

# Welcome to the NACC Session!

Topic	Speaker Names
Welcome	Walter Kukull, PhD (NACC)
UDSv4 Launch	Sarah Biber, PhD (NACC) Jess Welsch, MBA (NACC) Cindy Carlsson, PhD (Wisconsin ADRC) Sudeshna Das, PhD (Massachusetts ADRC)
NACC Data Platform	Sarah Biber, PhD (NACC)
Becoming More Multimodal and Expanding Interoperability	Kristen Russ, PhD (NCRAD) Gil Rabinovici, PhD (UCSF ADRC) Rhoda Au, PhD (Boston University ADRC) Bill Jagust, PhD (UC Berkeley ADRC)



# **NACC Data Platform: What's New and Where Are We Headed?**

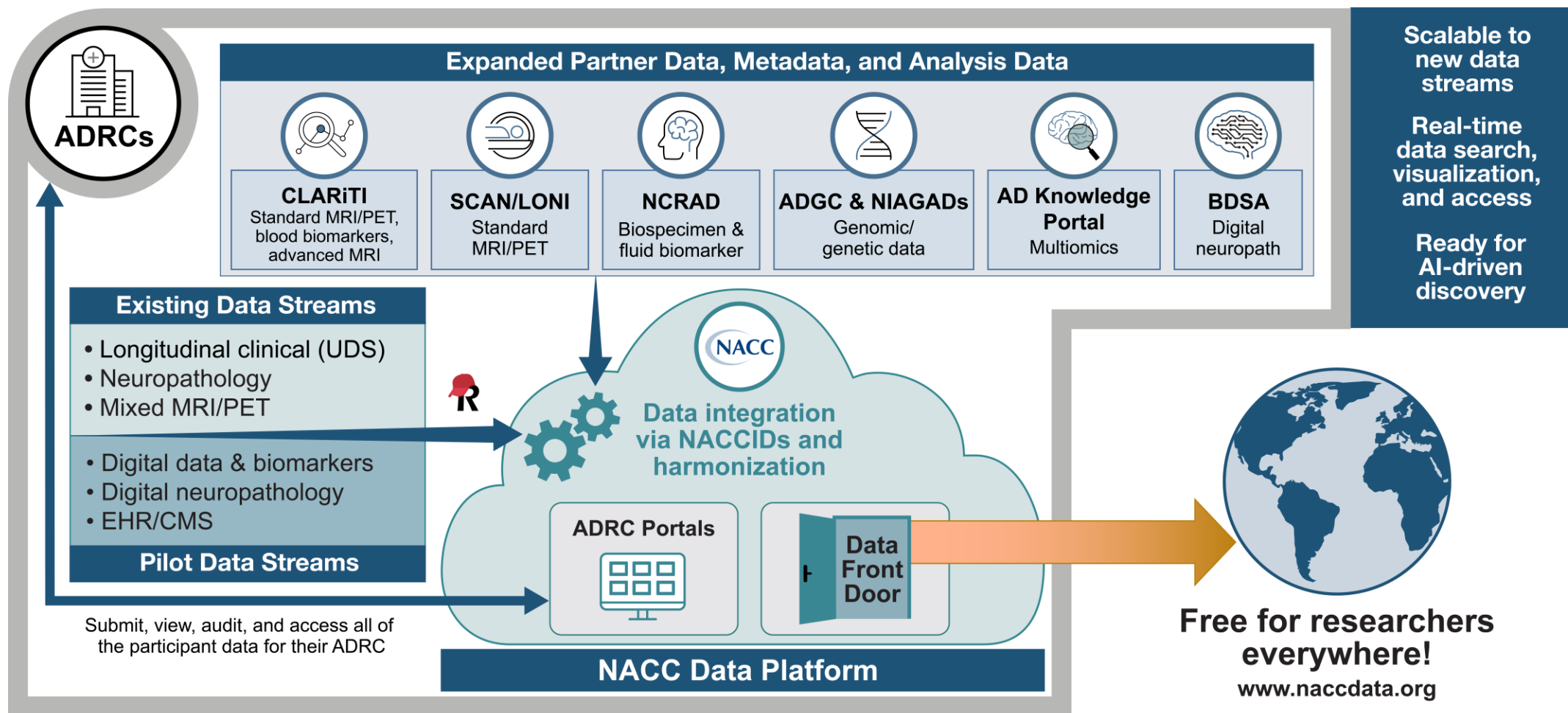
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**Sarah Biber, PhD – NACC Executive Director**  
**Thursday, October 17, 2024**  
**2024 Fall ADRC Meeting**

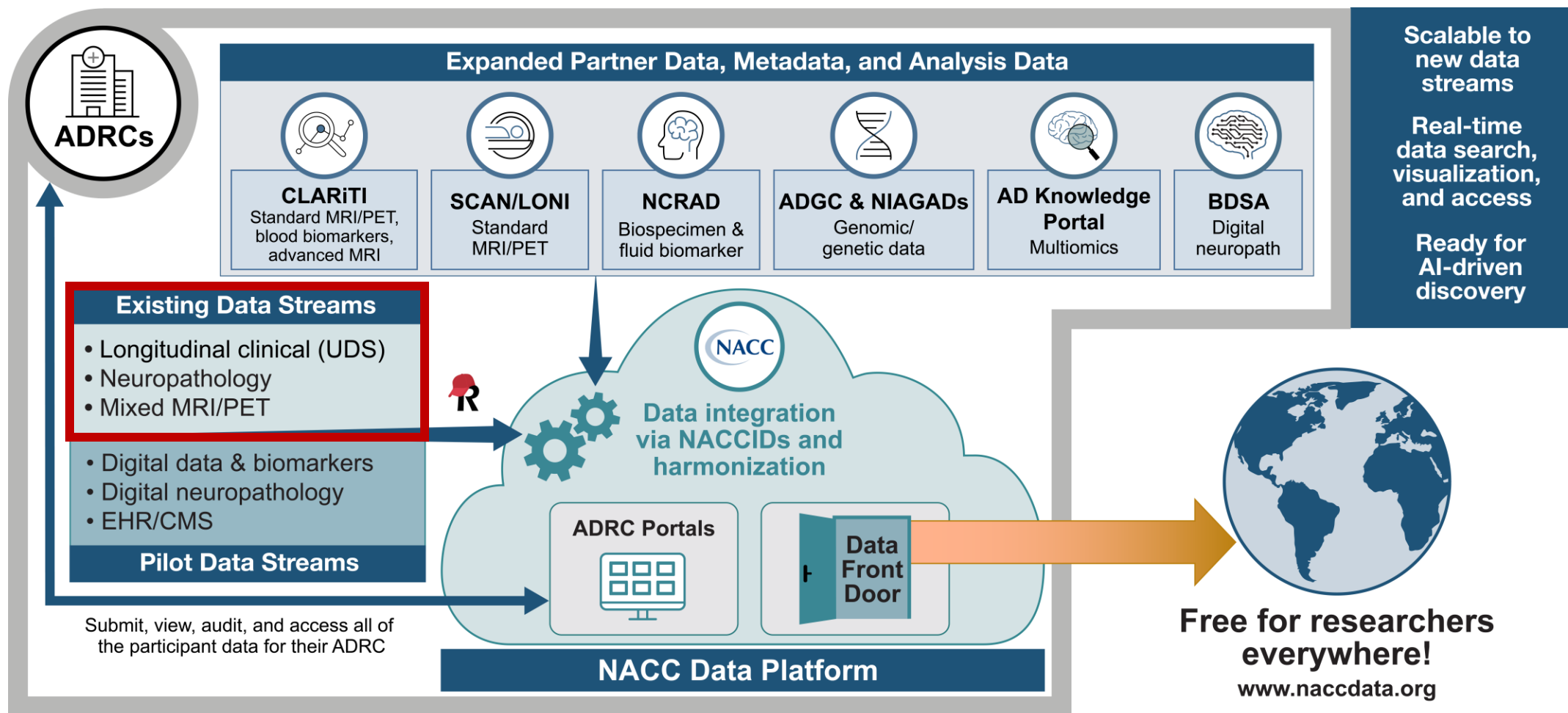
A network diagram background consisting of a complex web of light blue lines connecting various nodes. Some nodes are represented by solid teal circles, while others are smaller, semi-transparent grey circles. The lines are thin and create a dense, interconnected pattern across the entire slide.

# **NACC Data Platform: A Next-Generation Multimodal Data Integration, Interoperability, Harmonization, and Sharing Platform**

