

ADRC Directors Meeting

Nina Silverberg, Ph.D.

Director, Alzheimer's Disease Research Centers Program

National Institute on Aging

May 14, 2022

Big picture – and getting bigger!

- ADRCs play a central role in global AD/ADRD research
 - Lead the field scientifically, develop new approaches
 - Provide standardized data, samples and participants **across dementias and severity**
 - 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
- Centers act both within the network and locally within the (public and research) community
- Need to improve sharing and open science practices

ADRD Summit



Fantastic representation
of ADRCs on agenda,
demonstrating the ADRC
program contribution to
the science

NACC's Expanded Data Coordination Role Across the ADRCs

Coordinate data collection



Communication
Education
Evaluation/tracking
Meeting coordination

Co-develop pipelines



In collaboration with
partners e.g. SCAN,
LONI, ADRCs

Integrate the data



Connect all ADRC data types
to NACC IDs (with NCRAD
and NIAGADS)

Make data more integrated,
harmonized, and FAIR

Share and facilitate use of the data for impactful research



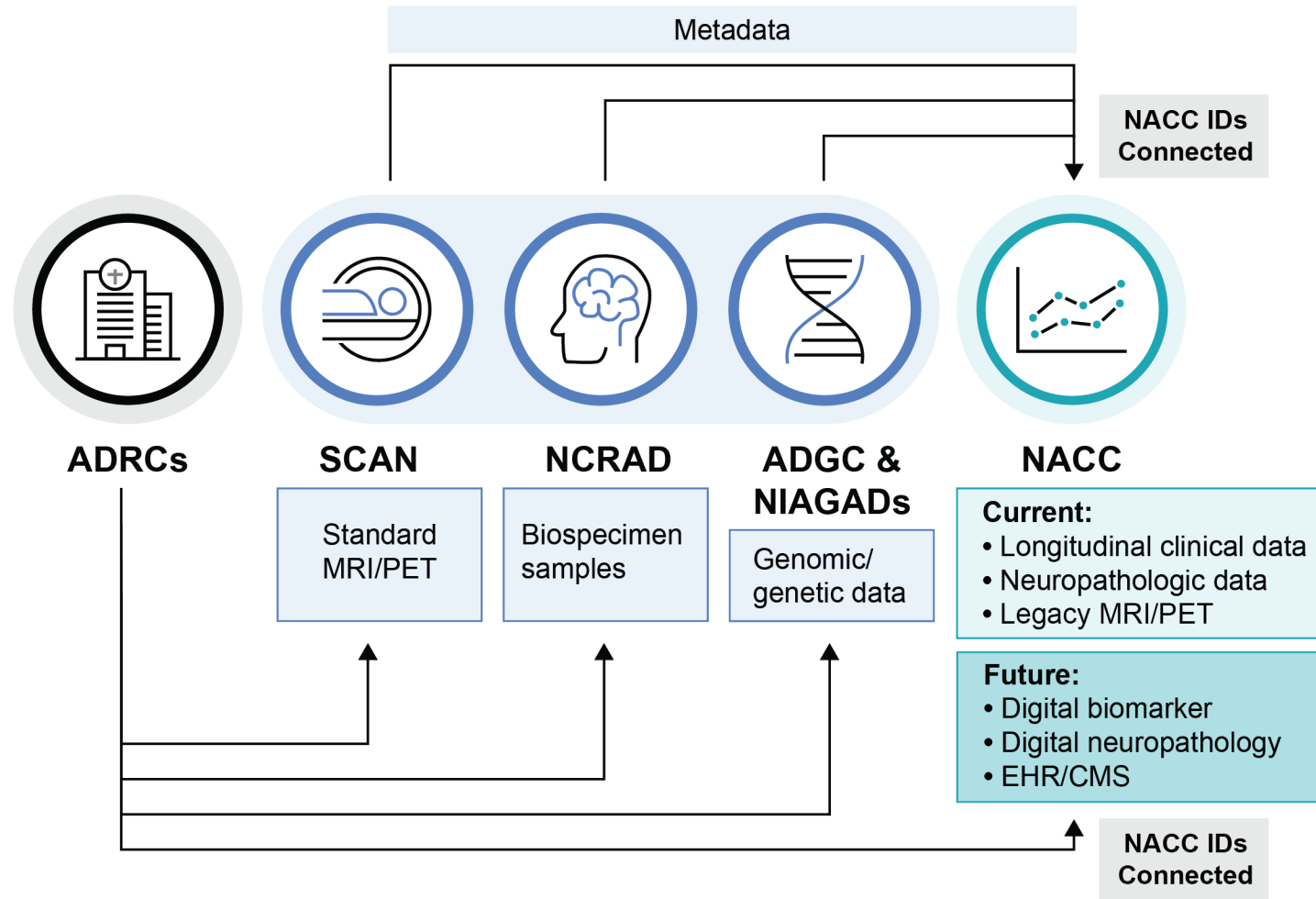
Co-develop and host the “front door/
one-stop-shop” for ADRC data
Provide tools for self-service access to data
Collaborate with ADRC researchers and
provide biostatistics consultations
Support ADRC dataset development
Fund early career AD investigators

