

ADRC Directors Meeting

Nina Silverberg, Ph.D.

Director, Alzheimer's Disease Research Centers Program


National Institute on Aging

October 20, 2022

DEI Theme

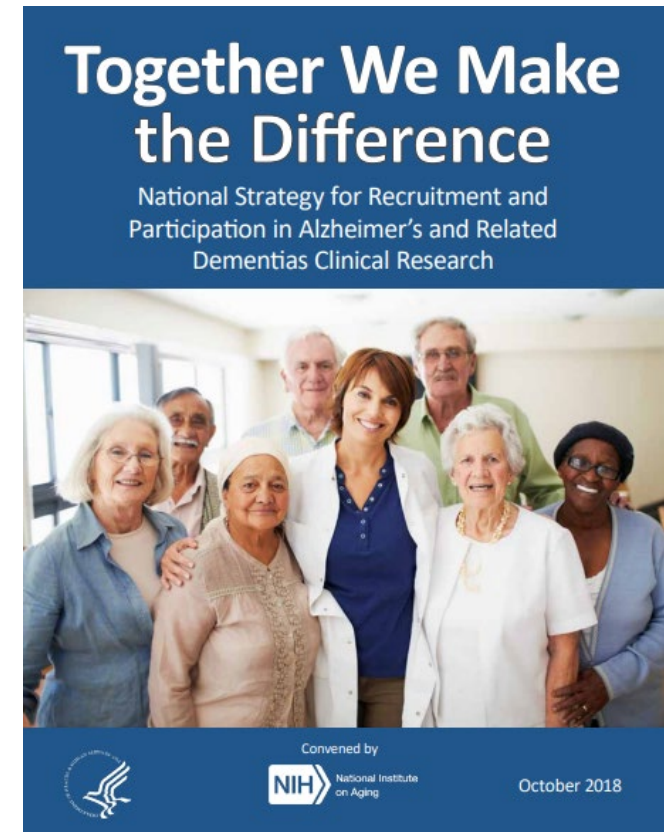
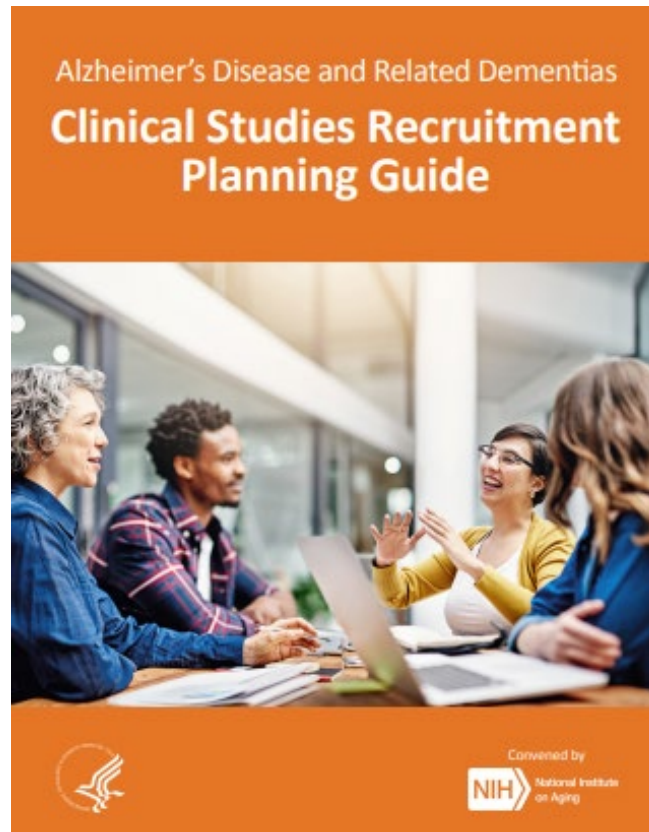
Science & Society

The Urgency of Justice in Research: Beyond COVID-19

Andrea Gilmore-Bykovskiy ^{1,*}
Jonathan D. Jackson,^{2,3} and
Consuelo H. Wilkins^{4,5}



The striking imbalance between disease incidence and mortality among minorities across health conditions, including coronavirus disease 2019 (COVID-19) highlights their under-inclusion in research. Here, we propose actions that can be adopted by the biomedical scientific community to address long-standing ethical and scientific barriers to equitable representation of diverse populations in research.