# New NACC Data Platform: A Modern Cloud-based Multimodal Data Integration, Harmonization, and Sharing Platform

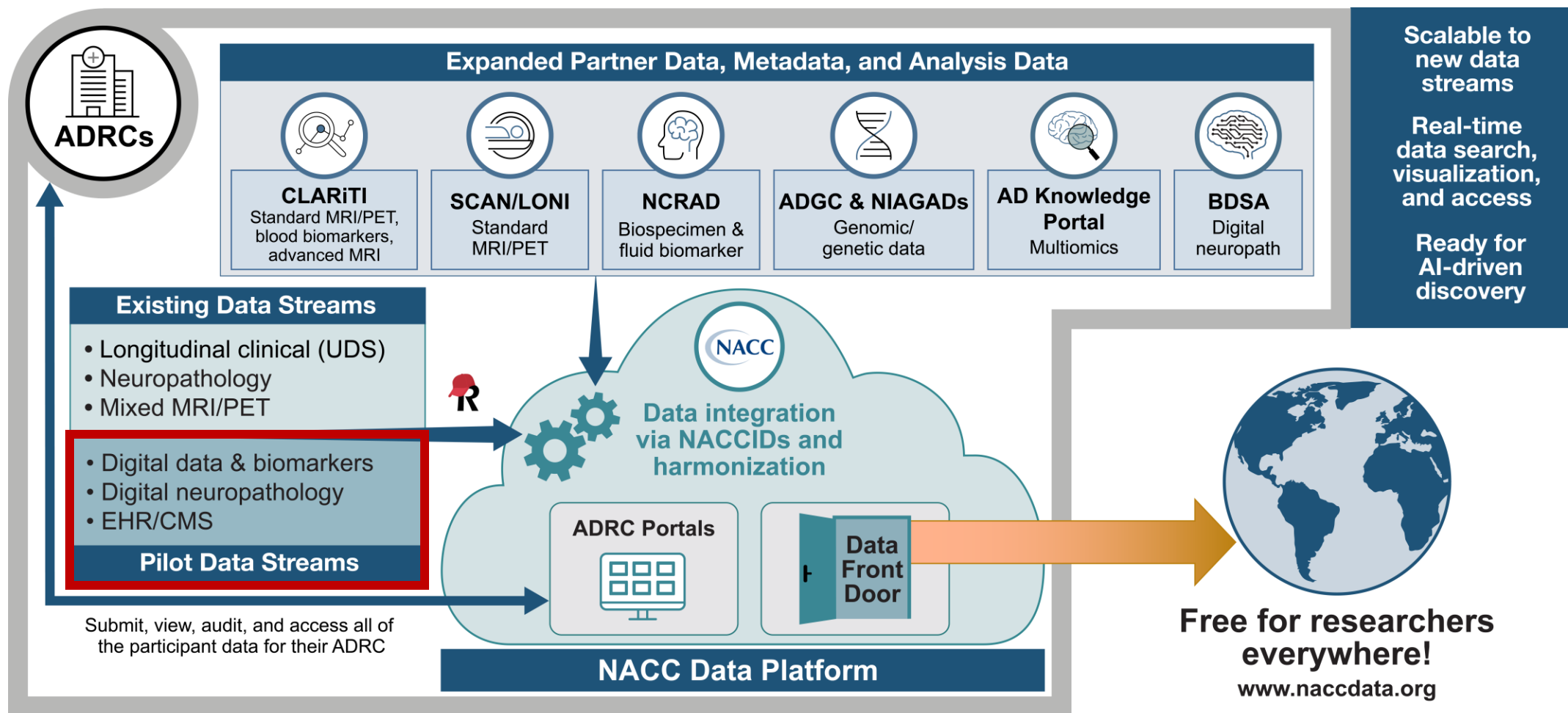


# New NACC Data Platform: A Modern Cloud-based Multimodal Data Integration, Harmonization, and Sharing Platform

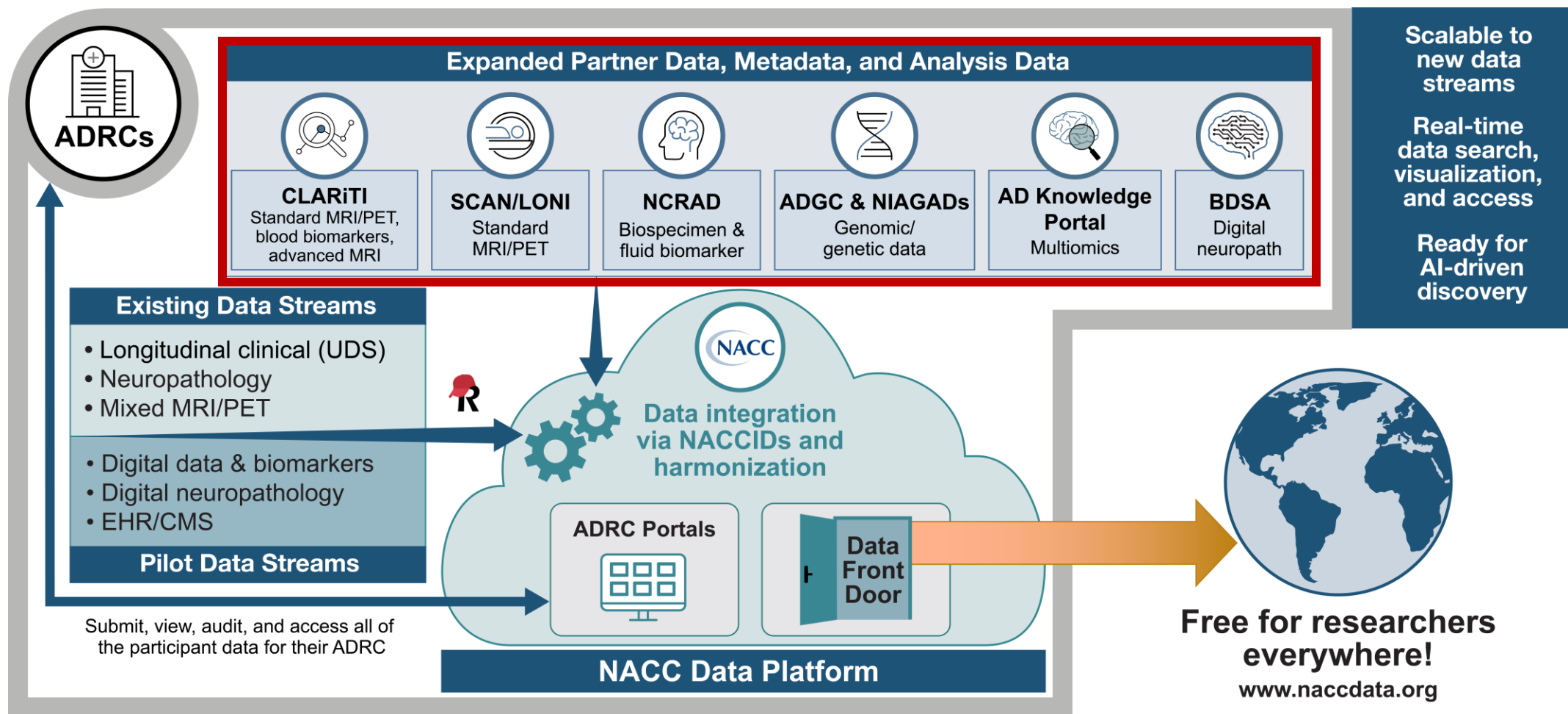





# New NACC Data Platform: A Modern Cloud-based Multimodal Data Integration, Harmonization, and Sharing Platform




# New NACC Data Platform: A Modern Cloud-based Multimodal Data Integration, Harmonization, and Sharing Platform




# Ongoing: Collaborating with numerous partners to establish and/or expand multimodal data integration and interoperability




**Socio-demographic**




**Neurocognitive tests**




**Neuro-pathology**




**Imaging (MRI/PET)**




**Biomarker**




**Genetic & genomic**



**EHR & Claims**



**Digital data**



**Multomics data**















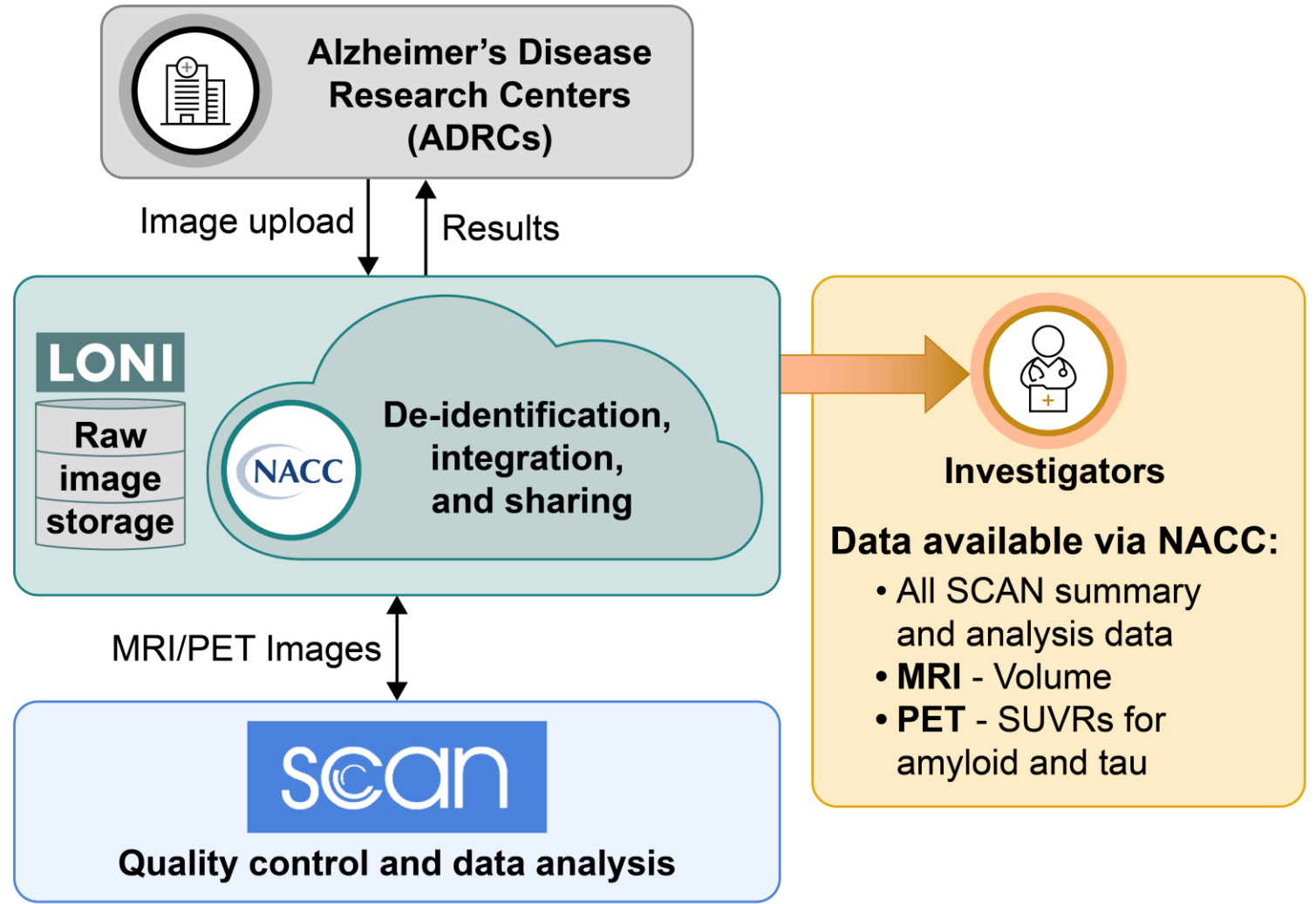





# Standardized MRI/PET Data



**Mission:** Collect large quantities of standardized imaging data, integrate it with other data modalities available via NACC, and share it with researchers around the world to advance the field.



