



NACC Update

Sarah Biber, PhD, NACC Executive Director

Wednesday, October 16, 2024

Directors Session, 2024 Fall ADRC Meeting

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

NIH National Institute on Aging (NIA)
Alzheimer's Disease Research Center Program



- State with NIA-Designated Center(s)
- State with Exploratory Center

NACC's Expanded Mission and Role

NACC is providing advanced informatics an operational infrastructure, implementing new frameworks to facilitate impactful communication and collaboration, and supporting the next generation of researchers across the ADRC Program

Data Coordination & Centralized Repository



Communication & Collaboration Hub



New Investigator Support

A network diagram background consisting of a complex web of light blue lines connecting various nodes. Some nodes are represented by solid dark teal circles, while others are smaller, semi-transparent light blue circles. The lines are thin and create a dense, interconnected pattern across the entire page.

Progress Highlights

A network diagram background consisting of a complex web of light blue lines connecting various nodes. Some nodes are represented by solid dark blue circles, while others are smaller, semi-transparent light blue circles. The connections are dense and form a mesh-like structure across the entire page.

Progress: More data and more data utilization!

NACC's Uniquely Valuable and Expanding Database!

UDS Impact



52,500+

Participants
(19,000+ active)



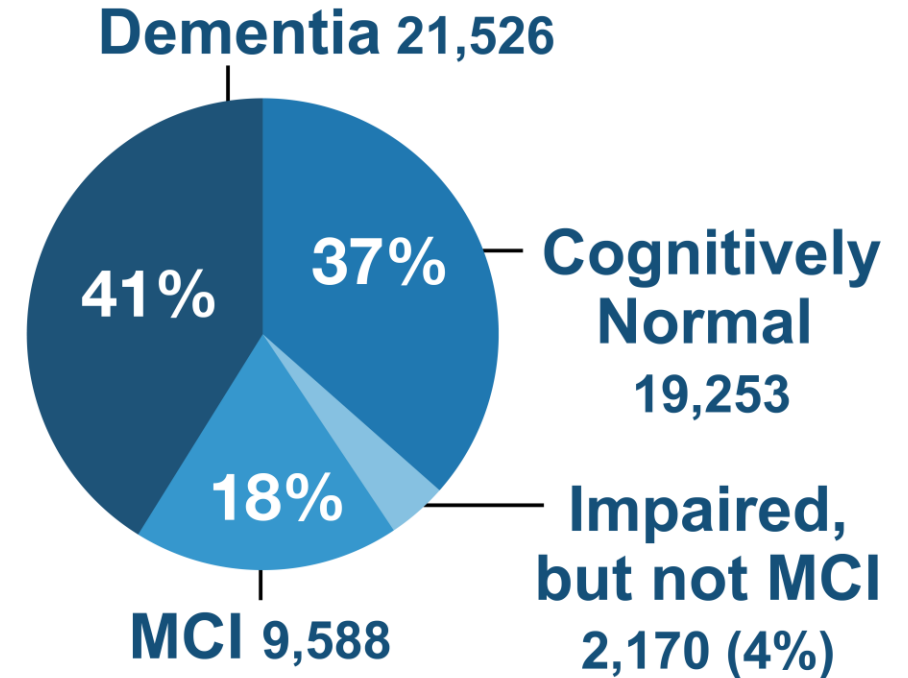
195,000+

Clinical assessments
(1-20 visits/per)



8,150+

Neuropathology datasets
(58% deceased)



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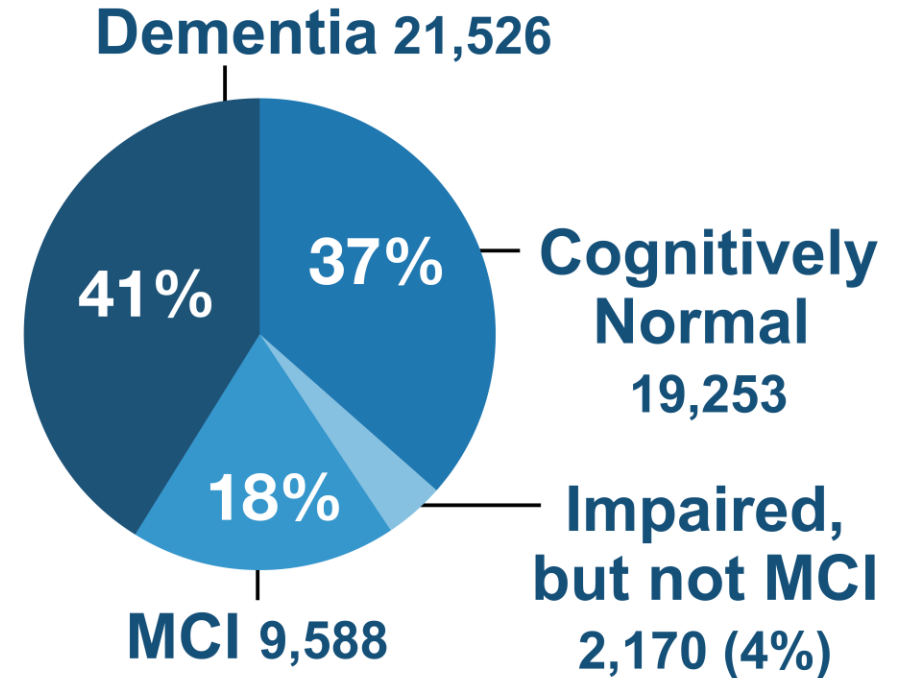
Neuropathology datasets
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Data Usage

