- Sandy Weintraub

Clinical Core Steering Committee
- Cynthia Carlsson
- Greg Jicha
- Mary Sano
- Jeff Burns
- Howie Rosen

UDS Workgroup Update

- Recommendations were presented to NACC Steering committee
- Will review recommendations with newly formed CTF and finalize implementation plans

Imaging Update

- **SCAN:** Standardized Centralized Alzheimer's and Related Dementias Neuroimaging
- Establishing an imaging steering committee

SCAN: Standardized Centralized Alzheimer's and Related Dementias Neuroimaging (U24 Clinical Trials Not Allowed)

U24 Resource-Related Research Projects – Cooperative Agreements

New

None

RFA-AG-20-043

None

See Section III. 3. Additional Information on Eligibility.

93.866

This funding opportunity will support a new, centralized infrastructure (U24) to aggregate, harmonize, manage, and share existing and future neuroimaging data collected in NIA-supported Alzheimer's Disease Research Centers (ADRCs). An additional activity will be to define appropriate imaging protocols, as well as assess and anticipate advances in neuroimaging technologies and techniques for inclusion in the standardized protocols to maximize utility for the field of Alzheimer's disease and Alzheimer's disease related dementias (AD/ADRD) research.

Biospecimen best practice guidelines for the Alzheimer's Disease Centers

Table of Contents

https://www.alz.washington.edu/BiospecimenTaskForce.html

ADC Panel Recommendations

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

ADC Panel Recommendations

Research

A. Gaps in disease recommendations and risk

B. Clinical research capacities

C. Maximize value of neuropathology expertise across ADCs

D. Translational research

Collaboration

E. Cross-ADC interactions/networking

F. Interactions beyond the ADC network

Enablement

G. Infrastructural supports to enable prior recommendations

H. Further development of training programs

ADC Panel Recommendations: Governance

A. Gaps in disease recommendations and risk

Recommendation: Objectives	Strategy	Governance recommendation
4. Incorporate opportunities to include the development and validation of environmental, wearable, and remote personal monitoring technology for high frequency sampling and naturalistic assessment of disease symptom onset and progression.	A4a. Evaluate their use as enrollment criteria and as outcome measures in interventional studies (pharmacologic and non-pharmacologic), and for additional contributions to diagnosis and treatment over usual clinical measures.	Digital Biomarker WG
5. Foster education and support of research participants and families to ensure that clinical endpoints are important and clinically meaningful, both in novel prevention studies as well as treatment in established disease.	A5a. Enable input on patient-oriented outcomes and quality-of-life measures in evaluations of optimal care practices.	Community Engagement Task Force
	A5b. Develop programs for ongoing feedback from research participants as sources of learning and information for ADCs to improve bilateral communications.	ORE Core
6. Because mixed dementias are more common than pure AD, enhance opportunities to describe the co-occurrence of neurodegenerative and other pathologies (particularly vascular pathology, but also others to ensure that complex etiologies are captured for study) from preclinical asymptomatic stages to dementia and death, utilizing structural/functional imaging, biomarkers and neuropathology.		Coordination with NGOs and NINDS

Clinical Core steering committee and NACC steering committee |

NeuroBioBank Update

About the NIH NeuroBioBank

Overview

The NIH-funded NeuroBioBank (NBB) was established in September 2013 as a national resource for investigators utilizing human post-mortem brain tissue and related biospecimens for their research to understand conditions of the nervous system.

With specimens that span neurological, neuropsychiatric, and neurodevelopmental diseases and disorders, the NBB serves as a central point of access to the world-class collections of our six biorepositories. In addition, the NBB provides researchers with a wealth of resources to facilitate their research, including medical records and clinical data sets (when available) as well as access to quality metrics and best practices used by each site.

Our sites adhere to the highest ethical standards when acquiring specimens for their collections, and protection of donor identity is assured. All brain tissue is procured, stored, and distributed according to applicable state and federal guidelines and regulations involving consent, protection of human subjects and donor anonymity.

Our Goals

1 To increase the availability of human disease and control brains and related biospecimens by increasing public awareness of the value of tissue donation for understanding brain disorders.

2 To facilitate the distribution of high-quality, well-characterized human post-mortem brain tissue for the research community.