## 1. Identify and address barriers

Institution	SCAN Connection
UNIVERSITY OF CALIFORNIA AT DAVIS	SCAN Collaborator, Imaging Steering Committee
MAYO CLINIC ROCHESTER	SCAN Co-I, Imaging Steering Committee
UNIVERSITY OF MICHIGAN AT ANN ARBOR	SCAN Collaborator
UNIVERSITY OF SOUTHERN CALIFORNIA	SCAN Collaborator, Supplement
UNIVERSITY OF WISCONSIN-MADISON	Imaging Steering Committee, Supplement
STANFORD UNIVERSITY	Imaging Steering Committee
RUSH UNIVERSITY MEDICAL CENTER	Imaging Steering Committee, Supplement
UNIVERSITY OF PENNSYLVANIA	Imaging Steering Committee
NORTHWESTERN UNIVERSITY AT CHICAGO	Imaging Steering Committee
NEW YORK UNIVERSITY	Supplement
UNIVERSITY OF KENTUCKY	Supplement
UNIVERSITY OF KANSAS MEDICAL CENTER	Supplement
MOUNT SINAI	Supplement
UNIVERSITY OF CALIFORNIA, SAN DIEGO	Supplement
EMORY UNIVERSITY	Supplement
UNIVERSITY OF WASHINGTON	Supplement
UNIVERSITY OF PITTSBURGH AT PITTSBURGH	Supplement
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO	Supplement
CLEVELAND CLINIC LERNER COM-CWRU	Supplement
UNIVERSITY OF CALIFORNIA-IRVINE	Supplement

- Site Interviews conducted in May and June of 2022
- Identified needed solutions (e.g., SCAN Dashboard)

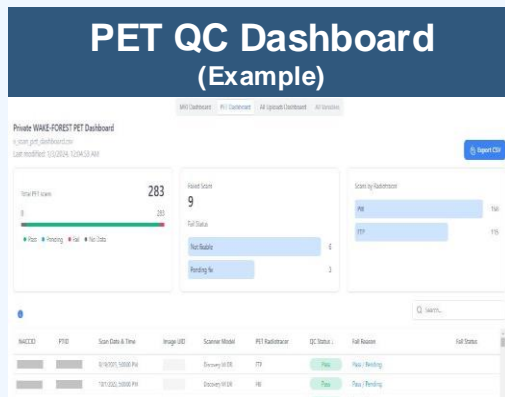
## 2. Facilitate ADRC participation



**100% of the 20 ADRCs found them beneficial**

- Developed and Deployed SCAN MRI/PET Checklists
- New SCAN Website
- A dramatic increase in SCAN submissions

## 3. Support data quality



- ADRC-specific SCAN QC Dashboards (MRI/PET): Sites can track the QC status of their MRI and PET submissions, allowing them to rapidly address errors

## 4. Provide data access

**SCAN Public Dashboard**

ALZHEIMER'S DISEASE RESEARCH CENTERS

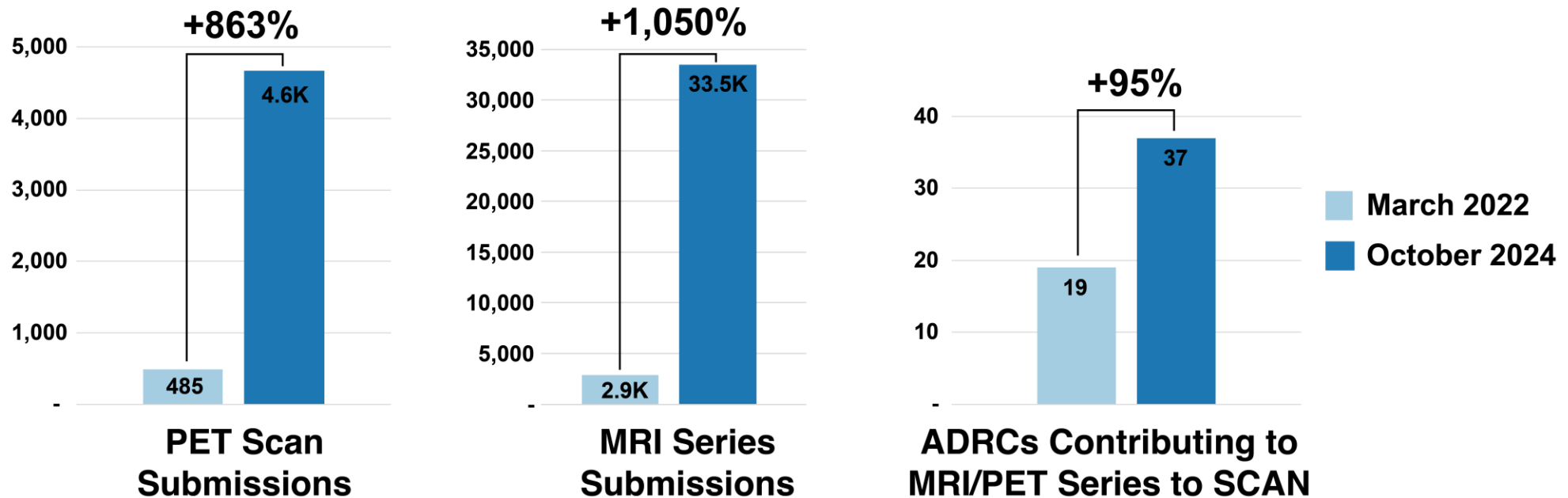
Institution	Total # of Participants	MRI				PET		ADRC-specific SCAN QC Dashboards
		# MRI participants	# MRI exams submitted	# MRI series submitted	# PET participants	# PET scans submitted		
Total	4,742	4,208	4,832	23,486	1,887	2,845		
Wake-Forest University	402	357	381	870	186	370	PRIVATE DASH	
University of Wisconsin	348	316	333	855	185	333	PRIVATE DASH	
University of Michigan	240	240	248	481	0	0	PRIVATE DASH	
Mayo Clinic	235	235	294	878	0	0	PRIVATE DASH	

- SCAN Public Dashboard
- SCAN MRI and PET images, summary and analysis data (Volumes and SUVRs) are now available to researchers worldwide via NACC's Data Front Door

# Standardized MRI/PET Data

## A dramatic increase in SCAN submissions

- **PET:** 4,669 PET scans
- **MRI:** 33,470 MRI (all series) / 6,111 MRI (T1)
- **ADRCs:** 35 ADRCs



# NACC Data Front Door: Quick Access File

Visit [scan.naccdata.org/](https://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



M  
UNIVERSITY OF  
MICHIGAN



UC DAVIS



Data on >3,000 MRI and >3,000 PET scan is available today!

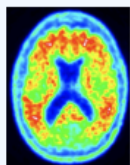
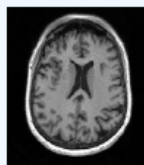
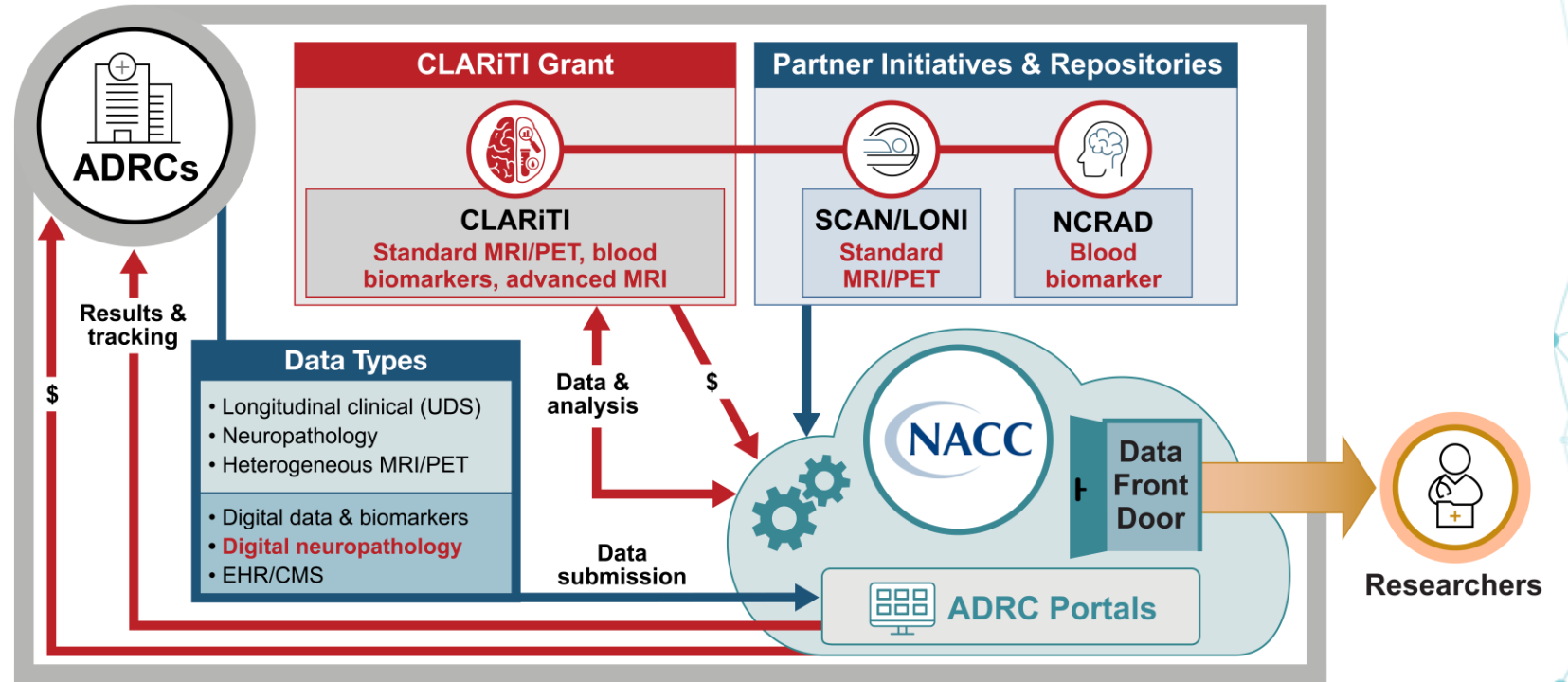