ADRCs global role in AD/ADRD research

- Lead the field scientifically, develop new approaches
- Support justice and equity
- Provide standardized data, samples and participants **across dementias and severity** to support recruitment for clinical trials and other national research efforts (e.g., ADNI, AGMP, ACTC, Diverse VCID, MarkVCID)
- Sustained support enables **strong community ties**, better retention
- **Train the next generation in a multidisciplinary environment**
- **Autopsy** services support participants, families and major research advancements
- Part of a **larger infrastructure** – NACC, NCRAD, SCAN, NIAGADS/AGSP
- Work both as part of a network and locally within the (public and research) community
- Need to improve sharing and open science practices

NIA Staff In Attendance

Division of Neuroscience

Eliezer Masliah

Director, Division of Neuroscience

Jennie Larkin

Deputy Director, Division of Neuroscience

Nina Silverberg

Director, ADRC Program

Cerise Elliott

Co-Director, ADRC Program

Grayson Donley

Health Specialist, ADRC Program

Division of Behavioral and Social Research

Elena Fazio

Director, Office of for AD-ADRD
Administration and Strategic Partnerships

Office of Legislation, Policy, and International Activities (OLPIA)

Courtney Wallin

Deputy Director, OLPIA

Office of Communications and Public Liaison

Katie Murray

Health Communications Specialist

Welcome Aleksandra Dakic



Aleksandra (Saša) Dakic will be joining the NIA next week. She will be working in the Division of Neuroscience to support the ADRC Program.

Dr. Dakic has more than 20 years of experience in basic science and medical research. She completed her PhD in Molecular Biology at the University of Belgrade (Serbia) and Georgetown University. Before joining the NIA, she was conducting stem-cell differentiation research at NIMH to clarify mechanisms for atypical macroscale brain organization in neuropsychiatric disorders.

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.

- [September 2022](#)
- [May 2022](#)
- [January 2022](#)

September 2022 Council

Approved concepts in this round:

- [Alzheimer's Disease Research Centers \(ADRCs\) Program Renewal](#)

The next RFA will fall under the new NIH Data Management and Sharing Policy ([NOT-OD-21-013](#)), which goes into effect January 25, 2023.

Additional information about the new DMS Policy can be found:

<https://sharing.nih.gov/>

Welcome the New ADRC Directors



Ann McKee, MD

Boston University ADRC



Justin B. Miller, PhD

Nevada eADRC



Gil Rabinovici, MD

UCSF ADRC



Julie Schneider, MD, MS

Rush University ADRC



Glenn Smith PhD, ABPP

(Interim)

1Florida ADRC

Thank you to Neil Kowall, Marwan Sabbagh, Bruce Miller, David Bennett, and Todd Golde for their contributions.

Overview of NACC's Mission and Role

NACC serves as the data, collaboration, and communication hub for NIA's ADRC Program