Collaborate with current and future ADRC data initiatives to maximize the impact

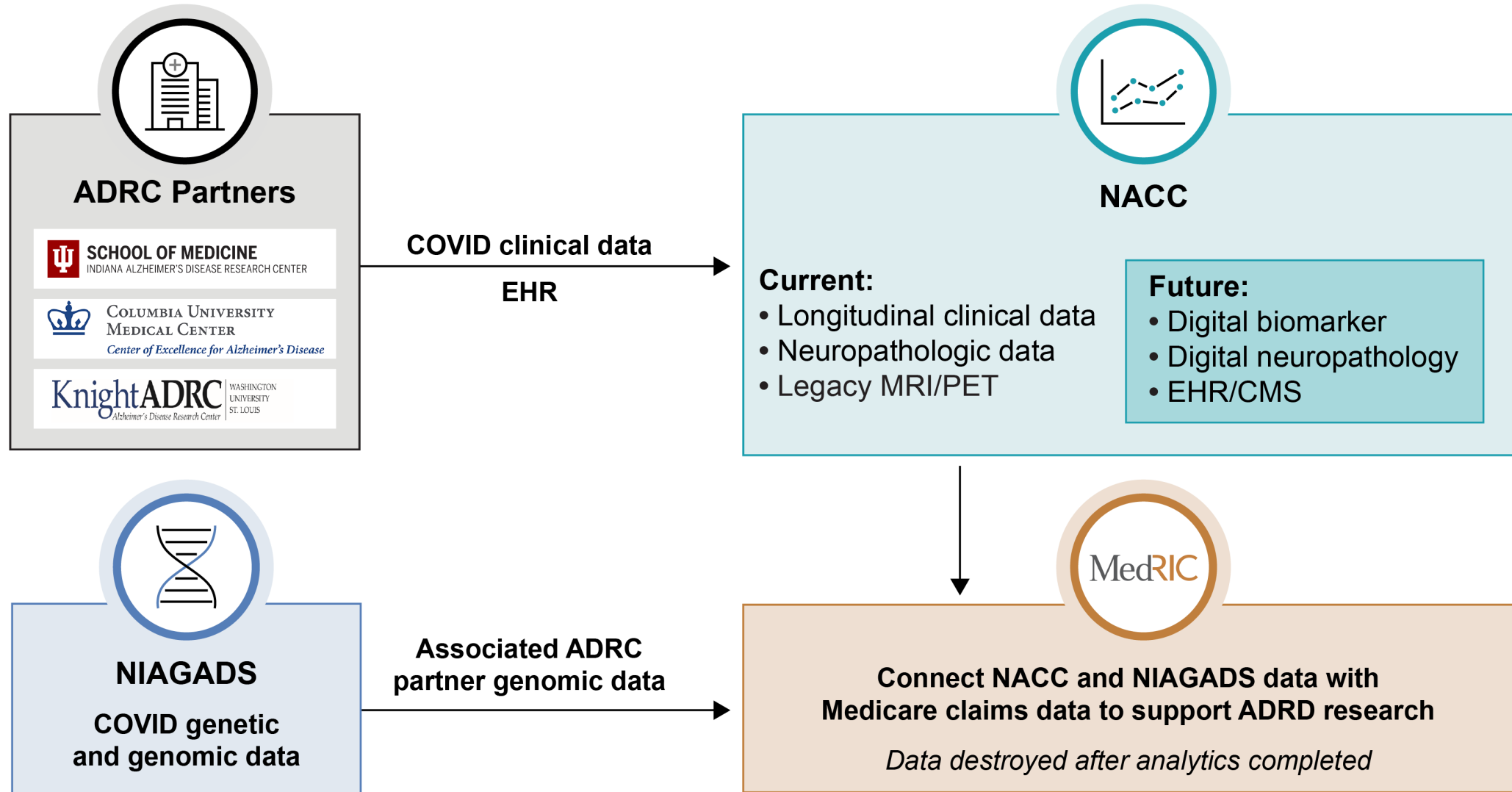


Streamline related initiatives
Align with NIH's data science strategy

UDSv4 – Pipeline and Database



COVID-19 Data Connections



NCRAD Updates

What is New at NCRAD?