# CLARiTI is Integrated into the ADRC Program Ecosystem via NACC's Informatics and Operational Infrastructure

## Join the CLARiTI Session!

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

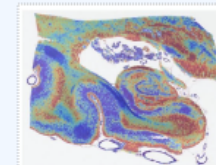
Location: Grand Ballroom



ATN Imaging and Plasma


	Initial Visit (T1)	Follow-up Visit (T2)	T3: Initial Visit (T3)	T4: Follow-up (T4)
A1: Subject Demographics				
A2: Co-participant Demographics				
A3: Subject Family History				
A4: Subject Medications				

Longitudinal UDS



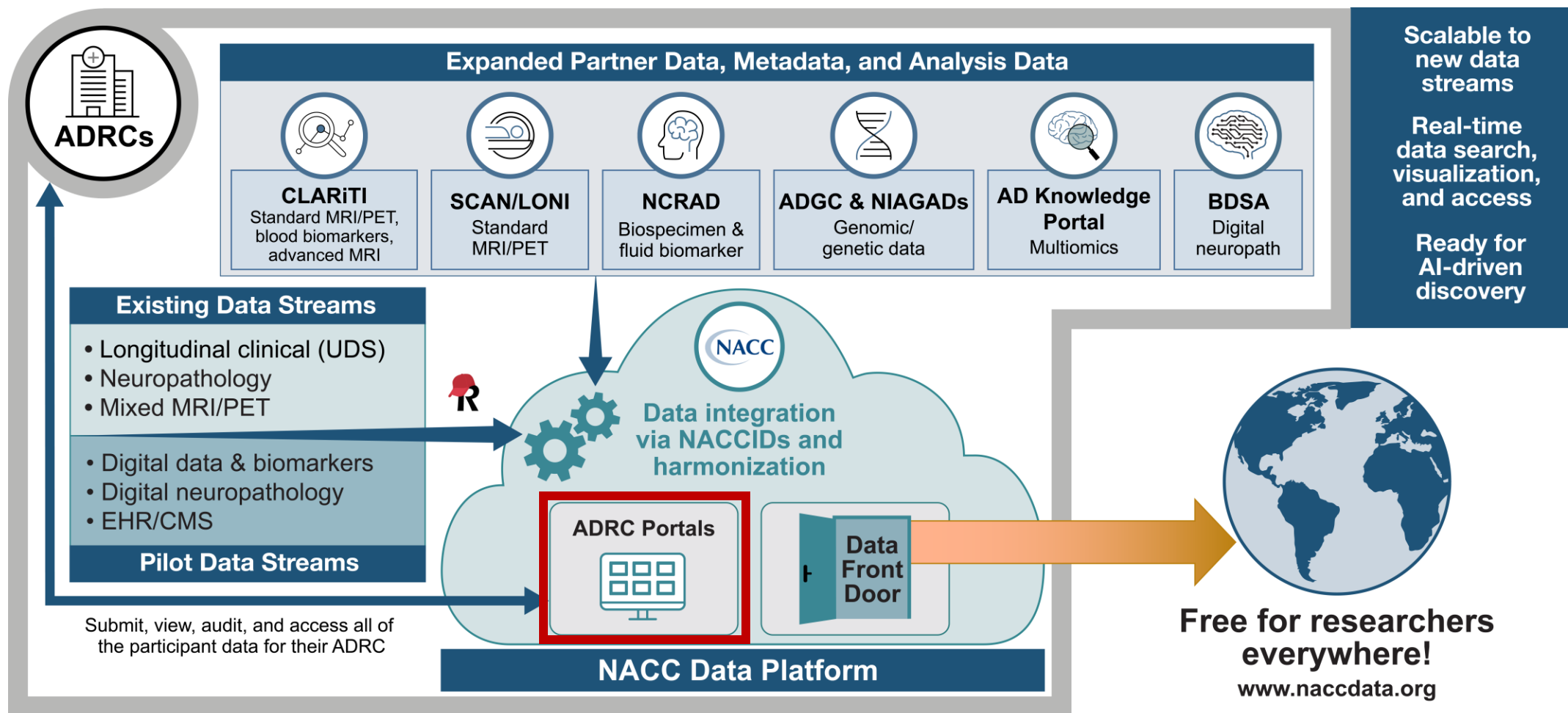
Digital Neuropath



A decorative background featuring a network diagram with light blue lines connecting various nodes. Some nodes are highlighted in a darker teal color, while others are light gray. The network is spread across the top and bottom of the slide.

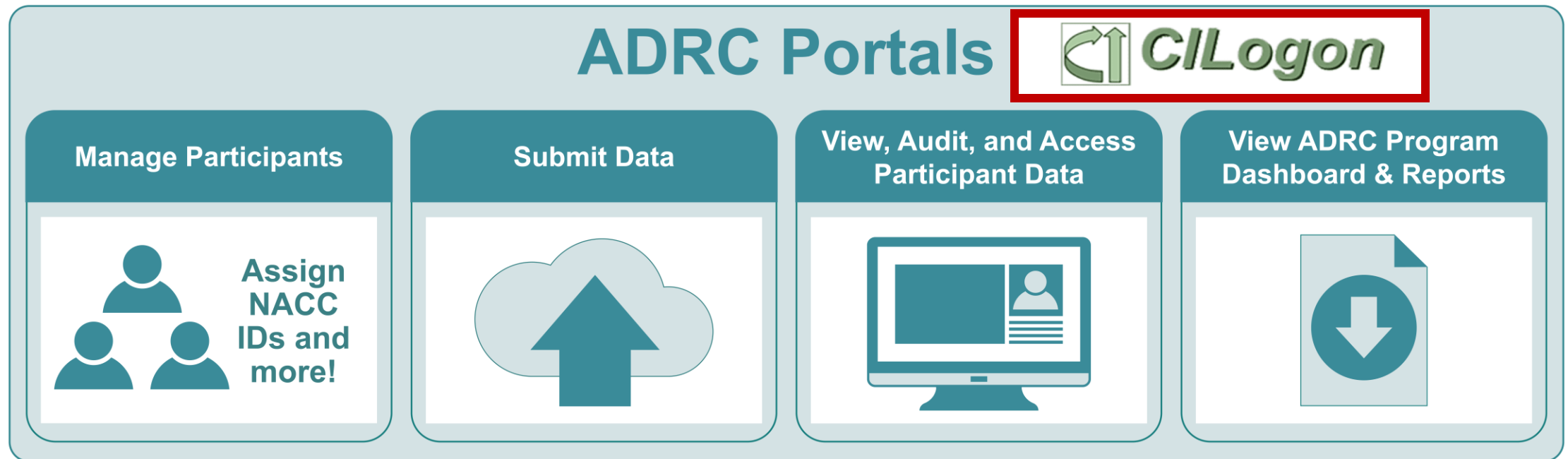
# **ADRC Portals: Empowering ADRCs with streamlined participant management and multimodal data submission and access**

# New NACC Data Platform: A Modern Cloud-based Multimodal Data Integration, Harmonization, and Sharing Platform



# ADRC Portals – Single Sign On Enabled!

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



# ADRC Portals – Launching New NACCID Process

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

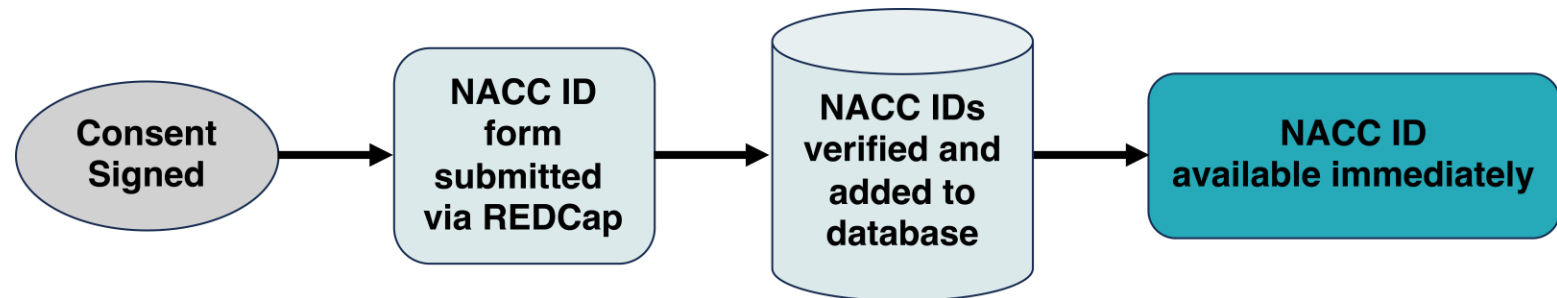
## ADRC Portals

Manage Participants

Assign  
NACC  
IDs and  
more!