Data

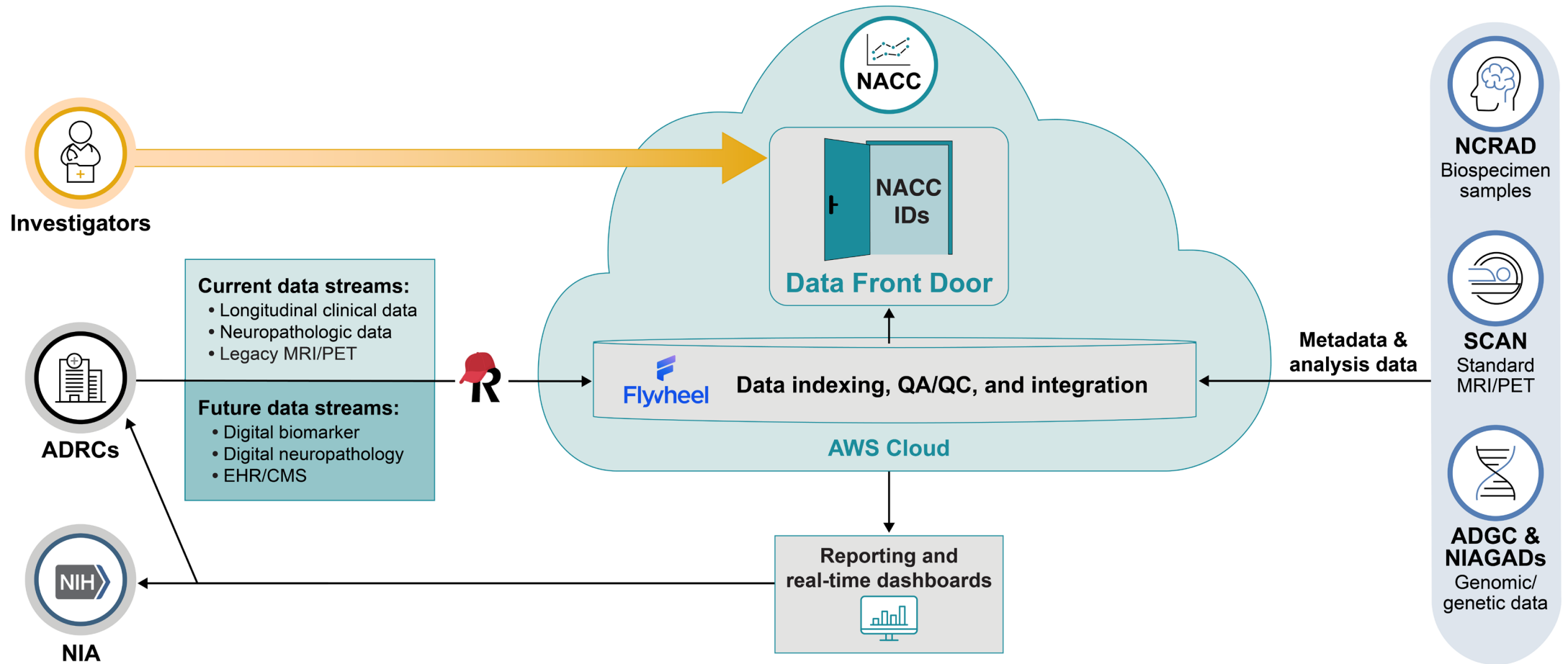
Findable 
Accessible 
Interoperable 
Reusable 

Communication & Collaboration



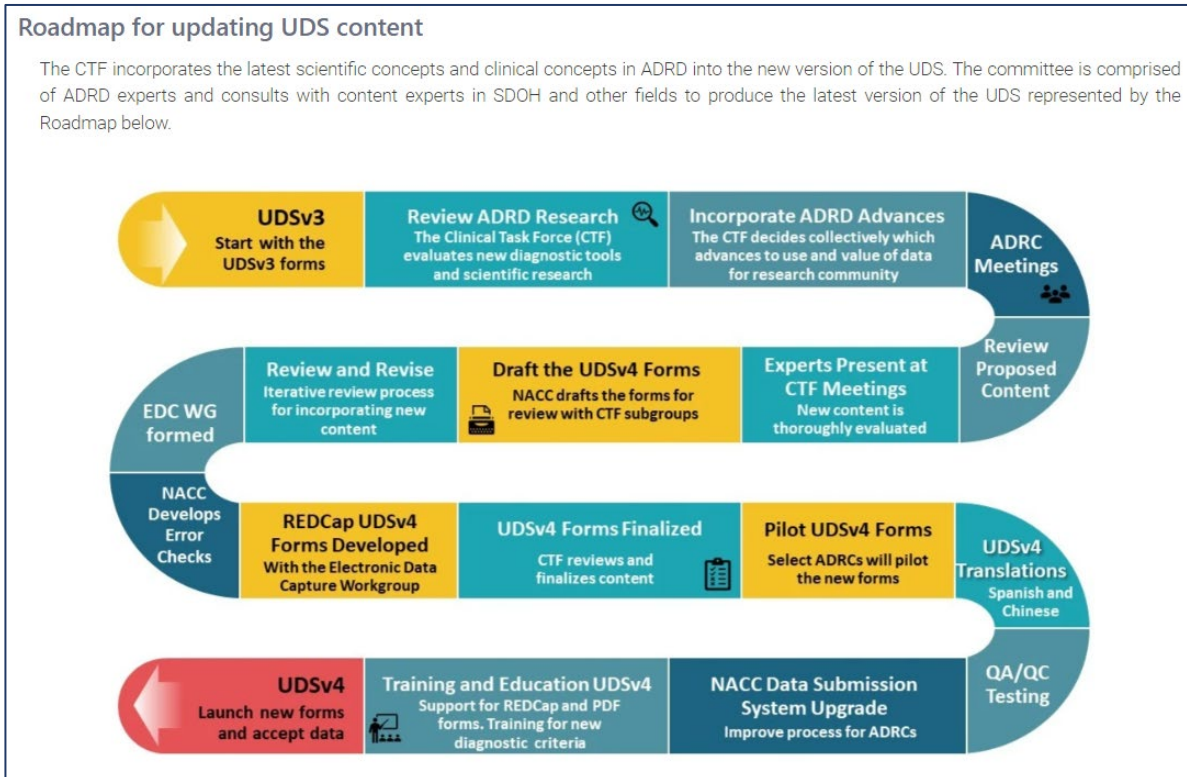
- Reports
- Newsletter
- Surveys
- Dynamic Website
- NACC Directory
- Program Support

