



# NACC Session

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Thursday, October 20 – 2022 Fall ADRC Meeting



# Welcome

**Walter Kukull, PhD**

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**October 20 – ADRC Fall 2022**

# Welcome to the NACC Session!

Topic	Speaker Name
<b>Delivering on NACC's mission and modernization</b>	Sarah Biber, PhD
<b>NACC's New Data Pipeline and Repository Solution: Benefits for the ADRC Program</b>	Ben Keller, PhD
<b>Building a novel platform to expand longitudinal COVID-19 data collection, integrate new data streams, and open the door to impactful new COVID-19 and ADRD discoveries</b>	Sean Mooney, PhD, Melissa Lerch, PhD, Kari Stephens, PhD
<b>Amplifying the SCAN Initiative</b>	Sarah Biber, PhD
<b>Progressing Towards a Digital UDS</b>	Sean Mooney, PhD
<b>The New NACC Directory</b>	Laura McLeod



# Delivering on NACC's Mission through Modernization

**Sarah Biber, PhD**

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**October 20 – ADRC Fall 2022**



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



**SARAH BIBER, PHD**  
Program Director



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



**SEAN MOONEY, PHD**  
Associate Director,  
NACC Chief Research  
Information Officer, UW  
Medicine



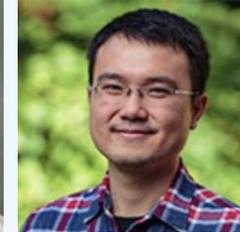
**CHARLES MOCK,  
MD, PHD, FACS**  
Associate Director,  
NACC Professor,  
Epidemiology and Surgery



**KWUN CHUEN GARY  
CHAN, PHD**  
Associate Director  
Professor, Biostatistics,  
Health Systems  
and Population Health



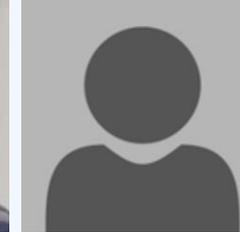
**DEAN K. SHIBATA, MD**  
Co-investigator, NACC;  
Professor, Radiology



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



**KYLE ORMSBY, PHD**  
Co-Investigator  
Visiting Associate  
Professor, Mathematics



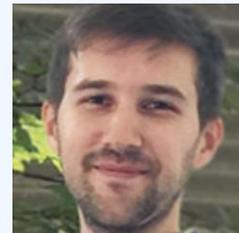
**WILL LONGSTRETH, MD**  
Co-investigator, NACC  
Professor, Neurology



**BEN KELLER, PHD**  
Software Engineer 3



**CHANDIMA HEWA-  
ADUNGODAGE, PHD**  
Software Engineer 3



**ZACH STARK, BBA**  
Software Engineer 3



**LAURA MCLEOD**  
REDCap Developer



**JOYLEE WU**  
Database Administrator



**JANENE  
HUBBARD, BS,** Research  
Consultant



**BRENDAN SMITH**  
Database Administrator



**HANNAH ROSENRETER**  
Manager of Special Projects



**BRITTANY HALE**  
Project Manager



**CLAIR CASSIDY**  
Admin Coordinator



**MELISSA LERCH, PHD**  
Research Manager



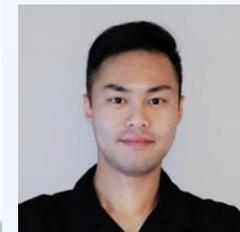
**JESSICA CULHANE**  
Research Scientist 3



**KATHRYNN  
GAUTHREAUX**  
Research Scientist 3



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Research Scientist 3



**YUEXUAN WU, PHD**  
Post-Doc



**ZACK MILLER**  
Research Consultant



**THERESA BARNHART,  
BSBA CRA** Grants &  
Finance Manager



**VALERIE HOCKENS**  
Program Ops Specialist -  
Finance



**AMY YOUNG**  
Public Information  
Specialist



**ALEEN IDA, MS**  
Communication Specialist



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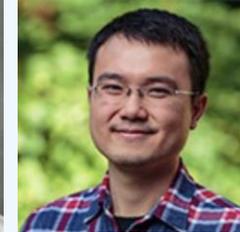
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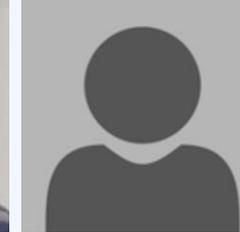
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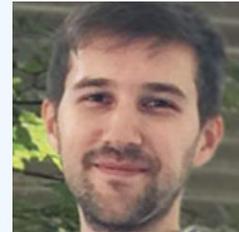
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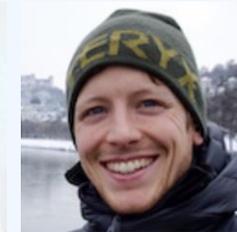
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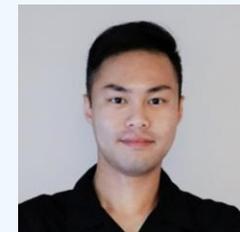
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**AMY YOUNG**  
Public Information  
Specialist



**ALEEN IDA, MS**  
Communication Specialist

# Overview of NACC's Expanded Mission and Role

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

## Data

**F**indable 

**A**ccessible 

**I**nteroperable 

**R**eusable 

## Communication & Collaboration



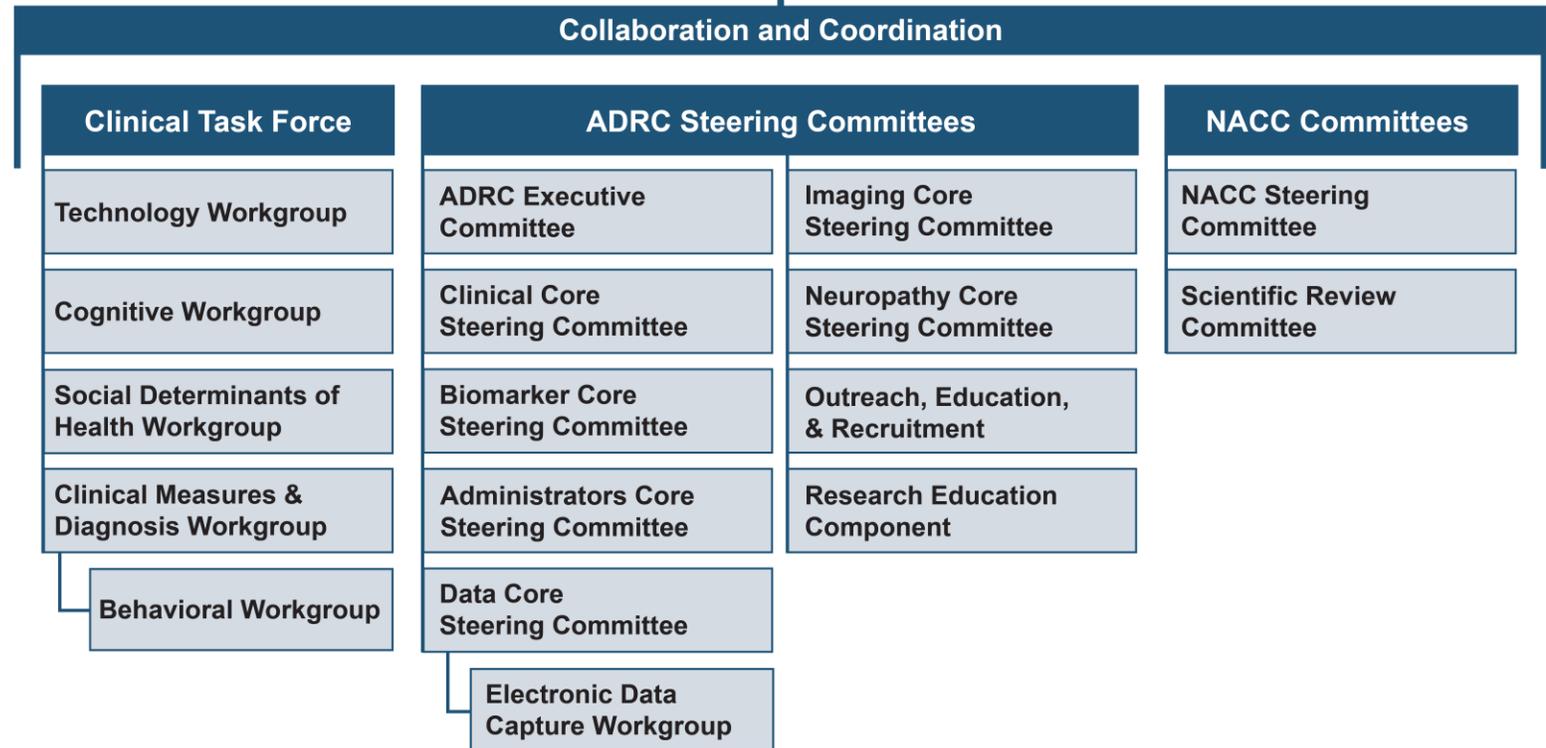
# NACC Communication and Collaboration Hub



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

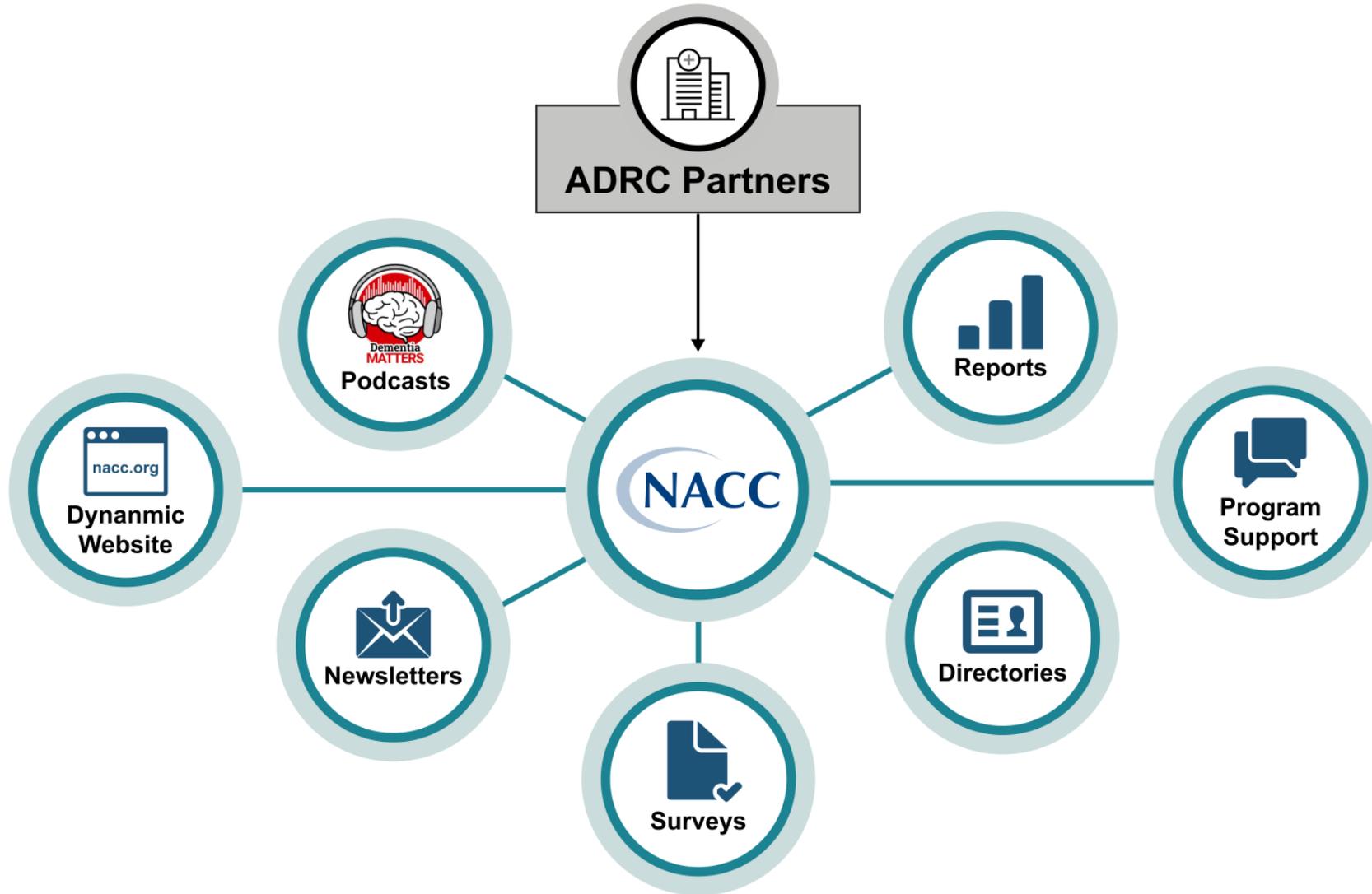
NIH National Institute on Aging (NIA)  
Alzheimer's Disease Research Center Program

NACC National Alzheimer's Coordinating Center

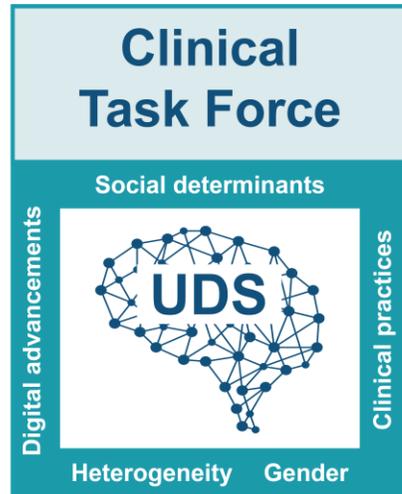




# NACC Communication and Collaboration Hub



# UDSv4 Transition: Content Update



**Updated UDS  
Content**

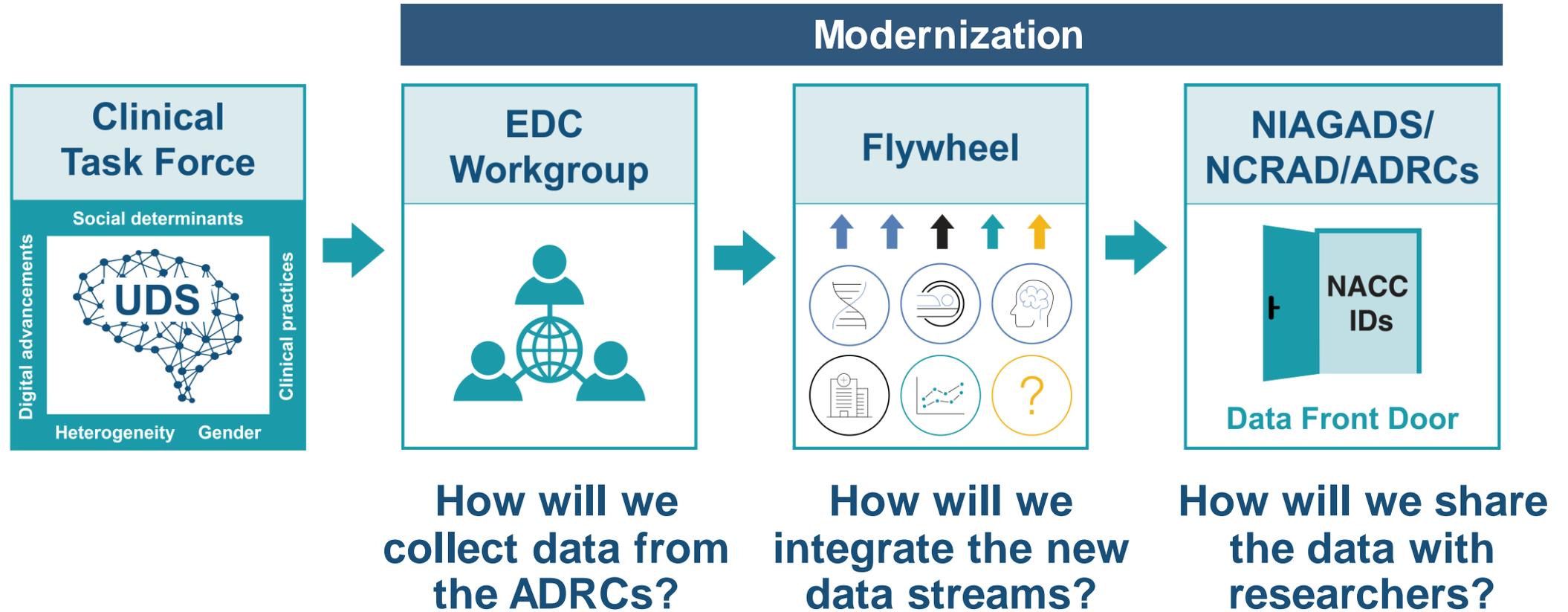
## CTF Status of the UDSv4 Forms Content (IVP)

Approved by CTF	Under Review by CTF	Pending Content
<ul style="list-style-type: none"><li>• Form B1</li><li>• <b>Form B3: UPDRS</b></li><li>• Form B4 *</li><li>• Form B5 *</li><li>• Form B6 *</li><li>• Form B7 *</li><li>• Form B8</li></ul> <p><i>* No changes from UDSv3</i></p>	<ul style="list-style-type: none"><li>• <b>Form A1a: SDOH</b></li><li>• <b>Form A2: SCD</b></li><li>• Form A3</li><li>• <b>Form A4a: AD-Specific Drugs</b></li><li>• Form A5/D2</li><li>• <b>Form B9: MBI, SCD</b></li><li>• <b>Form D1a: MBI</b></li><li>• Form D1b</li></ul>	<ul style="list-style-type: none"><li>• <b>Form A1: SCD</b></li><li>• Form A4</li><li>• Form C2</li><li>• Form Z1X</li></ul>

Virtual and in-person versions of each form are being developed

**Learn more at the CTF Session!**

# Aligning with NIH's Data Science Strategy

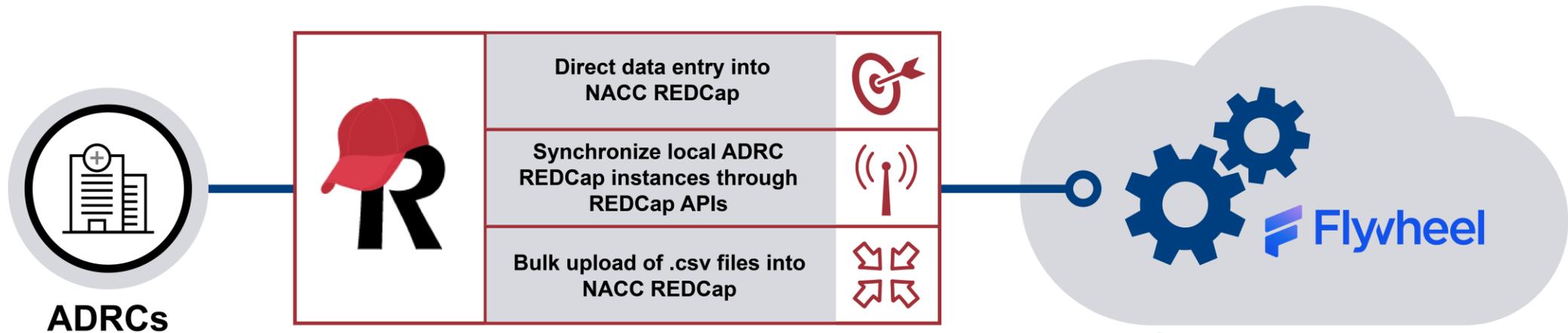


A network diagram background consisting of a complex web of light blue lines connecting various nodes. Some nodes are represented by solid teal circles, while others are smaller, semi-transparent light blue circles. The connections form a dense, interconnected structure.

# How will we collect data from the ADRCs?

# How Will We Collect Data From ADRCs?

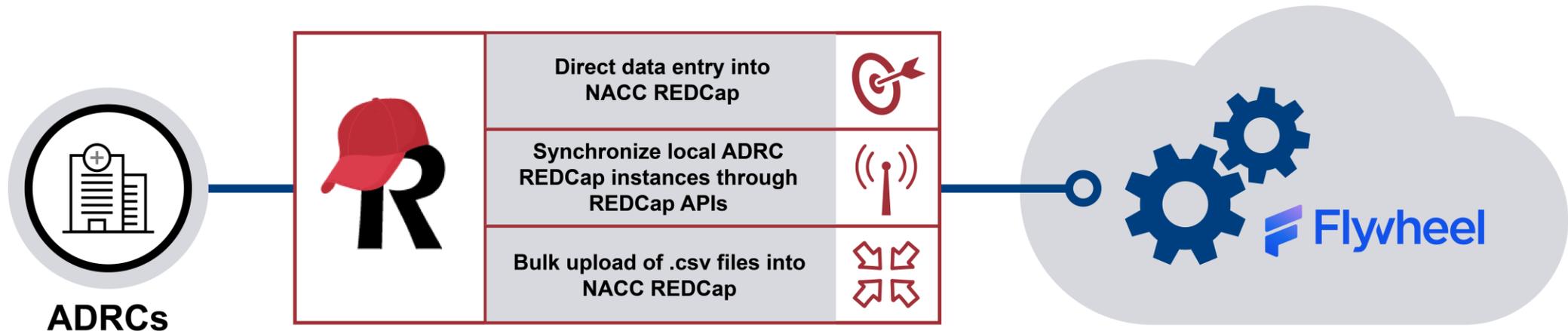
## Modern Electronic Data Submission Interface



We still have PDFs!

# How Will We Collect Data From ADRCs?

## Modern Electronic Data Submission Interface



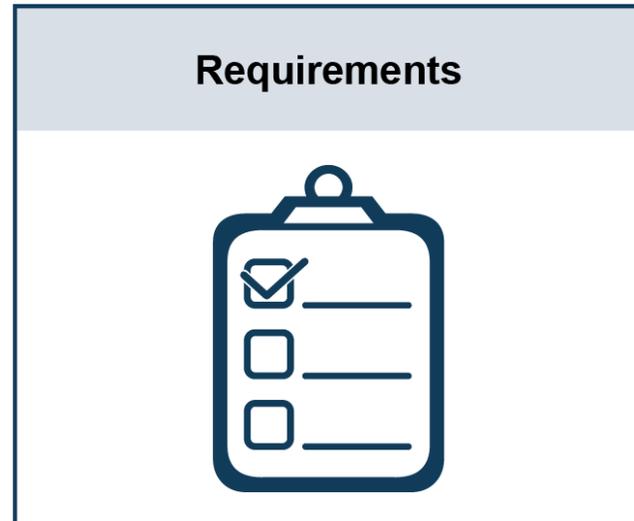
**We still have PDFs!**

**Forms can be used by researchers and clinicians anywhere in the world on any device**

# How Will We Collect Data From ADRCs?

## Electronic Data Capture Workgroup:

- Launched January 24<sup>th</sup>, 2022 in collaboration with the Data Core Steering Committee
- 75 people across 29 ADRCs that are collaborating across three subgroups
- 1,500+ people hours and counting



# Electronic Data Capture Workgroup Progress

## Development



- Streamlined and standardized the REDCap submission process, quality checks, and variable names
- Established the infrastructure for longitudinal data collection

## Requirements



- Determined the common UDS data flow used across 29 participating ADRCs: Survey to be sent to 37 all ADRCs
- Developed data management plan in alignment with NIH's data sharing policy: Valuable for ADRCs seeking renewal
- Summarized data quality checks for UDSv4: To be shared with all ADRCs

## Documentation and Training



- Built a curated directory of valuable REDCap resources
- Developed NACC-specific REDCap SOPs to facilitate ADRCs submitting UDSv4 data to NACC
- Designing a webpage to make resources accessible to the ADRCs



# Electronic Data Capture Workgroup

## Thank you EDC workgroup team members!

- **Co-Leads:** Sudeshna Das, PhD and Sarah Biber, PhD
- **Development Co-Leads:** Jon Reader, MS, and Ben Keller, PhD
- **Requirements Co-Leads:** Meredith Zozus, PhD and Kari Stephens, PhD
- **Documentation and Training Co-Leads:** Sarah Gothard, BS, Leah Reuter, BA, and Laura McLeod, BBA
- **Coordination:** Clair Cassidy

Scan QR code and  
fill out the form to join!