iPSCs

194 Total Banked

- AD, EOAD, ALS, FTD, MCI
- With and without mutations

Fibroblasts

322 Total Banked

- AD, EOAD, ALS, FTD, LBD, MCI, Vascular Dementia
- With and without mutations

Brain Tissue

- **NCRAD Family Study:** Fixed and frozen tissue from 258 subjects and 187 families
- **The Gift to Life Brain Collection:** Fixed tissue from 94 participants and mixed frozen tissue from 227 participants (DNA extractions)
 - 67% AD, 20% DLB, 7% FTD, 4% PSP

Catalogs at NCRAD website:

https://www.ncrad.org/accessing_data.html

ADRD Indications Banked at NCRAD

Early Onset Alzheimer Disease	Late Onset Alzheimer Disease
Frontotemporal Dementia	Parkinson Disease and Rapid eye movement (REM) sleep behavior disorder (RBD)
Alzheimer Disease Research Center	Studies of Aging
Down Syndrome	High Risk for AD

60 studies, 108K subjects

ADRC Fluid Biomarker Initiative

NCRAD accepts plasma, buffy coat and PBMCs from the ADRCs. NCRAD provides the kits and shipping. NCRAD also return APOE, GWAS data and now plasma biomarkers for Abeta 1-40/1-42, p-tau 181 and NfL for free for participating.

NCRAD encourage all Centers to send all of their subjects.

Would love to have more!

Thank You: ADRC Clinical Task Force

Allan Levey, CTF Chair

NACC

NIA staff

Clinical Measures & Diagnosis Group

Greg Jicha (co-lead)
Cindy Carlsson (co-lead)
Jeff Burns
Howie Rosen
Brad Boeve
Suzanne Schindler
Teresa Gomez-Isla
Liana Apostolova

Cognitive Working Group

Lisa Barnes (co-lead)
Andy Saykin (co-lead)
Sandy Weintraub
Rhoda Au
Suzanne Craft
Mary Sano

Special thanks for the support of Hannah Craft

Behavior Working Group

Howie Rosen (lead)
Katya Rascovsky
Mary Sano
Kostas Lyketsos
Brad Boeve

Technology Group

Rhoda Au (lead)
Jeffrey Kaye
Zachary Beattie
Felicia Goldstein
Greg Jicha
Jason Hassenstab
Howie Rosen
Ihab Hajjar
Teresa Gomez-Isla
Alan Lerner
Sudeshna Das

Special thanks for the support of Spencer Low

SDOH Working Group

Lisa Barnes (lead)
Megan Zuelsdorff (co-lead)
Rachel Whitmer
Monica Rosselli
Consuelo Wilkins
Shana Stites
Serggio Lanata
Greg Jicha
Joyce Balls-Berry
Gladys Maestre
Erin Abner
Patricia Jones

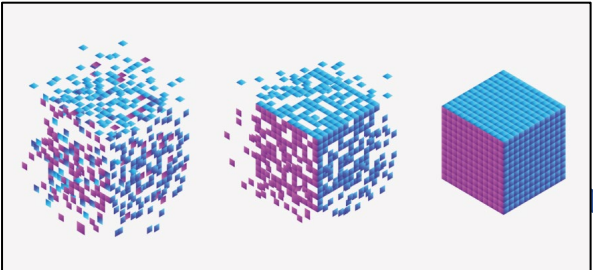
24 ADRCs represented
across CTF Working Groups