NACC is on a mission to modernize data collection, integration, and sharing to advance Alzheimer's research



UDSv4 Updates on NACC

- NACC developed a page on their website for UDSv4 Updates
- The CTF will provide an update during their session tomorrow morning



2022 Hybrid Fall ADRC Meeting Day Two: October 21st, 2022 CLINICAL TASK FORCE (CTF) SESSION	
8:00am - 8:05am (CT)	5min
Introduction	Allan Levey, MD, PhD Emory University, Goizueta ADRC
8:05am - 8:30am (CT)	10min Presentation , 15min Discussion
MBI Update	Howie Rosen, MD UCSF ADRC Constantine Lyketsos, MD Johns Hopkins ADRC
8:30am - 8:55am (CT)	10min Presentation , 15min Discussion
SCD Update	Lisa Barnes, PhD Rush University Alzheimer's Disease Center Andrew Saykin, PsyD Indiana University ADRC
8:55am - 9:00am (CT)	5min
Closing Remarks	Allan Levey, MD, PhD Emory University, Goizueta ADRC

Data Core Steering Committee: Activities and Initiatives

- **Extended cross-disciplinary collaborations beyond Data Core**
 - Members are serving on CTF cognitive, technology, and SDoH working groups
 - NACC members attend Steering Committee meetings
- **Launched EDC Working group collaboration with NACC in January 2022**
 - To develop electronic data capture (EDC) systems for UDSv4 to effectively serve the needs of the ADRC program
 - 75 members with representation from 28 ADRCs
 - To foster collaborative software development and quality analysis
 - To build robust and scalable solutions
 - To build a data community across ADRCs and NACC
 - To promote and share best practices
 - To make data driven decisions with user surveys

Define Requirements



Develop Submission Forms



Create Training and Education



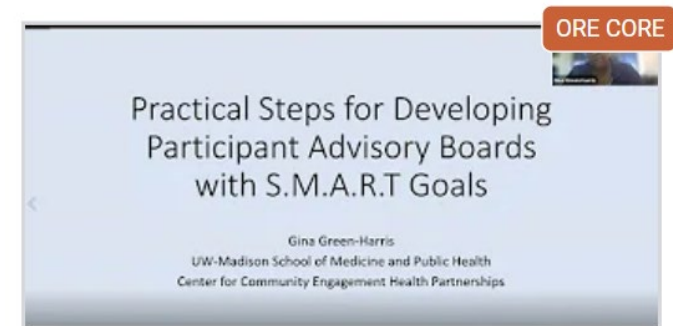
ORE Core Steering Committee Efforts

- **Hosted 2 webinars** focused on Participant Advisory Boards... How, When, and Why?
- Initiated discussions to begin exploring a **Faith-Based Model for recruitment**. Pastor Jenkins, one of the speakers tomorrow, has participated in these early discussions.
- Strategizing new ways to **increase peer support and collaborations** across ORE Cores.
- Organized a special meeting with ORE Core Leads. This gathering could serve as a model for other Cores to share experiences and address common challenges, and to facilitate **cross-Center collaborations**.
- Kept **diversity - demographically and professionally - at the center of all efforts** this year and prior.