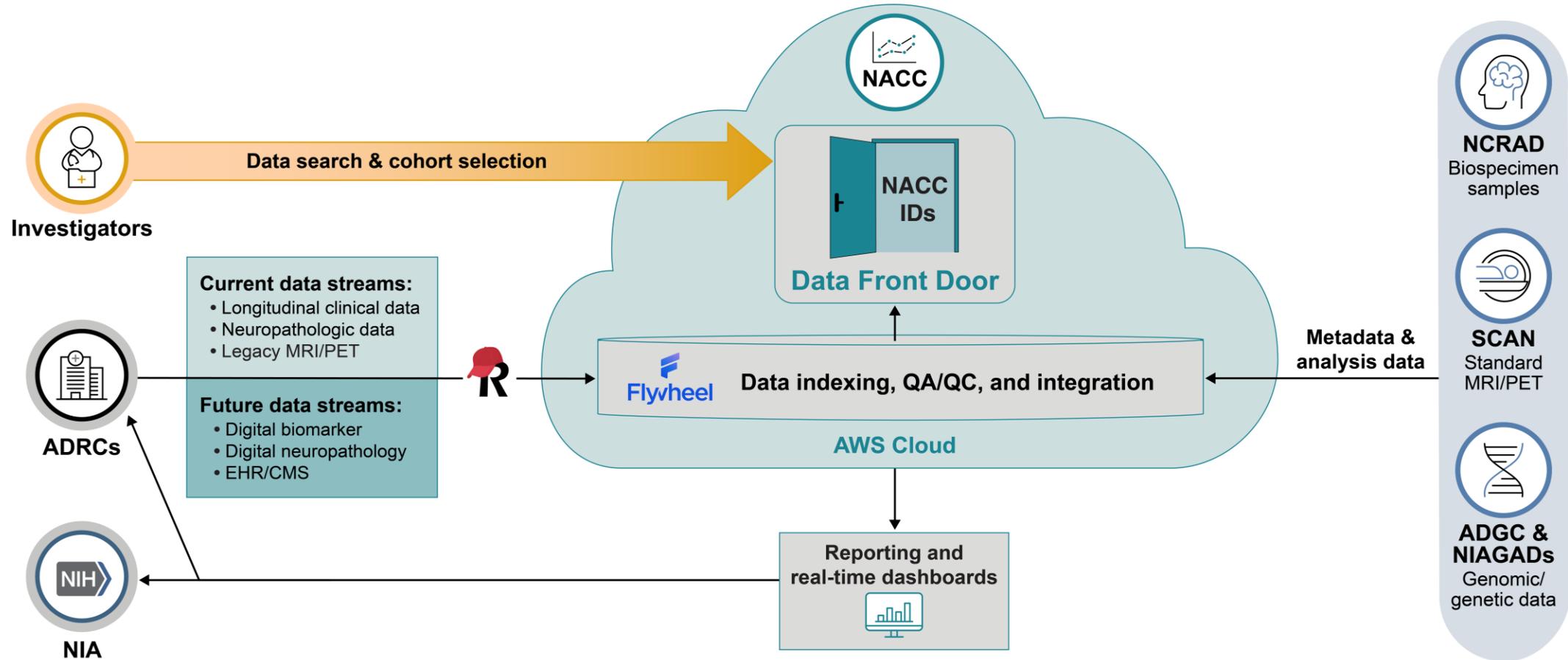
[naccddata.org/edc](http://naccddata.org/edc)



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# How will we integrate new data streams?

# NACC is on a Mission to Modernize Data Collection, Integration, and Sharing to Advance Alzheimer's Research



# How Will We Integrate the Data?

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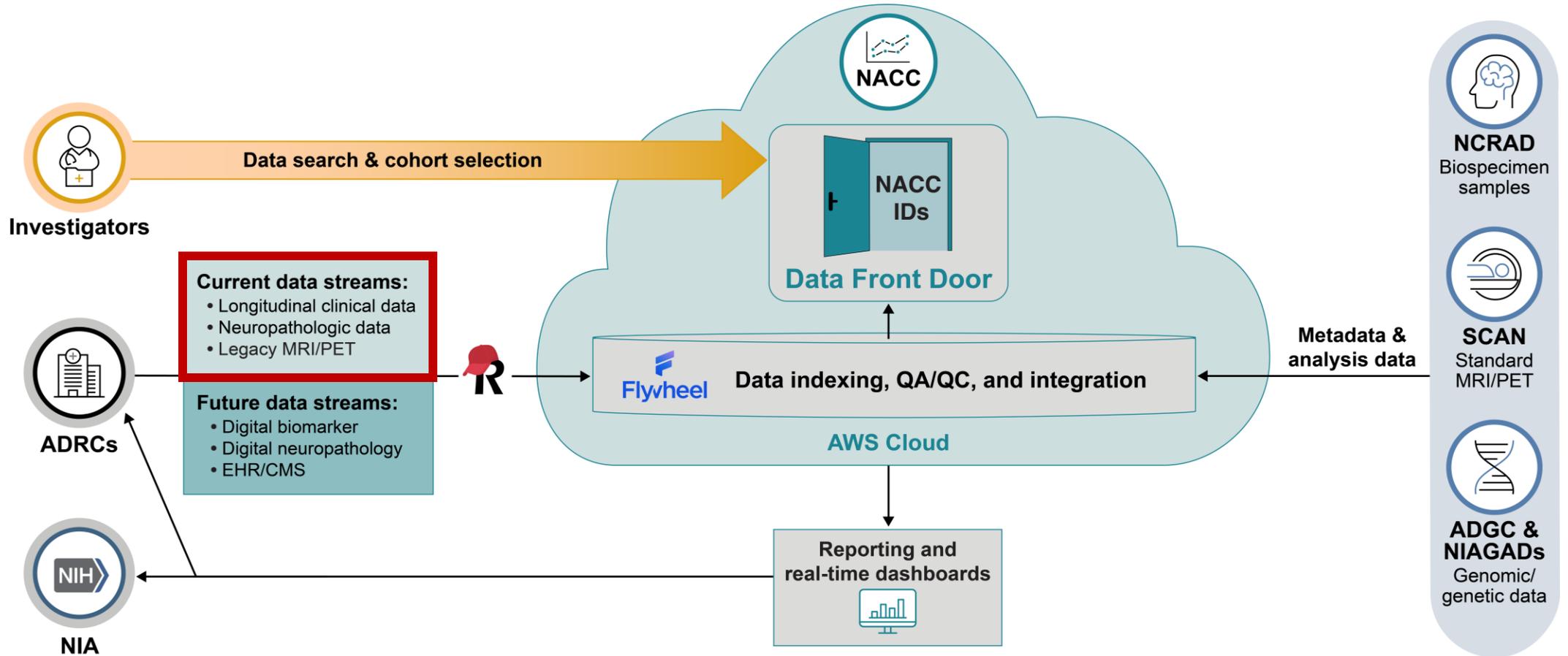
**Flywheel Will Integrate and Organize All ADRC Data Within our AWS Cloud and Provide Secure Sandboxes for Collaborative Data Analysis**

**Learn more from Ben Keller,  
PhD in the next talk!**

NACC's New Data Repository and Pipeline Solution: Benefits for the ADRC Program



# Modern Integration of Data from ADRCs and Partners



# Longitudinal Clinical and Neuropathologic Data

## UDS Data Impact



**46,000+**

Participants with data at NACC  
(16,000+ active participants)



**172,000+**

Clinical assessments  
(1-17 visits per participant; median =3)



**7,230+**

Neuropathology datasets  
(From 58% of deceased participants)



**1,100+**

Published studies using  
NACC data



**37**

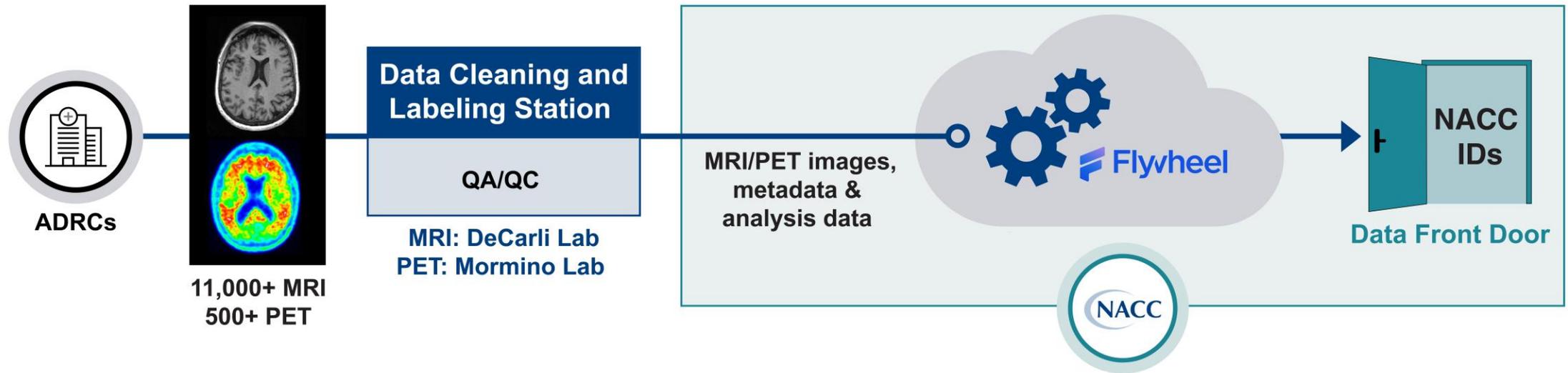
ADRCs are contributing data  
(Across 26 states, +2 provisional ADRCs)



■ State with NIA-Designated Center(s)

■ State with Exploratory Center

# Legacy MRI and PET Data



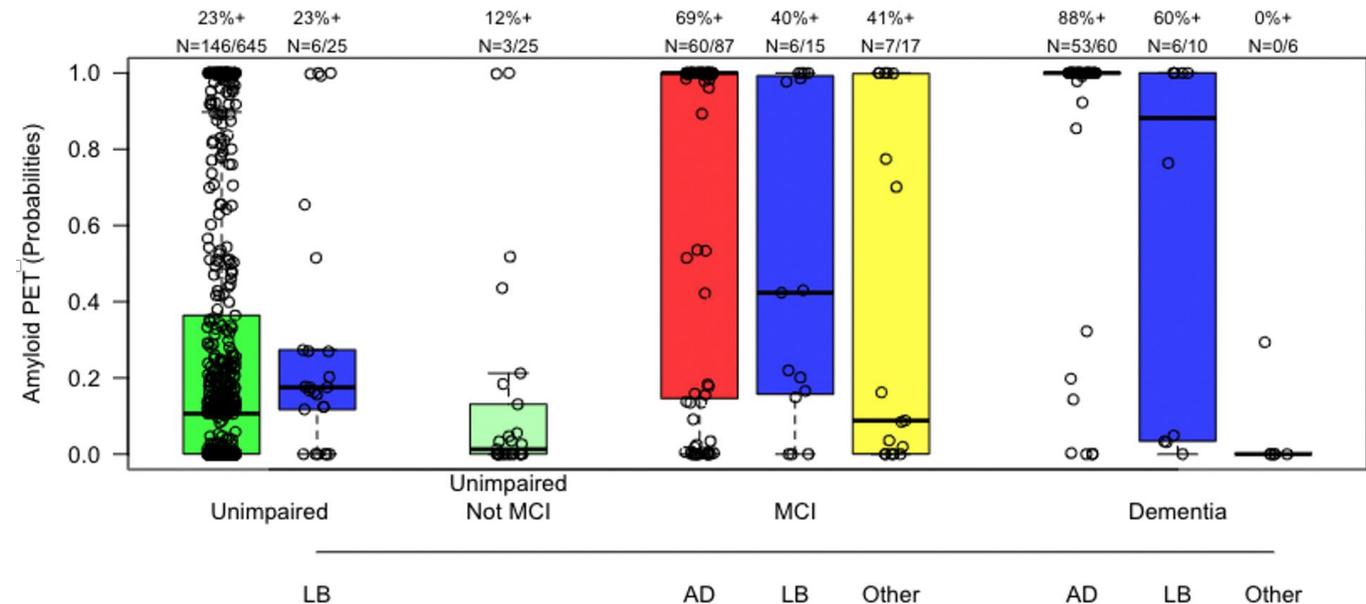
- **918 Amyloid PET Scans from Unique NACC participants Analyzed**

- **Contributing sites:**

- Cleveland ADRC
- Northwestern University ADRC
- Stanford University ARDC
- University of California Davis ADRC
- University of Florida ADRC
- University of Kansas ADRC
- University of Wisconsin ADRC

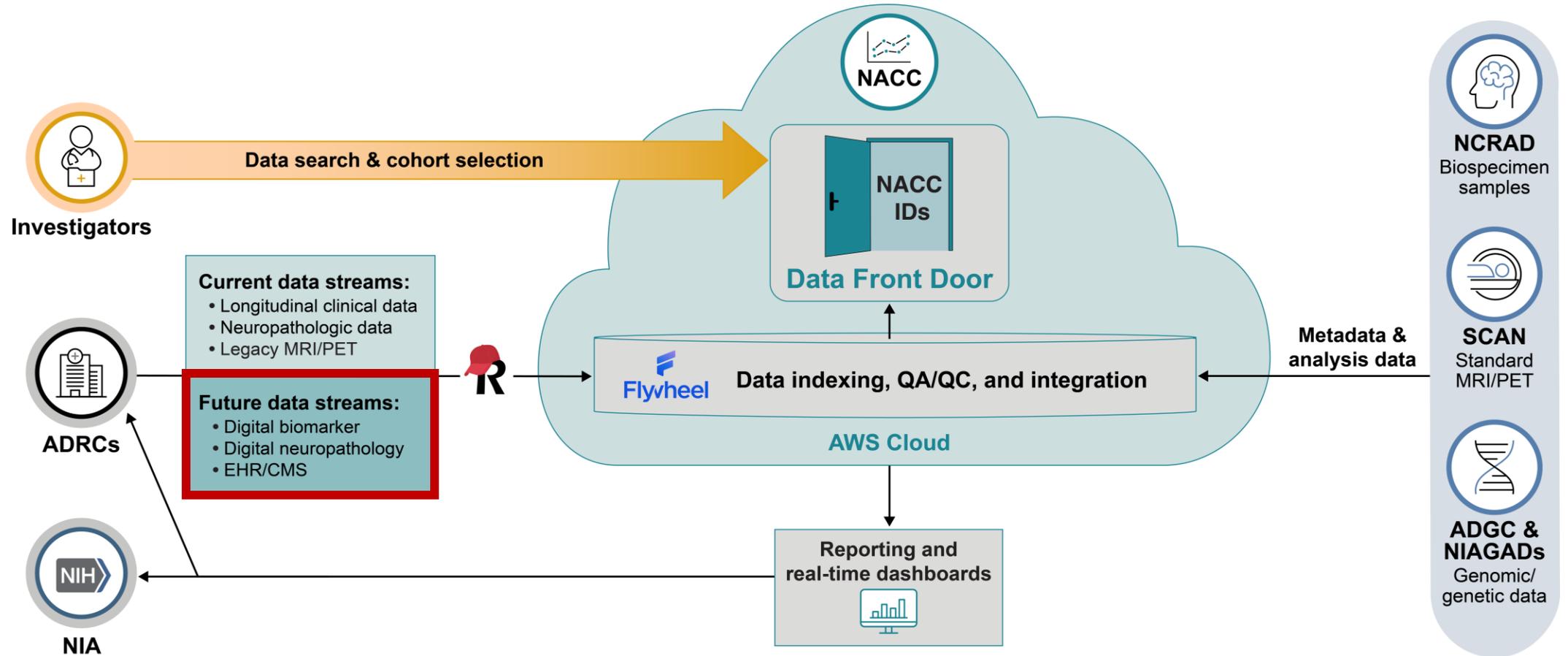
- **Will release curated images to LONI/NACC, extracted variables (SUVRs, CLs) to NACC**

	Primary Etiology							
	AD	Lewy Bodies/ PD	FTLD	Vascular	Neurologic/ Genetic	Psychiatric	Toxic/ Metabolic	NA, Not Impaired
Dementia	60	10	4	1	1	1	0	0
Impairment-Not-MCI	3	0	0	1	12	8	1	0
MCI	87	15	1	8	27	8	0	0
Unimpaired	0	25	0	0	0	0	0	645



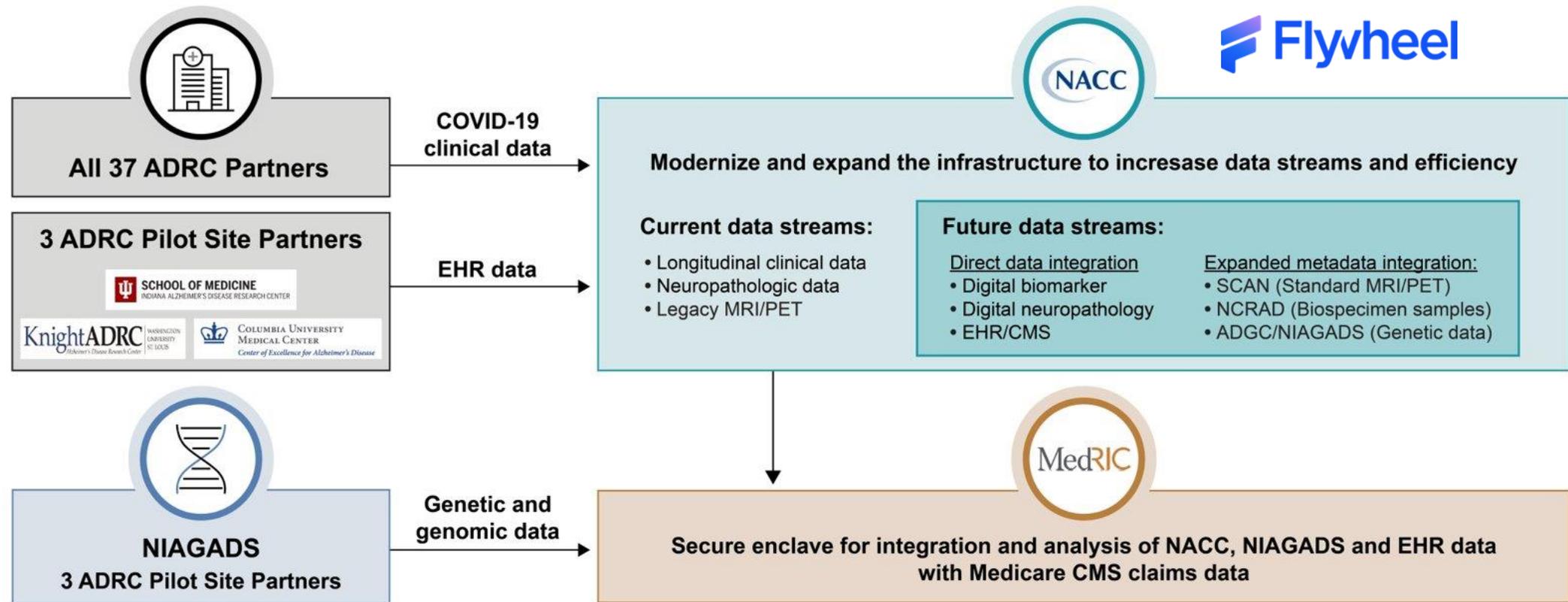


# Modern Integration of Data from ADRCs and Partners



# COVID-19 Admin Supplement: EHR and Claims Data

NACC is establishing a platform to collect and link clinical (EHR) and claims (CMS) data with genetic data (NIAGADS/ADSP) and phenotypic data (NACC) for consented ADRC participants.

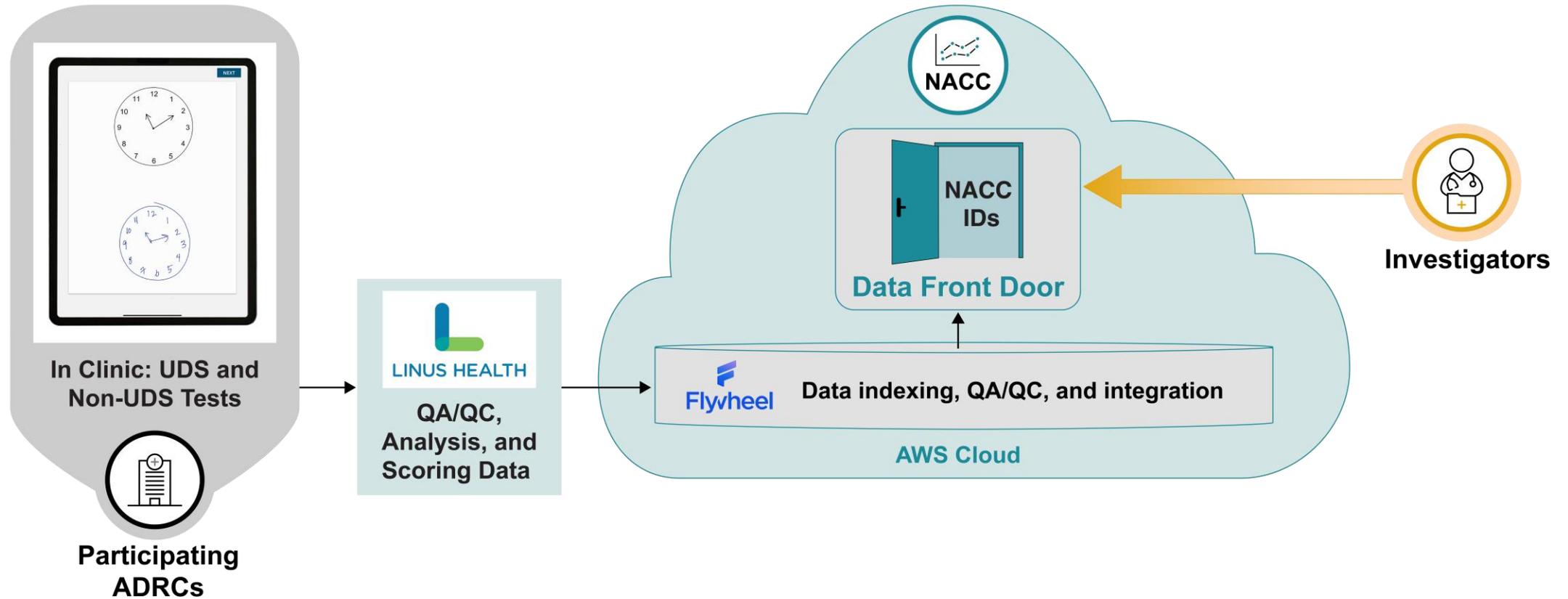


**Learn more in the NACC Session later today!**

**Building a novel platform to expand longitudinal COVID-19 data collection, integrate new data streams, and open the door to impactful new COVID-19 and ADRD discoveries.**

Kari Stephens, PhD, Sean Mooney, PhD and Melissa Lerch, PhD (NACC)

# Administrative Supplement: Digital Data and Phenotyping



Collaborators: Rhoda Au, PhD and Allan Levey, MD, PhD

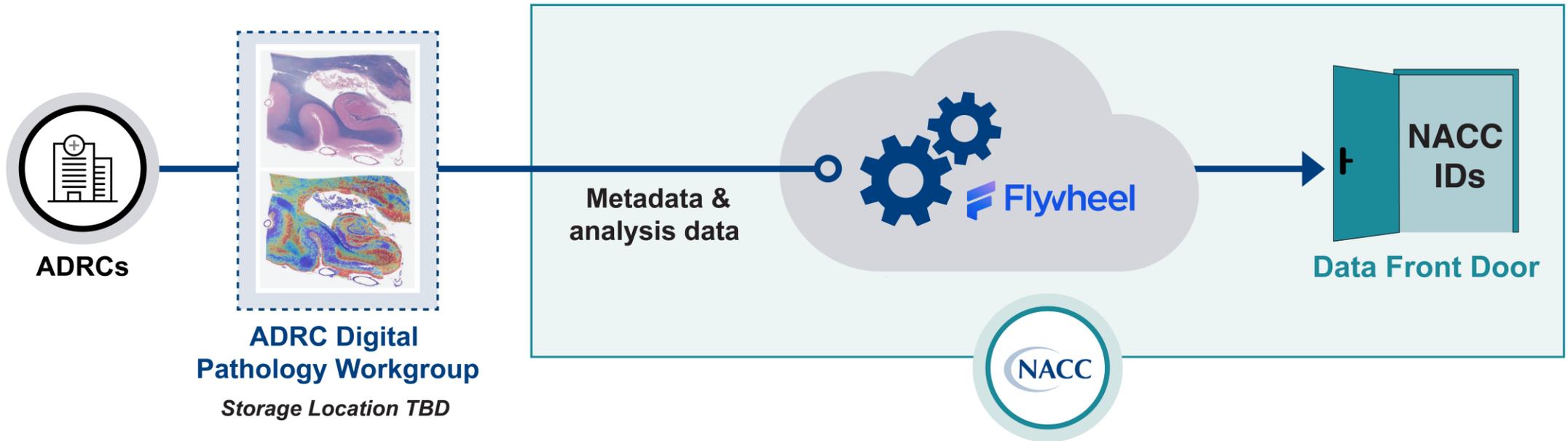
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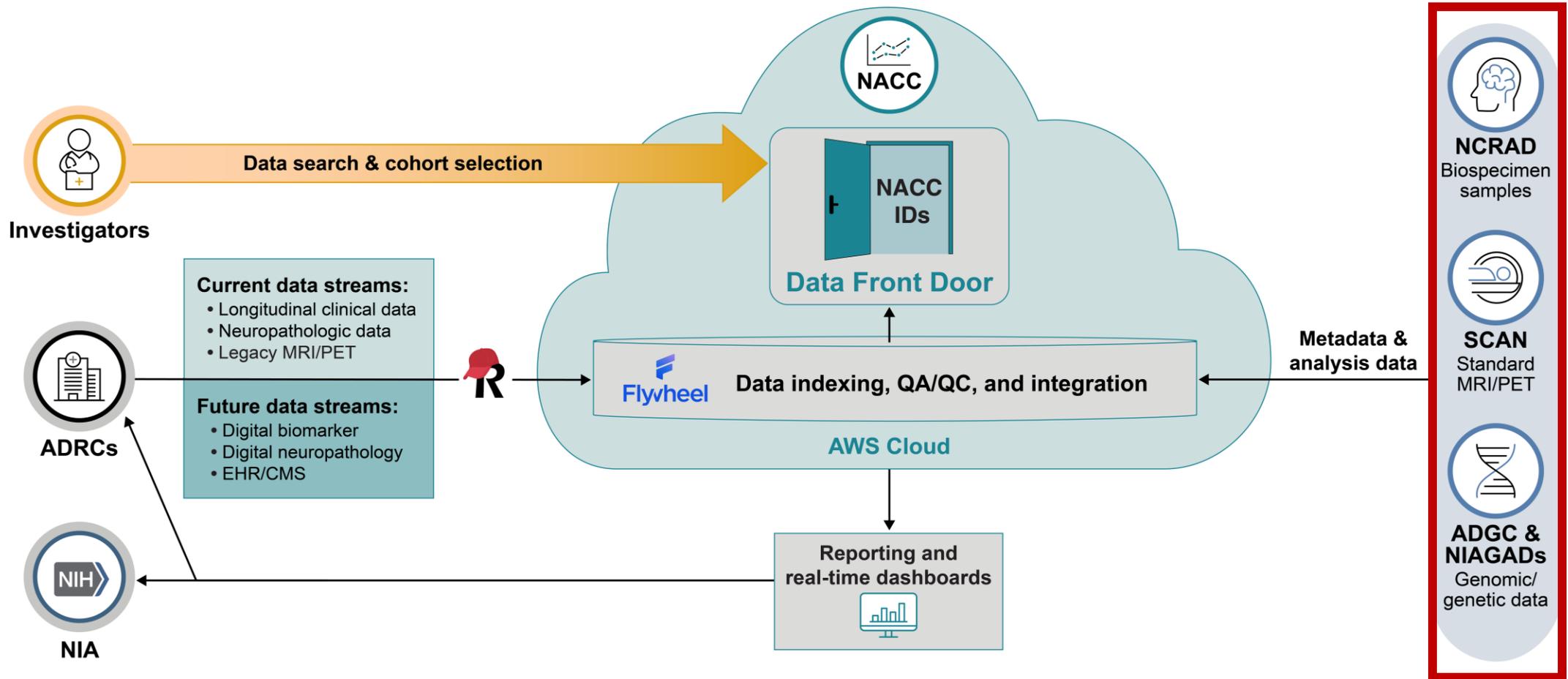
## **Progressing Towards a Digital UDS**