UDS 4.0 Technology Pilot

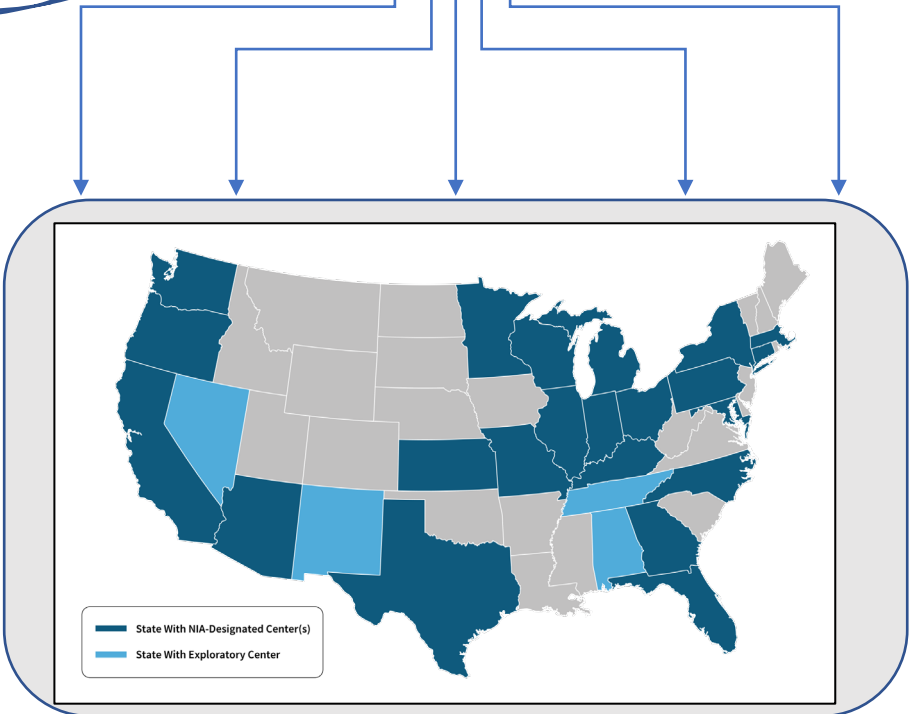
Research Clinic Administration



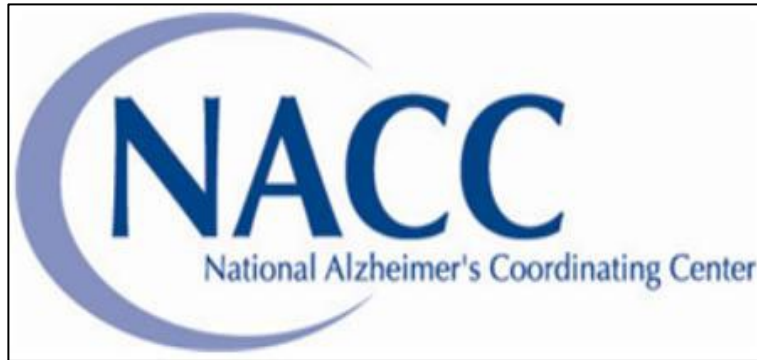
Data Processing Pipeline



Optional: Remote Administration



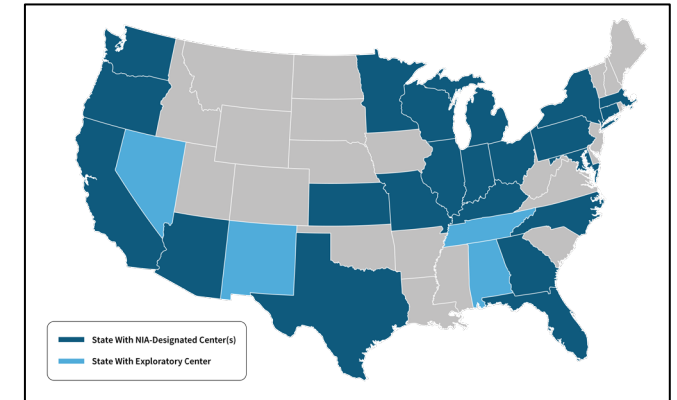
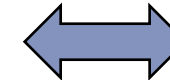
Technology Inventory



NACC survey



Goal: Build a network that encourages innovation in the digital space as the ADRC network moves into UDS 4.0 and beyond.



Connect ADRCs

Please indicate which of the following is true for your ADRC (check all that apply):
 We are collecting data using digital tools for:

	UDS Clinical Measures	Non-UDS Clinical Measures	UDS Cognitive Measures	Non-UDS Cognitive Measures	N/A
Research Clinic Only	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Remote Only	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Both	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please provide the name(s) of the people we can contact to gather detailed information about your ADRC's use of digital technology currently.
* must provide value

Please add contact information for them (email or phone number).
* must provide value

Are you interested in expanding your digital footprint?
☒ Yes
☐ No
* must provide value

reset

Goal: Gather contact information for those in ADRC network using digital technologies and determine who is the right person to contact for interest in digital expansion.

Interview to gather information on logistics, data, and domains of interest for expansion



Collate all data to form an inventory of what is being done in the digital space



Goal: Make this digital inventory available for ADRCs to access and connect with each other to share resources, protocols, administration techniques, etc.