3 To make available to the research community, a centralized resource of best practices and protocols used by our networked sites in the acquisition, preparation, and distribution of tissue.

NIA GUID Portal

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 the required information, you can create a pseudo GUID

- 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

NIA GUID Instance by the Numbers

Number of GUIDs in the System	4,028
Number of Active GUIDs	4,004
Number of Pseudo GUIDs	24
Number of Clinical Sites Participating	57

As of October 7, 2019

NIA Research Centers Collaborative Network (RCCN)

- Foster Collaborations across NIA Center Programs

- Prepare Emerging Investigators for Interdisciplinary and Inter-Institutional Research

Website: RCCN-AGING.ORG
Twitter: @RCCNaging

RESEARCH
CENTERS
COLLABORATIVE
NETWORK

RCCN Activities

Activity	Examples	For Early Career Investigators
Workshops convening researchers from multiple NIA center programs around a common problem.	1. Behavior Change for Older Adults (2018)* 2. Sex and Gender in Aging (June 2019)* 3. Resilience (Nov 11 - 12, 2019) 4. Life Course Factors Affecting Late Life Well – Being (Spring 2020) 5. TBD	-Travel Awards for Early Career Faculty -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.	-Early Career Faculty are encouraged to apply. -Participation of junior investigators is a review criteria.
Webinar Series Directed at Interdisciplinary Research Skills and Workshop Highlights	1. Building Cross-Disciplinary Collaborations in Aging Research* 2. Jumpstart Your Research Team* 3. Mechanisms of Behavior Change for Health Aging* 4. Sex / Gender in Aging Research (10/19) **5. Accessing NCRAD Biospecimens (11/19)**	Announced through Center Programs' Coordinating Centers and RCCN's twitter feed (@RCCNaging).

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

How NDRI Can Assist NIA Funded ADCs:

1. Coordinating post-mortem tissue recovery for:
   a) donors located outside of ADC catchment area
   b) trial participants being followed by NIH wherein no PM tissue collection plan is built into study