APRIL 12, 2022

[Developing Participant Advisory Boards to Support ADRC Research](#)



SEPTEMBER 16, 2022

[Participant Advisory Boards \(PAB\) Part 2](#)

Updates from Neuropathology Core Steering Committee

- In collaboration with the Digital Pathology Working Group, a **survey of neuropathology practices** has been sent to all ADCs and the results are available

1:55pm - 2:10pm (CT)	10min Presentation, 5min Q&A
Digital Pathology Working Group Update	Brittany Dugger, PhD UC Davis ADRC

- **NINDS FITBIR Common Data Elements** are currently being developed in collaboration with NP core leaders.
- Collaborating with REC Steering Committee (Dr. Liz Head leading effort) to think through how to **best share Clinical Pathology Conferences**.
- Coordinating with the ADRC consortium for CLarity in ADRD Research Through Imaging (CLARiTI) to help identify **best ways to collect tissue from deceased participants**.

Neurobiobank update

- Reminder: **pilot** to have Brain Donor Project refer to limited radius for 3 sites: University of Washington, University of Pittsburgh & Yale University
- Developed **triage plan** to emphasize needs including racial/ethnic diversity, control, CT participants, etc.
- Dirk Keene will provide a more detailed update during the Neuropathology Core Session tomorrow

Since 2013, the NIH NeuroBioBank has catalyzed scientific discovery through the centralization of resources aimed at the collection and distribution of human post-mortem brain tissue.

Our networked brain and tissue repositories distribute thousands of samples per year to the research community studying neurological, developmental, and psychiatric disorders.

[Learn more about the NIH NeuroBioBank](#)

Cross-Core Collaborative Sessions

Friday, October 21st from 4:15pm – 5:30pm CT

Session 1: Research Translation for All Persons: A Discussion of the ADRC Network Role, *Vevey Room*

Presentations by:

- Amy Kind, MD, PhD - Wisconsin ADRC
- Maria Carrillo, PhD - Alzheimer's Association
- Laura Baker, PhD - Wake Forest University ADRC
- Rachel Whitmer, PhD - UC Davis ADRC
- Patricia Jones, DrPH, MPH, MS, MBA - NIA

Session 2: The Diversification of Brain Tissue: Why and Ways Forward, *St. Gallen Room*

Presentations by:

- Julie A. Schneider, MD, MS - Rush ADRC
- Crystal M. Glover, PhD - Rush ADRC

These two concurrent sessions will bring leaders from across the ADRC community and feature **presentations followed by interactive discussion and brainstorming**. The sessions are intended to initiate ongoing work in these areas in the coming year.

NIA Research Centers Collaborative Network (RCCN)

Goals:

- Foster Collaborations across NIA Center Programs
- Prepare New Investigators for Interdisciplinary Research.

Most Recent Workshop:

- Aging, Race, and Health Disparities (June 2022)
- Recordings available on website

Upcoming Workshops:

- mHealth and Digital Approaches to Aging Research (Nov 2022)
- Nutrition for Better Aging (TBD)

→ Travel Awards for Early Career Faculty are Available

→ A Pilot RFA Follows Every Workshop

Website: www.rccn-aging.org/

Follow on Twitter: @RCCNaging



SCAN Compliance

Notice of Award Language

Amyloid PET, Tau PET and MRI collected in Clinical Core participants after January 1, 2021 **and supported by this award** must follow current SCAN protocol as communicated by NACC. The AD Center should complete all tasks required to upload images to the NACC.