Sean Mooney, PhD

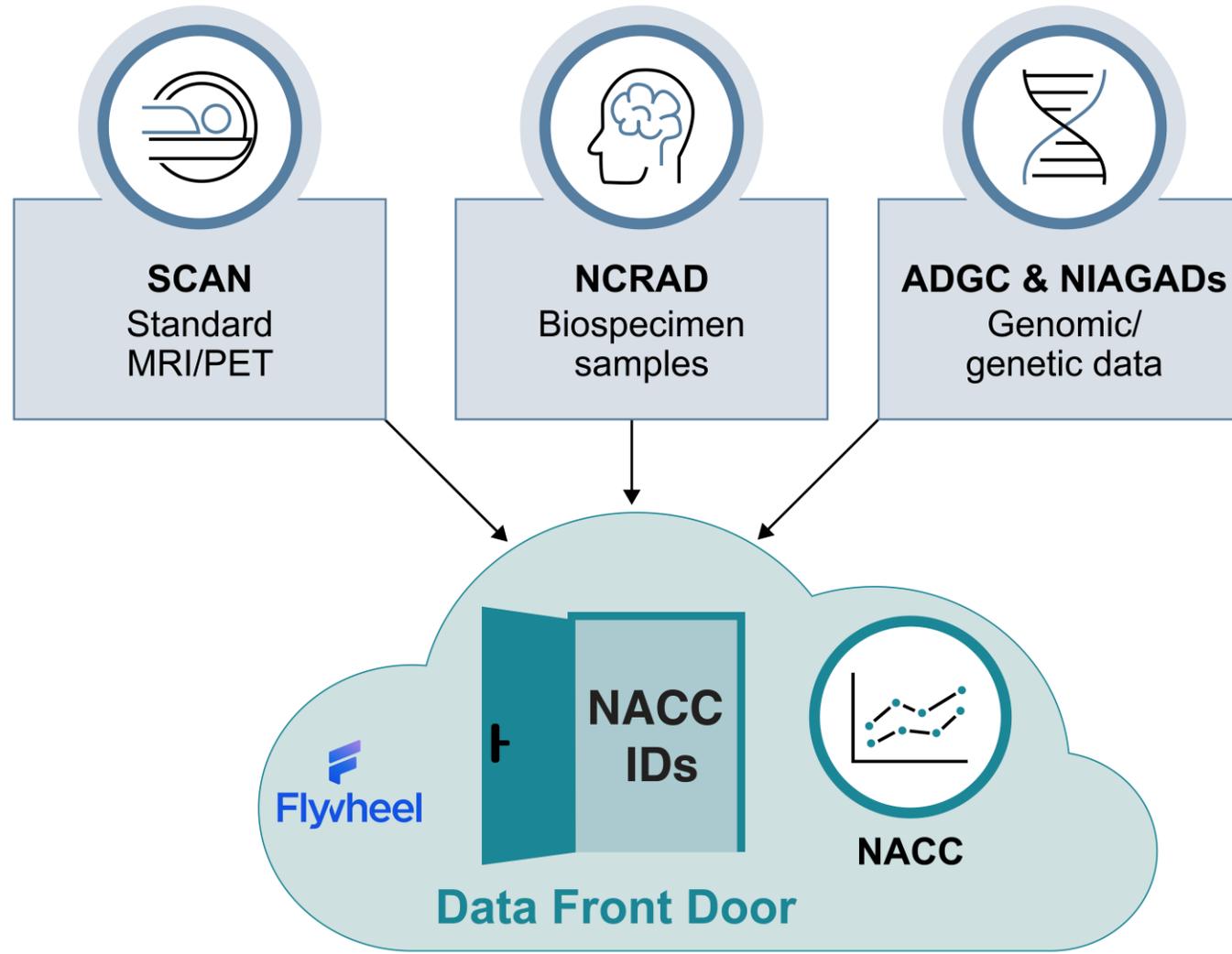
# Digital Neuropathology Data



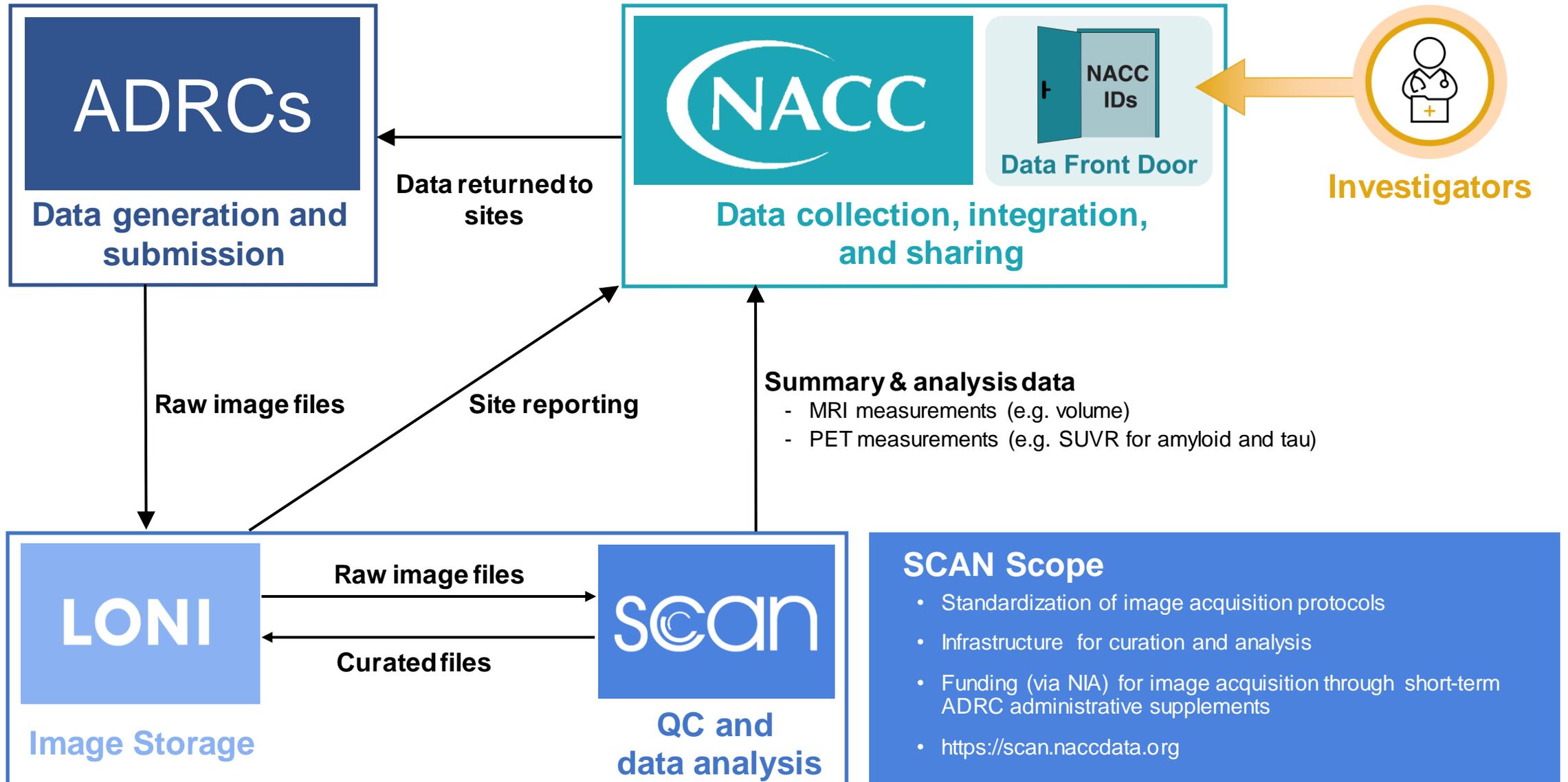
# Modern Integration of Data from ADRCs and Partners



# Metadata and Analysis Data from Partners







# SCAN: Public Dashboard



Jeevan

## SCAN Dashboard

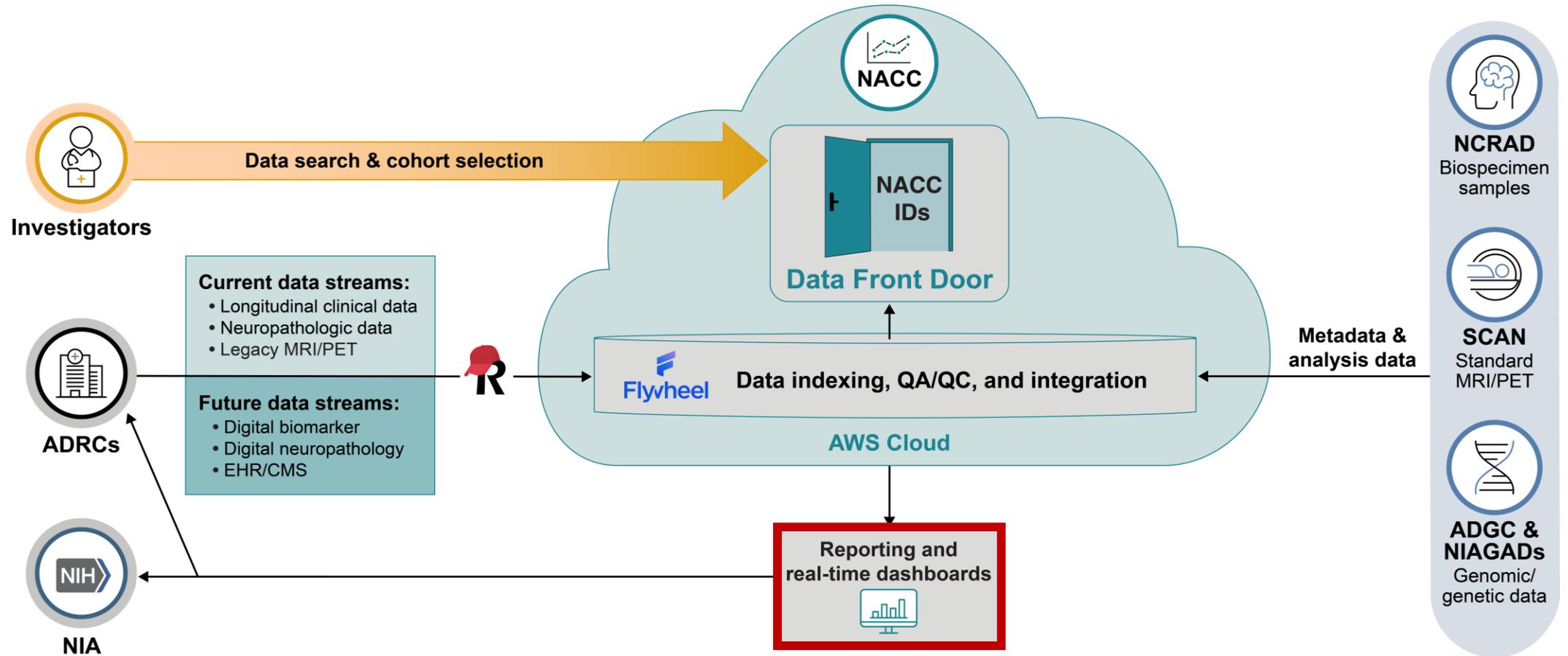
### Alzheimer's Disease Research Centers

Copy CSV Show 10 entries

Search:

Institution	SCAN Readiness		SCAN Participation						Review SCAN Submissions	
	Update your SCAN Readiness Status	Current SCAN readiness status	Total # of participants	MRI			PET		Review your MRI submissions to date and check QC status	Review your PET submissions to date and check QC status
				# MRI Participants	# MRI Exams Submitted	# MRI Series Submitted	# PET Participants	# PET Scans Submitted		
TOTAL			1724	1349	1382	7767	775	1148		
AN EXAMPLE ADRC	<a href="#">Update</a>	Completed Checklist	65	53	53	433	12	17	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Arizona ADC	<a href="#">Update</a>	N/A	113	28	28	640	105	212	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Boston University	<a href="#">Update</a>	N/A	42	42	42	629	0	0	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Cleveland Clinic Lerner COM - CWRU	<a href="#">Update</a>	Completed Checklist	129	105	105	212	105	105	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Cleveland Clinic, Las Vegas	<a href="#">Update</a>	N/A	37	37	37	411	0	0	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Columbia University	<a href="#">Update</a>	N/A	62	62	65	764	0	0	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Emory University	<a href="#">Update</a>	Completed Checklist	17	17	17	34	0	0	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Indiana University	<a href="#">Update</a>	N/A	1	1	1	5	0	0	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Johns Hopkins University	<a href="#">Update</a>	N/A	22	22	22	65	0	0	<a href="#">Review MRI</a>	<a href="#">Review PET</a>

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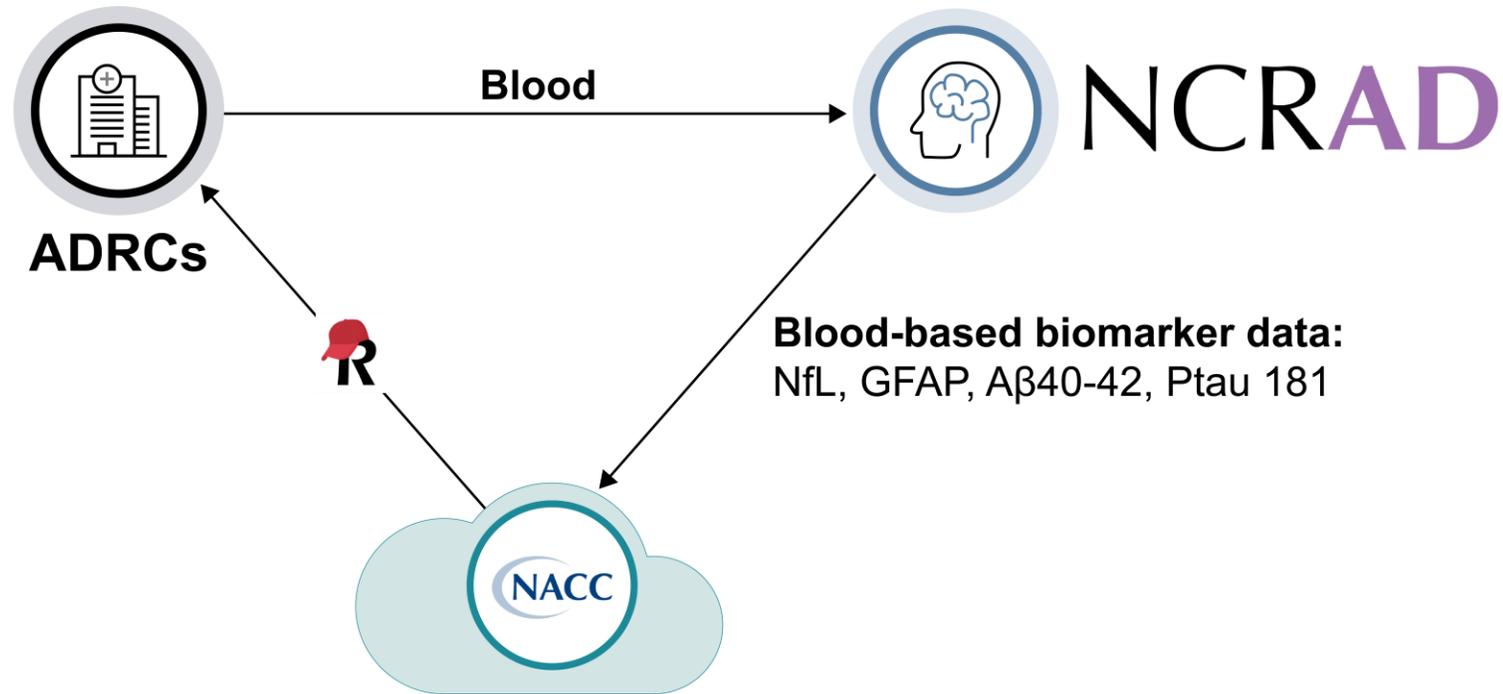
# Progress on Integrating SCAN Data

**Learn more in the NACC Session later today!**

## **Amplifying SCAN**

Sarah Biber, PhD

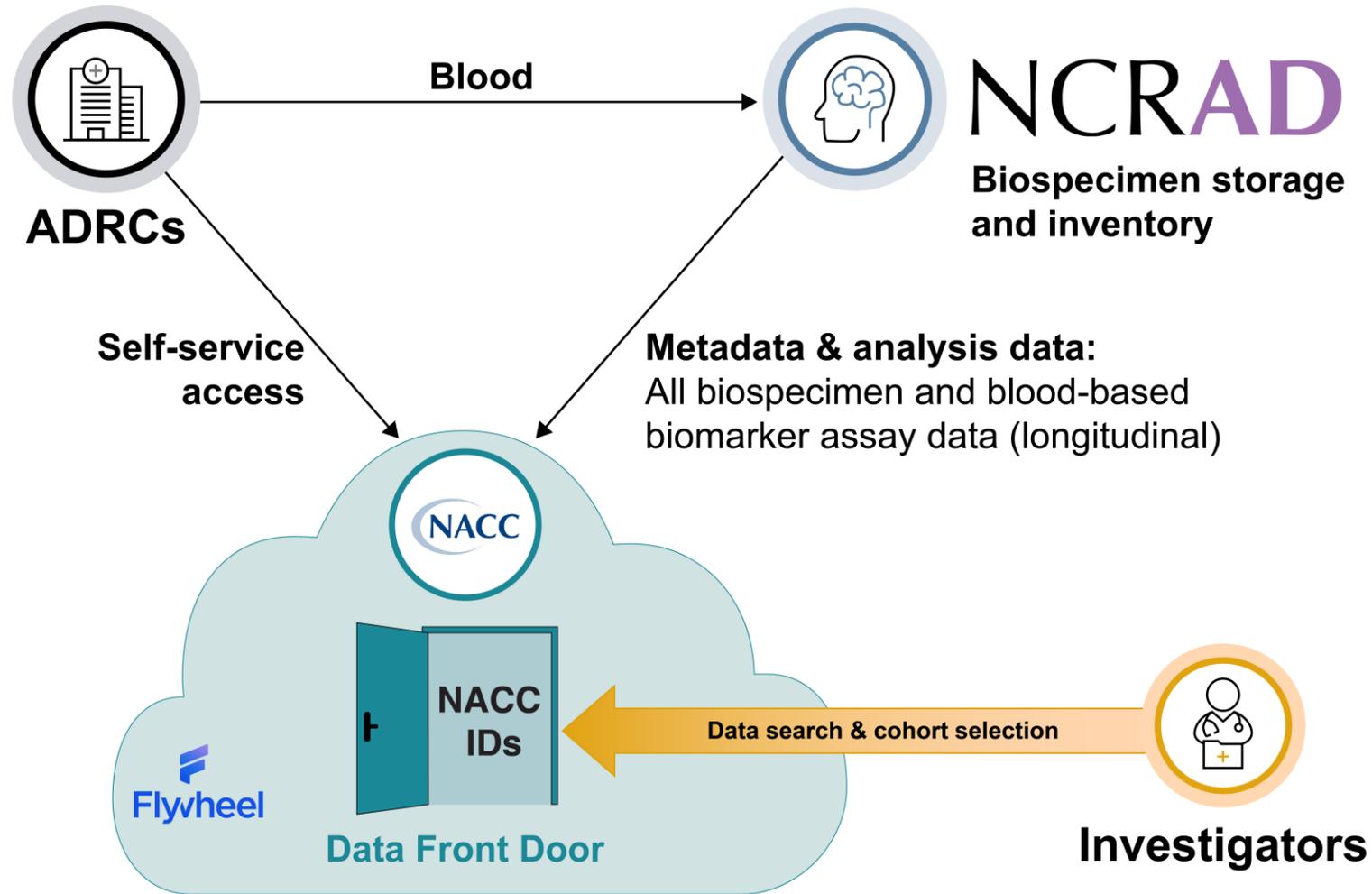
# NCRAD: Biospecimen Metadata and Analysis Data - Pilot



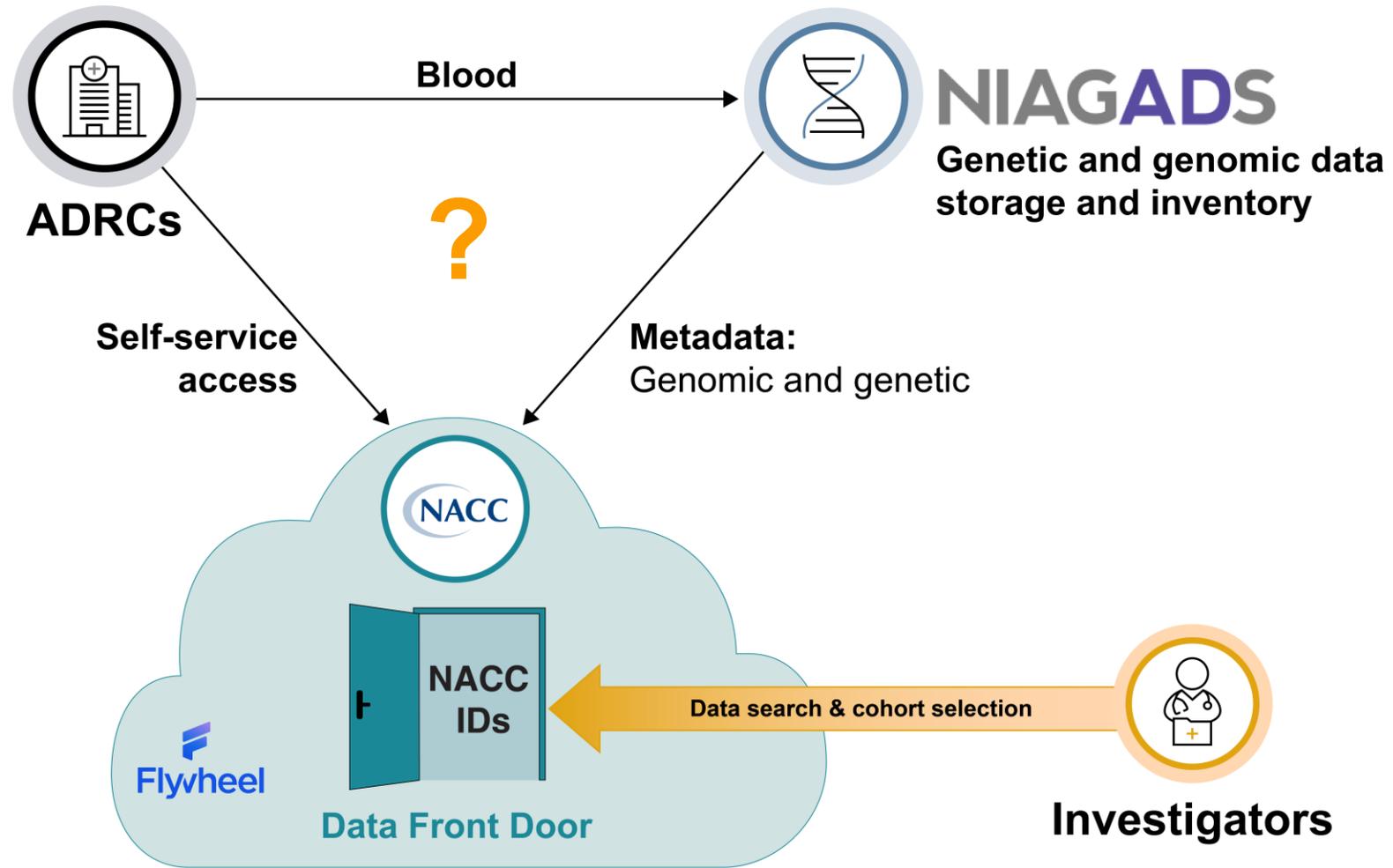
## Returning blood-based biomarker assay values to the ADRCs

- Earlier this month: NACC distributed these values to the ADRCs for their participants (via REDCap)

# NCRAD: Biospecimen Metadata and Analysis Data – Future Integration



# NIAGADS: Genetic and Genomic Metadata and Analysis Data



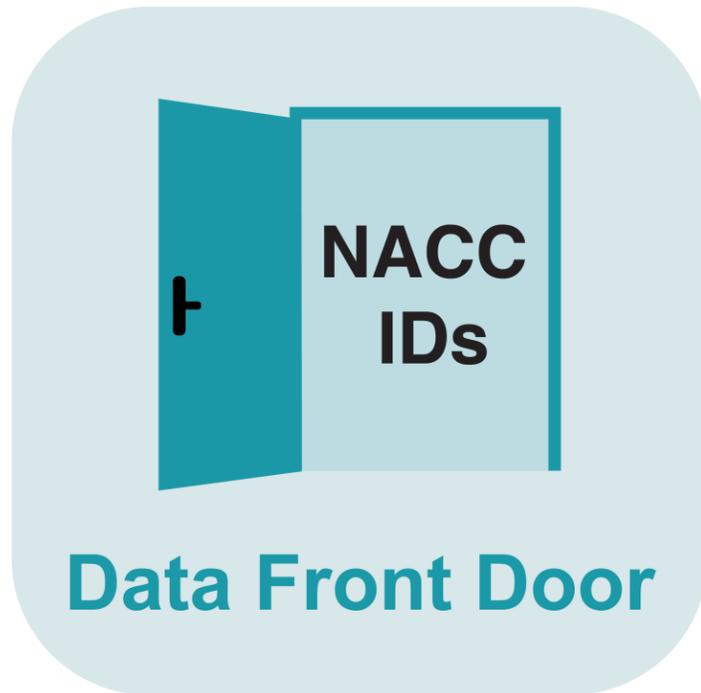
A network diagram background consisting of a complex web of light blue lines connecting various nodes. Some nodes are represented by solid teal circles, while others are smaller, semi-transparent grey circles. The network is dense and spans the entire width of the slide.