2. Providing ADCs with normal control brains

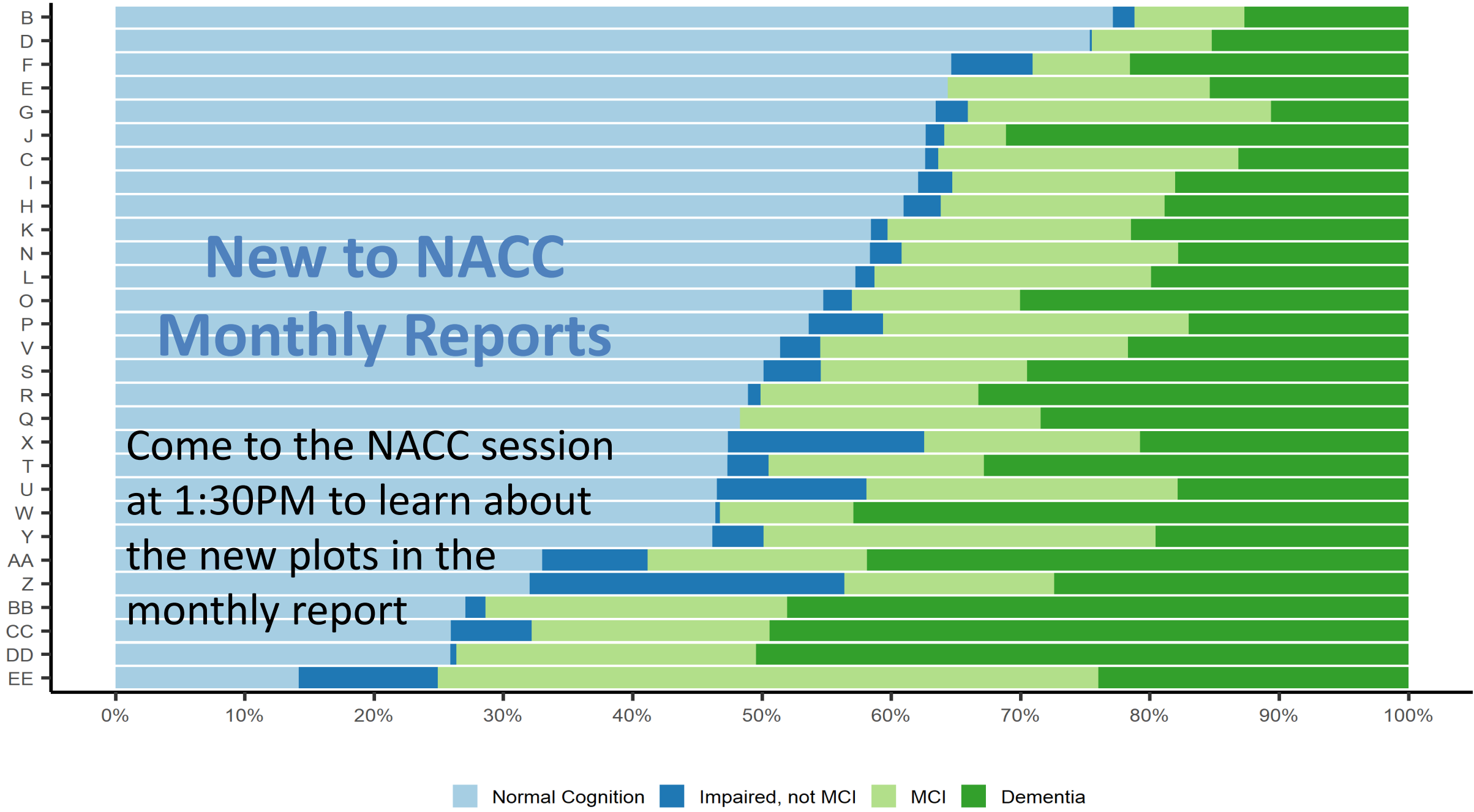3. Scheduling in-home blood collection

NDRI can also support the promotion of ADCs' sample distribution (via researcher referral).

Contact us to learn more:
Gene C. Kopen, PhD SVP, Strategic Initiatives
gkopen@ndriresource.org
www.ndriresource.org

National Disease Research Interchange

Advancing Medical Research through Organ and Tissue Donation

NDRI
Empowering Research and Discovery

New to NACC Monthly Reports

Come to the NACC session at 1:30PM to learn about the new plots in the monthly report

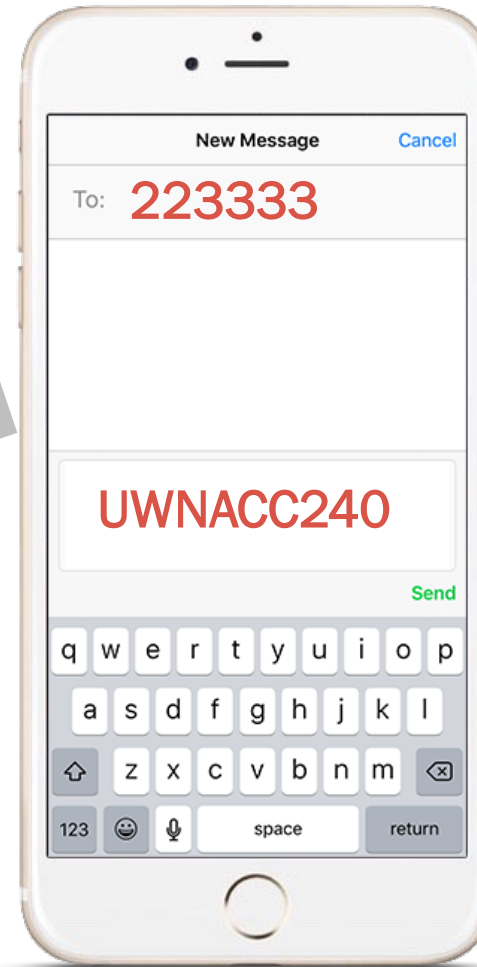Legend: Normal Cognition | Impaired, not MCI | MCI | Dementia

Future ADRC Directors' Meetings

- Biomarker Session – May 2019
- Junior Investigator Session – October 2019
- Imaging Session – May 2020

- October 2020
  - Virtual Site Visit
  - Biomarker/Imaging Sessions
  - TBD

Responding with Poll Everywhere

Web voting

Text voting