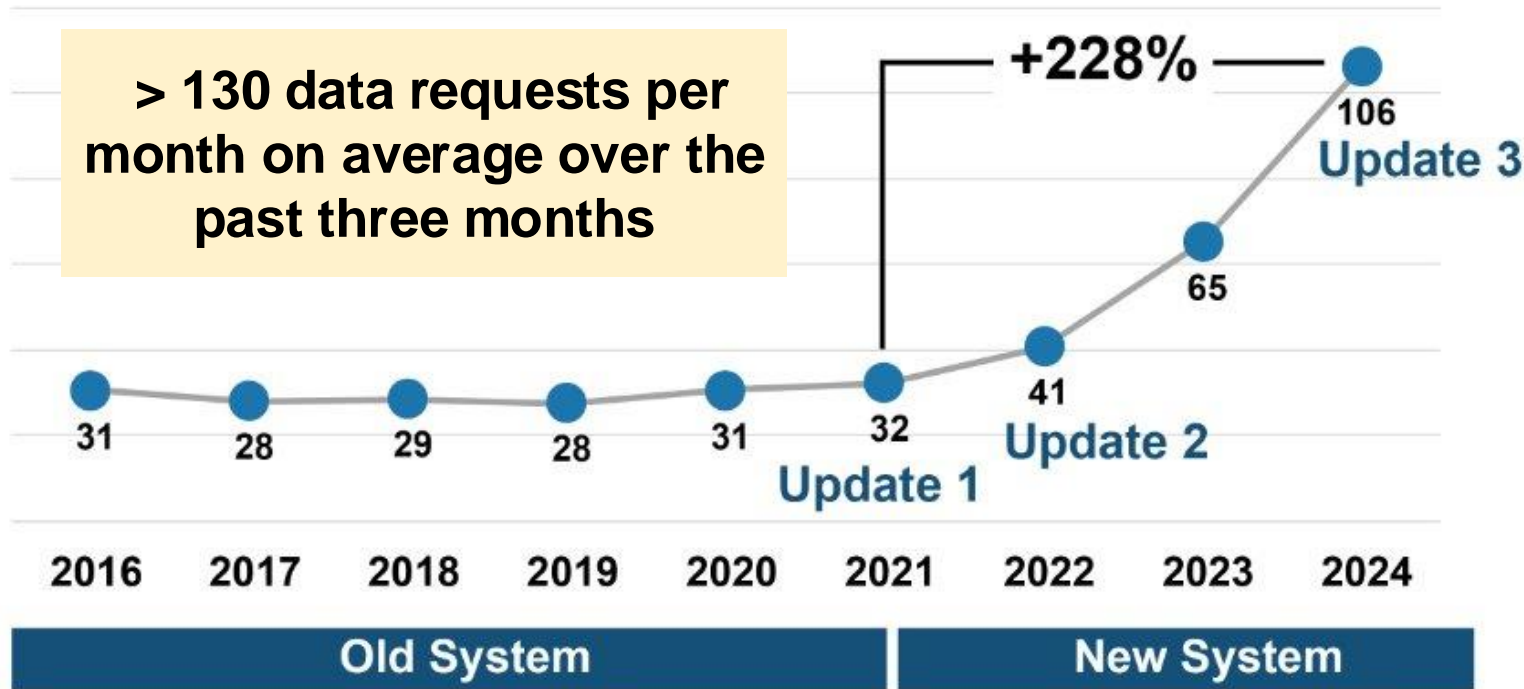
1,350+ Publications

26% Increase since 2021!



Increased NACC Data Utilization - More FAIR!

 **228% Increase in Average Data Requests per Month**



955 data requests in 2024!

74% of new requests include imaging data

Update 1 (Nov 3, 2021): Expanded Quick-Access file types (FTLD, LBD, CSF, MRI, PET, scans)

Update 2 (Jun 4, 2023): Data request survey through REDCap

Update 3 (Apr 30, 2024): SCAN analysis data available

Special Issue of the Journal of Alzheimer's and Dementia

Celebrating the
ADRC Program's
40th and NACC's
25th Anniversary!

Call for proposals can be
viewed at:

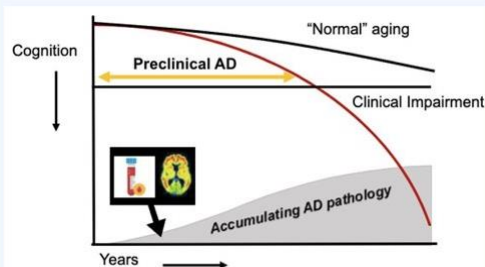
[https://bit.ly/NACC AD Spe
cial Issue](https://bit.ly/NACC_AD_Special_Issue)



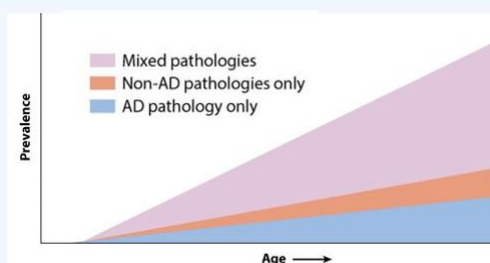
Submission Deadline:
December 31, 2024

GOAL: Highlight the impact these programs have had
on advancing ADRD translation and discovery and their ongoing and
critical role in tackling the most pressing challenges in the field