# How will we share the data with researchers?



# Data Front Door

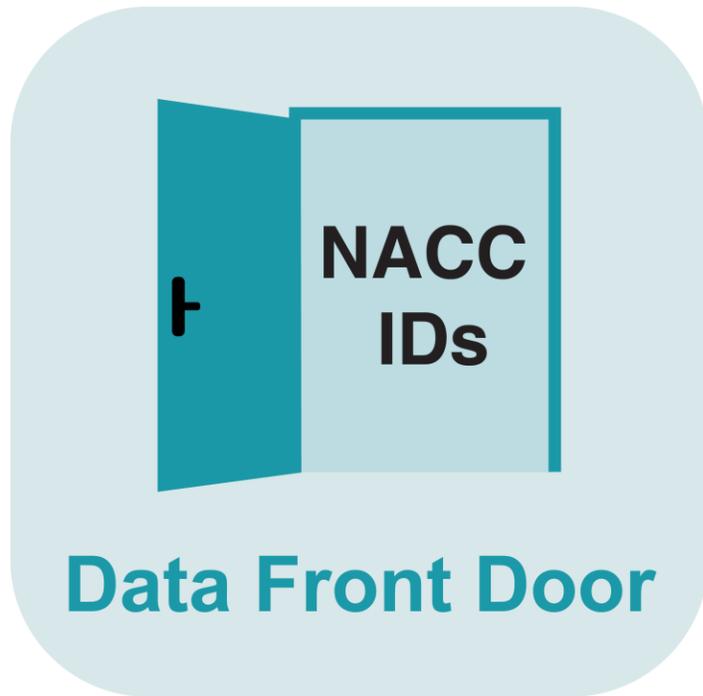
We will make all ADRC data findable and accessible to researchers across the world through a one-stop-shop data search and access interface – the Data Front Door



- **Cohort-discovery enabled**
- **Easy to use**
- **Self-service**
- **Real-time**
- **Integrated**
- **MVP: Connecting Flywheel to Leaf**



# Data Front Door – How to get involved!



## Requirements Pilot Project

- Collaboration between NACC, NCRAD, NIAGADS, and hopefully you!

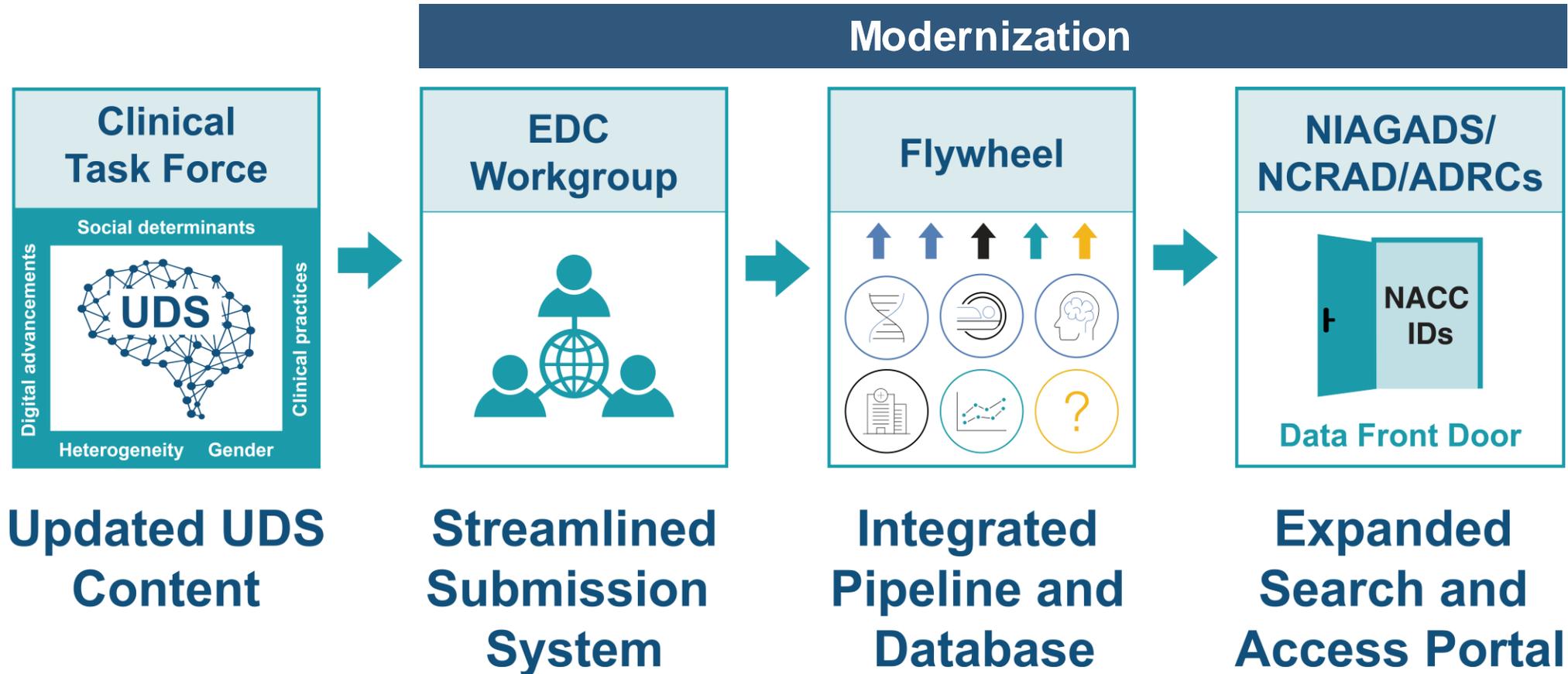
## Provide input!

- Focus group sessions will be held in January 2023
- We will be soliciting nominations from ADRC Directors
- You can all sign up to participate



[bit.ly/DFDFocusGroup](https://bit.ly/DFDFocusGroup)

# Aligning with NIH's Data Science Strategy



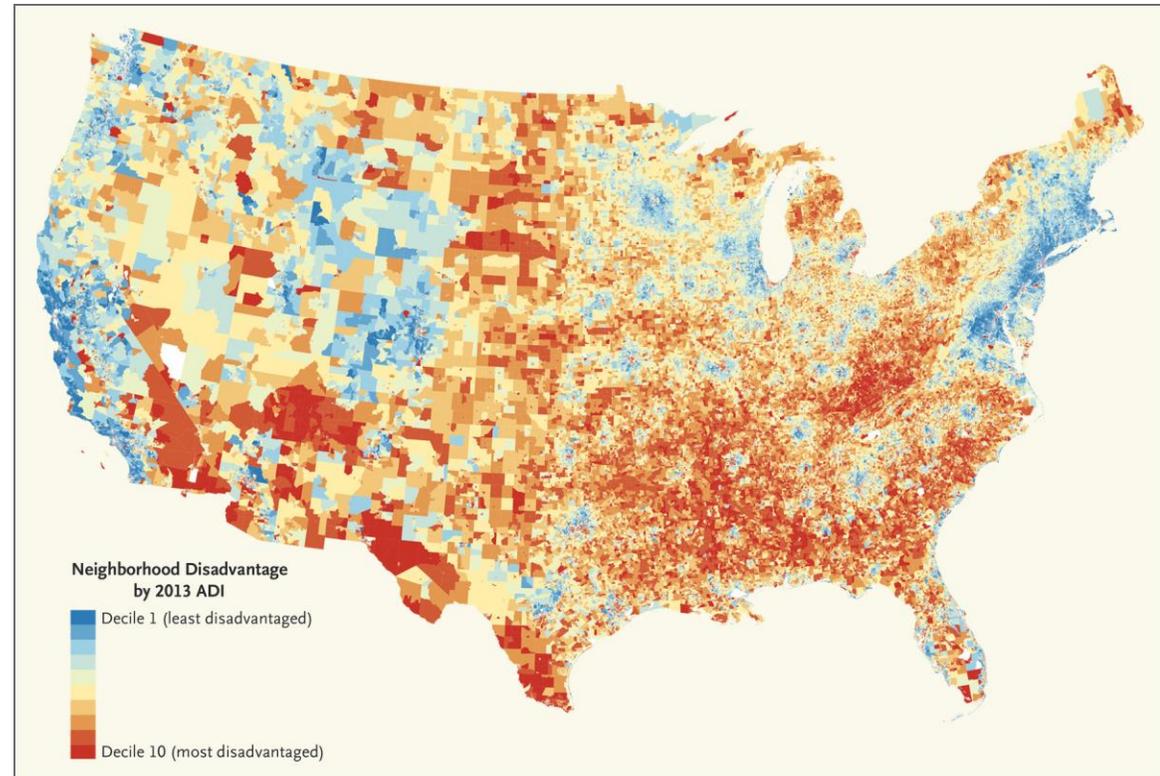
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# **How will we facilitate more inclusive ADRD research to advance our understanding of ADRD and health disparities?**

# New UDSv4 Tools to Support DEI and Disparities Research

## Forms focused on the social determinants of health:

- **Mandatory (Form A1)**
  - **Area Deprivation Index (Any Kind)**
  - **SDOH** – 11 Questions - income, access to healthcare, discrimination exposure
- **Optional**
  - **SDOH** – transportation access, financial security, social connections, access to healthcare



<https://www-nejm-org.offcampus.lib.washington.edu/doi/full/10.1056/NEJMp1802313>

# New Tools to Help Recruit More Diverse ADRC Participants

## Expanding UDSv4 Access:

- Providing validated and harmonized multilingual cognitive assessments: **Spanish and Chinese**
- Tele-cognitive assessments



# Developing and Distributing Best Practices for Responsible Management and Sharing of AI/AN Participant Data

## Data Sovereignty Initiative:

- A collaboration led by the Indigenous ADRD Advisory Board



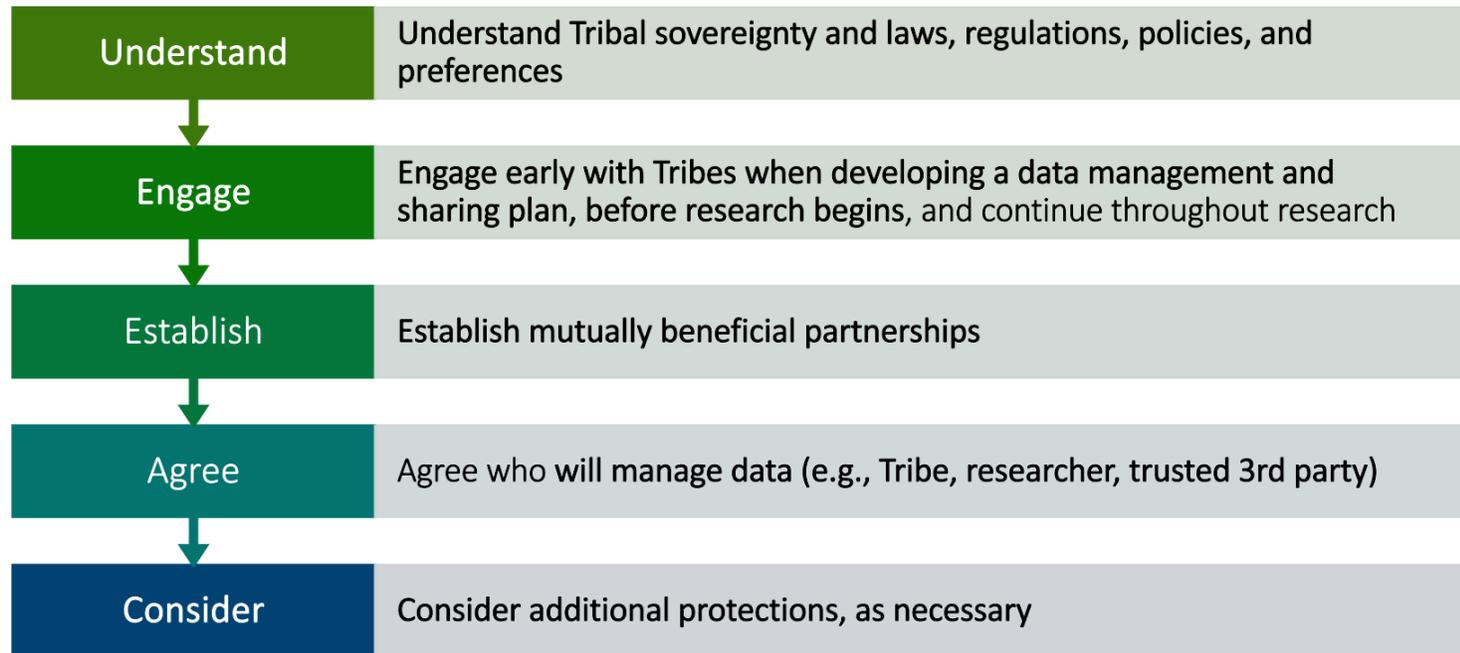
**JORDAN P. LEWIS, PHD**  
Associate Director,  
Professor  
Wisconsin ADRC



**L.W. YOWELUNH  
MCLESTER-DAVIS**  
PhD Candidate  
Wisconsin ADRC



**CAREY GLEASON,  
PHD. MS**  
Associate Professor,  
Wisconsin ADRC



# Supporting DEI-Related Initiatives Across the ADRC Program

## DEI-Focused ADRC Meeting

**2022 FALL**  
**ADRC**  
**MEETING**

**October 20<sup>th</sup>-21<sup>st</sup>**

### Speaker/Interviewee Highlights

### Talk Title

**Lisa Barnes, PhD**

Rush University Alzheimer's Disease Center

**Social Determinants of Health and Health Equality**

**Margaret Pericak-Vance, PhD**

John P. Hussman Institute for Human Genomics

**Genetics of AD in Minoritized Populations**

**Michelle Mielke, PhD**

Wake Forest University ADRC

**Impact of Race and Ethnicity on AD Biomarkers**

**Monica Rivera Mindt, PhD**

Fordham University

**Race and Ethnic Differences in Clinical AD phenotype**

**Gina Green-Harris, MBA**

Wisconsin ADRC

**Building Strong, Bi-directional, and Sustainable Community Partnerships to Support Recruitment for AD trials**

**Amy Kind, MD, PhD**

Wisconsin ADRC

**The New Paradigm of Federal Equity Policy: Role of the ADI**

**Crystal Glover, PhD**

Rush ADRC

**The Diversification of Brain Tissue: Why and Ways Forward**

**Maria Carrillo, PhD**

Alzheimer's Association

**A Personal Perspective: The Importance of Equal Access to Care and Intervention in AD**



# Supporting DEI-Related Initiatives Across the ADRC Program

## DEI-Focused ADRC Meeting



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<b>Lisa Barnes, PhD</b> Rush University Alzheimer's Disease Center	<b>Social Determinants of Health and Health Equality</b>
<b>Margaret Pericak-Vance, PhD</b> John P. Hussman Institute for Human Genomics	<b>Genetics of AD in Minoritized Populations</b>
<b>Michelle Mielke, PhD</b> Wake Forest University ADRC	<b>Impact of Race and Ethnicity on AD Biomarkers</b>
<b>Monica Rivera Mindt, PhD</b> Fordham University	<b>Race and Ethnic Differences in Clinical AD phenotype</b>
<b>Gina Green-Harris, MBA</b> Wisconsin ADRC	<b>Building Strong, Bi-directional, and Sustainable Community Partnerships to Support Recruitment for AD trials</b>
<b>Amy Kind, MD, PhD</b> Wisconsin ADRC	<b>The New Paradigm of Federal Equity Policy: Role of the ADI</b>
<b>Crystal Glover, PhD</b> Rush ADRC	<b>The Diversification of Brain Tissue: Why and Ways Forward</b>
<b>Maria Carrillo, PhD</b> Alzheimer's Association	<b>A Personal Perspective: The Importance of Equal Access to Care and Intervention in AD</b>

# New Investigator Awards: Call for Applications!

Two awards will be given (**\$135k** each):

Two tracks to choose from:

1. **Traditional award:** Open to proposals focused on any ADRD–related research topic
2. ***New!* DEI–focused award:** Open to proposals with a strong DEI or health disparities research focus within ADRD

**Application deadline:** January 17th, 2023

Find out more and  
apply:

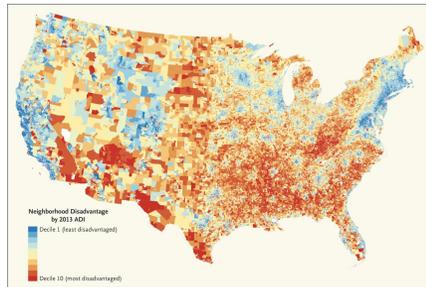
[bit.ly/NI-awards](https://bit.ly/NI-awards)



# Facilitating More Inclusive ADRD Research to Advance Our Understanding of ADRD and Health Disparities



## Expanding UDS Participant Diversity and Access



## Building Tools for DEI and Disparities Research



## Promoting Best Practices

2022 **FALL**  
**ADRC**  
**MEETING**

New Investigator Awards

Funding Opportunity

Supporting DEI-Related Research

# Impact on Scientific Discovery

## Opens the door to asking and answering new questions in ADRD

- Access to integrated longitudinal standardized data streams for research and analysis
- Data available for developing, testing, and scaling algorithms
- Facilitating earlier disease detection and the development of more impactful therapeutics
- Understanding the impact of SDOH on ADRD
- More opportunities to build bridges with other NIH big data initiatives



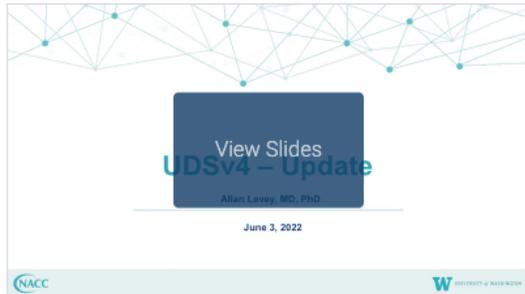
Category	Task	Q4 2022	Q1 2023	Q2 2023	Q3 2023	FUTURE
<b>Flywheel</b>	Existing NACC data (forms and legacy images) transferred to Flywheel	Yellow				
	Authorization system deployed leveraging NACC Directory		Yellow			
	Sites will be able to see their own data		Yellow			
	COVID v2 data submission system active		Yellow			
<b>UDSv4 Implementation</b>	UDSv4 content finalized (Initial VP, Follow-up VP, Remote: TIP, TFP)		Yellow			
	UDSv4 pilot at select centers		Yellow			
	UDSv4 forms developed in REDCap		Yellow			
<b>UDSv4 Training</b>	UDSv4 coding guidebooks and videos			Yellow		
	UDSv4 training: clinicians and data managers			Yellow		
<b>UDSv4 Initiation</b>	Centers start using and submitting UDSv4 (REDCap and PDF)				Yellow	
	Centers start using new participant registration process				Yellow	
	Stop date for UDSv3 submission			Yellow		
<b>Additional Data Integrations</b>	SCAN metadata and analysis data integrated		Yellow			
	NCRAD/NIAGADS metadata and analysis data pilots					Yellow
	EHR/CMS pilot data				Yellow	
	Digital Biomarker & Digital Neuropathology					Yellow
<b>DFD Prototype</b>	Flywheel connected to Leaf (data queries and access)			Yellow		

## UDSv4 Webpage

### UDSv4 Webinars and Presentations

#### June 3, 2022 CTF/NACC UDSv4 Webinar

The June 3rd Webinar covered some of the new UDS content, provided an overview of the modern systems coming online at NACC, and how REDCap can facilitate capturing the UDS at ADRCs.

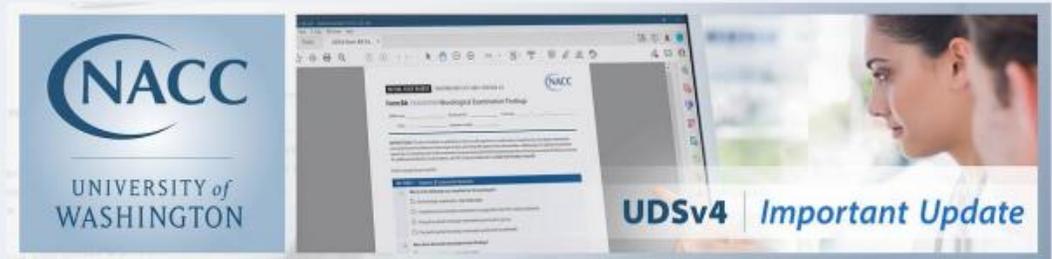


#### Agenda

Overview of UDSv4	Allan Levey, MD of Emory University, Goizueta ADRC
Neuropsychiatric Symptoms (NPS & MBI)	Kostas Lyketsos, MD of John's Hopkins ADRC
AD Specific Treatment Form	Suzanne Schindler, MD, PhD of Washington University, Knight ADRC
Subjective Cognitive Decline	Andrew Saykin, PhD of Indiana ADRC
Social Determinants of Health	Lisa Barnes, PhD of Rush ADRC and Megan Zuelsdorff, PhD of Wisconsin ADRC
COVID F2/F3 Forms	Carlos Cruchaga, PhD of Washington University, Knight ADRC
UDSv4 - Next Steps	Sarah Biber, PhD and Laura McLeod of NACC

[bit.ly/UDSv4Updates](https://bit.ly/UDSv4Updates)

## UDSv4 Email Updates



Dear ADRC Colleague,

**NACC and the CTF are making great progress towards completing the content for UDSv4.**

We wanted to update you on some key areas of progress and highlight some new resources that we have built to keep you in the loop.

NACC and the CTF will be sharing updates on UDSv4 and the modern UDSv4-related infrastructure that we are developing at the Fall ADRC Meeting.

We hope you can join us there!