A roundtable between NIA, Alzheimer's Association and ADRC REC on Early Career Funding Opportunities



When: Friday, December 9 at 12 pm CT

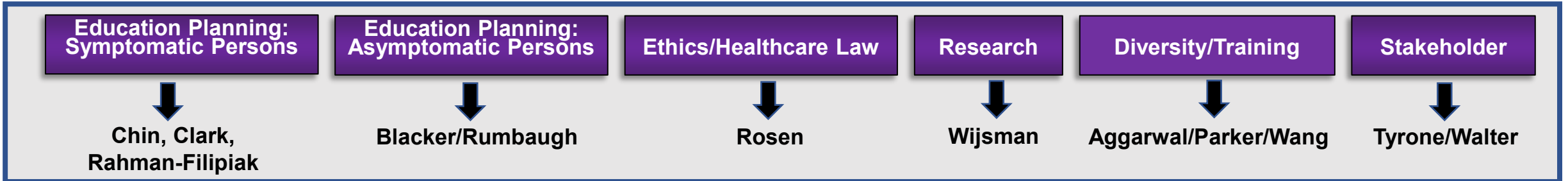
Purpose: To summarize major early career funding opportunities for ADRD scholars and focus on resources, strategies and tips for successful career development.

- **Hosted by:** The Alliance of Women Alzheimer's Researchers (AWARE) PIA, Diversity and Disparities, PIA to Elevate Early Career Researchers (PEERs) and Research and Education Component (REC) of Alzheimer's Disease Research Centers.
- **Moderators:** Barbara Bendlin, Elizabeth Head, C. Elizabeth Shaaban, Duygu Tosun-Turgut, Hussein Yassine, Megan Zuelsdorff
- **Panelists:** Representatives of the National Institute of Aging and Alzheimer's Association
- **Registration:** To register for the live event, please visit: https://alz-org.zoom.us/webinar/register/WN_rStcLBjUQqSIA3c8iViN8g

Advisory Group on Risk Evidence Education for Dementia (AGREEDementia.org)

Neelum Aggarwal, Allyson Rosen

- Aims:**
- 1) Risk Evidence Evaluation of Science
 - 2) Guide When and How to Provide Effective Risk Evidence Education
 - 3) Consultation to support ethical and legal risk mitigation



Publications: Communication and Use of Dementia Risk Evidence

- Journal of Alzheimer's Disease: Mini-Forum: 14 articles, Coming out in November (Rosen)
<https://www.j-alz.com/vol90-3>

Webinars: (See AGREEDementia.org/Events and AGREEDementia.org/Lectures)

- [Diversity Webinar Series](#) 2022-3 (AGREEDementia.org/Diversity: Aggarwal/Parker/Wang)
- Monthly Lectures (AGREEDementia.org/Lectures)
- Collaborations with ISTAART/Alzheimer's Association (Oliveira), MRCT (Multiregional Clinical Trials, Tyrone)
- AAIC Talks: Lived Experience (Walter), 2 Symposia on Communicating Dementia Risk (Rahman-Filipiak/Roberts, Jeromin)

Products: Communication Tools: Amyloid PET, Blood Amyloid (Symptomatic Group)



- Piloting decision tools with diverse cohorts

Collaborations on Grants:

- Hartz and Mozersky (R01), Wang (R56,U24) , Rahman-Filipiak (State Grant), two additional to be submitted/under review




Participant FIRST

Putting participants and study partners FIRST when clinical trials end early

Emily A. Largent  Sarah Walter, Nancy Childs, Penny A. Dacks, Shana Dodge, Hana Florian, Jonathan Jackson, Jorge J. Llibre Guerra, Erin Iturriaga, David S. Miller ... [See all authors](#) 

First published: 02 August 2022 | <https://doi.org/10.1002/alz.12732> | Citations: 1

 SECTIONS

 PDF  TOOLS  SHARE

Abstract

Between 2018 and 2019, multiple clinical trials ended earlier than planned, resulting in calls to improve communication with and support for participants and their study partners (“dyads”). The multidisciplinary Participant Follow-Up Improvement in Research Studies and Trials (Participant FIRST) Work Group met throughout 2021. Its goals were to identify best practices for communicating with and supporting dyads affected by early trial stoppage. The Participant FIRST Work Group identified 17 key recommendations spanning the pre-trial, mid-trial, and post-trial periods. These focus on prospectively allocating sufficient resources for orderly closeout; developing dyad-centered communication plans; helping dyads build and maintain support networks; and, if a trial stops, informing dyads rapidly. Participants and study partners invest time, effort, and hope in their research participation. The research community should take intentional steps toward better communicating with and supporting participants when clinical trials end early. The Participant FIRST recommendations are a practical guide for embarking on that journey.