DIGITAL BIOMARKER CTF SESSION

Saturday, May 14th
3:00 – 4:00 PM PT

Digital Biomarker / CTF Tech Session

Hollywood Ballroom

Join us for a quick but mighty, hour-long session chaired by Rhoda Au, leader of the CTF Technology Workgroup.

Planned Pilot Protocol: *Rhoda Au*

Demo- Linus platform: *Zach Popp*

Overview: Interviewing ADRCs on Technology Footprint & Interests: *Rhoda Au*

NACC Support for Digital Biomarker Data Coordination: *Sean Mooney*

ADRD Data and Indigenous Nation Sovereignty

- Crossroad between 2 movements:
 - Big Dataset efforts
 - Recognition of Sovereignty i.e., Indigenous Nation's rights to control AI/AN data
- Indigenous-led initiative started to provide guidance for use of these data
 - Lauren W. Y. McLester-Davis, Oneida Nation of Wisconsin, lmclesterdavis@tulane.edu
 - Jordan P. Lewis, PhD, Aleut from the Native Village of Naknek jplewis@d.umn.edu
- Would like to start by partnering with NIA, but hope to disseminate more broadly
- Potential stakeholders are encouraged to reach out to leaders, especially tribal representatives, elders, and community representatives
- NIH Tribal Health Research Office:

Emergency Award: Rapid Acceleration of Diagnostics Tribal Data Repository (RADx TDR) (U24 Clinical Trial Not Allowed)

[NIH Tribal Consultation on Draft Policy for Data Management and Sharing | DPCPSI](#)

ADRC Native American Interest Group Listserv

ADC_NatAm@uw.edu

Brain Donation Resources

Brain Donation: A Gift for Future Generations

Brain donation helps researchers study brain disorders, such as Alzheimer's disease and related dementias, that affect millions of people. Learn about why people donate their brains, the process of brain donation, and how you can enroll to make this generous gift.

<https://www.nia.nih.gov/health/brain-donation-gift-future-generations>

Collaboration, culture, coordination: Keys to supporting brain donation

March 04, 2020

<https://www.nia.nih.gov/research/blog/2020/03/collaboration-culture-coordination-keys-supporting-brain-donation>

Brain Donation Resources for ADRCs

- [Brain Donation FAQs](#)
- [Tips on Communicating About Brain Donation](#)

<https://www.nia.nih.gov/health/brain-donation-resources-adrcs>

RESEARCH HIGHLIGHTS

Inside the brain: The role of neuropathology in Alzheimer's disease research

March 14, 2022

<https://www.nia.nih.gov/news/inside-brain-role-neuropathology-alzheimers-disease-research>



SCIENCE

Why My Grandmother Carried a Plastic Brain in Her Purse

She is donating her brain to science, so I visited the place where it will end up.

DARA BRAMSON APRIL 11, 2018

<https://www.theatlantic.com/science/archive/2018/04/grandmother-brain-donation/557510/>

Neurobiobank update

- Reminder: **pilot** to have Brain Donor Project refer to limited radius for 3 sites: University of Washington, University of Pittsburgh & Yale University
- Successful in integrating ADRC/Neurobiobank!
- Developed **triage plan** to emphasize needs including racial/ethnic diversity, control, CT participants, etc.
- Referrals successful, brains collected; neuropathology UDS, toxicology, data upload to NBB
- Next phase send samples to requestors; benefit to have central site, increase autopsy with available data
- Will update in Fall at Neuropath Core meeting

LATE Meeting 2022

+ Virtual Workshop Tackles LATE, a Cause of Late-life Dementia

25 Feb 2022


At LATE 2022, researchers hashed out neuropathological and clinical characteristics of limbic predominant age-related TDP-43 encephalopathy, a major contributor to late-life cognitive decline and potential bungler of AD clinical trials.

+ Scientists Say LATE Worsens Cognitive Decline

02 Mar 2022

Limbic predominant age-related TDP-43 encephalopathy is strikingly common among octo- and nonagenarians, and it causes their cognition to slide. LATE dramatically boosts the risk of dementia among people who also have plaques and tangles.

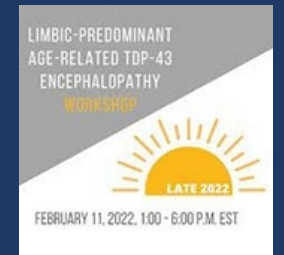
+ Does LATE Subvert Alzheimer's Trials? Biomarkers, Please!

 1 COMMENTS

04 Mar 2022

Limbic TDP-43 pathology accelerates cognitive decline in people with or without AD. Exosome and imaging biomarkers look promising.