[Register for 2022 Fall ADRC Meeting](#)

[bit.ly/nacc-stay-connected](https://bit.ly/nacc-stay-connected)

# How Can You Get Involved?

- **Join the Electronic Data Capture Workgroup**

[naccddata.org/edc](http://naccddata.org/edc)



- **Apply for the NI Award**

[bit.ly/NI-awards](http://bit.ly/NI-awards)

- **Learn more about NACC Data**

[naccddata.org](http://naccddata.org)

- **Sign up to participate in a DFD Focus Group**

[bit.ly/DFDFocusGroup](http://bit.ly/DFDFocusGroup)



- **Give feedback on Flywheel as you start to interact with it by emailing us**

[nacchelp@uw.edu](mailto:nacchelp@uw.edu)

# Connect with NACC

Sarah Biber, PhD, Program Director

[Biber@uw.edu](mailto:Biber@uw.edu)





# Thank you!





# Data Repository and Pipeline

**Ben Keller, Ph.D.**

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**20 October 2022 – Fall ADRC 2022**

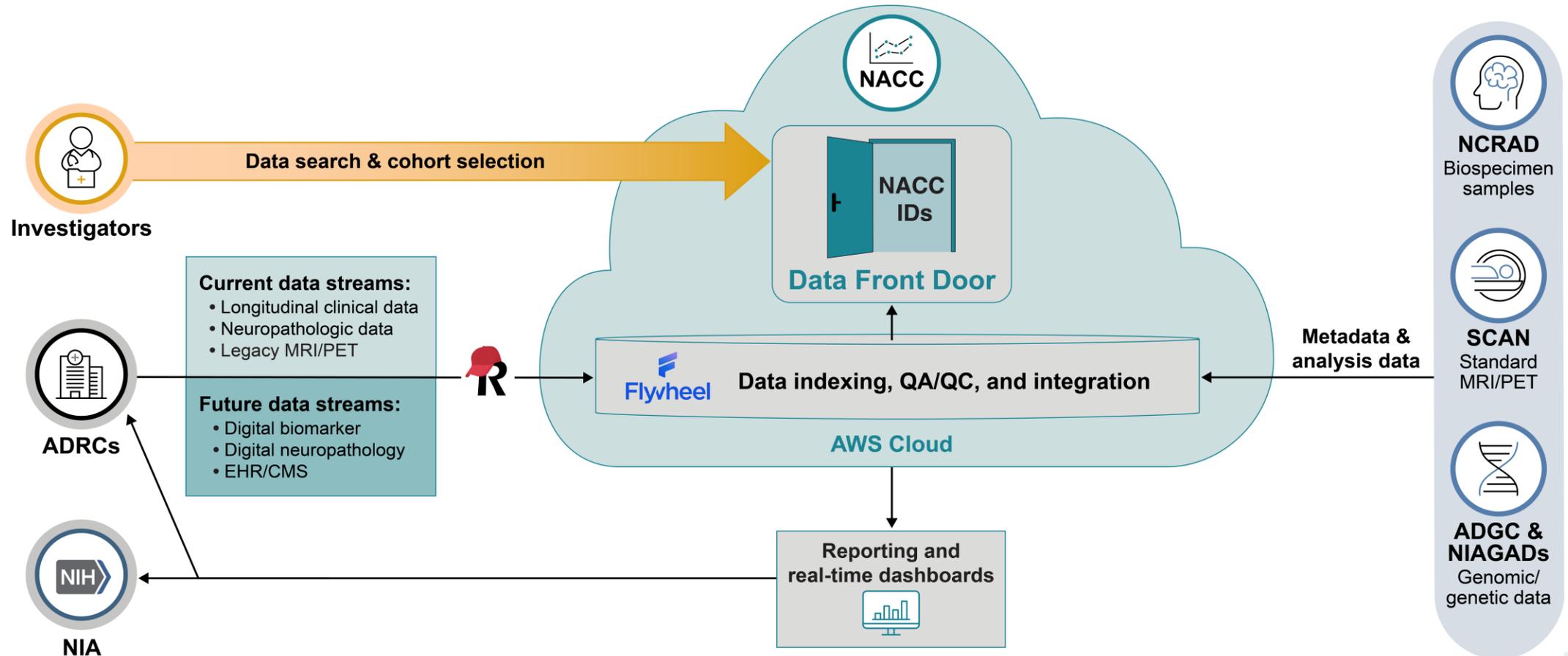


**NACC is migrating to Flywheel as the data repository**

This will make data submission, harmonization, dissemination scalable and more user friendly for ADRCs and ADRD researchers

# The Architecture We Are Building

Flywheel will integrate and organize all ADRC data



# Why Flywheel?

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Flywheel allows the integration of current and future data streams

- Flywheel used at ADRC institutions for imaging
- NACC 6-week pilot demonstrated our ability to use Flywheel for forms data
- File-based – going beyond forms and images
- Opens potential for sandboxed analysis



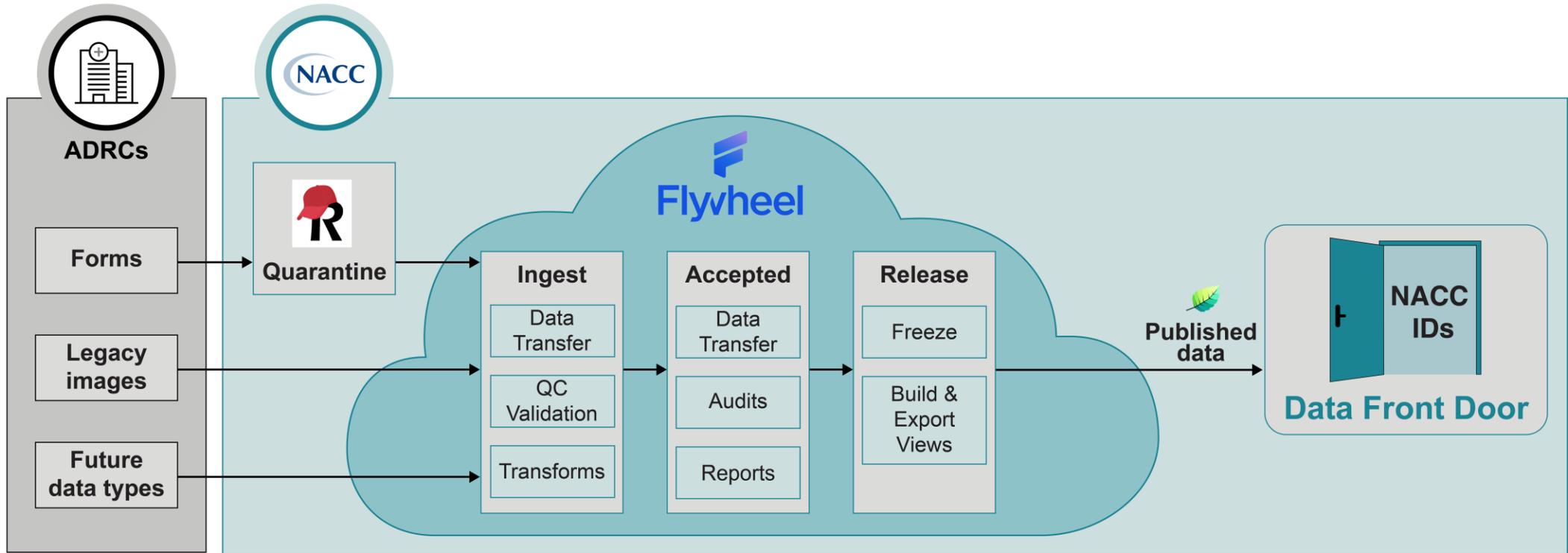
# New Capabilities

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- More consistent ways to submit data
- Easier to see, track and use your submitted data
- Scalable to new data types for ADRC collaborative proposals
- Streamlined access management

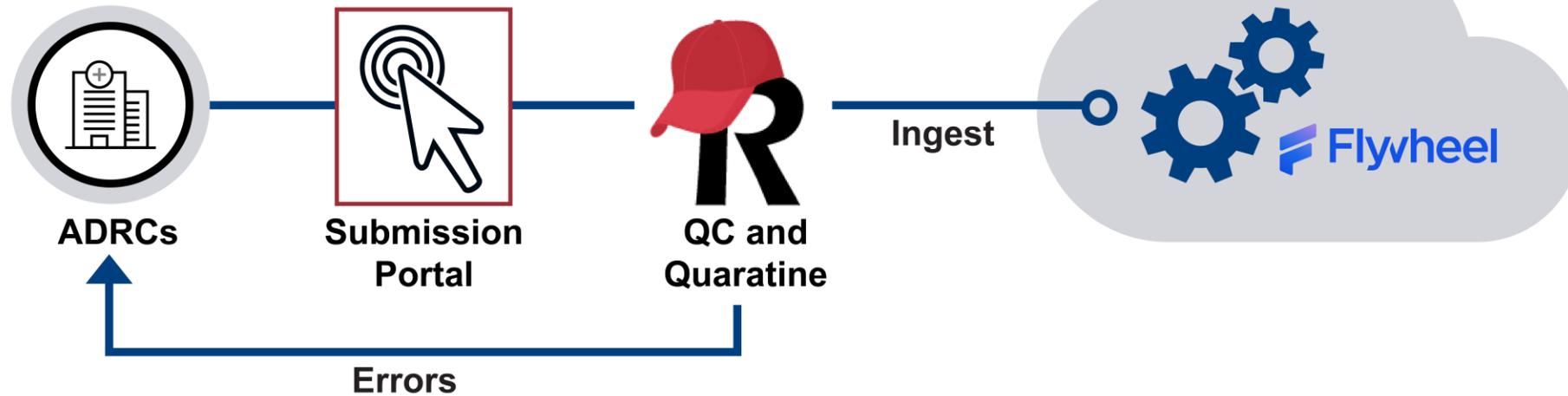


# Future ADRC Data Pipeline



# The Future of NACC Data Submission

- Actively building REDCap-based submission of forms
- Expect REDCap to REDCap, and submission portal
- Other data types (legacy images, digital data, clinical data/EHR) through Flywheel
- Form QC resources will be available to centers





# The Future of NACC Access Management

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- NACC will support single sign on with institutional credentials via InCommon (using CILogin or ORCID)
- Accounts and authorizations will be managed by integrating the REDCap-based NACC directory with Flywheel



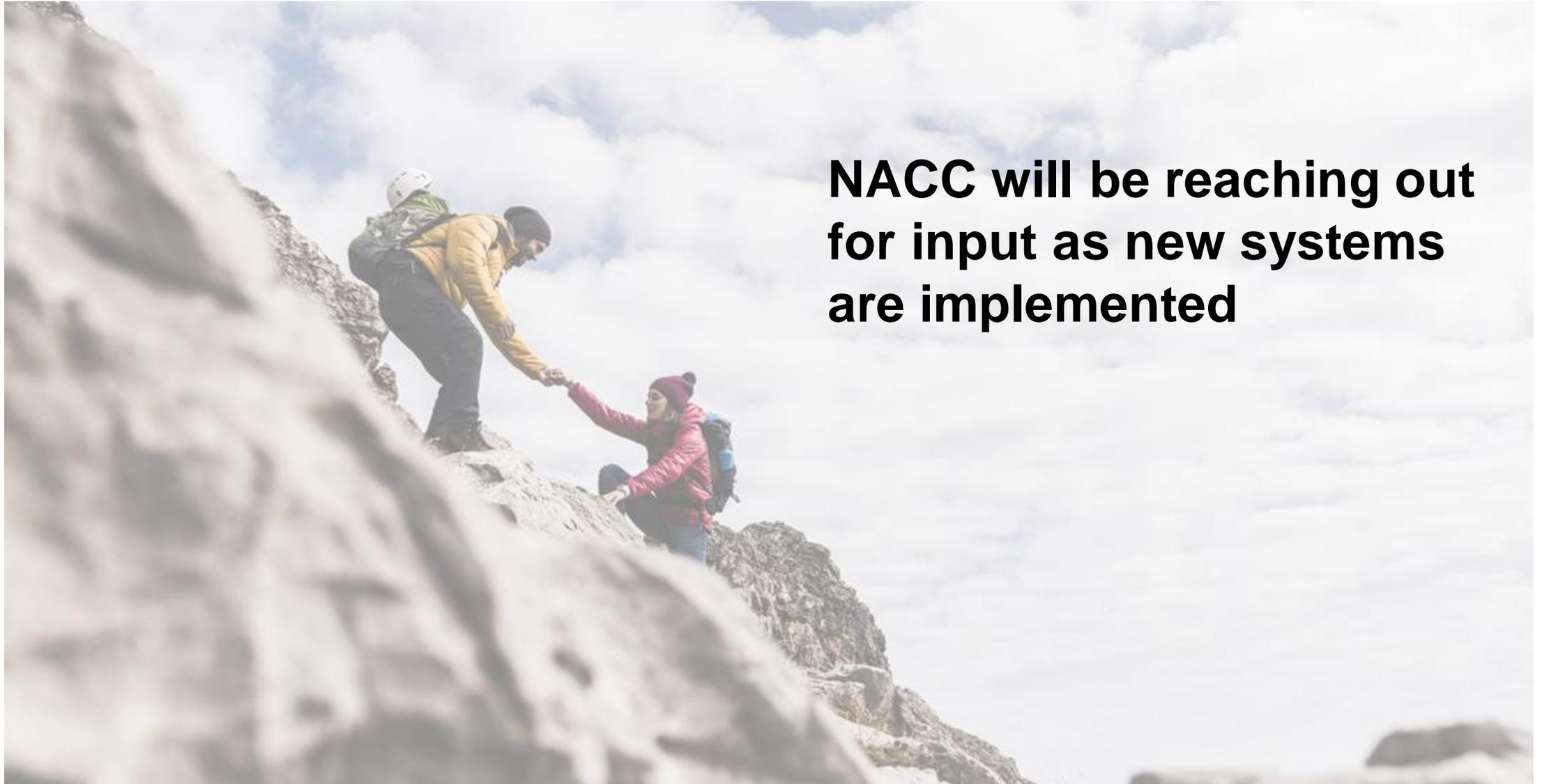
# Roadmap

Quarter	Objective
Q4 2022	Design and configure
Q1 2023	Build infrastructure
Q2 2022	Move-in
Q3 2023	Move-out*
Q4 2023	Enhance and extend

\*Some tasks tied to end of UDSv3 submission



# You Can Help!



**NACC will be reaching out for input as new systems are implemented**

# Connect with NACC

**Ben Keller – Tech Lead**

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[bjkeller@uw.edu](mailto:bjkeller@uw.edu)





# NACC COVID-19 Supplement Update

Sean Mooney, PhD, Melissa Lerch, PhD, and Kari Stephens, PhD

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Thursday, October 20 – ADRC Fall 2022

# Opportunity

Build a platform to facilitate uncovering the relationship between COVID-19 and ADRD



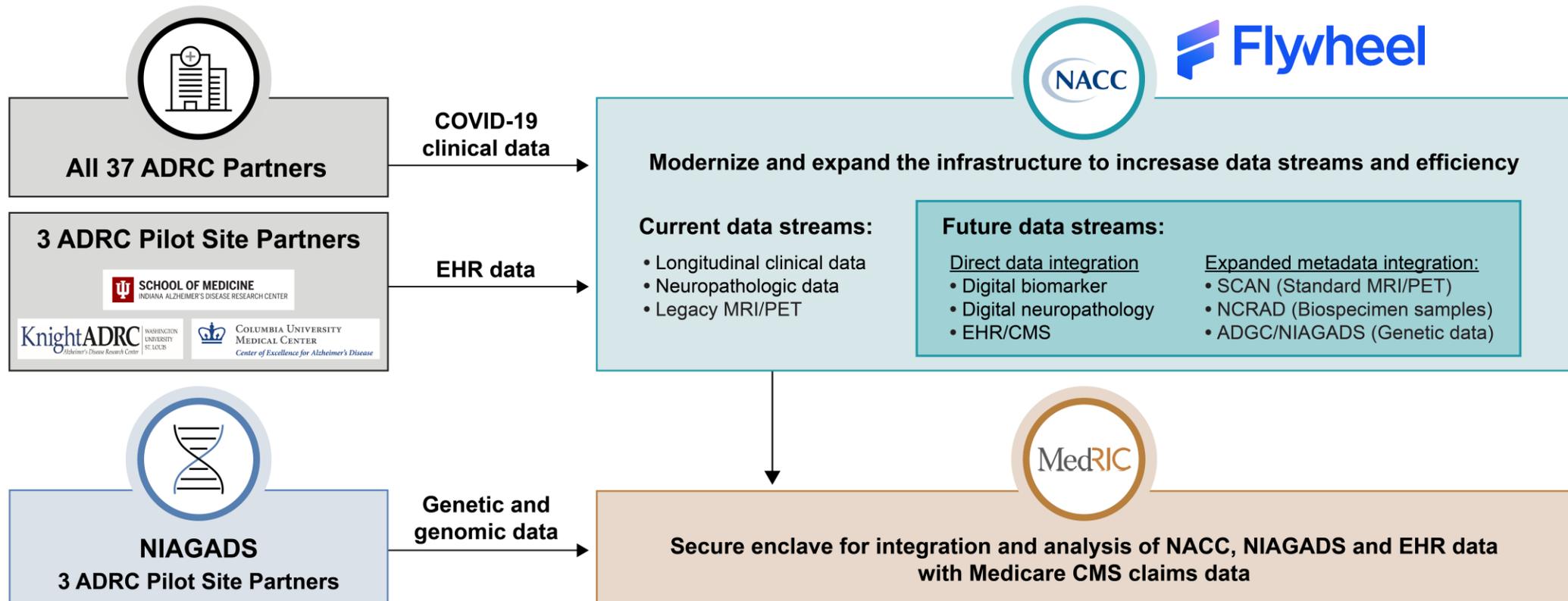
# NACC COVID-19 Supplement

- **Aim 1:** Support study design, recruitment and enrollment at three pilot sites and collect baseline data.
- **Aim 2:** Demonstrate integration of EHR and CMS data with phenotypic and previously collected genetic data.
- **Aim 3:** Facilitate computational analysis of genetic information with participant phenotypic and genetic data.



# NACC COVID-19 Supplement

NACC is establishing a platform to collect and link clinical (EHR) and claims (CMS) data with genetic data (NIAGADS/ADSP) and phenotypic data (NACC) for consented ADRC participants.





# Building a Roadmap for Expansion to All 37 ADRCs

Standard operating procedures are under development to facilitate governance and data linkage processes.

## Why? Unique Value of NACC Data

- Includes cognitively normal, MCI, and dementia participants
- Rich longitudinal neurocognitive data from populations at high risk for the development of Long Covid - collected prior to infection
- 16,000+ active participants - one of the largest and most comprehensive longitudinal datasets in the world for an age group at high risk for COVID-19 infection
- Integrated with a multitude of valuable data streams for ADRC participants - including standardized MRI/PET imaging
- NACC has the infrastructure to track participants longitudinally

# Why Expand to All ADRCs?

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## Builds on NIH/NIA's investments:

- Build on NIA's investments in NACC, NIAGADS, and the ADRC Program
- Promotes MedRIC platform (NIA funded partner)
  - Secure computer enclave for combining and analyzing the data collected through this new consortium model for the ADRC community
- If the pilot is expanded to the full ADRC Program, it will also complement other NIH-funded COVID studies such as RECOVER and N3C and create promising opportunities for collaboration.

- **RECOVER**
- **ADSP** (Collaborating with NIAGADS to improve integration of phenotypic and genetic data)
- **Align with VA projects** (Working with VA data)
- **N3C**

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.

# COVID Form Update

# COVID Data Collection from the ADRC Program

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## COVID Technology Assessment

- Focus: Determining the best follow-up with participants during the pandemic:
- Released: June 2020
- Collected 2070 responses from 12 ADRCs

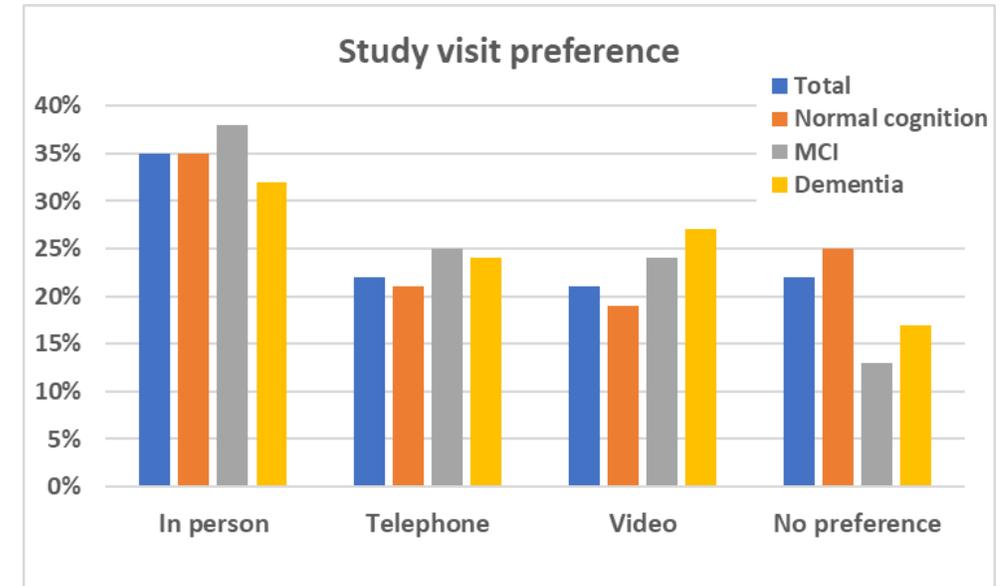
## Original COVID Impact Survey Forms

- Focus: COVID testing, infections, and impact of pandemic from participant and co-participant
- Released: June 2020
- About 5000 COVID Impact Surveys v1 forms from 22 ADRCs

# COVID Data Collection from the ADRC Program

## Recent Publication

- Manuscript from OHSU accepted
- Participants want to connect with ADRCs using a variety of methods irrespective of cognitive state
- Participants with dementia/MCI were less likely to use the internet

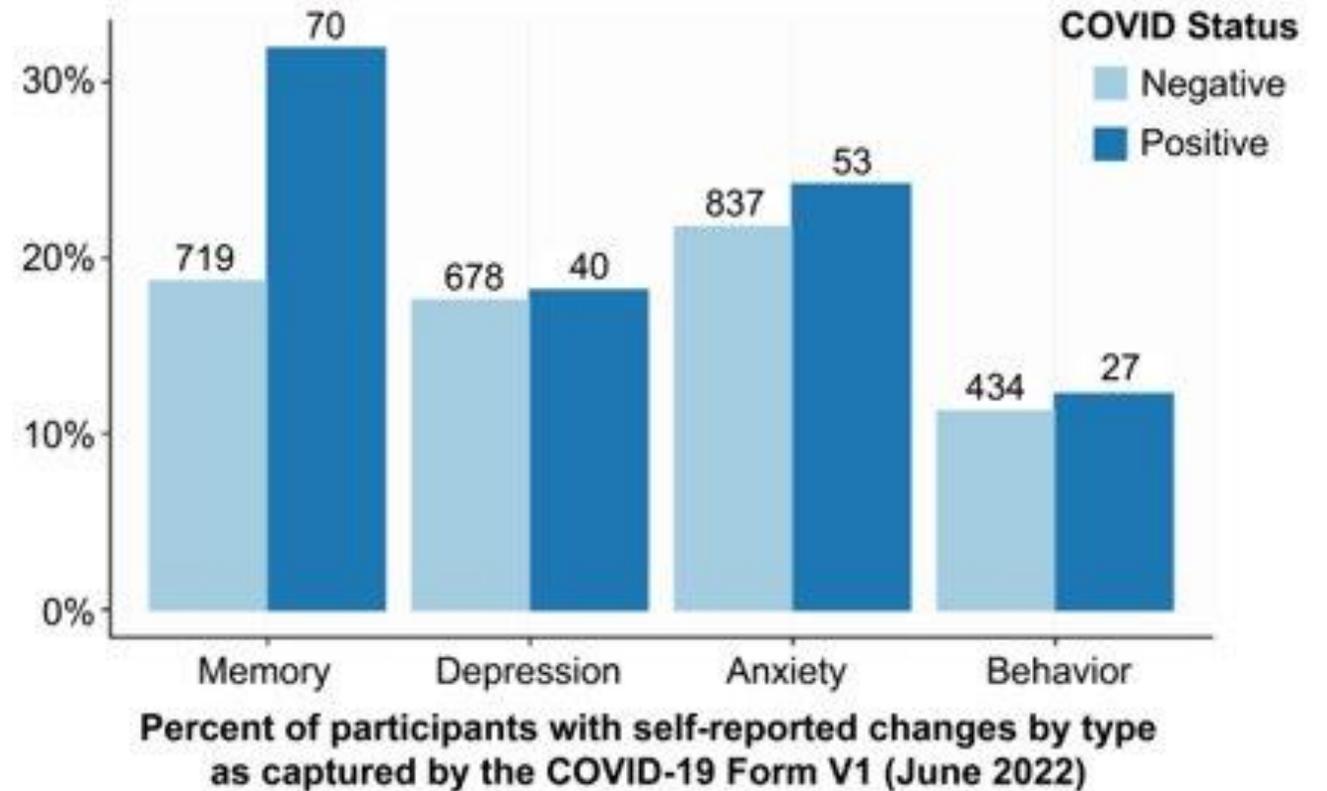


M. Nunnerley N. Mattek, J. Kaye, Z. Beattie, Preferences of NIA Alzheimer's Disease Research Center Participants Regarding Remote Assessment During the COVID-19 Pandemic (2022) *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*. Accepted.