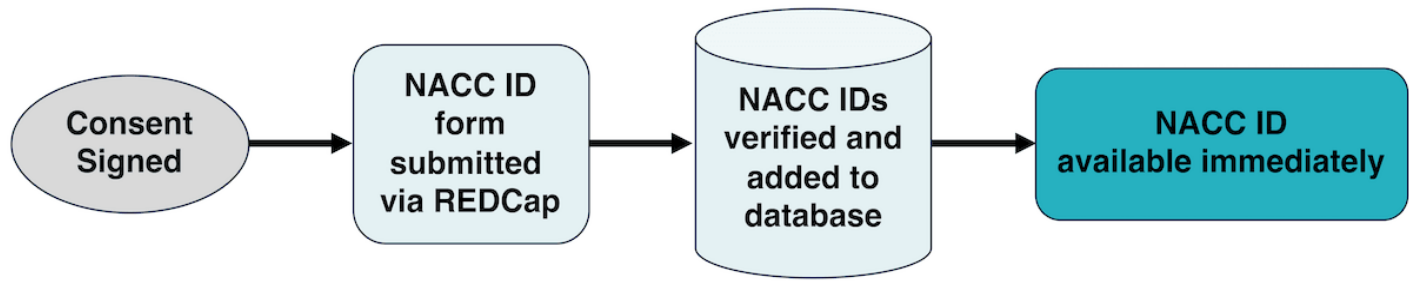
NACCIDs Assigned at Consent












# New NACCID Process

- Streamlines multimodal data collection and integration
- Additional verification and Improves participant tracking

*Example NACCID:*  
**NACC000000**



### Multimodal Data

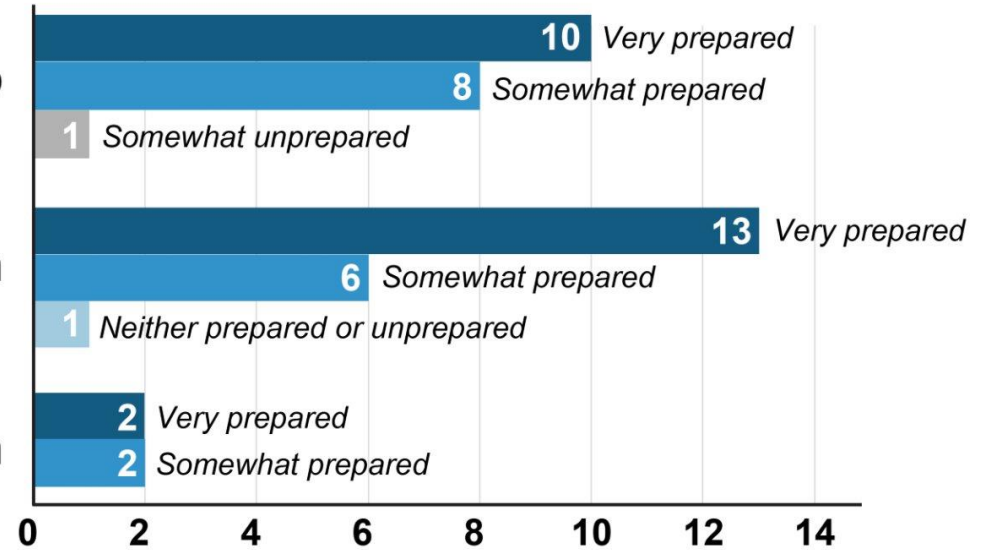
 <b>Socio-demographic</b>	 <b>Neurocognitive tests</b>	 <b>Neuro-pathology</b>
 <b>Imaging (MRI/PET)</b>	 <b>Biomarker</b>	 <b>Genetic &amp; genomic</b>
 <b>EHR &amp; Claims</b>	 <b>Digital data</b>	 <b>Multiomics data</b>



# NACCID Pilot Survey Results

97% of pilot respondents reported feeling prepared or somewhat prepared to assign NACCIDs via our new process

**Direct Entry to NACC-Hosted REDCap**



**Batch upload via CSV to the NACC Data Platform**

**API Upload to the NACC Data Platform**

**Number of Responses**

42 Feedback Surveys Returned  
32 Sites Participated in the Pilot

# New NACCID Process

## Launching January 1, 2025



Attend the informational webinar on  
**November 13, 2024**



Full details and demo video  
available at:  
[bit.ly/NACCID](https://bit.ly/NACCID)

# ADRC Portals – Launched New EDCS System!

ADRCs can submit, view, audit, access, and manage participant data across multiple data modalities

## ADRC Portals

Manage Participants



Assign  
NACC  
IDs and  
more!