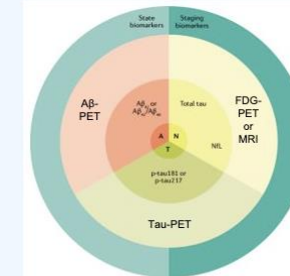
Advance Early Detection



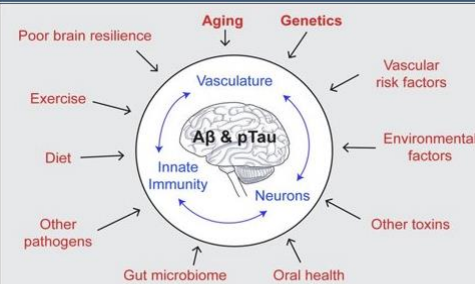
Disentangle Heterogeneity



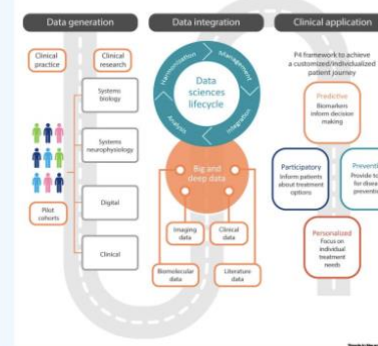
Validate Blood Biomarkers



Identify and Stratify Risk Factors and Protective Mechanisms



Precision Medicine



Improve Generalizability



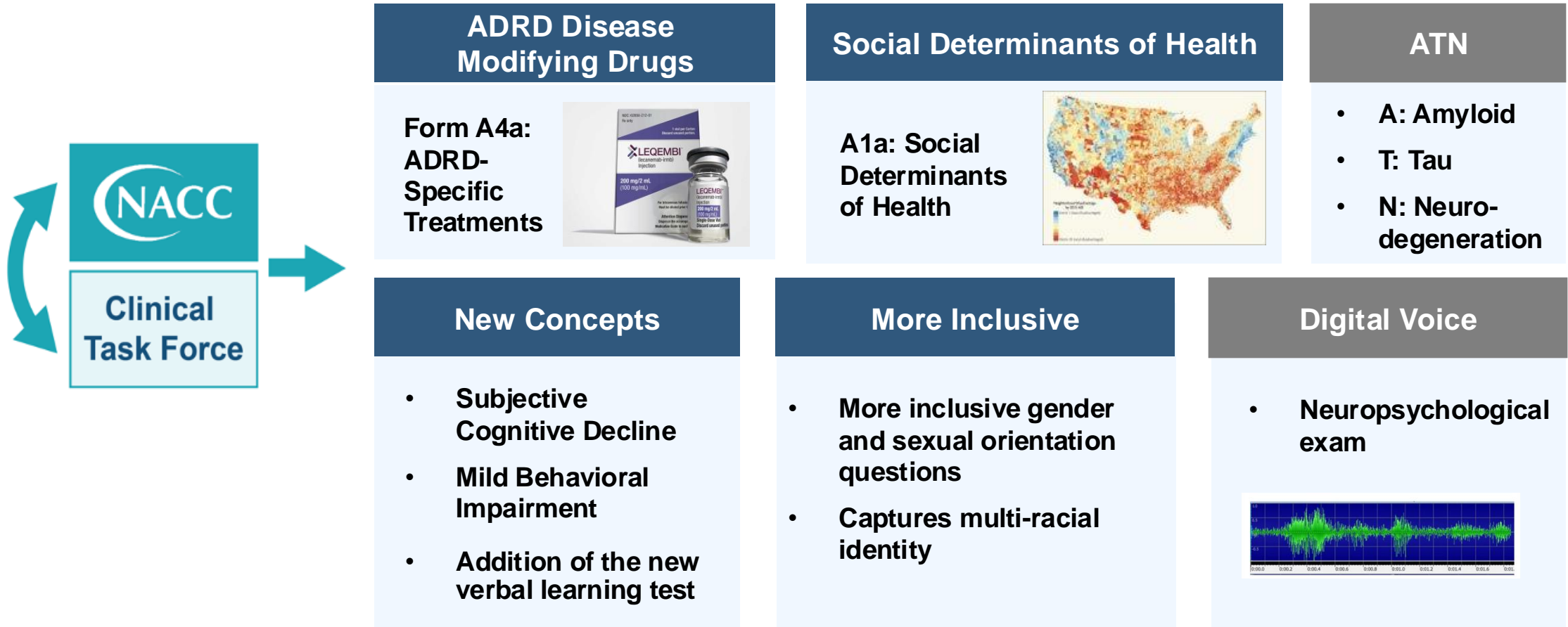
NACC data has and continues to drive major breakthroughs in AD/ADRD

A decorative background featuring a network diagram with teal lines and dots of varying sizes, some solid and some semi-transparent, connected in a complex web pattern.

Progress: UDSv4 is Launching!

UDSv4: Defining a new standard for the field

Aligned with key scientific advances

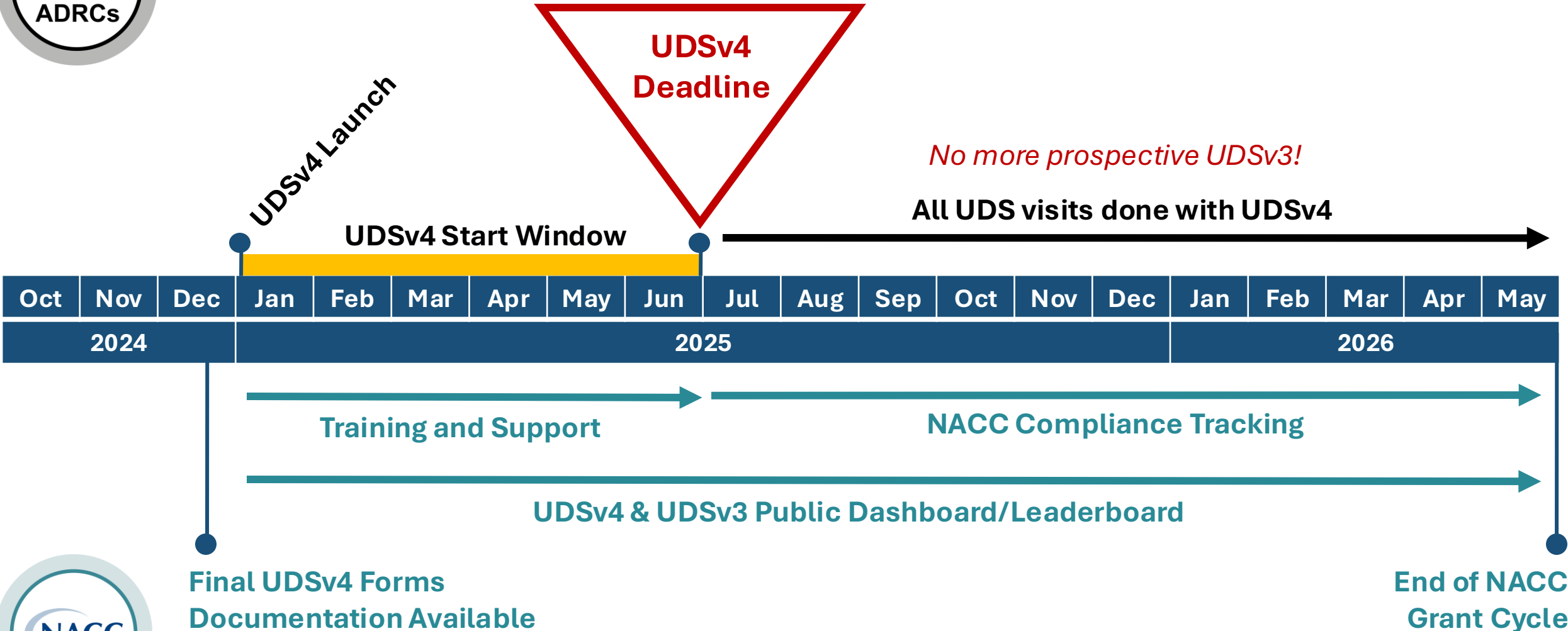


UDSv4 contents and PDF and REDCap forms 100% complete!