More than 350 attendees
from 14 different
countries

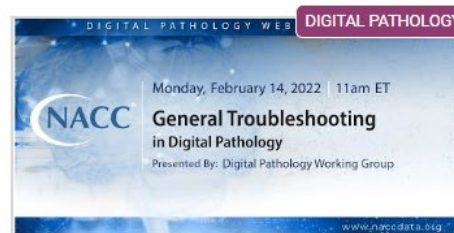


Digital Neuropathology Webinar Series

- Webinar series started in March 2021 with *History and Overview of Digital Pathology*
- Thank you to Maggie Flanagan, Northwestern ADRC

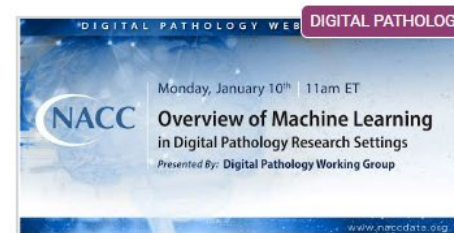
Past webinars

ALL	CLINICAL CORE	DATA CORE	DIGITAL PATHOLOGY	IMAGING CORE	ORE CORE	ADDITIONAL TOPICS
2022	2021	2020	2019			
						SORT BY: ^ NEWEST v OLDEST



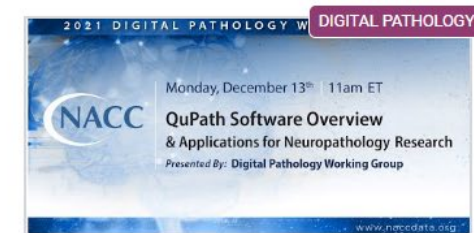
FEBRUARY 14, 2022

General Troubleshooting in Digital Pathology



JANUARY 10, 2022

Overview of Machine Learning in Digital Pathology: Research Settings



DECEMBER 13, 2021

QuPath Software Overview and Applications for Neuropathology Research

<https://naccdigital.org/adrc-resources/adrc-webinars>
<https://www.youtube.com/playlist?list=PLxZHxTrYnx--xdXxjxCeIKD6FtJU1zE8P>

Developing Participant Advisory Boards to Support ADRC Research



**ORE CORE PAB
webinar**

GINA GREEN-HARRIS
UNIVERSITY OF WISCONSIN- MADISON
SCHOOL OF MEDICINE AND PUBLIC HEALTH
CENTER FOR COMMUNITY ENGAGEMENT AND HEALTH
PARTNERSHIPS
APRIL 12, 2022

Play (k)

4:05 / 58:54

Developing Participant Advisory Boards to Support ADRC Research - ORE Core Webinar - April 12, 2022



46 views • Apr 12, 2022

LIKE DISLIKE SHARE SAVE ...

The image shows a YouTube video player interface. At the top right is a small video thumbnail of Gina Green-Harris. The main title 'ORE CORE PAB webinar' is in large, bold, black font. Below it, the presenter's name and affiliation are listed in a smaller, grey font. The video player controls at the bottom show a progress bar at 4:05 / 58:54, a play button, and various icons for volume, subtitles, settings, and full screen. The video title and view count are displayed below the player.

<https://www.youtube.com/watch?v=B0aNtBtwrBU>

ADRC Best Practices

<i>Blood/Urine</i>	<i>GUIDs</i>
 Brain	 Informatics
 Consent / Confidentiality	 Intellectual Property
 Cost Recovery	<i>iPSCs</i>
<i>CSF</i>	 Material Transfer
 Digital Neuropathology	<i>Metabolomics / Proteomics</i>
<i>Disseminating / Discarding</i>	<i>Microbiome</i>
 DNA / RNA / Protein	 Rigor and Reproducibility
 EAC Guidelines	<i>Technology</i>

Coming soon:

- Administrators Steering Committee will work to develop a new general “EAB best practices” document
- Genomic Data Sharing (GDS) Policy
- Risk and Biomarker Results Disclosure

NIA Research Centers Collaborative Network (RCCN)

- **Research Compass**

The [RCCN Research Compass](#) is a bibliometric tool to allow searchers to identify which NIA Centers are working in what areas. The tool uses the funding acknowledgements and key words from PubMed to allow searchers to see which centers are publishing in what specific areas using a graphical interface.