Submit Data



View, Audit, and Access  
Participant Data

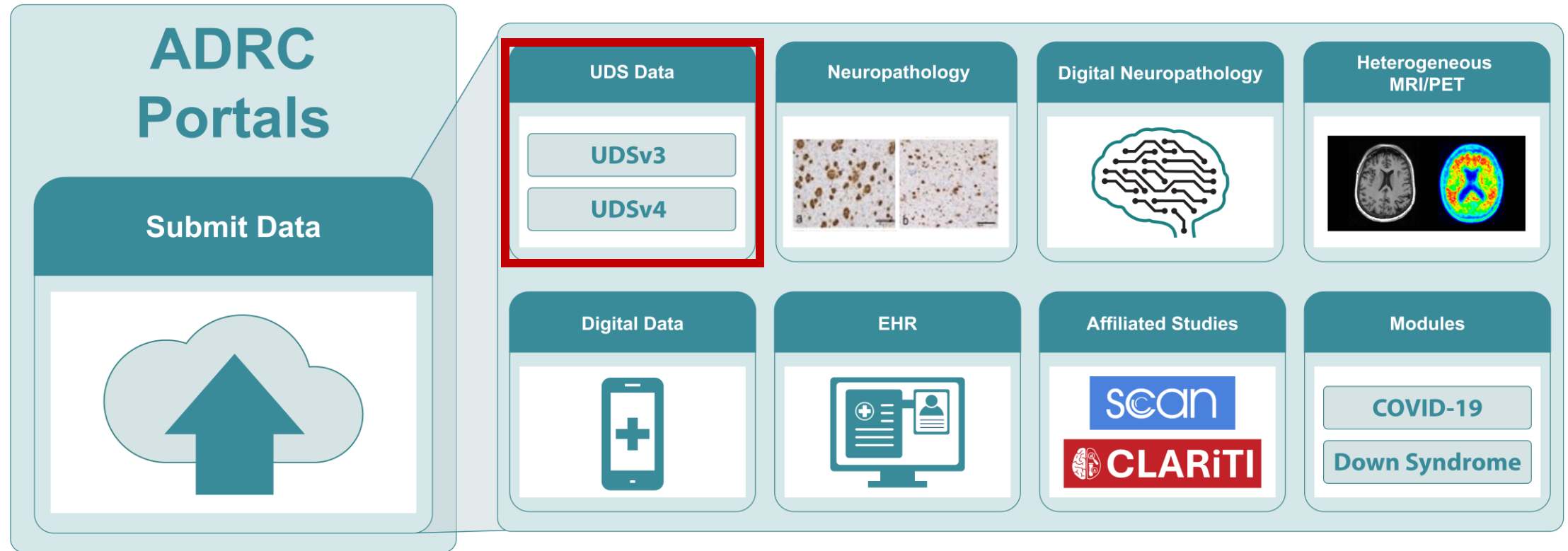


View ADRC Program  
Dashboard & Reports

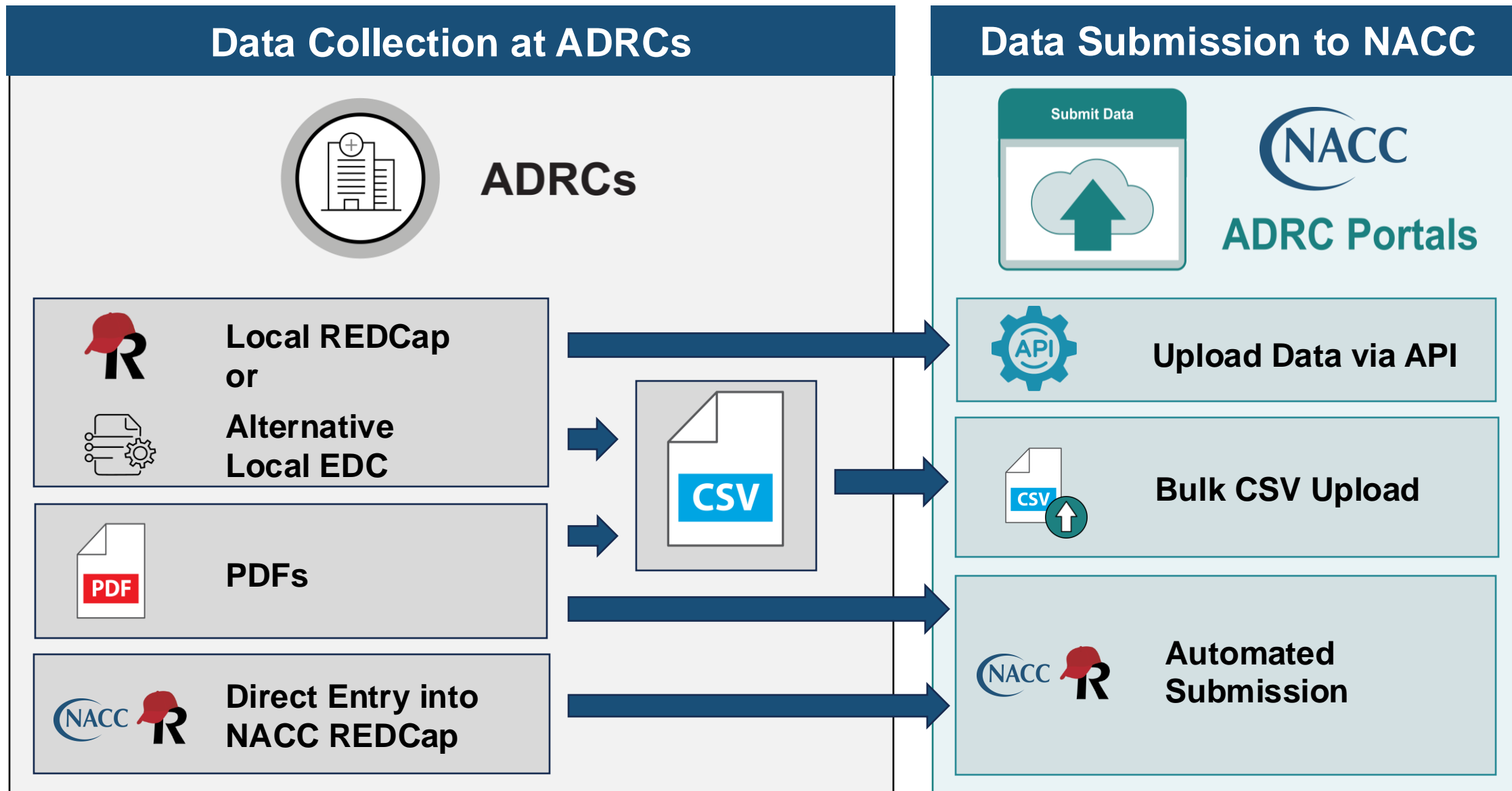


# ADRC Portals – Submit Data!

ADRCs can submit a wide range of data modalities



# New Modern EDCS System



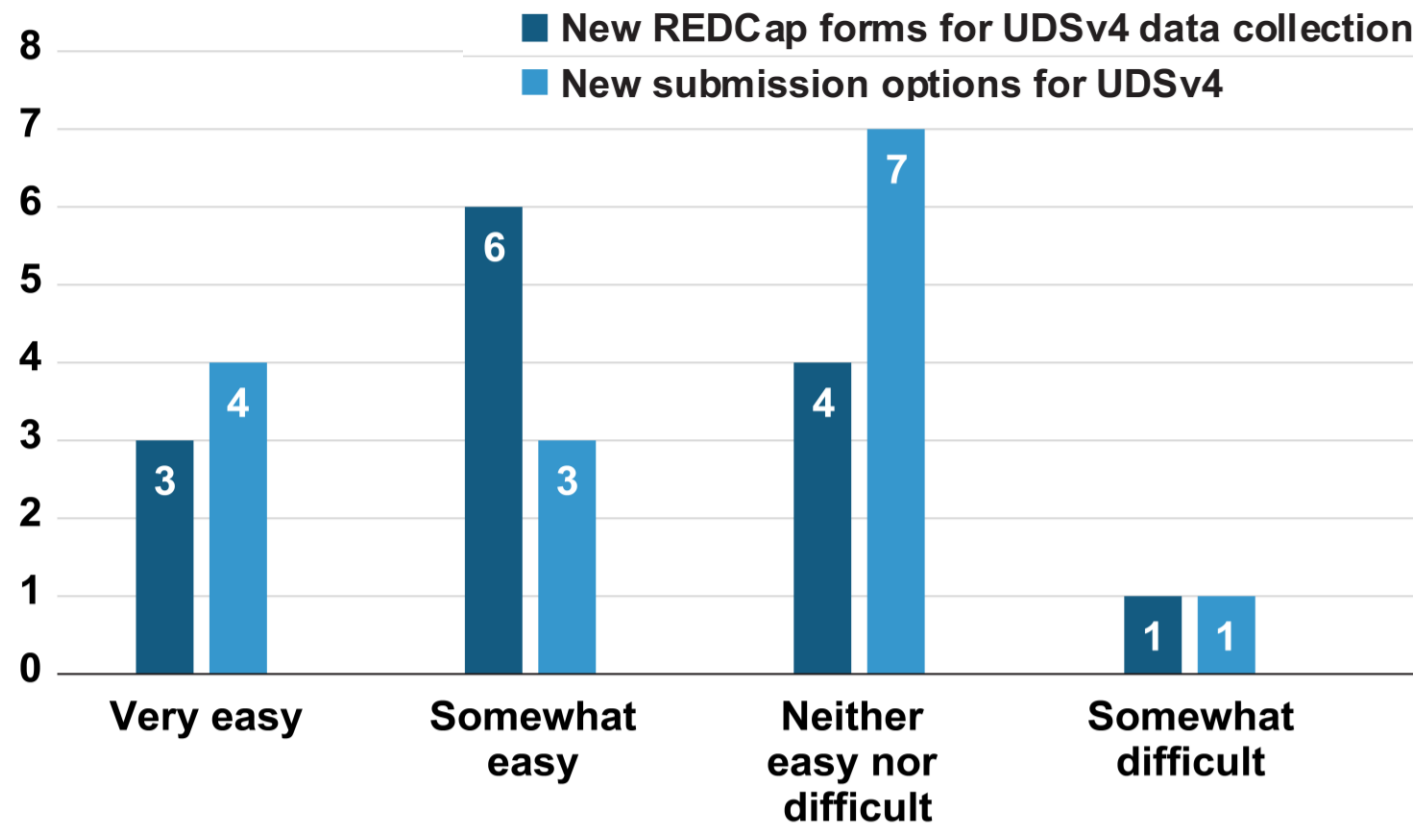
**Streamlined data collection and submission!**



# NACC UDSv4 Pilot Survey Results

ADRCs are off to a great start our new electronic data capture and submission system tools

## ADRC Responses



August 2024 Survey

# ADRC Portals – View, Audit, and Access Data

ADRCs can submit, view, audit, access, and manage participant data across multiple data modalities

## ADRC Portals

Manage Participants



Submit Data



View, Audit, and Access Participant Data




View ADRC Program Dashboard & Reports

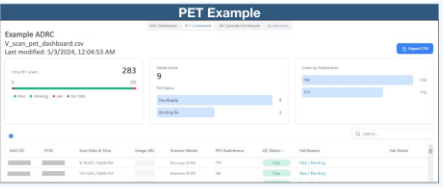


# ADRC Portals – New Data Types Accessible!


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



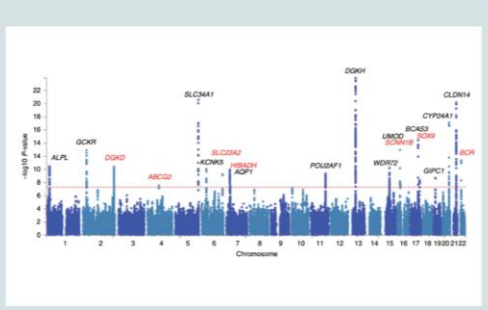
**SCAN**




- All data variables
- SCAN QC Dashboard



**GWAS Data**



**Imputation Data**

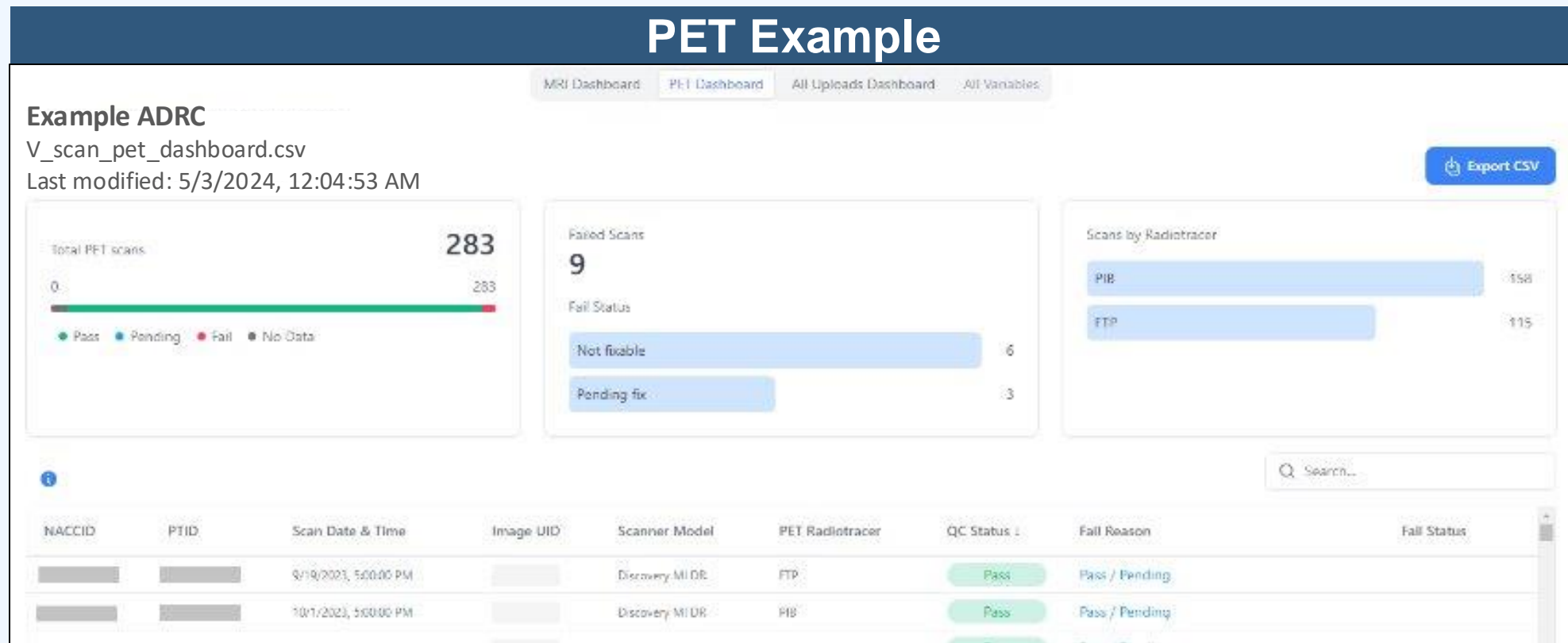


Access your participant data from partner repositories/initiatives

# Real-time ADRC-Specific SCAN QC Dashboards (MRI and PET Versions)

## Available via ADRC Portals within the NACC Data Platform

- Sites can track the QC status of their MRI and PET submissions, allowing them to rapidly address errors
- Serves as an auditable record of all SCAN MRI and PET data submitted to date, downloadable as a CSV file



# ADRC Portals – More Data Types Coming Soon!

ADRCs can view, audit, and access their participant data across a wide range of data modalities

## ADRC Portals

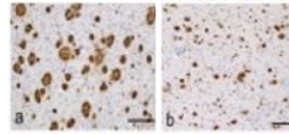
View, Audit, and Access Participant Data



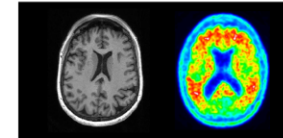
### Harmonized Phenotypic Data (UDS)