ADRC Sites



ADRCs



NACC

NACC Session

Thursday, October 17th between 8:00 - 9:30 am ET

Location: Grand Ballroom

All UDSv4 Resources
Accessible on the NACC Website

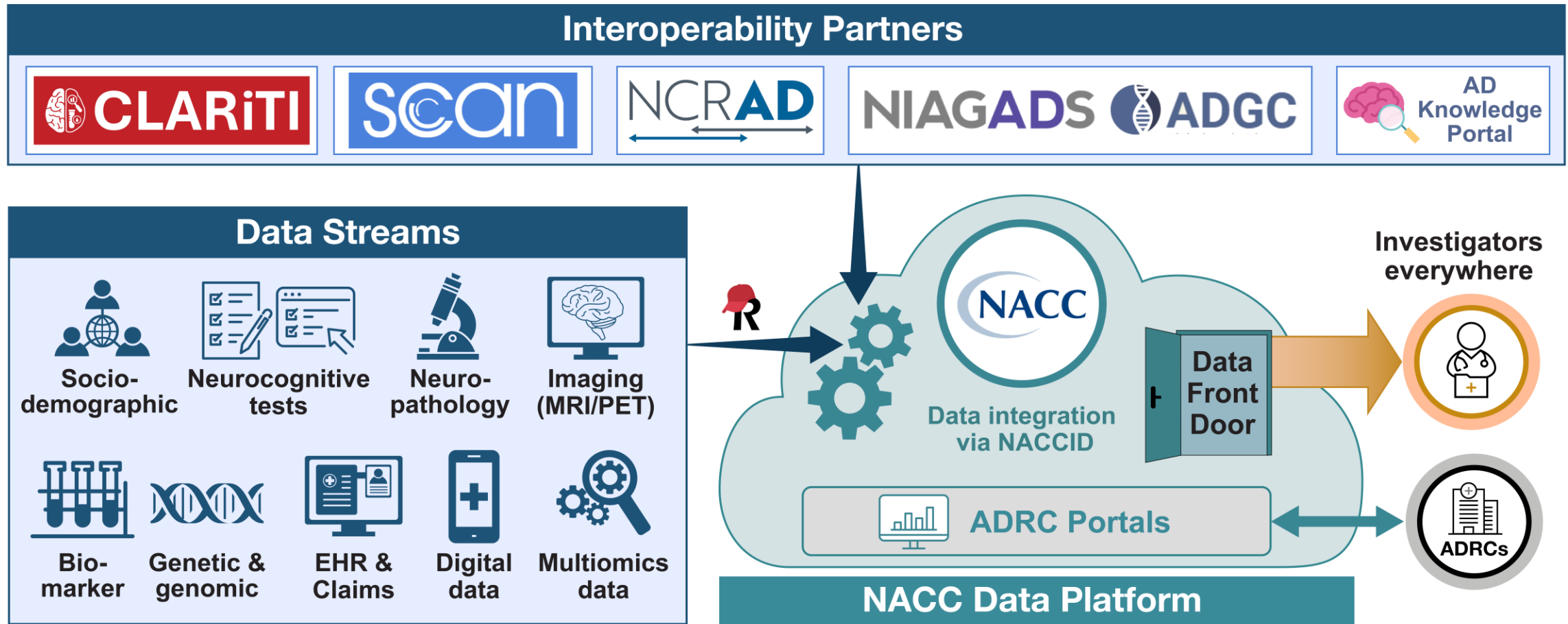
bit.ly/UDSv4Updates



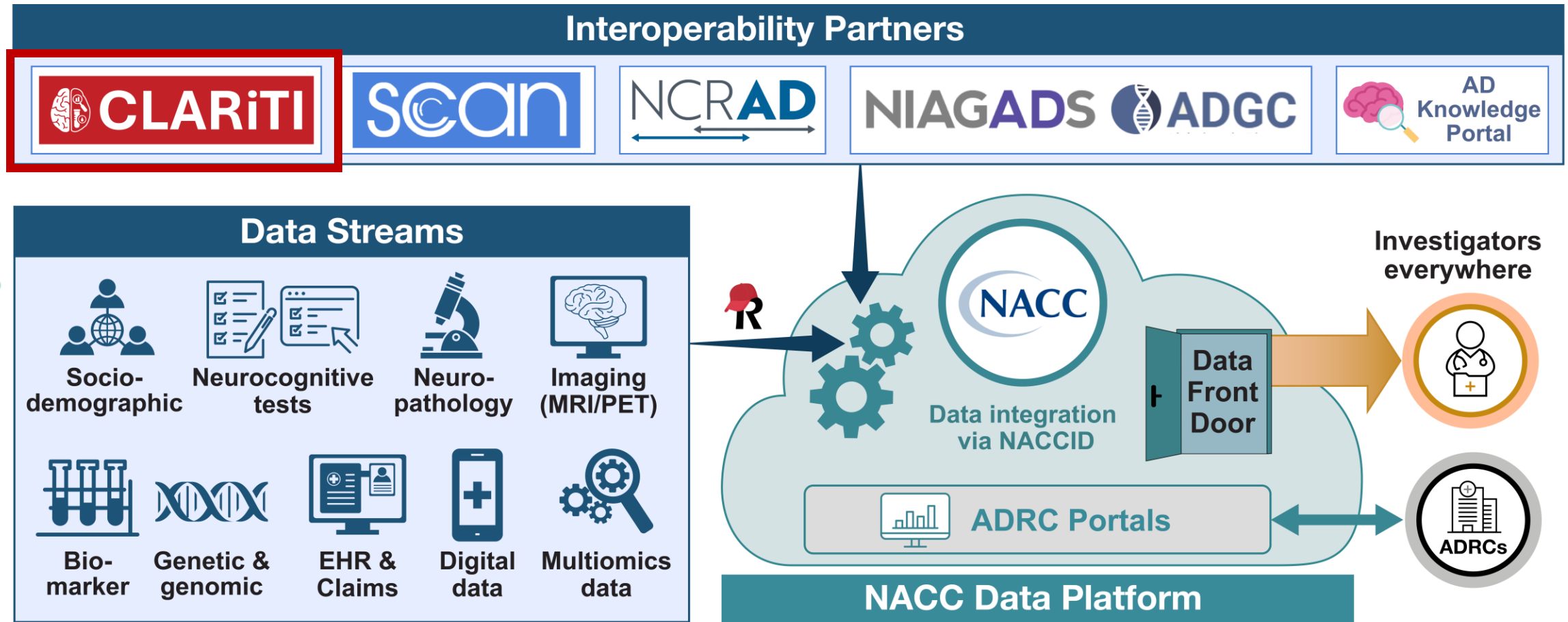
A network diagram background consisting of a complex web of light blue lines connecting various nodes. Some nodes are represented by solid dark blue circles, while others are smaller, semi-transparent light blue circles. The lines are thin and create a dense, interconnected pattern across the entire slide.