- **Upcoming RCCN workshops** (attend virtually at no cost)

- Aging, Race and Health Disparities - June 28-29, 2022
- mHealth – November (exact dates to be confirmed)

- **For more information go to**

- RCCN-AGING.ORG
- <https://twitter.com/RCCNAGING>



The Geriatric Emergency care Applied Research Network 2.0

Advancing Dementia Care (**GEAR 2.0 – ADC**)

R61AG069822 Hwang/Shah

Mission: Advance the science supporting emergency medical care for people with cognitive impairment (CI) or dementia (ADRD) by engaging with a wide variety of stakeholders, with emphasis on people with dementia and their care partners.

R61: Identify and prioritize research gaps (Care Transitions, Communication & Shared Decision Making, Detection, ED Practices) in emergency care for people who have CI or ADRD (2020-2022)

R33: Support and grow research(ers) to improve emergency care for people who have CI or ADRD by awarding \$1.1 million in partnered research funding support (2022-2025)

Goals: Transdisciplinary and inter-organizational partnership growth

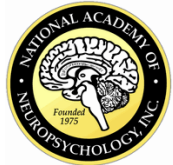
9 partnered research grants

Dissemination and communication across networks

Publication of prioritized research gaps and GEAR 2.0 funded projects

Sustainability

<https://gearnetwork.org>



R61 Accomplishments:

- 2021 Consensus Conference
 - 2-day virtual meeting with 50+ content experts and PLWD and CP
 - Research priorities for each workgroup developed and ranked by conference stakeholders
- Scoping Reviews & Manuscripts
 - care of patients with cognitive impairment/dementia in the ED setting
 - Communication and Decision Making
 - Detection and Identification
 - ED Care Transitions
 - ED Practice
 - 4 Manuscripts, 1 from each workgroup in press (JAMDA)
 - 1 Editorial about GEAR 2.0 (JAMDA)
 - 1 methods manuscript GEAR 1.0 / 2.0 approach (BMJ Open)(April 2022)
<https://bmjopen.bmj.com/content/bmjopen/12/4/e060974.full.pdf>

R33 Next phase:

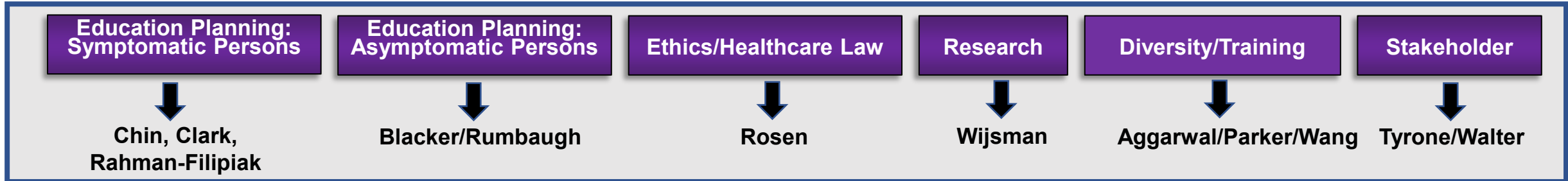
- ***We need your help! Get the word out!***
- Support and grow research(ers) to improve emergency care for persons living with dementia
- 3 rounds of annual pilot funding (total \$1.1 million in partnered support)
- Round 1: Will select proposals (\$90,000/award) in conjunction with the Emergency Medicine Foundation and the West Heath Institute
- New funding opportunities for release late-summer / early-fall 2022
- <https://gearnetwork.org/grants-and-funding-opportunities/>



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

Aggarwal, Gleason, 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: 7 articles in press, 2 under revision (Rosen)
 - Galasko et al, Schindler et al, Parra, Daly et al, Largent et al., Mozersky et al., Karikari
- The Journal of Family Practice- Communication of *APOE* Carrier Status (Stites et al.)

Webinars: (See [AGREEDementia.org/Events](https://www.agreedementia.org/Events) and [AGREEDementia.org/Lectures](https://www.agreedementia.org/Lectures))

- VA GRECC-Connect to Rural Healthcare Providers: 2 Webinars on Clinical Use of Dementia Risk Evidence (Rosen)
 - Clinical Diagnosis: Rosen, Schindler
 - Ethics: Roberts, Largent
- Diversity Webinar Series 2022 (Aggarwal/Parker/Wang)
 - 9 part webinar series in collaboration with a Chicago based health care disparities organization, focusing on research participation and disclosure practices in diverse populations –AGREEDementia/Diversity
- Monthly Lectures ([AGREEDementia.org/Lectures](https://www.agreedementia.org/Lectures))
- Collaborations with ISTAART/Alzheimer's Association (Oliveira), MRCT (Multiregional Clinical Trials, Tyrone)

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

PAR-22-093

Notice of Special Interest: Collaborative Studies on Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD)