# COVID-positive Participants report Memory Changes

## COVID Impact Survey

- COVID-positive participants have increased self-reported changes in memory compared to COVID-negative
- Data from 4500 participants in June data freeze



# Dynamic Response to the Pandemic

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- **As the pandemic evolved, the COVID forms were adapted to capture:**
  - Vaccinations
  - Outpatient treatments
  - Hospitalizations
- **Forms provide a tool for capturing long COVID data**
- **New! COVID Impact F2/F3 v2 forms released July 2022**
  - Currently being translated into Spanish
- **Data Submission system being developed in REDCap**

# Dynamic Response to the Pandemic

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**Required lots of effort from lots of folks – thank you!**

- **James Noble** and **Carlos Cruchaga** designed the v2 Form
- **ADRCs** provided feedback through surveys
- **CTF** worked to approve the form for use
- **Katya Rascovsky** working on Spanish translation with **CADLAS** (US Consortium of Aging, Dementia and Latino Studies)



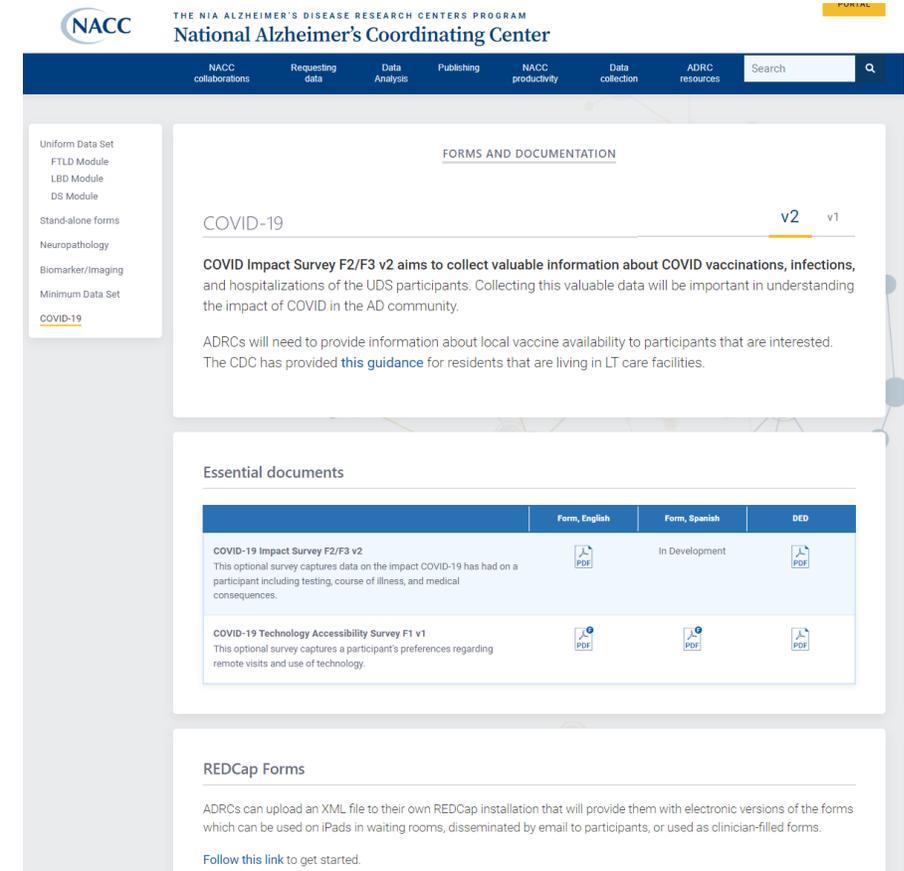
# New COVID Impact v2 Forms are Ready

## Two formats available on NACC website:

- Traditional Form (.pdf) with DED
- REDCap XML and DED (.csv) are available

## REDCap forms offer advantages:

- Use in waiting rooms on iPads
- Send by email anytime
- Currently being developed into a dynamic auto-populated form for multiple use



The screenshot shows the NACC website interface. The header includes the NACC logo and the text "THE NIA ALZHEIMER'S DISEASE RESEARCH CENTERS PROGRAM National Alzheimer's Coordinating Center". A navigation bar contains links for "NACC collaborations", "Requesting data", "Data Analysis", "Publishing", "NACC productivity", "Data collection", and "ADRC resources", along with a search bar. The main content area is titled "FORMS AND DOCUMENTATION" and features a "COVID-19" section with tabs for "v2" and "v1". The "v2" tab is active, displaying text about the "COVID Impact Survey F2/F3 v2" and a link to "this guidance". Below this is an "Essential documents" table with columns for "Form, English", "Form, Spanish", and "DED". The table lists two surveys: "COVID-19 Impact Survey F2/F3 v2" and "COVID-19 Technology Accessibility Survey F1 v1". The "REDCap Forms" section at the bottom explains that ADRCs can upload XML files to their REDCap installation for use on iPads, email, or as clinician-filled forms, and provides a link to get started.

	Form, English	Form, Spanish	DED
<b>COVID-19 Impact Survey F2/F3 v2</b> This optional survey captures data on the impact COVID-19 has had on a participant including testing, course of illness, and medical consequences.		In Development	
<b>COVID-19 Technology Accessibility Survey F1 v1</b> This optional survey captures a participant's preferences regarding remote visits and use of technology.			

<https://bit.ly/nacc-covid19-v2>

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.

# Supplement Progress Update

# Supplement Progress

Infrastructure for linking NACC phenotypic, clinical EHR, claims (CMS Medicare), and NIAGADS (genetic) data on a well-studied population with informed consent.

## Creating Governance

- **IRB modifications for COVID-19 and EHR data collection have been approved at all sites**
- **IRB modifications for CMS data collection in progress**
- **Consortia model has been developed and MedRIC agreements are being negotiated by NACC, MedRIC, and the sites**
  - Will enable establishment of a secure enclave to access CMS data

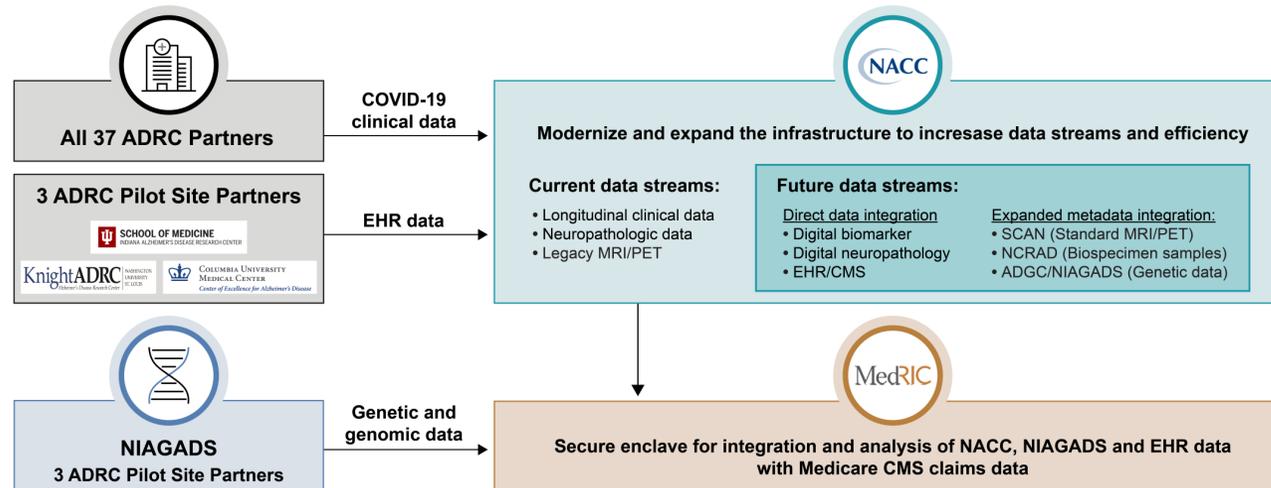


# Supplement Progress

Infrastructure for linking NACC phenotypic, clinical EHR, claims (CMS Medicare), and NIAGADS (genetic) data on a well-studied population with informed consent.

## Creating Governance

- Discussions are underway with NIAGADS

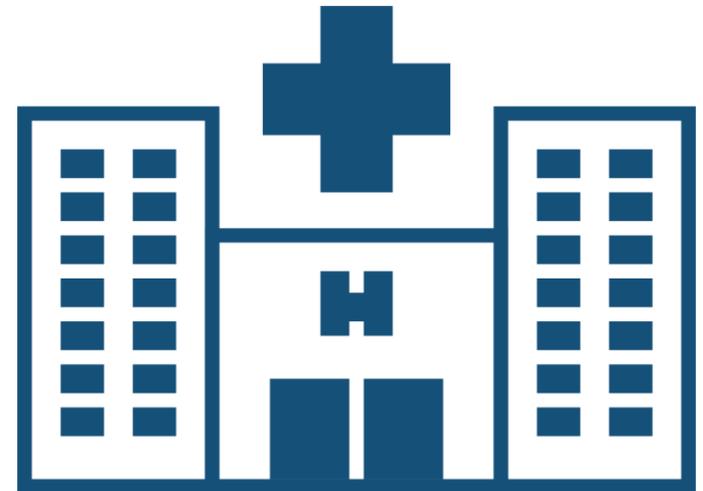


# Supplement Progress

Infrastructure for linking NACC phenotypic, clinical EHR, claims (CMS Medicare), and NIAGADS (genetic) data on a well-studied population with informed consent.

## Developing a Clinical (EHR) Workflow

- **EHR specification and extraction processes are under development**
- **OMOP data model and alignment with other national data sharing efforts**



# Supplement Progress

Infrastructure for linking NACC phenotypic, clinical EHR, claims (CMS Medicare), and NIAGADS (genetic) data on a well-studied population with informed consent.

## Developing a Clinical (CMS) Workflow

- **Workflow being developed in anticipation of the MedRIC enclaves being implemented**
  - MedRIC provides access to CMS claims data using a cloud-centric computing platform that NACC will manage on behalf of the ADRC Program



**Medicare & Medicaid Resource Information Center (MedRIC)**

# Supplement Progress

Infrastructure for linking NACC phenotypic, clinical EHR, claims (CMS Medicare), and NIAGADS (genetic) data on a well-studied population with informed consent.

## Pilot Study Development

### NACC and three ADRCs to develop observational study to test data linkages

- Targeting group launch in September 2022

Table 1. Projected Cohort Data	Controls	MCI	Dementia
Estimated total # of UDS participants from the three pilot sites (from July 2022 to July 31, 2024)	1,109	214	224
Data Types and Projected # of Participants (From the Above Total UDS Participants)	Controls	MCI	Dementia
EHR	637 (57%)	137 (64%)	184 (82%)
Modified COVID-19 Form V2	1,066 (96%)	202 (94%)	215 (96%)
Genomic data from NIAGADS	1,090 (98%)	208 (97%)	216 (96%)
EHR + Modified COVID-19 Form V2 + Genomic data from NIAGADS	619 (56%)	132 (62%)	176 (79%)

# Advancing ADRD and COVID Research

## Potential Future Studies

- Identify genetic and other biomarkers associated with the risk of dementia and cognitive complaints after COVID-19 infection
- Quantify polygenic risk of poor outcomes in ADRD with and without history of COVID-19
- Investigate long term effects of COVID-19 on cognitive impairment
- Characterize the relationship between healthcare access and outcomes in COVID-19 and ADRD







**Thank you!**



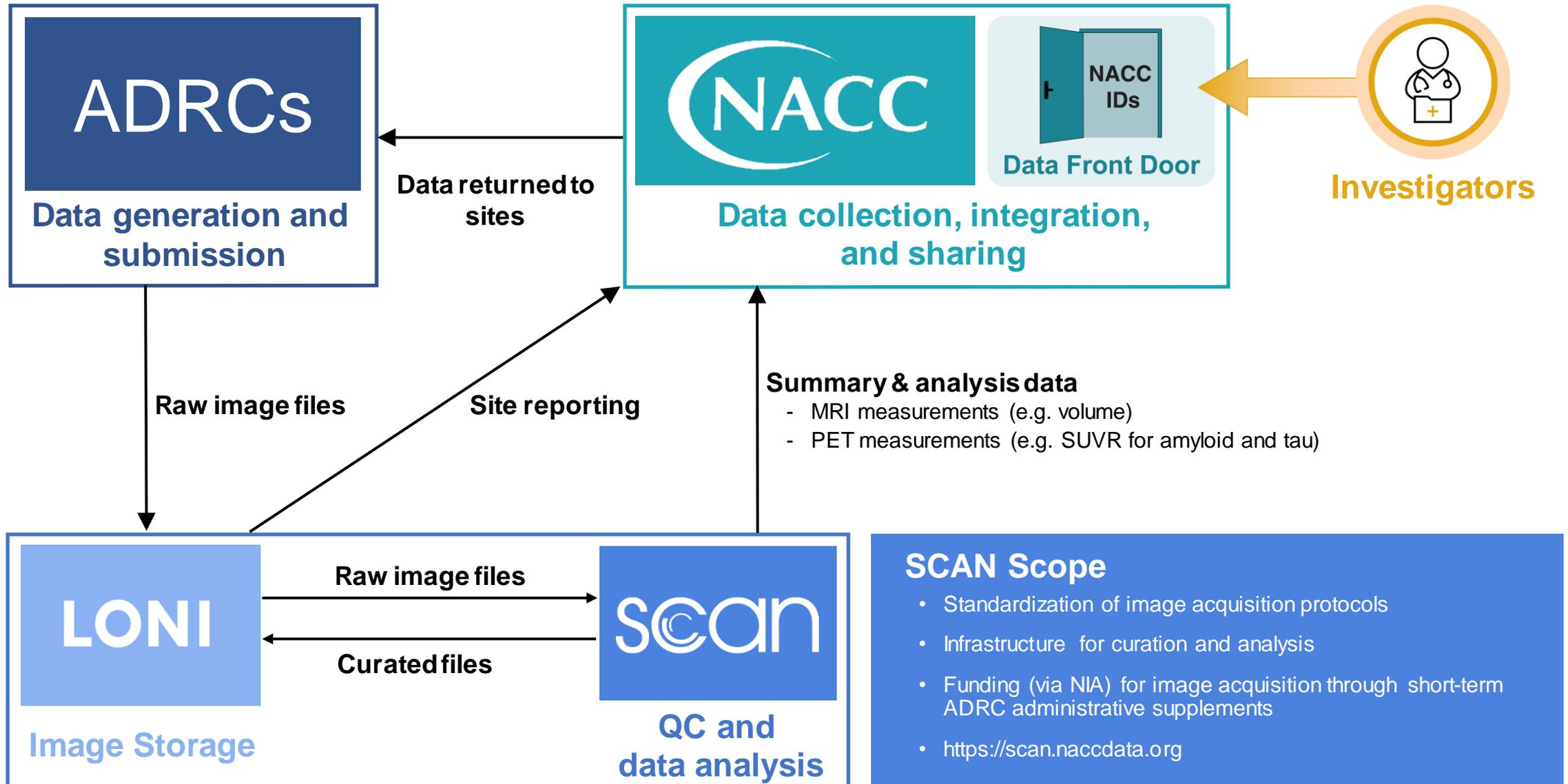


# Amplifying **SCAN**

**Sarah Biber, PhD**

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**Thursday, October 20 – ADRC Fall 2022**



# SCAN - How is it going?

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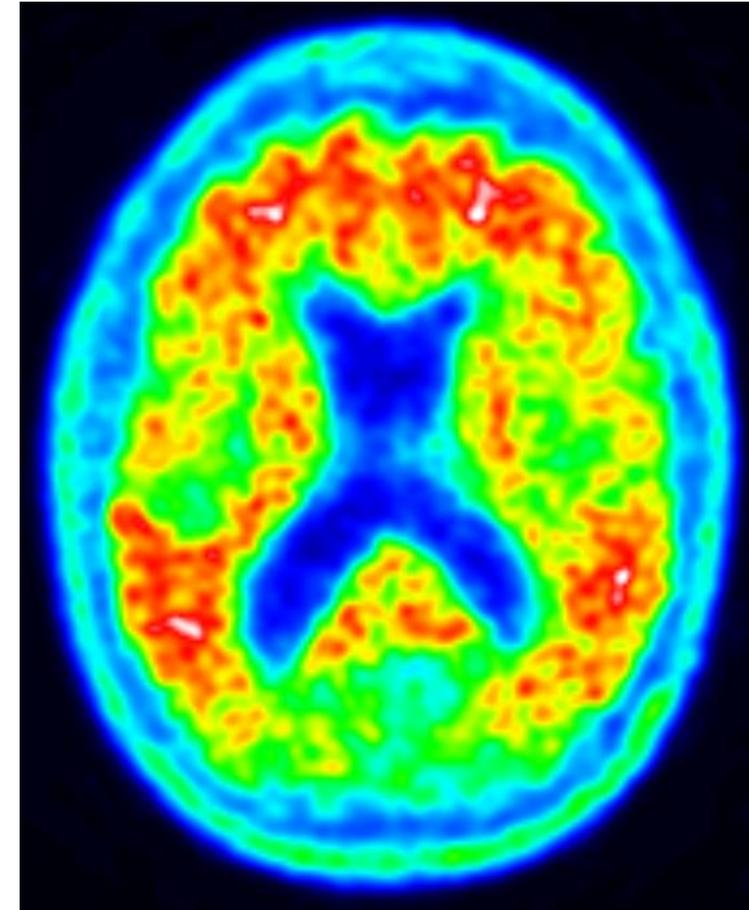
## SCAN Submission Summary

Participant #	SCAN Types
1,402	MRI scan submitted
790	PET scan submitted
401	Both MRI and PET scan submitted - 51% of PET participants have at least 1 MRI scan

# PET - How is it going?

## 1,098 PET Scans Received from 15 ADRCs

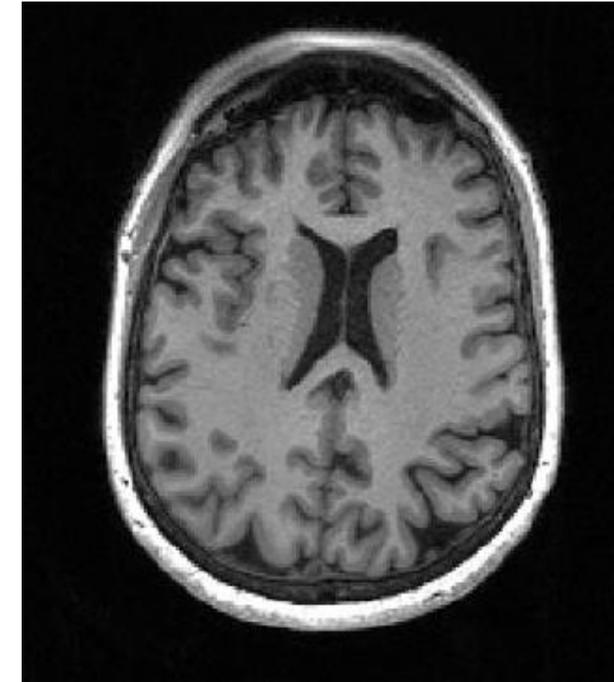
Scans Uploaded	Number
PIB	236
Florbetapir	146
Florbetaben	185
NAV4694	97
<b>Total Amyloid</b>	<b>664 (69% ADNI protocol)</b>
Flortaucipir	134
MK6240	177
PI2620	84
<b>Total tau</b>	<b>395</b>
<b>FDG (Fluorodeoxyglucose)</b>	<b>105</b>



# MRI - How is it going?

## 1,289 Exams Submitted from 27 ADRC

Series Type	# Received
T1	1,378
FLAIR	1,220
T2	448
dTI	406
ASL	274
GRE or MEGRE	336
<b>Total Series Received</b>	<b>5,772</b>



# Amplifying the SCAN initiative

AAA  
☰ ☱

## NACC

### MRI & PET Checklist - SCAN Readiness

- This survey will collect your site contact information. It will also help your site in completing steps 1 and 2 of the MRI and/or PET SCAN checklist. We intend to use your current progress on the MRI and/or PET SCAN checklists to build our live leaderboard hosted on the NACC website to showcase where each of the ADRC sites are in the MRI and/or PET SCAN readiness process.
- If you need to pause and continue filling out this survey later, you can scroll to the bottom of the page at any point in the survey and click the 'save and return' button. **If you do so, please enter your email address into the screen you see next.** This will email you a unique survey link so that you can continue the survey later.
  - **Please do not start a new survey and instead return to the original survey that you started by using the link sent to your email.**
  - If you attempt to start a new survey - an error message will pop up stating that your information is already associated with another survey response.
- At the end of this survey you will be asked to create a username and password. This will be necessary to update your SCAN checklist progress throughout the SCAN readiness process. **Please save these login credentials.**
- If you have any issues with retrieving a survey you started, please reach out to halebri@uw.edu.

Please indicate who is completing this survey

First name* <i>must provide value</i>	Last name* <i>must provide value</i>	Email address* <i>must provide value</i>
<input type="text"/>	<input type="text"/>	<input type="text"/>

Next Page >>

Save & Return Later

## Developed and deployed a SCAN Checklist

### Purpose:

- Roadmap for getting SCAN ready
- Standard tool for assessing SCAN readiness
  - REDCap-based
  - Can be updated by sites in real-time

### Impact:

- **100%** of queried sites found the checklist helpful or thought it would have been helpful in getting SCAN ready

### Next steps:

- Will survey all sites on SCAN readiness in early November 2022

# Amplifying the SCAN initiative

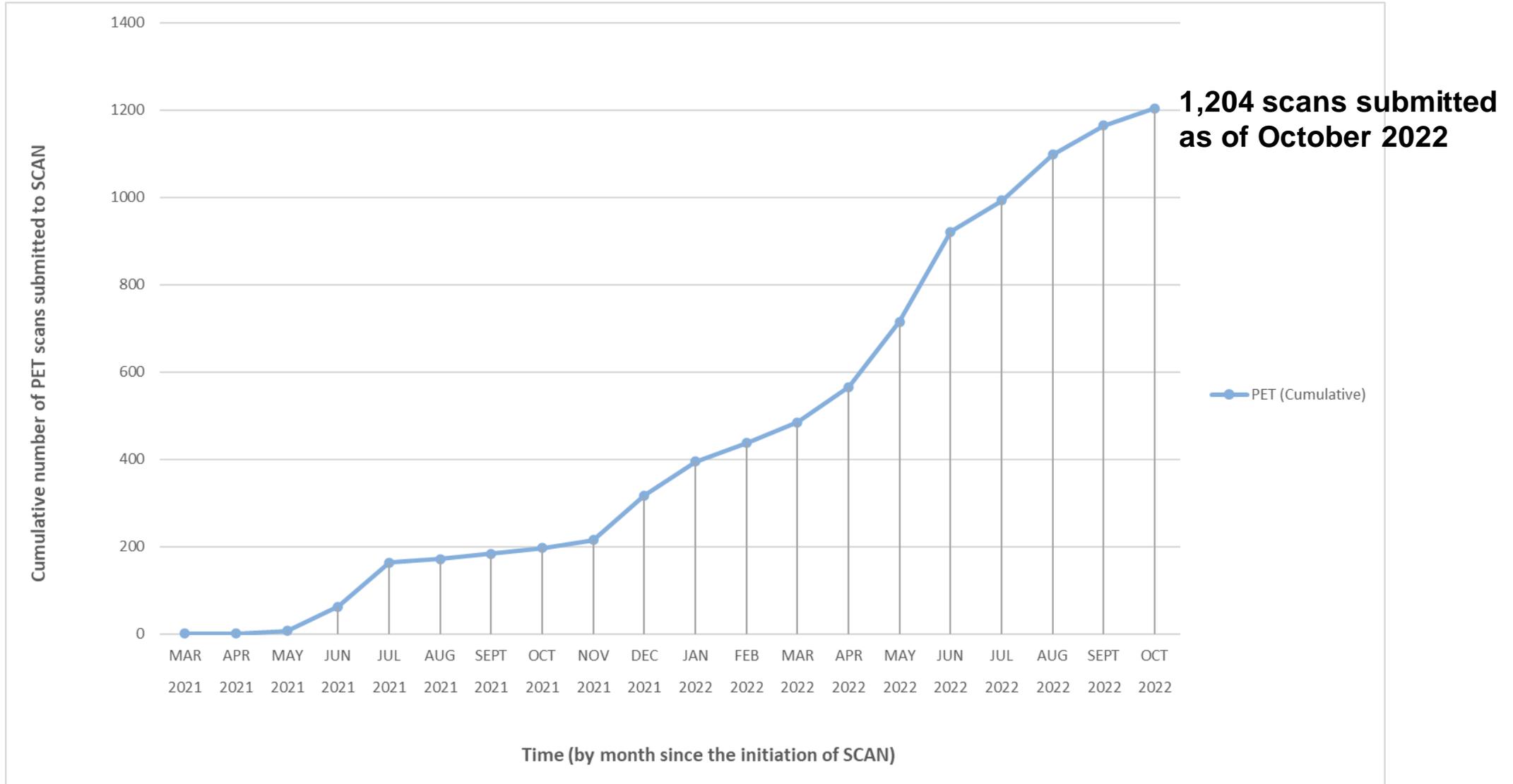
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## 20 Site Interviews Conducted (May - June 2022)