Progress: Building a One-Stop-Shop for ADRC Program Data

NACC Data Platform: Advanced ADRC Participant Data Integration, Harmonization, Interoperability, and Access



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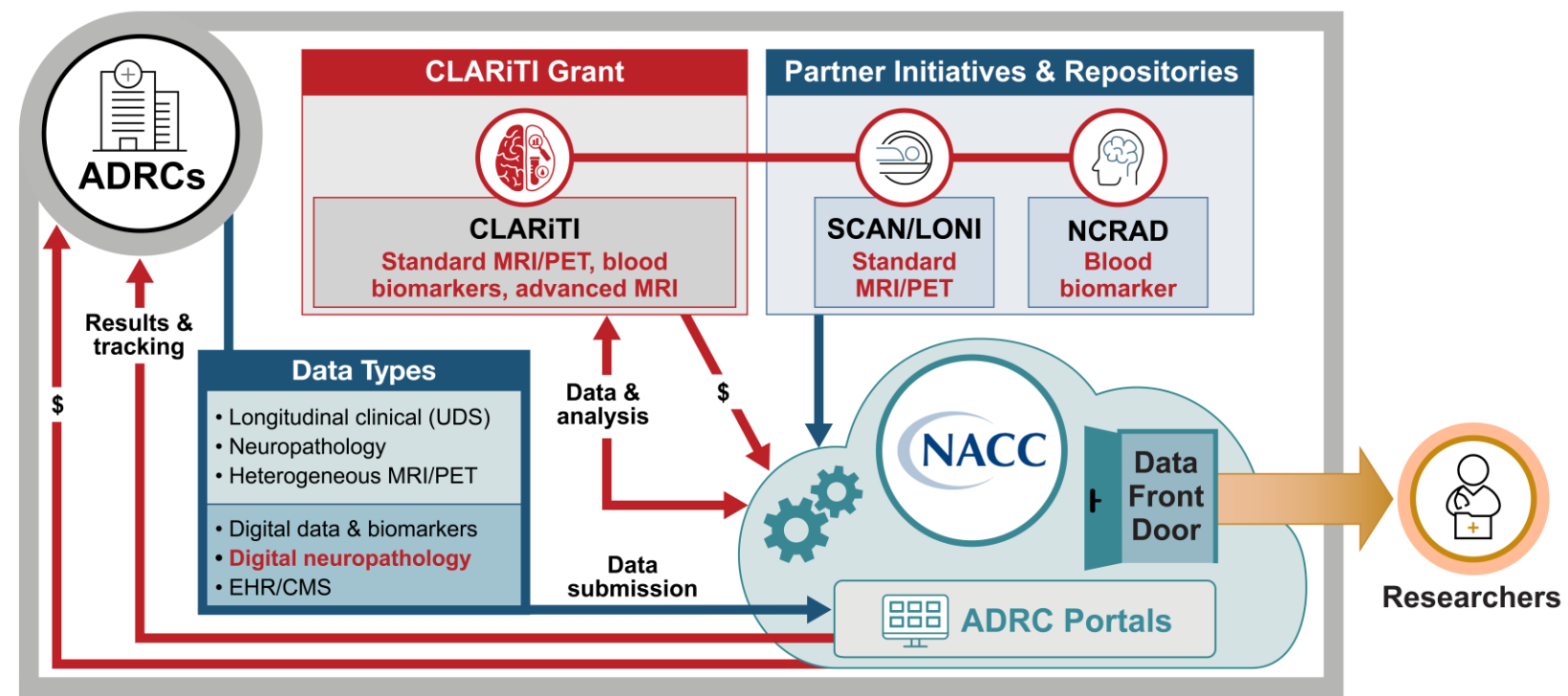


CLARiTI is Integrated into the ADRC Program Ecosystem via NACC's Informatics and Operational Infrastructure

Join the CLARiTI Session!