Notice Number:

NOT-AG-21-035

Key Dates

Release Date:

December 30, 2021

First Available Due Date:

March 11, 2022

Expiration Date:

November 13, 2024

Related Announcements

[PAR-22-093](#) - Research on Current Topics in Alzheimer's Disease and Its Related Dementias (R01 Clinical Trial Optional)

Alzheimer's and Brain Awareness Month

Highlight Alzheimer's science and research resources on Twitter

#AlzScience Twitter Chat

Date: June 15 at 1-2pm, ET

Hosted by: [@NIHAging](https://twitter.com/NIHAging)

How to join: Email reese.western@nih.gov for questions and materials

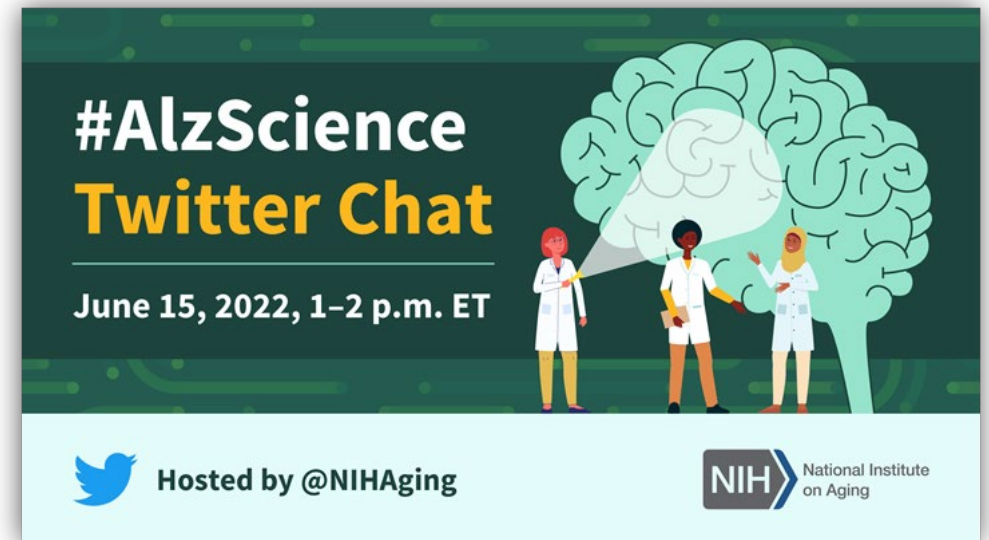
Raise awareness of Alzheimer's disease and resources to support people living with AD, caregivers, and families

Date: Throughout June

Hosted by: [NIA's Facebook](https://www.facebook.com/NIA)

Share resources, stories, and videos on weekly topics:

- Basics of Alzheimer's Disease
- Living with Alzheimer's Disease
- Alzheimer's Caregiving
- Helping Future Generations



NAPA 10th Anniversary

This year marks the 10th anniversary of the National Alzheimer's Project Act! NIA will be promoting AD research and resources and encouraging others to share about their work.

Alzheimers.gov Spanish Launched Fall 2021

Alzheimers.gov is now available in Spanish!

Your destination for dementia information, resources, and research is now available in Spanish.

Visit www.Alzheimers.gov/es



¡Alzheimers.gov ahora disponible en español!

Alzheimers.gov es su destino para información, recursos y actualizaciones de investigación sobre la demencia.

Visite www.Alzheimers.gov/es



New NIA Publications and Videos

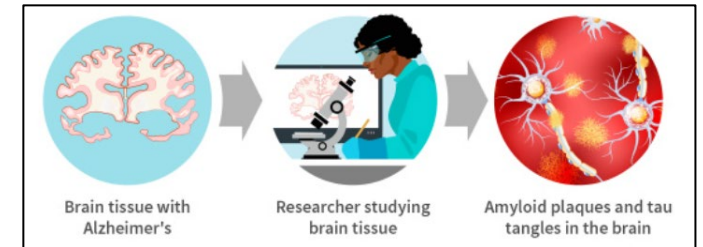
Forgetfulness: Normal or Not?

Handout and Posters to order or download at <https://order.nia.nih.gov>
Animated Video in English <https://youtu.be/wX68gvahj9Q> & Spanish <https://youtu.be/YwvHN0Xs7y0>



Inside the brain: The role of neuropathology in Alzheimer's disease research

<https://go.usa.gov/xuBM2>



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Free Print/PDF Publications | <https://order.nia.nih.gov>
Infographics | www.nia.nih.gov/health/infographics
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