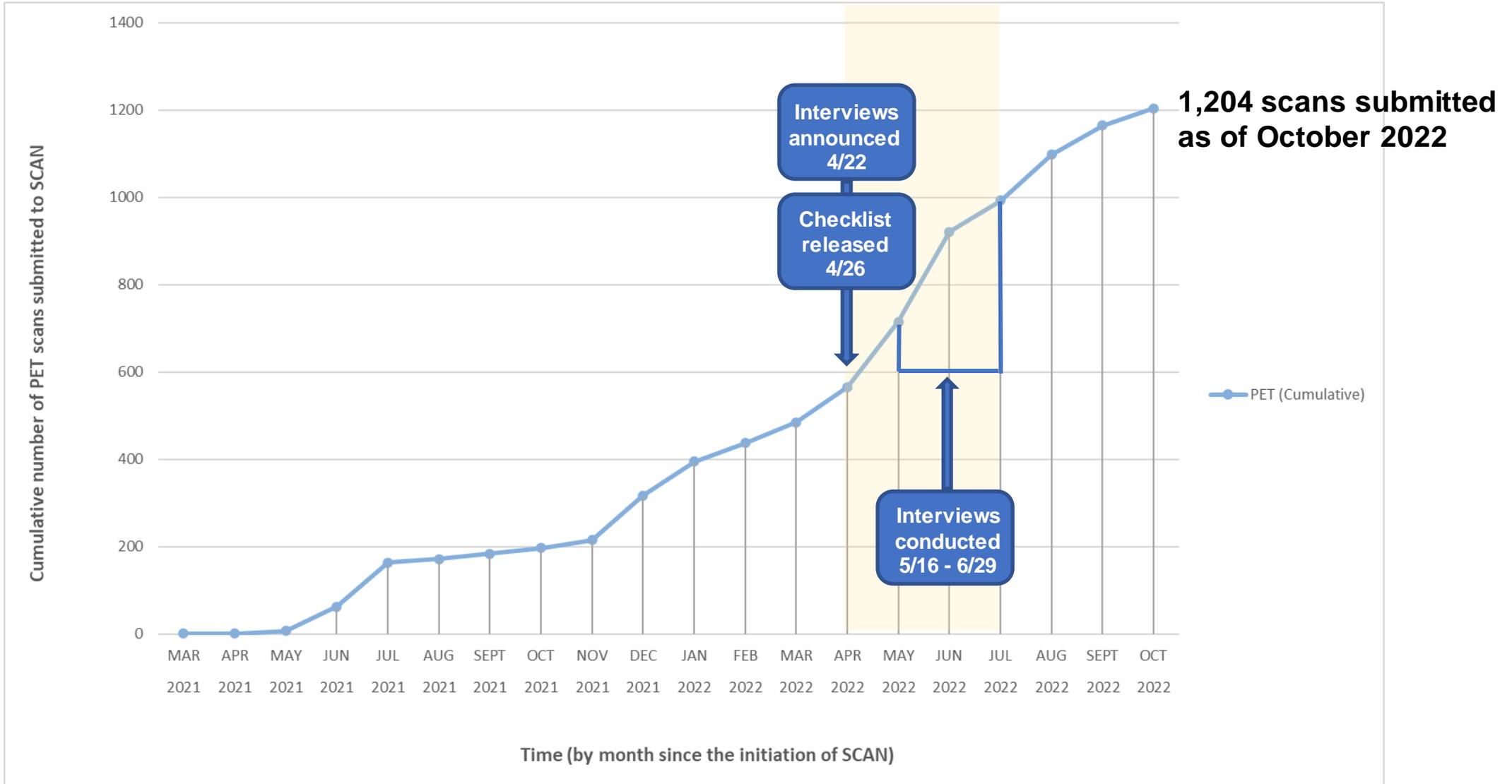
- **Goal:**
  - Discuss SCAN progress and identify roadblocks
  - Identify how to best support and amplify site participation in the SCAN initiative
- **How sites were selected for interviews:**
  - SCAN Co-I
  - Represented in the imaging steering committee
  - Received an admin supplement for SCAN participation
- **Interviewees:**
  - ADRC directors, imaging core leaders, admins
- **Outcomes:**
  - Identified common site challenges and barriers to participation
  - Informed the development of several tools and solutions to amplify the SCAN initiative



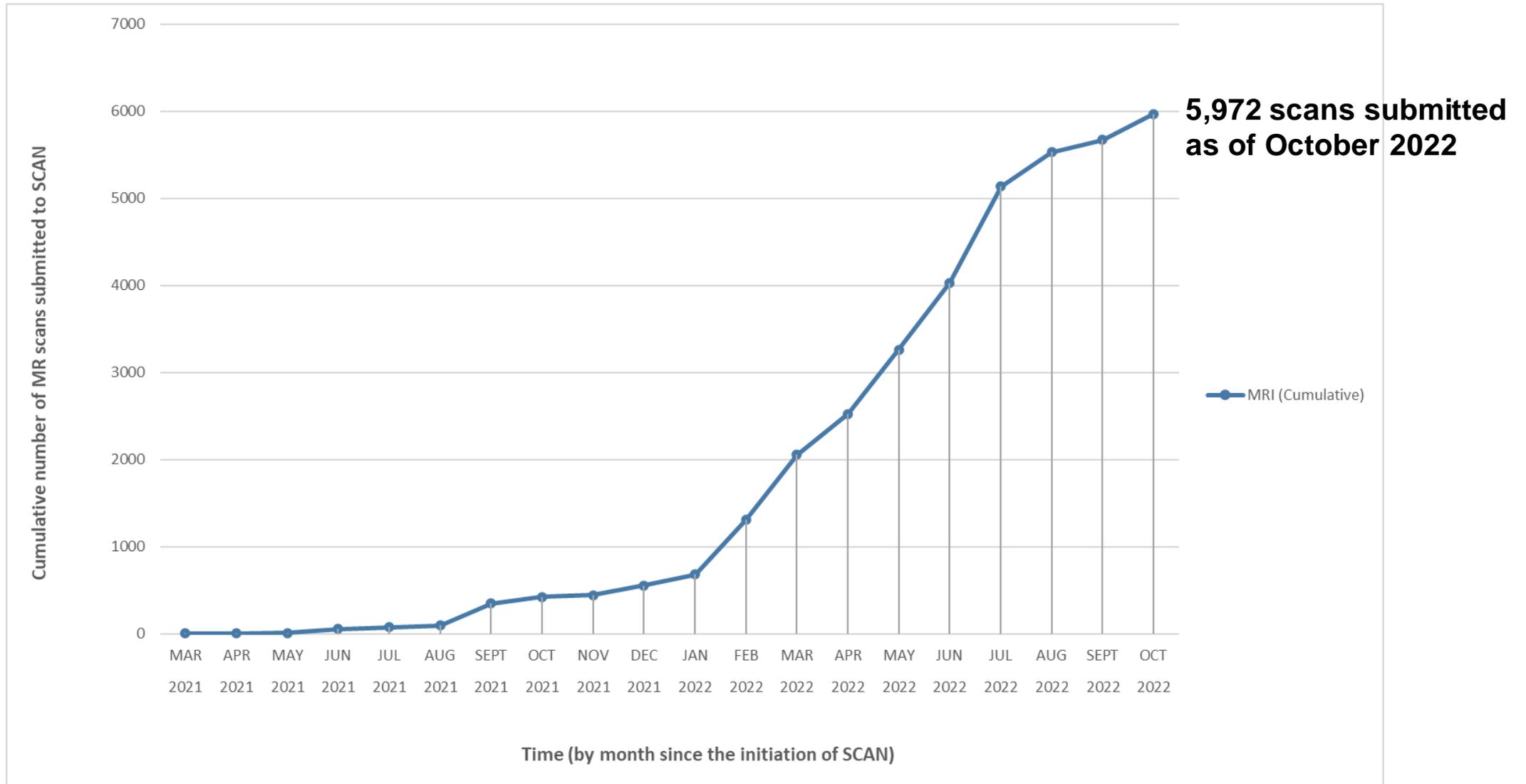
# How is it going? PET



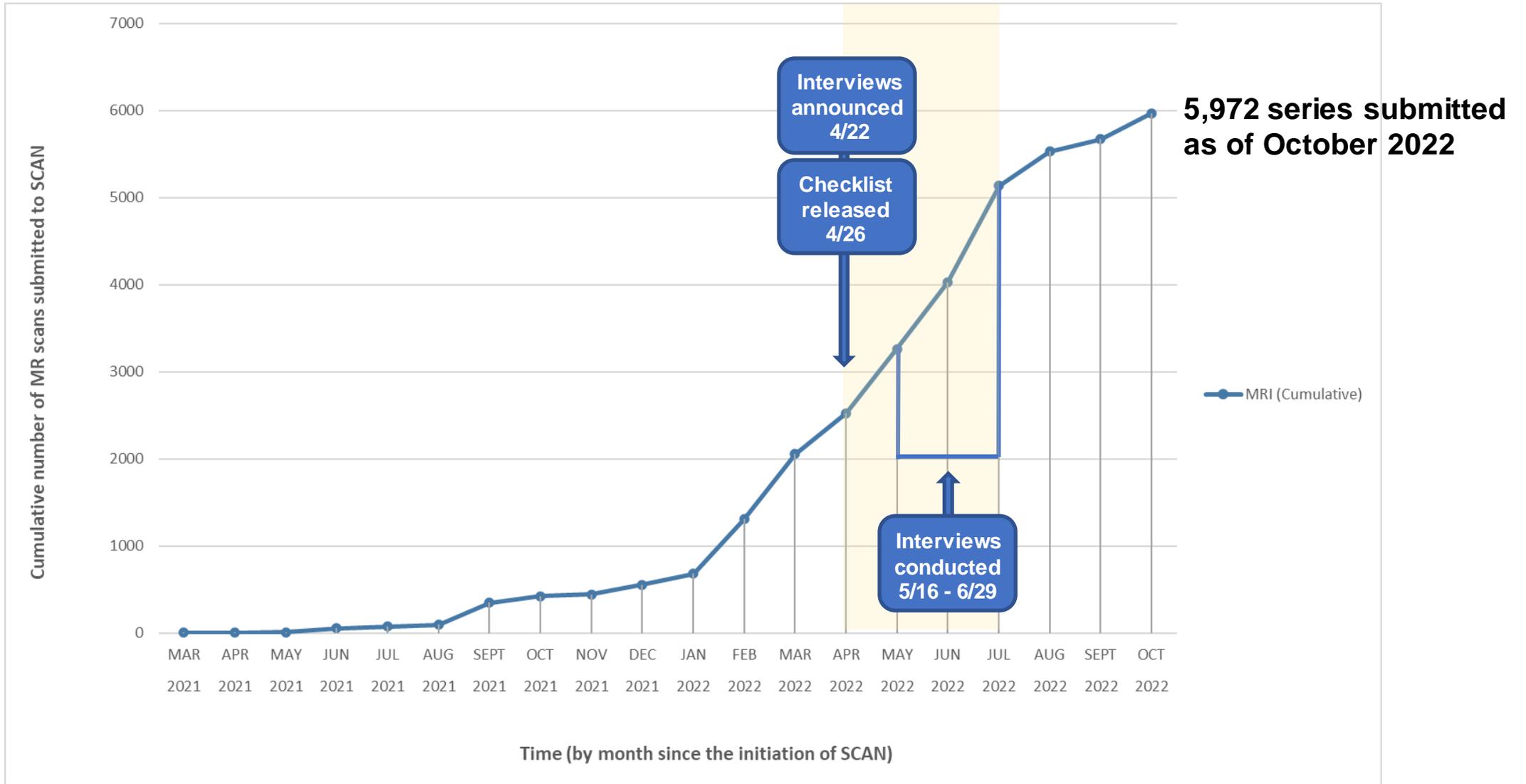
# How is it going? PET



# How is it going? MRI



# How is it going? MRI



# SCAN Solutions Being Built in Collaboration with SCAN/LONI

- **Real-time SCAN Dashboards**
  - SCAN - Public Dashboard
  - SCAN - Site-Specific Dashboards with downloadable data submission records and QA/QC feedback
- **Streamlined and Harmonized SCAN Resources**
- **New Scalable NACC ID Assignment Process**
- **New SCAN Web Portal**
- **Optimizing MRI/PET search through the Data Front Door**
  - Metadata and analysis data
  - Cohort selection tools

# SCAN: Public Dashboard

## Real-time Public Dashboard – [view here](#)

- Tracks each ADRC's SCAN readiness and participation
- Self-service tool for sites to update their readiness and track their SCAN submissions
- Provides researchers with up-to-date information on the number of standard images that are available for analysis

SCAN Dashboard

Alzheimer's Disease Research Centers

Copy CSV Show 10 entries Search:

Institution	SCAN Readiness		SCAN Participation						Review SCAN Submissions	
	Update your SCAN Readiness Status	Current SCAN readiness status	Total # of participants	MRI			PET		Review your MRI submissions to date and check QC status	Review your PET submissions to date and check QC status
				# MRI Participants	# MRI Exams Submitted	# MRI Series Submitted	# PET Participants	# PET Scans Submitted		
TOTAL			1724	1349	1382	7767	775	1148		
AN EXAMPLE ADRC	<a href="#">Update</a>	Completed Checklist	65	53	53	433	12	17	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Arizona ADC	<a href="#">Update</a>	N/A	113	28	28	640	105	212	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Boston University	<a href="#">Update</a>	N/A	42	42	42	629	0	0	<a href="#">Review MRI</a>	<a href="#">Review PET</a>

# SCAN: Public Dashboard

## Real-time Public Dashboard

- Tracks each ADRC's SCAN readiness and participation
- Self-service tool for sites to update their readiness and track their SCAN submissions
- Provides researchers with up-to-date information on the number of standard images that are available for analysis

SCAN Dashboard

Alzheimer's Disease Research Centers

Copy CSV Show 10 entries Search:

Institution	SCAN Readiness		SCAN Participation						Review SCAN Submissions	
	Update your SCAN Readiness Status	Current SCAN readiness status	Total # of participants	MRI			PET		Review your MRI submissions to date and check QC status	Review your PET submissions to date and check QC status
				# MRI Participants	# MRI Exams Submitted	# MRI Series Submitted	# PET Participants	# PET Scans Submitted		
TOTAL		NA	1724	1349	1382	7767	775	1148	Review MRI	Review PET
AN EXAMPLE ADRC	<a href="#">Update</a>	Completed Checklist	65	53	53	433	12	17	Review MRI	Review PET
Mayo Clinic	<a href="#">Update</a>	Completed Checklist	152	152	155	602	0	0	Review MRI	Review PET
University of Michigan	<a href="#">Update</a>	Steps 1-2 Completed	N/A	N/A	N/A	N/A	N/A	N/A	Review MRI	Review PET

# SCAN: Site-Specific Dashboards

## Features:

- Sites can track the QC status of their MRI submissions
- Record of all SCAN MRI data submitted to date – downloadable as a csv file

## MRI Example

[Site-Specific Dashboard](#) > Central South Dakota MRI Data

**Alert:** PLEASE NOTE THAT THIS EXAMPLE DATA HAS BEEN FABRICATED AND DOES NOT REPRESENT ANY REAL ADRC, PARTICIPANT, OR DATA.

**Review MRI Data**

Copy CSV Show 10 entries Search:

ADRC	NACCID	PTID	Study					Series						Visual QC	QC Comments
			Study Date and Time	Scanner Model	Study UID	Exam Compliance	Study Comments	Series Time and Date	Series Number	Series Type	Released for Analysis	Protocol Status	Protocol Comments		
Central South Dakota	NACC18247	916	9/1/2022 0:00	Achieva dStream	2.16.124.113543.6...	-1		9/1/2022 0:00	301	T2w	-1	3	Matching SQS parameters did not match		
Central South Dakota	NACC293187	493	12/1/2021 0:00	Achieva dStream	2.16.124.113543.6...	-1		12/1/2021 0:00	301	FLAIR	1	1			
Central South Dakota	NACC293187	493	12/1/2021 0:00	Achieva dStream	2.16.124.113543.6...	-1		12/1/2021 0:00	201	T1w	1	1			



# SCAN: Site-Specific Dashboards

## Features:

- Sites can track the QC status of their PET submissions
- Record of all SCAN PET data submitted to date – downloadable as a csv file

## PET Example

[Site-Specific Dashboard](#) > Western Iowa PET Data

Alert: PLEASE NOTE THAT THIS EXAMPLE DATA HAS BEEN FABRICATED AND DOES NOT REPRESENT ANY REAL ADRC, PARTICIPANT, OR DATA.

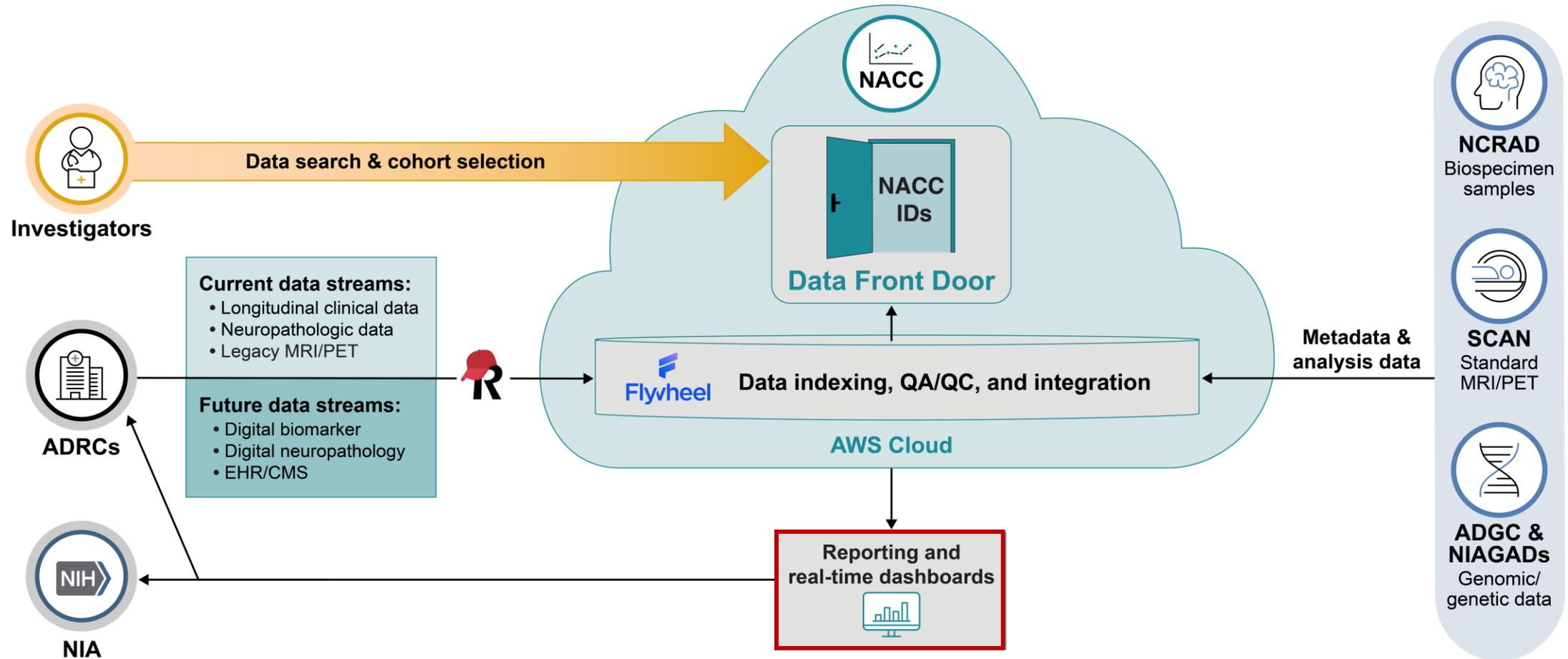
### Review PET Data

Copy CSV Show 10 entries

Search:

ADRC	NACC ID	PTID	Study				QC Status	If failed, why?
			Study Date and Time	Image UID	Scanner Model	PET radiotracer		
Western Iowa	NACC462907	188	6/1/2022 0:00	I10160420	Biograph Horizon	Florbetapir	Passed	
Western Iowa	NACC114092	1189	4/1/2022 0:00	I10150975	Biograph Horizon	Flortaucipir	Passed	
Western Iowa	NACC228673	728	6/1/2022 0:00	I10150995	Biograph Horizon	PIB	Passed	
Western Iowa	NACC228673	728	6/1/2022 0:00	I10150996	Biograph Horizon	Flortaucipir	Passed	
Western Iowa	NACC42459	450	7/1/2021 0:00	I10033850	Biograph Horizon	NAV4694	Passed	

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



# SCAN Dashboard Demo Station

Check out  
the demo!

Located in the in Foyer at the  
Swissotel, Chicago

Thursday, Oct 20th

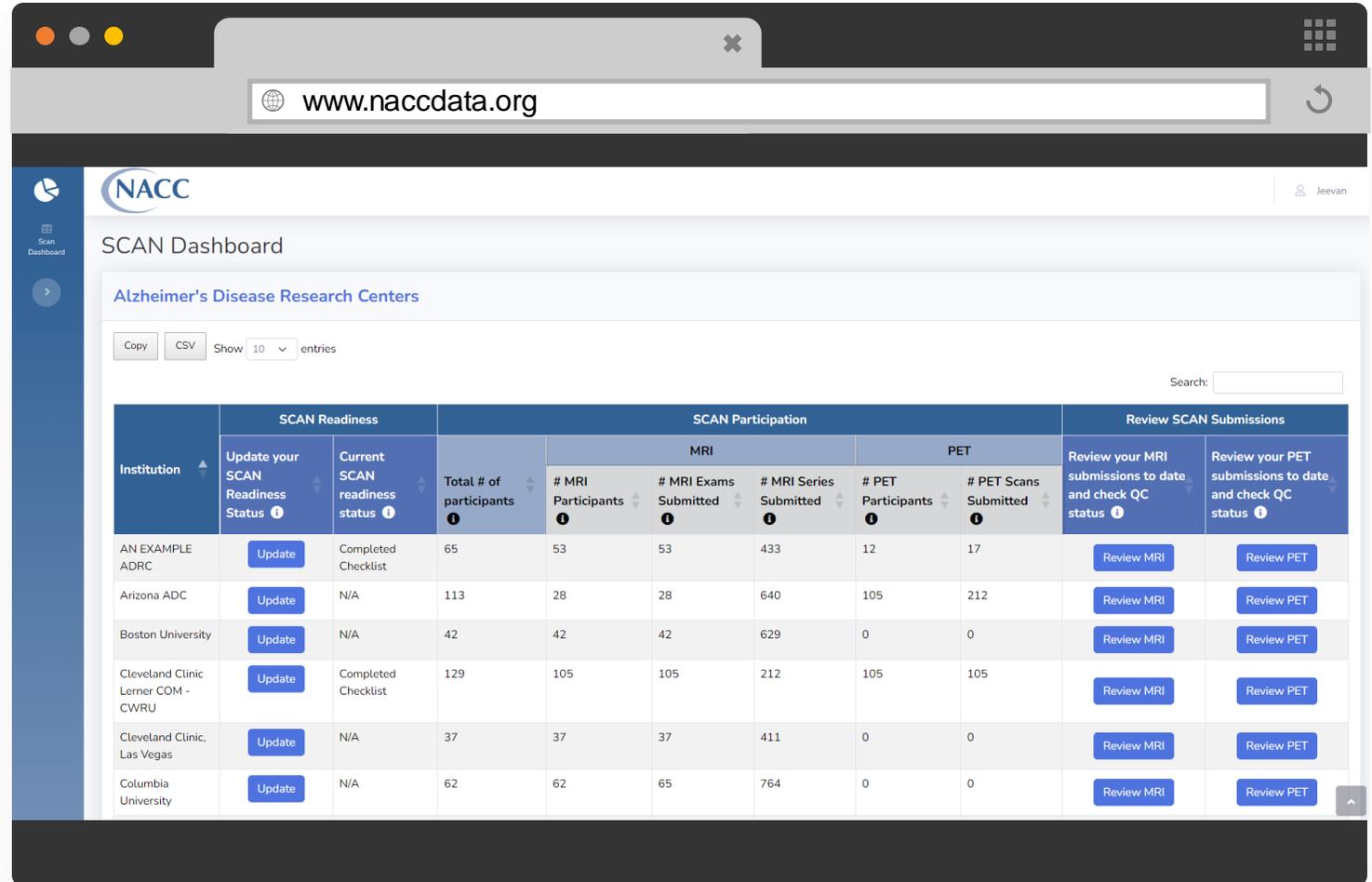
5:30-6:00pm CT

*After the Data Core Session*

Friday, Oct 21st

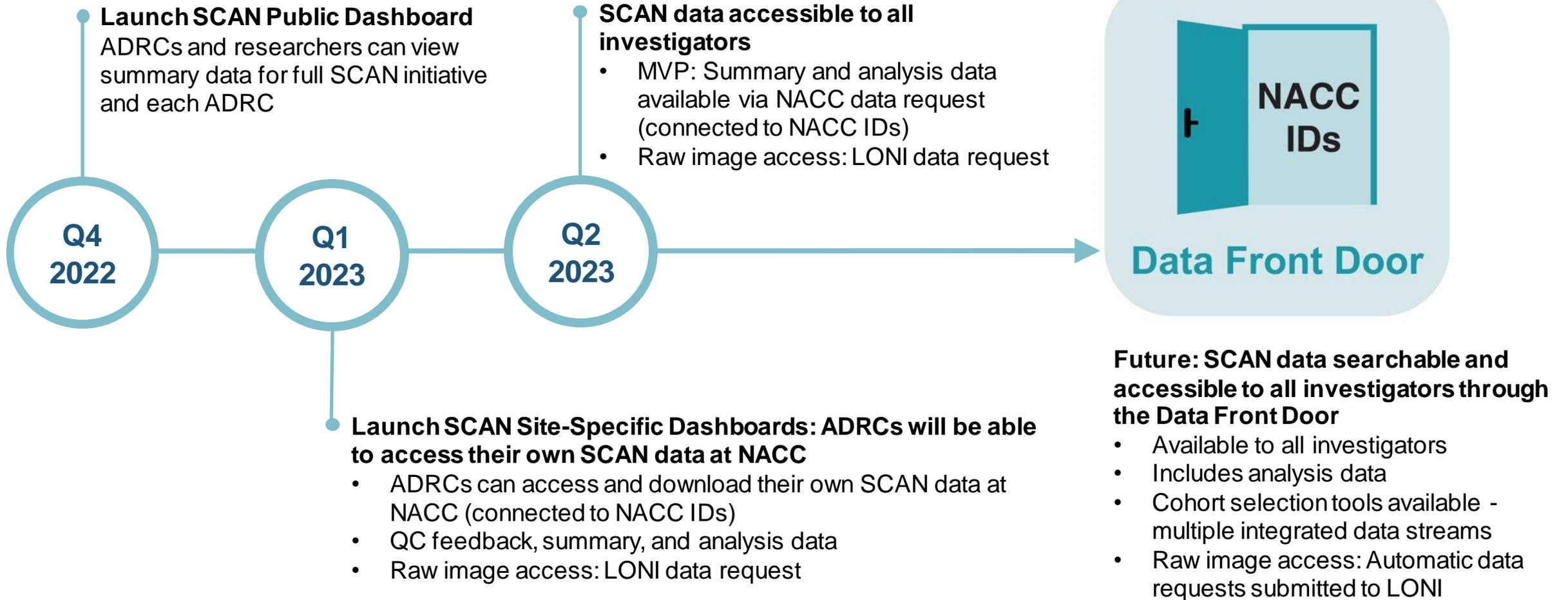
9:00-9:30am CT

*During the Networking Break*



The screenshot shows the NACC SCAN Dashboard for Alzheimer's Disease Research Centers. The page includes a search bar, a table with columns for Institution, SCAN Readiness, SCAN Participation (MRI and PET), and Review SCAN Submissions. The table lists several research centers with their respective participation statistics and readiness status.