Thursday, October 17th
2:15 - 3:45 am ET

Location: Grand Ballroom

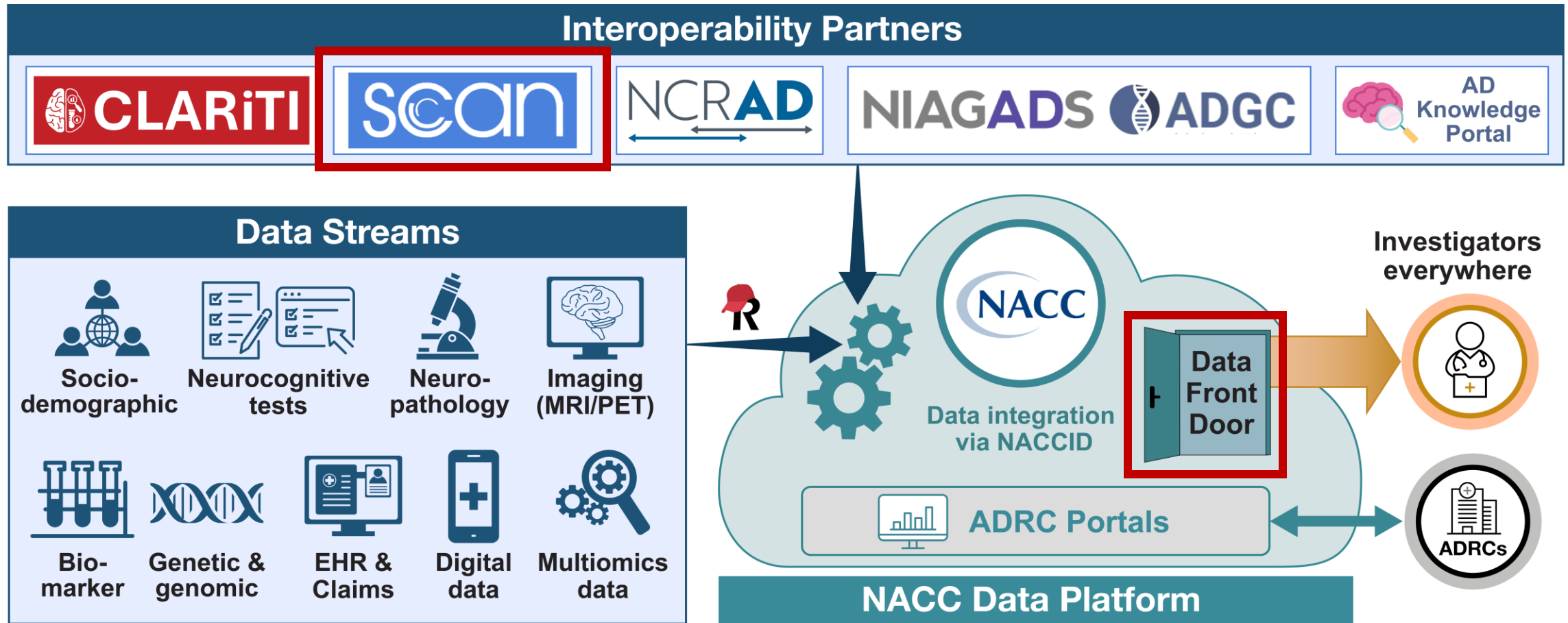


ATN Imaging and Plasma

Longitudinal UDS

Digital Neuropath

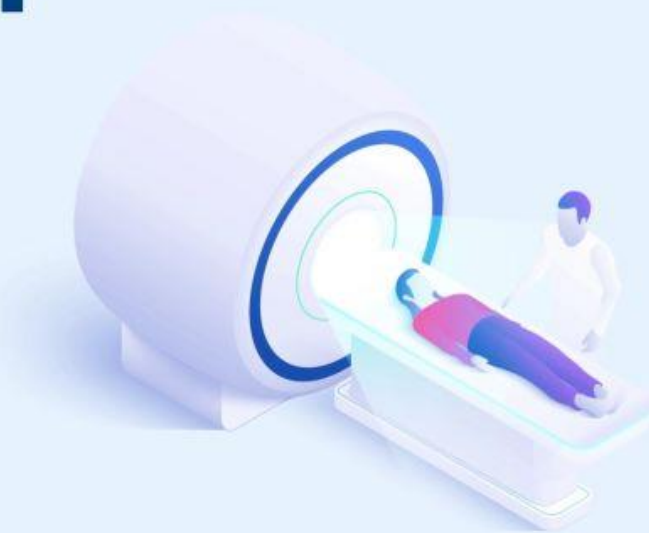
NACC Data Platform: Advanced ADRC Participant Data Integration, Harmonization, Interoperability, and Access



NACC Data Front Door: Quick Access File

Visit scan.naccdata.org/

scan
data is
available
at NACC!



SCAN summary,
analysis, and
image data available at
NACC:

- MRI - Volumes
- PET - SUVRs for amyloid, tau, and FDG
- Defaced MRI and PET images

Berkeley
UNIVERSITY OF CALIFORNIA



UNIVERSITY OF
MICHIGAN



UC DAVIS



15 min request, data sent within 24 hours!