	Initial Visit (PV1)	Follow-up Visit (FV1)	Tx1 Initial Visit (FV1)	Tx2 Follow-up (FV1)
A1: Subject Demographics				
A2: Co-participant Demographics				
A3: Subject Family History				
A4: Subject Medications				

### Neuropathology Reports



### Mixed Protocol MRI/PET



### SCAN



- All data variables
- SCAN QC Dashboard

### ADGC & NIAGADS (Genetic/Genomic)



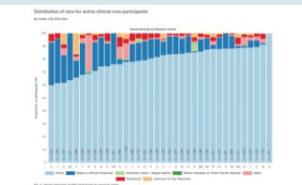
### NCRAD (Liquid Biomarker/Biospecimen)



### CLARiTi



### Participant Diversity Dashboard





# ADRC Portals – Program-Wide Dashboards and Reports

ADRCs can submit, view, audit, access,  
and manage participant data across multiple data modalities

## ADRC Portals

Manage Participants



Submit Data



View, Audit, and Access  
Participant Data



View ADRC Program  
Dashboard & Reports



# ADRC Portals – Program-Wide Dashboards and Reports

ADRCs and NIA can now access on-demand ADRC Program Reports

## ADRC Portals

View ADRC Program Dashboard & Reports



Alpha University ADRC Portal

Harmonized Phenotypic Data (UDS)

View Error Reports | Documentation | View Individual Participant Data

Most Recent Cognitive Status

- Normal
- Impaired, not MCI
- MCI
- Dementia

Enrollment

	n	%
Subjects with ADC IDs		
active	606	45%
initial	8	1%
deceased	404	30%
discontinued	272	20%
minimal	44	3%
Total	1,334	
Autopsies Performed	347	86%
NP Forms Received	320	
FTLD Module Subjects*	20	
Affiliated study subjects	807	
MDs only	154	
Transfer Subjects	1	

Race & Ethnicity

	n	%	% Hispanic
Subject with ADC IDs			
White	1,200	90%	12%
Black/African American	18	1%	6%
American Indian/Alaskan Native	72	5%	1%
Hawaiian/Pacific Islander	6	0%	0%
Asian	16	1%	0%
Other	13	1%	8%
Unknown	10	1%	10%
Total	1,334	11%	

\* Unique number of Subjects with dementia per primary etiologic diagnosis. Subjects can have more than 1 dementia syndrome.

NACC is funded by the National Institute on Aging (U24-AG072122) and located in the Department of Epidemiology at the University of Washington School of Public Health, Walter A. Kukull, PhD, Director. © 2023 University of Washington. Privacy policy Terms of service

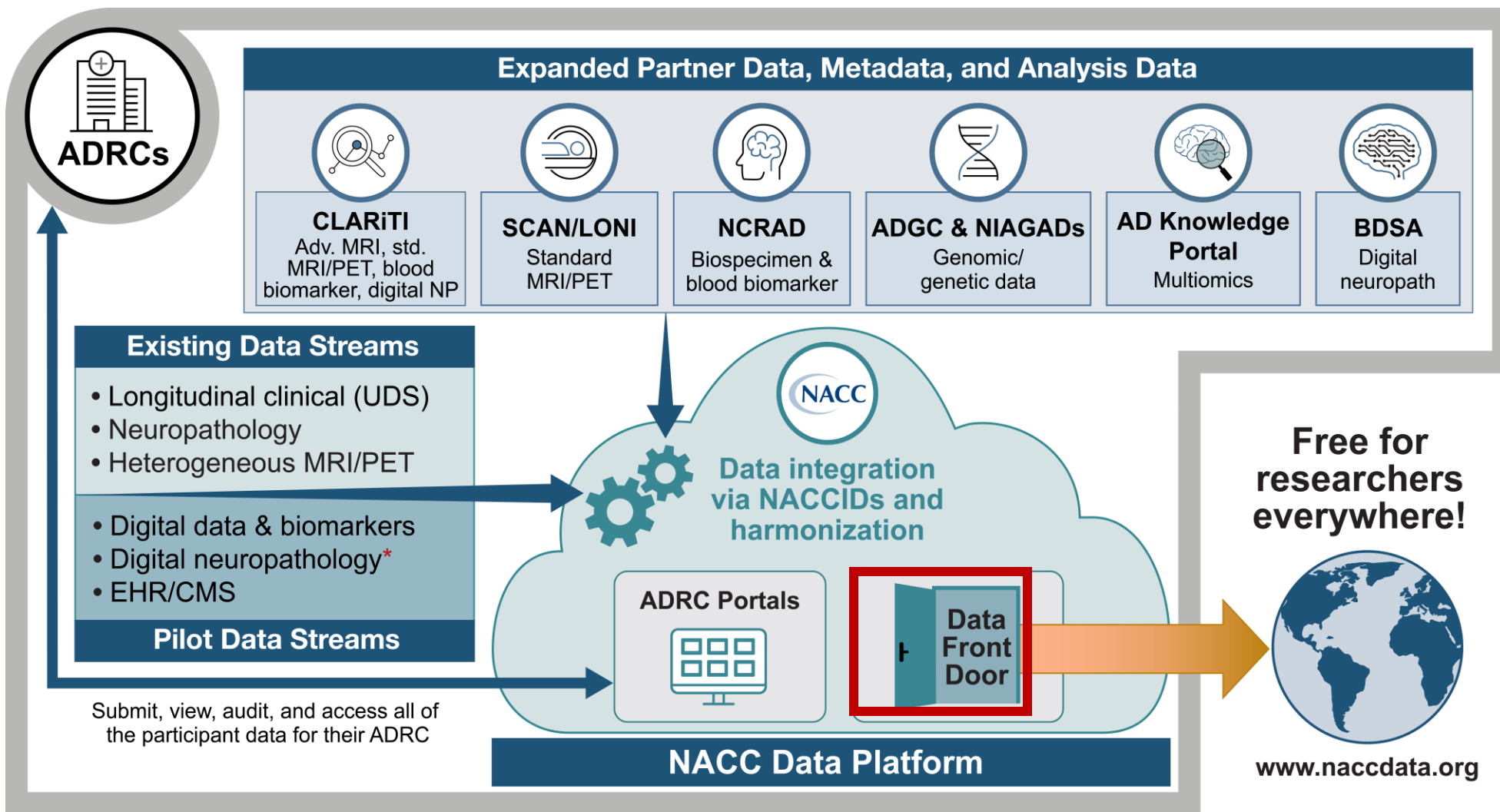
New State

Real-time On-demand Reports

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 pattern across the entire slide.

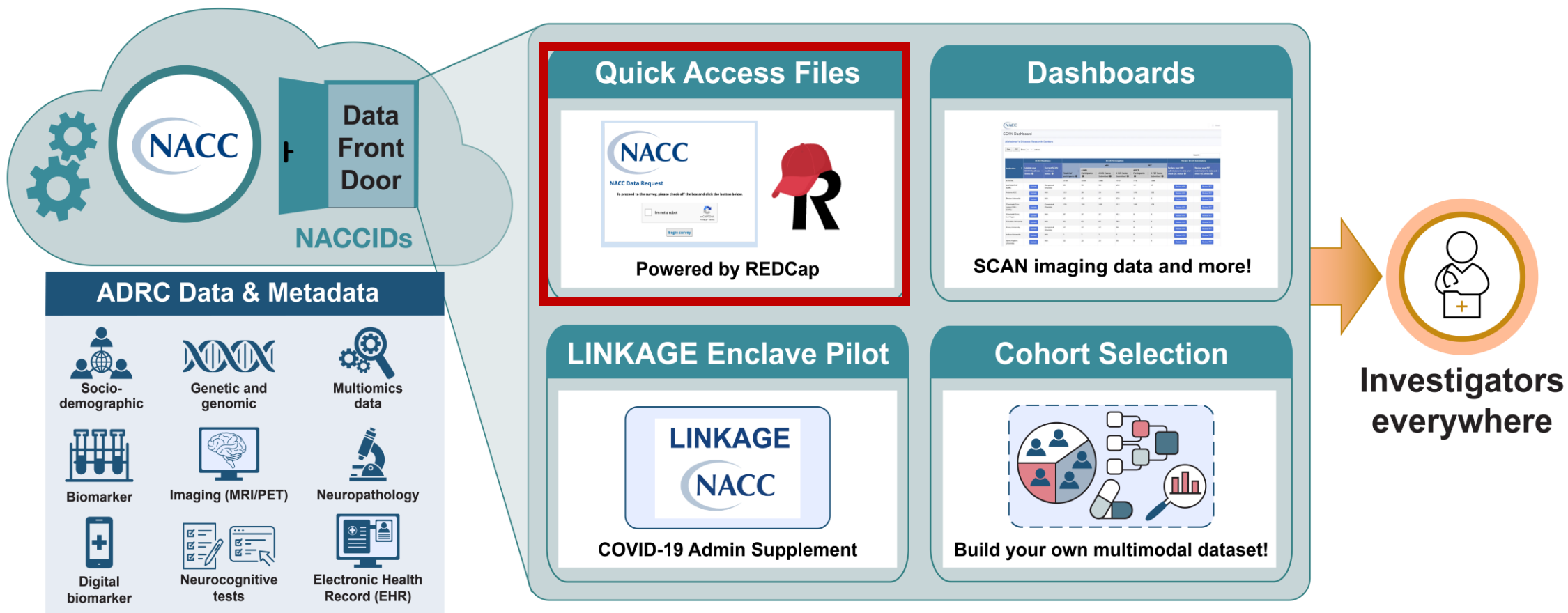
# **Data Front Door: A one-stop-shop for ADRC participant data**