Institution	SCAN Readiness		Total # of participants	SCAN Participation					Review SCAN Submissions	
	Update your SCAN Readiness Status	Current SCAN readiness status		MRI		PET		Review your MRI submissions to date and check QC status	Review your PET submissions to date and check QC status	
			# MRI Participants	# MRI Exams Submitted	# MRI Series Submitted	# PET Participants	# PET Scans Submitted			
AN EXAMPLE ADRC	<a href="#">Update</a>	Completed Checklist	65	53	53	433	12	17	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Arizona ADC	<a href="#">Update</a>	N/A	113	28	28	640	105	212	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Boston University	<a href="#">Update</a>	N/A	42	42	42	629	0	0	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Cleveland Clinic Lerner COM - CVRU	<a href="#">Update</a>	Completed Checklist	129	105	105	212	105	105	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Cleveland Clinic, Las Vegas	<a href="#">Update</a>	N/A	37	37	37	411	0	0	<a href="#">Review MRI</a>	<a href="#">Review PET</a>
Columbia University	<a href="#">Update</a>	N/A	62	62	65	764	0	0	<a href="#">Review MRI</a>	<a href="#">Review PET</a>



- Coming this November!
- Update your SCAN readiness using the SCAN MRI and PET Checklist (REDCap-based)
- Roadmap for getting SCAN ready
- In the future, ADRCs will be able to access their SCAN readiness anytime

## SCAN Dashboard

### Alzheimer's Disease Research Centers

Show  entries

Institution	SCAN Readiness	
	Update your SCAN Readiness Status	Current SCAN readiness status
TOTAL	<input type="button" value="Update"/>	NA
AN EXAMPLE ADRC	<input type="button" value="Update"/>	Completed Checklist
Mayo Clinic	<input type="button" value="Update"/>	Completed Checklist

## SCAN MRI team

- Clifford Jack MD (PI)
- Chadwick Ward
- Bret Borowski
- Christopher Schwarz
- Denise Reyes
- Leonard Matoush
- Robert Reid
- Anne Efron
- Gregory Preboske MS
- Jeffrey Gunter PhD
- Matthew Senjem MS

## SCAN PET team

- William Jagust MD (PI)
- Bob Koeppe PhD
- Susan Landau PhD
- JiaQie Lee
- Pablo Aguilar
- Tessa Harrison

## Other SCAN Contributors

- Charles DeCarli, MD
- Suzanne Baker

## LONI

- Arthur Toga PhD
- Karen Crawford MLIS

## NACC Team

- Bud Kukull, PhD
- Sarah Biber PhD
- Ben Keller PhD
- Dean Shibata MD
- **Jeevan Anandasakaran**
- **Brittany Hale**
- Hannah Rosentreter



**WILLIAM JAGUST, MD**  
Berkeley Professor, Public Health  
and Neuroscience



**CLIFFORD R. JACK, MD**  
Mayo Clinic Professor,  
Neuroscience

**Bill Jagust and Clifford Jack will be available for questions during the Q+A at the end of the NACC session**  
*2:45pm – 3:00pm CT*

# Connect with NACC

**Sarah Biber, PhD**

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Biber@uw.edu





# Moving Toward Routine Digital Data Collection

**Sean Mooney, PhD**

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**Thursday, October 20 – ADRC Fall 2022**



# Moving from Paper to Digital

There are substantial efforts to digitize existing paper-based or other administered assessments as phenotyping or diagnostic tools.

MONTREAL COGNITIVE ASSESSMENT (MOCA)  
Version 7.1 Original Version

NAME: \_\_\_\_\_ Education: \_\_\_\_\_ Date of birth: \_\_\_\_\_  
Sex: \_\_\_\_\_ DATE: \_\_\_\_\_

**VISUOSPATIAL / EXECUTIVE** Copy cube (1 pt) Draw CLOCK (Ten past eleven) (1 pt) Points

End (E) A (A) 2 (2) B (B) 1 (1) D (D) 4 (4) C (C) 3 (3) Begin

Contour Numbers Hands

Points: /5

**NAMING** Lion Rhinoceros Camel

Points: /3

**MEMORY** Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED	No. points
1st trial						
2nd trial						

**ATTENTION** Read list of digits (1 digit/ sec). Subject has to repeat them in the forward order [ ] 2 1 8 5 4 Subject has to repeat them in the backward order [ ] 7 4 2

Read list of letters. The subject must tap with his hand at each letter A. No points if > 3 times [ ] FBACMNAJKLBAFAKDEAAJAMOFAB

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65

4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt

Points: /3

**LANGUAGE** Repeat: I only know that John is the one to help today. [ ] The cat always hid under the couch when dogs were in the room. [ ]

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] (N > 11 words)

Points: /1

**ABSTRACTION** Similarity between e.g. banana - orange = fruit [ ] train - bicycle [ ] watch - ruler

Points: /2

**DELAYED RECALL** Has to recall words WITH NO CLUE [ ] FACE [ ] VELVET [ ] CHURCH [ ] DAISY [ ] RED [ ] Points for UNCLUED recall only

Optional Category cue [ ] Multiple choice cue [ ]

Points: /5

**ORIENTATION** [ ] Date [ ] Months [ ] Year [ ] Day [ ] Place [ ] City

Points: /6

© Z.Nasreddine MD www.mocatest.org Normal > 26 / 30 TOTAL Add 1 point if < 12 years

Points: /30

MOCA

Paper to Tablet

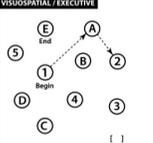


Digital in clinic assessments

# Moving from Paper to Digital

## Advantages:

- Structured data elements
- Preservation of computable data
- No scanning – less likely to be lost in EMR or research EDC system
- Less waste

MONTREAL COGNITIVE ASSESSMENT (MOCA)		NAME:	Date of birth:				
Version 7.2.1 (04/2014) - Ver 6.0 (en)		Education:	DATE:				
		Sex:					
<b>SPATIAL / EXECUTIVE</b>	Copy cube	Draw CLOCK (Ten past eleven)					
							
<b>NAMING</b>							
<b>MEMORY</b>	Read list of words, subject must repeat them. Do 2 trials, repeat if not recalled. Do a recall after 5 minutes.	FACE	VELVET	CHURCH	DAISY	RED	No points
<b>ATTENTION</b>	Read list of digits (1 digit) sec. Subject has to repeat them in the forward order	1st trial	2nd trial				
<b>LANGUAGE</b>	Repeat: I only know that John is the one to help today. I ...						
<b>ABSTRACTION</b>	Similarity between e.g. banana - orange - fruit						
<b>DELAYED RECALL</b>	Has to recall words WITH NO CUE	FACE	VELVET	CHURCH	DAISY	RED	Points for delayed recall only
<b>Optional</b>	Category test						
<b>ORIENTATION</b>	Date	Month	Year	Day	Place	City	
© L. Nasreddine MD		www.mocatest.org		Normal 0-26 / 30		TOTAL	
Administered by:						Add 1 point if 6/12 or less	



# Digital Data and Phenotyping

## Clinically Administered



MONTREAL COGNITIVE ASSESSMENT (MOCA)		NAME	Education	Date of birth
Version 2.2 (2012) (English) (Metric)			Year	MM/YY
<b>SPATIAL EXECUTIVE</b>	Draw CLOCK (10-point clock)			
<b>NAMING</b>				
<b>MEMORY</b>	Repeat list of words, delayed free recall (after 5 min), list for both sessions	FACE	VEGET	CHURCH
<b>ATTENTION</b>	Repeat list of digits (1 digit each), Subject has to repeat them in the backward order	EMERY	WED	
<b>LANGUAGE</b>	Repeat 10 phrases (copying and oral)			
<b>ABSTRACTION</b>	Similarity between 2 human concepts (bird - fish)			
<b>DELAID RECALL</b>	Repeat list of words, delayed free recall (after 5 min), list for both sessions			
<b>Optional</b>				
<b>ORIENTATION</b>	Date, Month, Year, Day, Hour, Day			

MOCA, Balance and Gait

## Remotely Administered



Remote Cognitive Assessments

## Out of Clinic Collection



Heart Rate, Mobility, Steps, Accidental Falls, Sleep, Consumer Testing, Home Monitoring

# Axes of Digital Data

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**There are many questions around data that can be collected. These could include:**

- Active vs Passive out of clinic data collection
- A test that is established UDS vs novel
- A test that is Validated vs Innovative
- In clinic vs active assessments outside of clinical in person visit

*Collaboration with Rhoda Au  
and Allan Levey*

## Overview

Digital data collection covers a lot of concepts and is very heterogenous

Many are collecting data and there are few, if any, standards or standardization

# THE DIGITAL WILD WEST



# Bringing Some Harmonization

---

**At NACC, we feel that we should help standardize, harmonize, ensure efficacy, and collect established instruments**

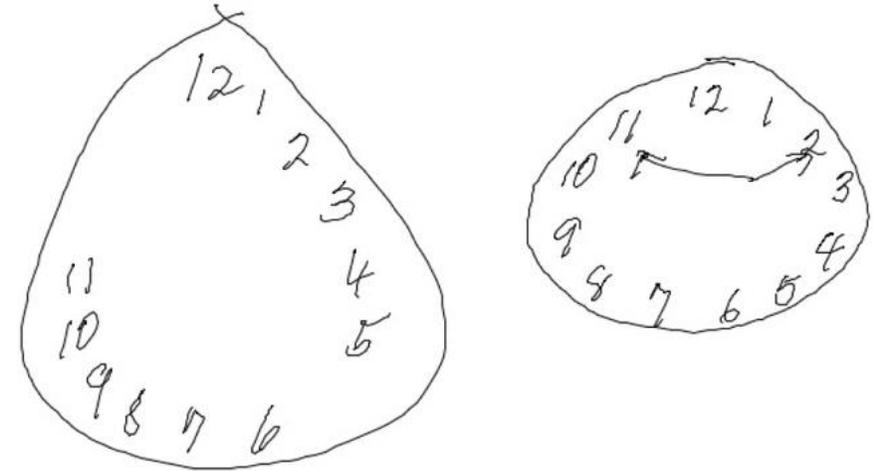
... And ...

**Facilitate discovery using new technologies that have research value that are very likely to be unharmonized**

# Significant Opportunity to Digitally Collect Established Tools

**Established assessments can be implemented for in clinic and remote administration digitally and include:**

- MOCA
- Image recall tests
- Digital clock drawing test
- Category naming tests
- Candy theft picture description
- TabCAT
- DANA
- VisMET



(b) Alzheimer's Disease



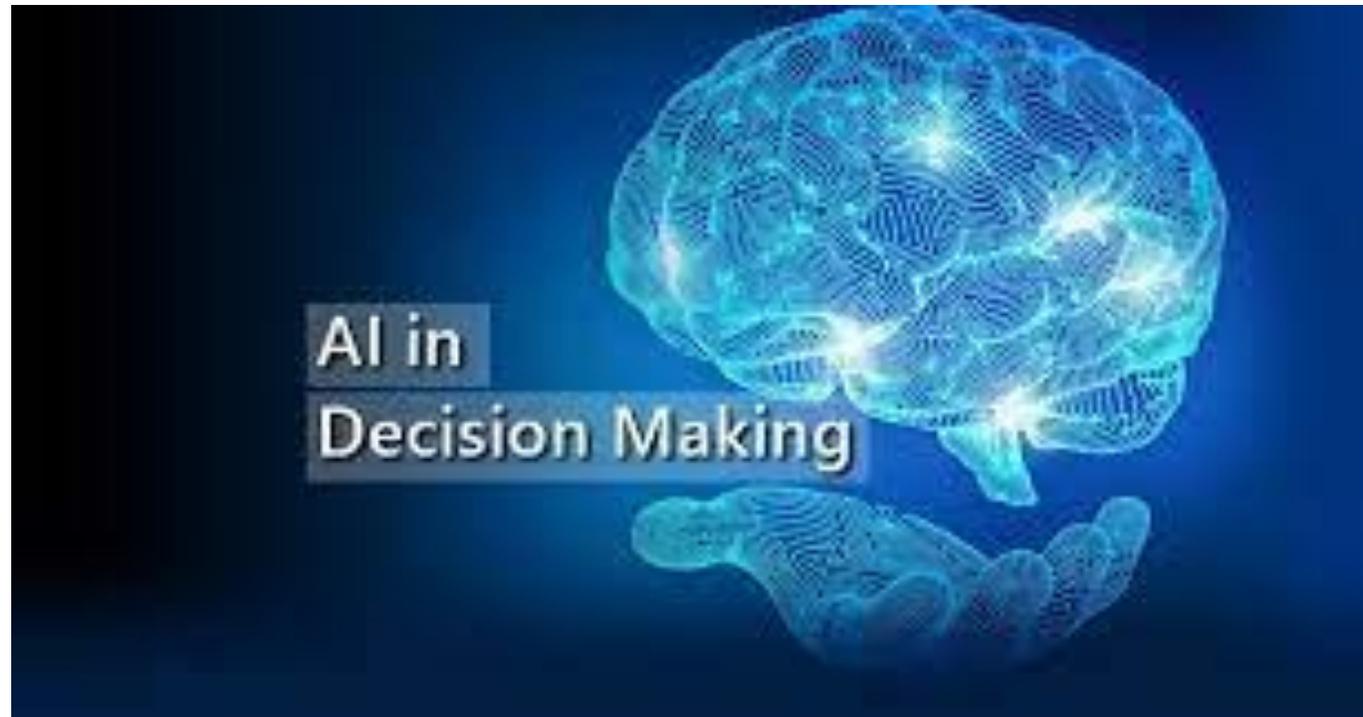
(c) Parkinson's Disease



# Digital Tools Enable AI-Based Decision Support

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**Human interpretation takes time, is variable, and could potentially be replaced by supervised machine learning algorithms**





# Consumer Digital Health Tools and New Data Digital Markers (In clinic or out of clinic)

**Out of clinic administered tests or digital health tools are far less standardized but are important for research.**

There are needs:

- Access to participants and good phenotypes
- Sandboxes for data collection and analysis
- Unbiased assessments for data



# Digital Data and Phenotyping Supplement

**GOAL:** Establish a common platform and develop processes for ADRCs to collect and share digital biomarker data

**Aim 1: Demonstrate intake of existing pipeline with Boston University**

- Send existing data for five tasks that are in Linus to NACC, connected to NACC IDs

**Aim 2: Analyze the integrated clinical and digital data in the NACC cloud**

**Aim 3: Establish the collection of prospective digital data from 2 ADRCs who will pilot the same digital tasks**

# Digital Data and Phenotyping

## UDS Tests

### Digital clock drawing test

- Administered via Linus tablets

### Category naming tests

- Digital recall/memory test

## Non-UDS Tests

### Candy theft picture description

- Capturing digital voice recordings

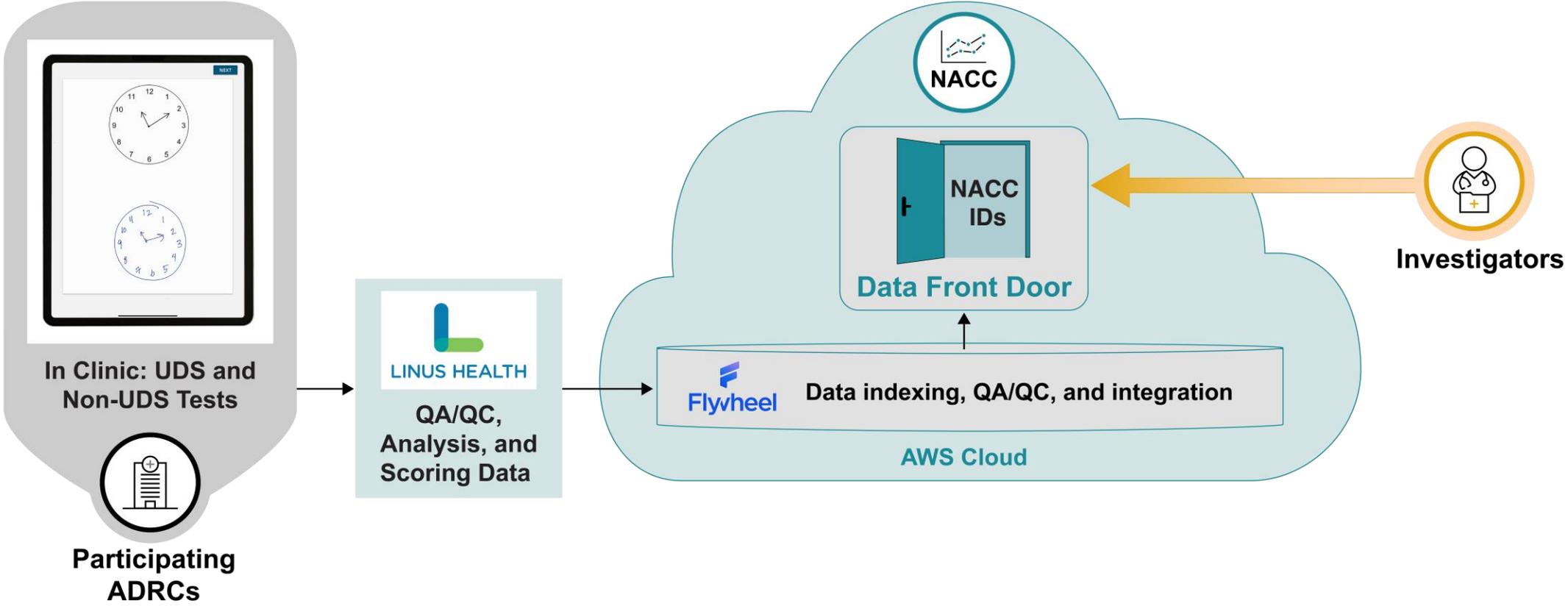
### TabCAT

- Cognitive, memory, language, and motor skills and visuospatial tests

### VisMET

- Visuospatial memory assessment with eye tracking

# Administrative Supplement: Digital Data and Phenotyping



# Open Science on Digital Data

---

**Data Science ‘Community Challenges’ are a popular way to do science**

**They pose questions that data scientists can answer and the answers are only known by the organizers**

**These challenges have facilitated unbiased improvement in machine learning in many fields**

**My group (Mooney) has been leading, participating, and advising these challenges for decades**



# Open Science on Digital Data

---

**Collection of digital data opens the possibility of doing new approaches to facilitate open science**

**DREAM Challenges and Kaggle, have platforms for building and evaluating machine learning**

**We are strategizing a potential challenge around data on the most technical forefront of potential markers of disease or treatment response such as Digital Recordings of clinics**

**DREAM**   
**CHALLENGES**

*powered by Sage Bionetworks*

# Connect with NACC

## Stay Tuned!

Digital Footprint Survey for feedback from ADRC digital capability  
We are also developing a digital roadmap and will, with Rhoda Au's team,  
be looking to collaborate with ADRCs!

**Sean Mooney, PhD and Sarah Biber, PhD**

---

[sdmooney@uw.edu](mailto:sdmooney@uw.edu) | [biber@uw.edu](mailto:biber@uw.edu)

# Thank you!







# **NACC The New NACC Directory**

**Laura McLeod**

---

**October 21, 2022 at 2:40 pm | NACC Session**

# Overview

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## **Purpose:**

- To provide resource with contact information about ADRCs, NACC, and NACC Strategic AD/ADRD partners

## **Previously:**

- Called the ADRC Personnel Directory
- Limited to only ADRC information and was a static document

## The new NACC directory is:

- Comprehensive, spanning across ADRD organizations
- Online
- Interactive
- Dynamic



# Content Timeline

---

- 
- 1 ADRC Leadership and Committee information
  - 2 Individuals update their information
    - Confirmed/approved information is published
  - 3 Monthly reporting/freeze process
  - 4 Portal/FlyWheel access management
  - 5 Listserv management

# Advantages

---

- ✓ Information is always up to date
- ✓ Ability for members to update information themselves
- ✓ Search interface to find content you need
- ✓ Allows members to find and connect with others
- ✓ Easier for researchers across the world to identify potential collaborators from across the ADRC program

# Key Components

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## Content Management:

- Members update their own information
- Administrators update Center information
- NACC updates Committee information



## Authentication system



## Published content:

- Private (*with email addresses*)
- Public (*without email addresses*)

# Search the Directory now!

Go to

[bit.ly/NACCDirectory](https://bit.ly/NACCDirectory)

or scan this QR code!



# NACC Directory

This directory provides information about ADRC, NACC and NACC Strategic AD/ARD partners.

---

## General ADRC Information

*(address, website, grant #s, etc)*

[ADRC Contact Information](#)

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## ADRC Leadership Information

[ADRC Administrators](#)

[ADRC Core Leaders](#)

[ADRC Directors](#)

---

## Committee/WorkGroup information

[ADRC Committees](#)

[Electronic Data Capture Workgroup](#)

[NACC Committees](#)



# Share your feedback!

## Information table

Thursday, Oct. 20th

- 3:10 – 3:30 p.m. (During Networking Break)
- 5:30 – 6:00 p.m. (During Administrators Gathering)

Friday, Oct. 21st

- 9:00 – 9:30 a.m. (During Networking Break)
- 1:00 – 1:45 p.m. (Second half of Lunch Break)

# Timeline

- ★ 1 ADRC Leadership and Committee information  
*(public version)*
- 2 Individuals update their information
  - Confirmed/approved information is published
- 3 Monthly reporting/freeze process
- 4 Portal/FlyWheel access management
- 5 Listserv management



Ongoing: Automated Reminders to members/Center Administrators to review/update information on a bi-annual basis

- Andrea Schmitt (Arizona ADRC)
- Beverly Young (Boston University ADRC)
- Anna Sturtevant & Darcy Loviscek (Cleveland ADRC)
- Allison Heaps (Columbia University ADRC)
- Sara Patillo (Duke/UNC ADRC)
- Cecelia Manzanares (Emory University, Goizueta ADRC)
- Christy Steinway-Rodkin (1 Florida ADRC)
- Sarah Van Heiden (Indiana University ADRC)
- Jamie Lester (Johns Hopkins ADRC)
- Catherine Ribeiro (Massachusetts ADRC)
- Josie Williams (Mayo Clinic ADRC)
- Allison Ardolino (Mount Sinai School of Medicine ADRC)
- Freley Hosannah & Kirsten Calvin (Nevada Exploratory ADRC)
- Jill Prestopnik (New Mexico Exploratory ADRC)
- Eskedar Alem (Northwestern ADRC)
- Karyn Marsh (NYU ADRC)
- Heather Schiffke (Oregon Health and Science University, ADRC)
- Kathy Jedrziwski (Penn ADRC/Penn Memory Center)
- Annie Barz (Rush University Alzheimer's Disease Center)
- Eric Shipp (South Texas ADRC)
- Nusha Askari (Stanford ADRC)
- Carol Chambless (UAB Exploratory ADRC)
- Delia Roberts (UC Davis ADRC)
- Andrea Wasserman (UC Irvine, ADRC)
- Emily Little (UCSD Shiley-Marcos ADRC)
- Rosalie Gearhart & Harli Grant (UCSF ADRC)
- Anne Arthur (University of Kansas ADRC)
- Beverly Baesler (University of Kentucky ADRC)
- Arijit Bhaumik & Nancy Laracey (University of Michigan ADRC)
- Leslie Dunn & Kathie Savage (University of Pittsburgh ADRC)
- Annika Noreen (University of Washington ADRC)
- Helena Chui (USC ADRC)
- Jenna Boué (Vanderbilt Exploratory ADRC)
- Sharon Letchworth & Hari Vittal Rao (Wake Forest University, ADRC)
- Krista Moulder (Washington University Knight ADRC)
- Hanna Blazel (Wisconsin ADRC)
- Charlene Bloch (Yale University ADRC)

## **NACC**

Amy Young, Hannah Rosentreter  
Brendan Smith, Janene Hubbard  
Ben Keller, Clair Cassidy