NACC Data Front Door: Public Real-Time SCAN Dashboards

Visit scan.naccdata.org/

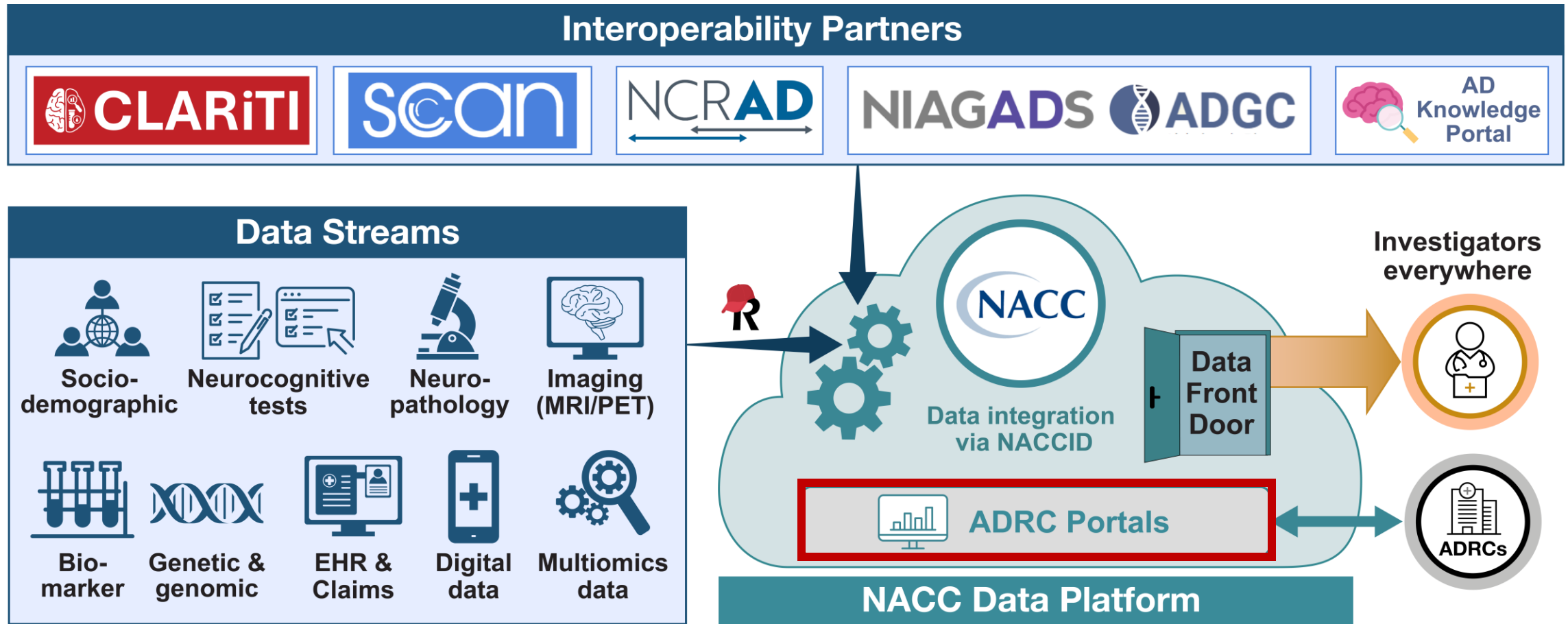
Real-time numbers on how much MRI/PET data has been provided by each ADRC that has passed QC and is available for analysis to the research community.

ALZHEIMER'S DISEASE RESEARCH CENTERS								COPY CSV	Search
Institution	SCAN Participation						ADRC-specific SCAN QC Dashboards		
	Total # of Participants	MRI			PET				
		# MRI participants	# MRI exams submitted	# MRI series submitted	# PET participants	# PET scans submitted			
Total	4,742	4,208	4,832	23,466	1,887	2,845			
Wake Forest University	402	357	391	870	196	310	PRIVATE DASH		
University of Wisconsin	348	316	393	865	185	393	PRIVATE DASH		
University of Michigan	240	240	246	491	0	0	PRIVATE DASH		
Mayo Clinic	235	235	294	878	0	0	PRIVATE DASH		

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Progress: Making it easier for ADRCs to manage their participants and data

NACC Data Platform: Advanced ADRC Participant Data Integration, Harmonization, Interoperability, and Access



ADRC Portals

ADRCs can manage their participants and submit, view, audit, and access their multimodal data

ADRC Portals

Manage Participants



Submit Data



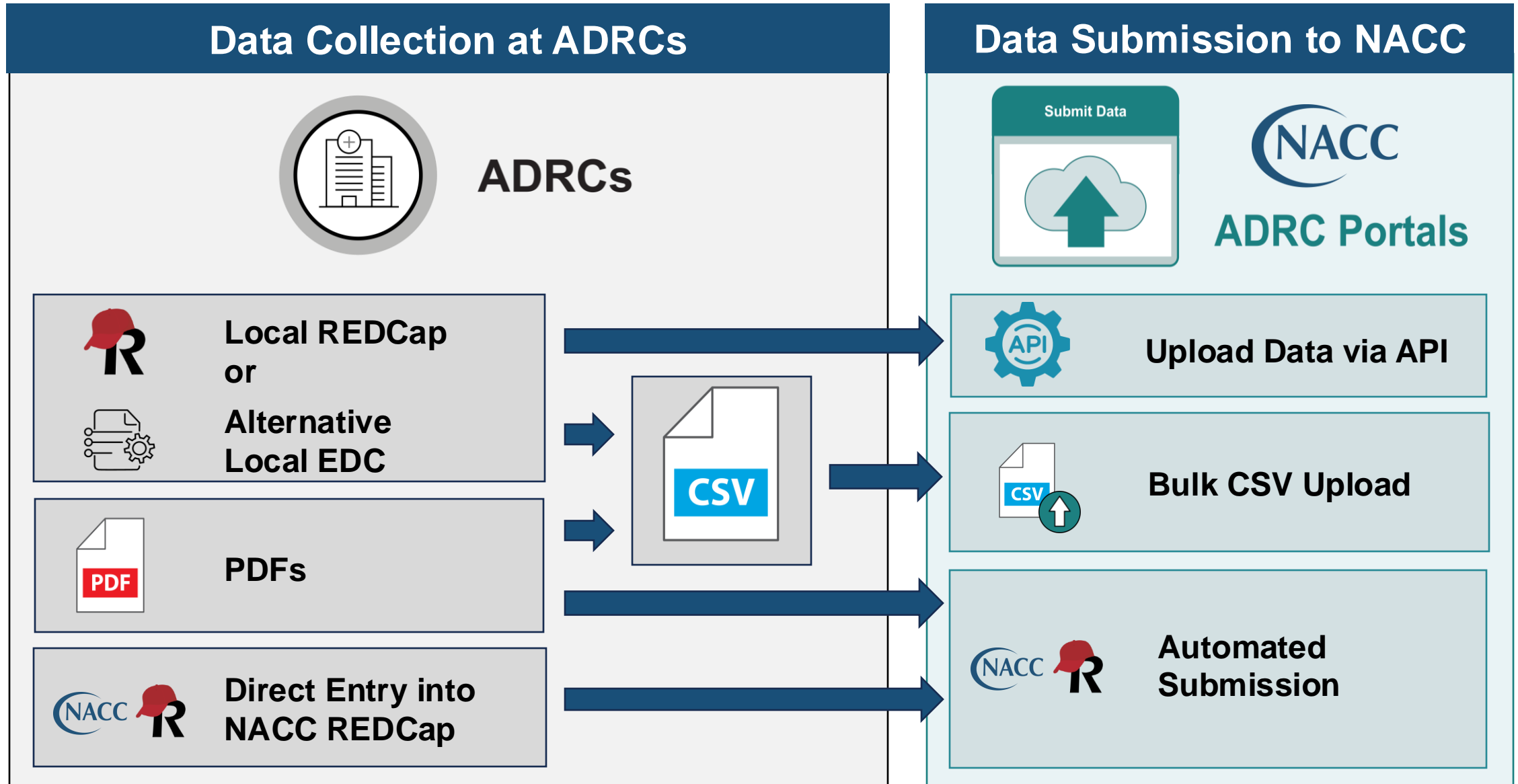
View, Audit, and Access Participant Data



View ADRC Program Dashboard & Reports




New EDCS System Ready to Go for UDSv4!