ANNOUNCEMENTS

Participant FIRST Work Group releases recommendations to improve study participants' experience when clinical trials end early



LAUNCHED AUGUST 2022

PARTNERS



LEADERSHIP



Maria Carrillo,
Ph.D.



Gil Rabinovici,
M.D.



Michael Raffii,
M.D., Ph.D.

PURPOSE

Real world data/ evidence are necessary elements for tracking FDA-approved drugs in general population.

ALZ-NET is a treatment agnostic network following patient treatment/ care in real-world clinical settings.

Designed to work in conjunction with affiliated studies conducted by academia, industry, federal or ALZ-NET project teams.

GOALS & OBJECTIVES



Develop a multi-site network for enrollment and data collection.



Build, implement resources for clinical readiness in a new phase of treatment (i.e., education and training).



Collect patient data at the start of treatment and over time, including measures of cognition, function and safety.



Collect and archive brain scans, as well as genetic and biomarker data and biosamples.



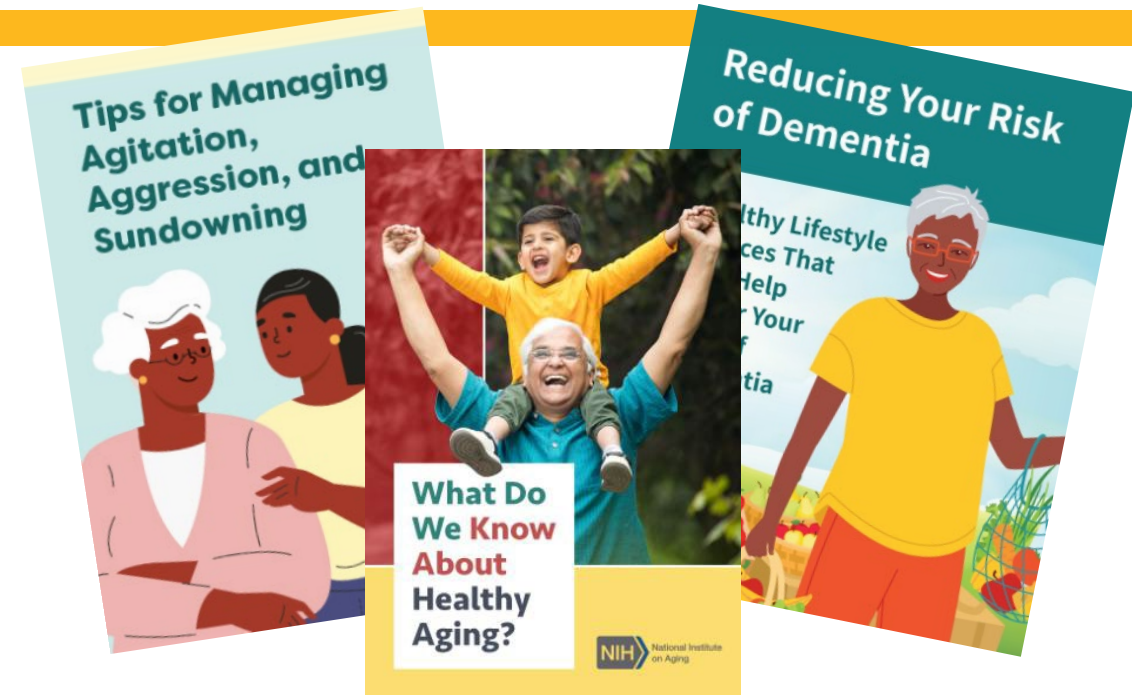
Track health outcomes and resource utilization of participants.



Share de-identified data, brain scans and blood samples with the research community.