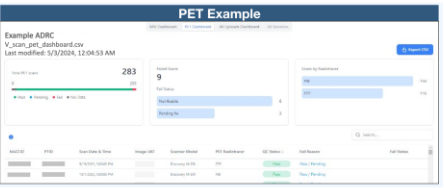


ADRC Portals – New Data Types Accessible!


ADRCs can manage their participants and submit, view, audit, and access their multimodal data



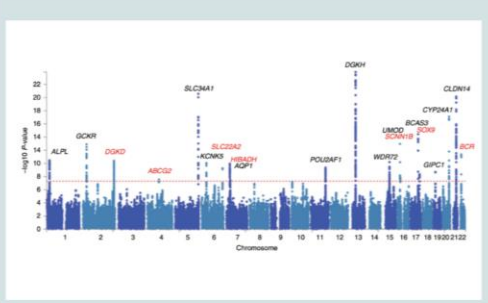
SCAN




- All data variables
- SCAN QC Dashboard



GWAS Data



Imputation Data



Access your participant data from partner repositories/initiatives

Join the NACC Session to learn more!

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Progress: Supporting the Next Generation of Researchers

New Investigator Award Program

- **Collaboration with the Alzheimer's Association!**
- **10 awards!**
- **Funding – \$135K in direct costs** per award
- **Eligibility** – open to any early career investigators that are affiliated with an ADRC



NIAP Mentorship Program

Mentorship available to all applicants!

2023 Mentorship Program Highlights:

- **77%** of applicants were matched with mentors
- **80.2%** of mentees reported that the mentorship strengthen their proposals
- **92.2%** of mentees said they would apply guidance from mentors to future grant applications
- **95.4%** of mentors expressed interest in serving as mentors for future award cycles.

NACC



**Share Your Expertise:
Become a NIAP Mentor!**



<https://bit.ly/NIAP-Mentor-2025>

NIAP Timeline

Key Dates

- **October 24, 2024: NIAP Webinar - 9:30-10:30am PST**
- **November 8, 2024, 5pm EST: Letter of Intent / Request a Mentor Deadline**
- **January 16, 2025, 5pm EST: Application Deadline**
- **May 2025: Announcement of award recipients at the 2025 Spring ADRC Meeting in San Francisco, CA**

Learn more about the NIAP program and apply

bit.ly/NewInvestigatorAwards



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Progress: Building an Incredible Team at NACC



WALTER KUKULL, PHD
PI/Director, NACC
Professor,
Epidemiology



SARAH BIBER, PHD
Executive Director



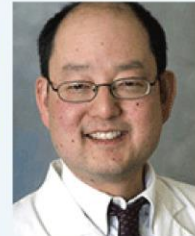
KARI STEPHENS, PHD
Associate Director,
NACC,
Professor, Family
Medicine



**CHARLES
MOCK, MD, PHD, FACS**
Associate Director,
NACC Professor,
Epidemiology
and Surgery



**KWUN CHUEN
GARY CHAN, PHD**
Associate Director
Prof., Biostatistics,
Health Systems &
Population Health



DEAN K. SHIBATA, MD
Associate Director,
Co-investigator, NACC;
Professor, Radiology



YEN-CHI CHEN, PHD
Co-investigator, NACC
Assistant Professor,
Statistics



HEATHER O'CONNELL
Program Manager



HANNAH KOENIG
Data Manager



JESSICA CULHANE, MS
Research Team
Manager



**KATHRYN
GAUTHREAUX, MS**
Research Ops Lead



LIAM LANE, MS
Senior Research
Coordinator



ZACK MILLER, BS
Research Consultant



SARAH YASUDA
Research Coordinator



**SHILPA
ALLIMATTI, MS, MBA**
Tech Team Manager



BEN KELLER, PHD
Technology Lead



**CHANDIMA
HEWANADUNGODAGE,
PHD**
Software Engineer 3



ZACH STARK, BBA
Software Engineer 3



DAN PETERSON
Software Engineer 3



LAURA MCLEOD
REDCap
Administrator 3



**JANENE
HUBBARD, BS**
Research Consultant



JOYLEE WU, MS
Database
Administrator



EMILY CHENG, BS
Software Engineer 2



BRENDAN SMITH, BS
Software Engineer 2



**JESSICA
WELSCH, MBA**
Senior Project
Manager



ELISE GRUBER
Project Manager



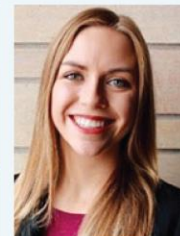
**SATISH
MATTHEW, MBA**
Sr. Technical Project
Manager



BRITTANY HALE
Project Manager



HALYMAH AHMACH
Administrative
Assistant



**HANNAH
ROSENTRETER**
Events &
Collaborations
Manager



JANE XIA, MHA
Grants & Finance
Manager



VALERIE HOCKENS
Grants Specialist
Manager



EMILY ALMEDA
Administrative
Coordinator



MARK BAUER, EDD
Manager of
Communications



AMY YOUNG, MS
Public Information
Specialist



AILEEN IDA, MA
Communications
Specialist



TINA MONROE
Human Resources
Specialist



**FAITH BUCKLEY,
MBA, MS**
Administrative
Specialist

A decorative background featuring a network diagram with teal lines and dots of varying sizes and colors (teal and light grey) connected in a complex web pattern.

Thank You!