New NIA Publications, Videos, and News

- **Reducing Your Risk of Dementia**
 - **Tips for Managing Agitation, Aggression, and Sundowning**
 - **What Do We Know About Healthy Aging?**
- Order free copies or download at <https://order.nia.nih.gov>
- **Biomarkers and How They Help Diagnose Dementia**



View at www.youtube.com/NatInstituteOnAging

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Keep up with the ADRCs on Twitter!

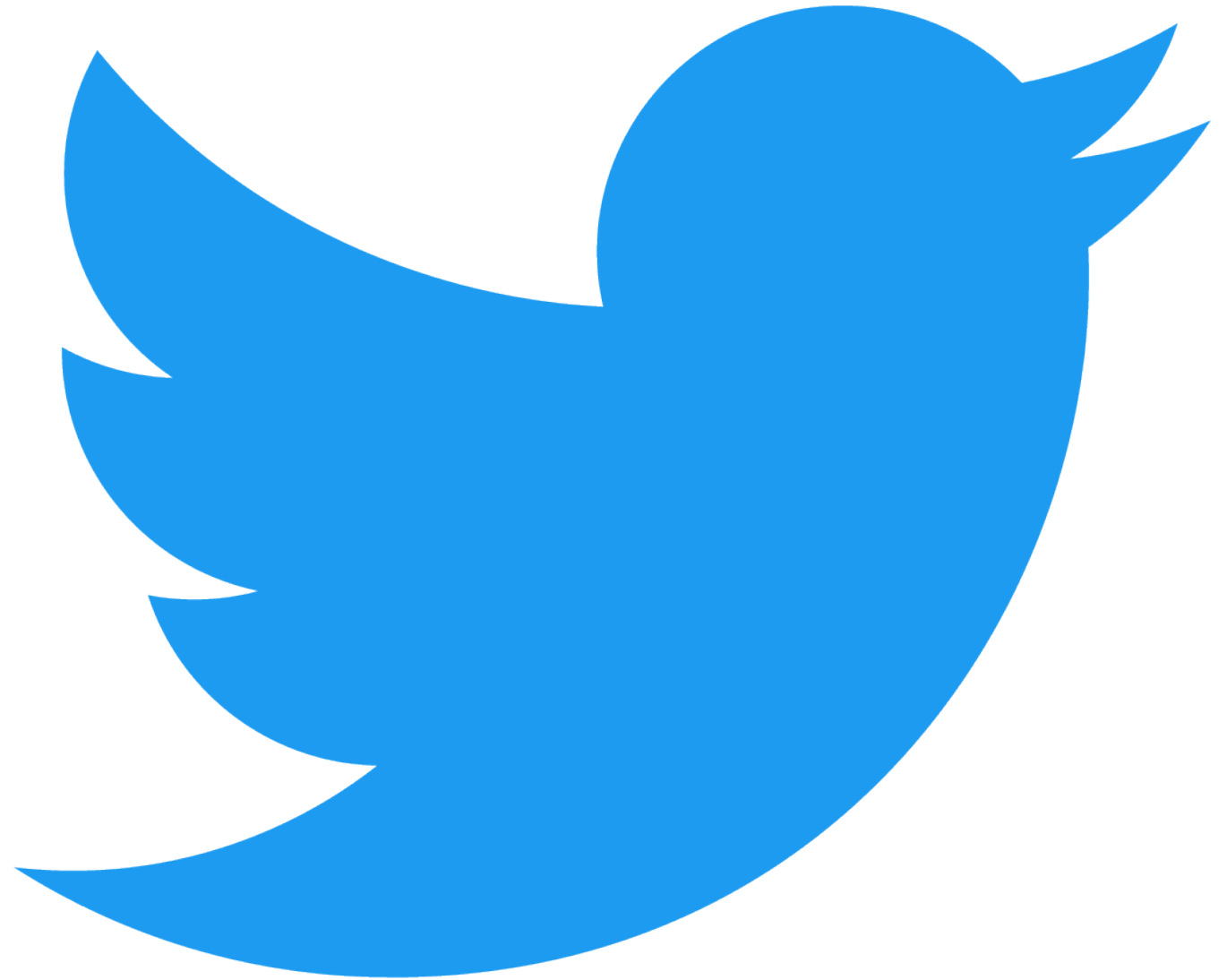
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