# New NACC Data Platform: A Modern Cloud-based Multimodal Data Integration, Harmonization, and Sharing Platform



# Data Front Door: Advanced Data Search, Visualization, & Access

## One-Stop-Shop for All ADRC Data





# Data Front Door: NACC Quick Access File

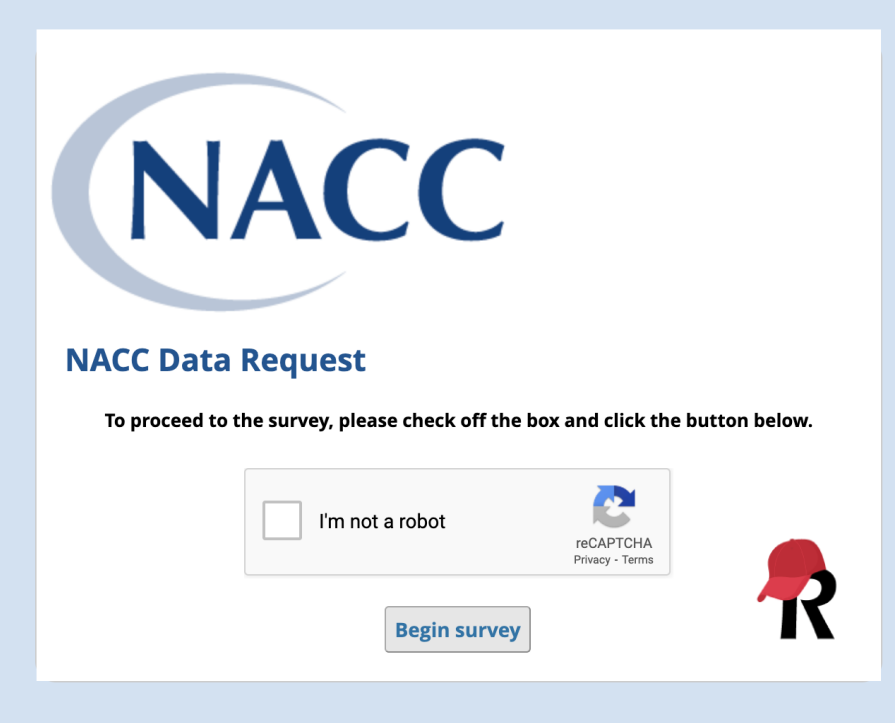
## One-Stop-Shop for All ADRC Data

### Submit a data request (15 min)

**Step 1.** Sign a Data Use Agreement and submit a title with specific aims.

**Step 2.** NACC reviews request.

**Step 3.** Approved requests typically receive datasets in < 48 hours.



The screenshot shows the NACC Data Request form. At the top is the NACC logo. Below it is the title "NACC Data Request". A instruction reads: "To proceed to the survey, please check off the box and click the button below." There is a checkbox labeled "I'm not a robot" and a reCAPTCHA logo with "reCAPTCHA Privacy - Terms" text. A blue "Begin survey" button is located below the checkbox. On the right side of the form is a red and black logo featuring a stylized "R" with a red circle above it.

**Login into the existing data request system:**

<https://naccddata.org/requesting-data/data-request-process>

# NACC Data Front Door: Quick Access File

Visit [scan.naccdata.org/](https://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
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Berkeley  
UNIVERSITY OF CALIFORNIA



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UNIVERSITY OF  
MICHIGAN



UC DAVIS

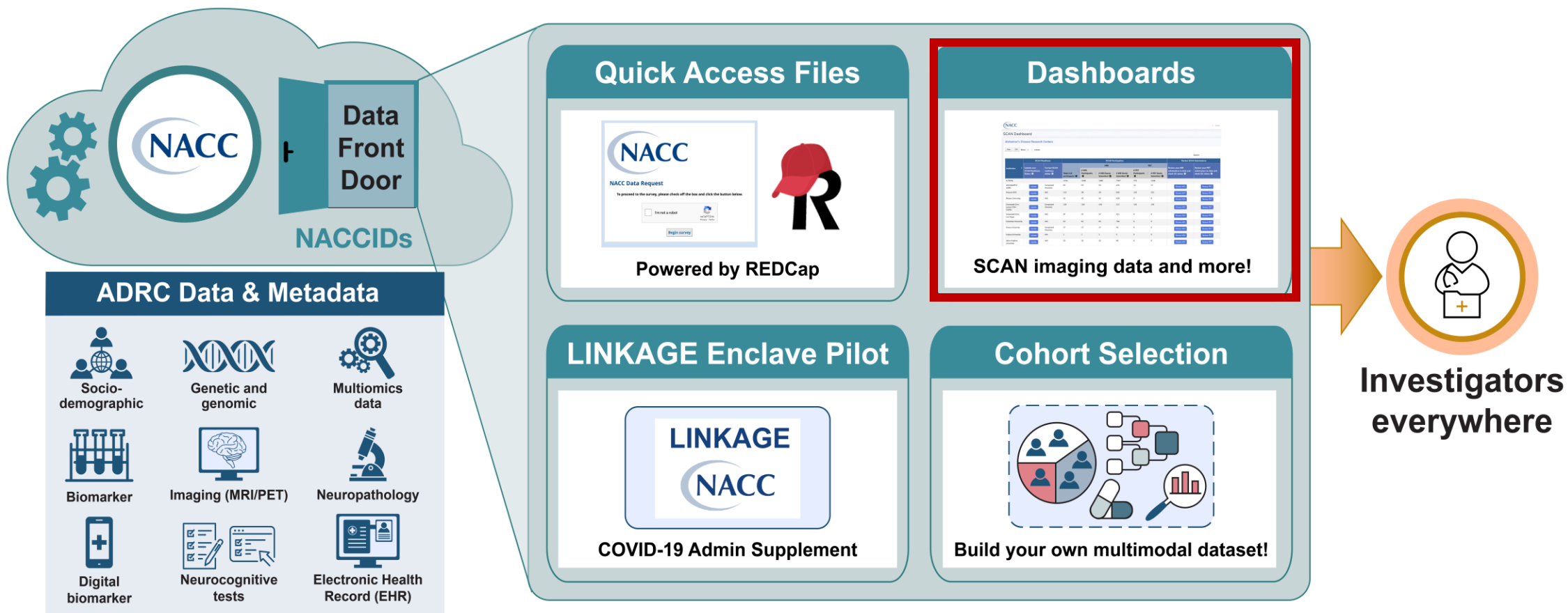


Data on >3,000 MRI and >3,000 PET scan is available today!



# Data Front Door: Advanced Data Search, Visualization, & Access

## One-Stop-Shop for All ADRC Data



# Data Front Door: SCAN Public Dashboard and Leaderboard

## One-Stop-Shop for All ADRC Data

Real-time numbers on how much standardized and QC-ed MRI/PET analysis data is available to the research community from across the ADRC Program.

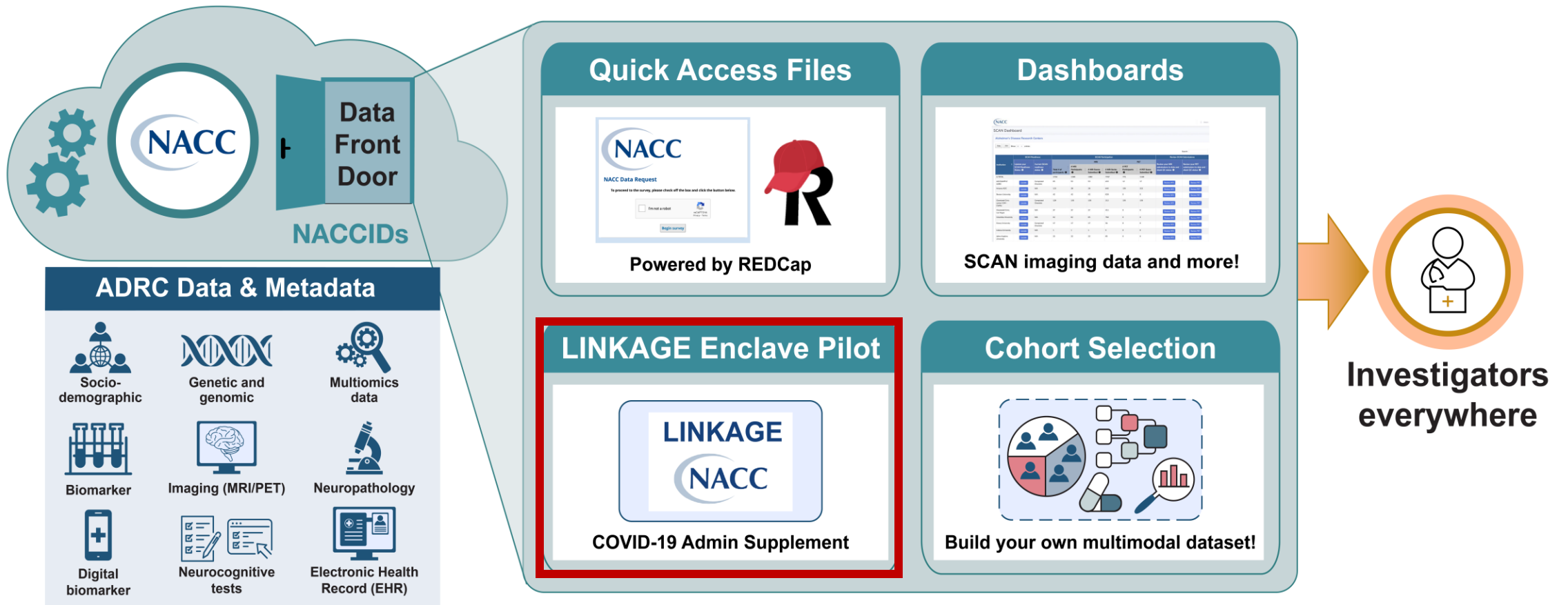
ALZHEIMER'S DISEASE RESEARCH CENTERS COPY CSV

Institution	SCAN Participation						ADRC-specific SCAN QC Dashboards
	Total # of Participants	MRI			PET		
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<b>Total</b>	4,742	4,208	4,832	23,466	1,887	2,845	
Wake Forest University	402	357	391	870	196	310	PRIVATE DASH
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Mayo Clinic	235	235	294	878	0	0	PRIVATE DASH

Visit [scan.naccddata.org](https://scan.naccddata.org)

# Data Front Door: Advanced Data Search, Visualization, & Access

## One-Stop-Shop for All ADRC Data

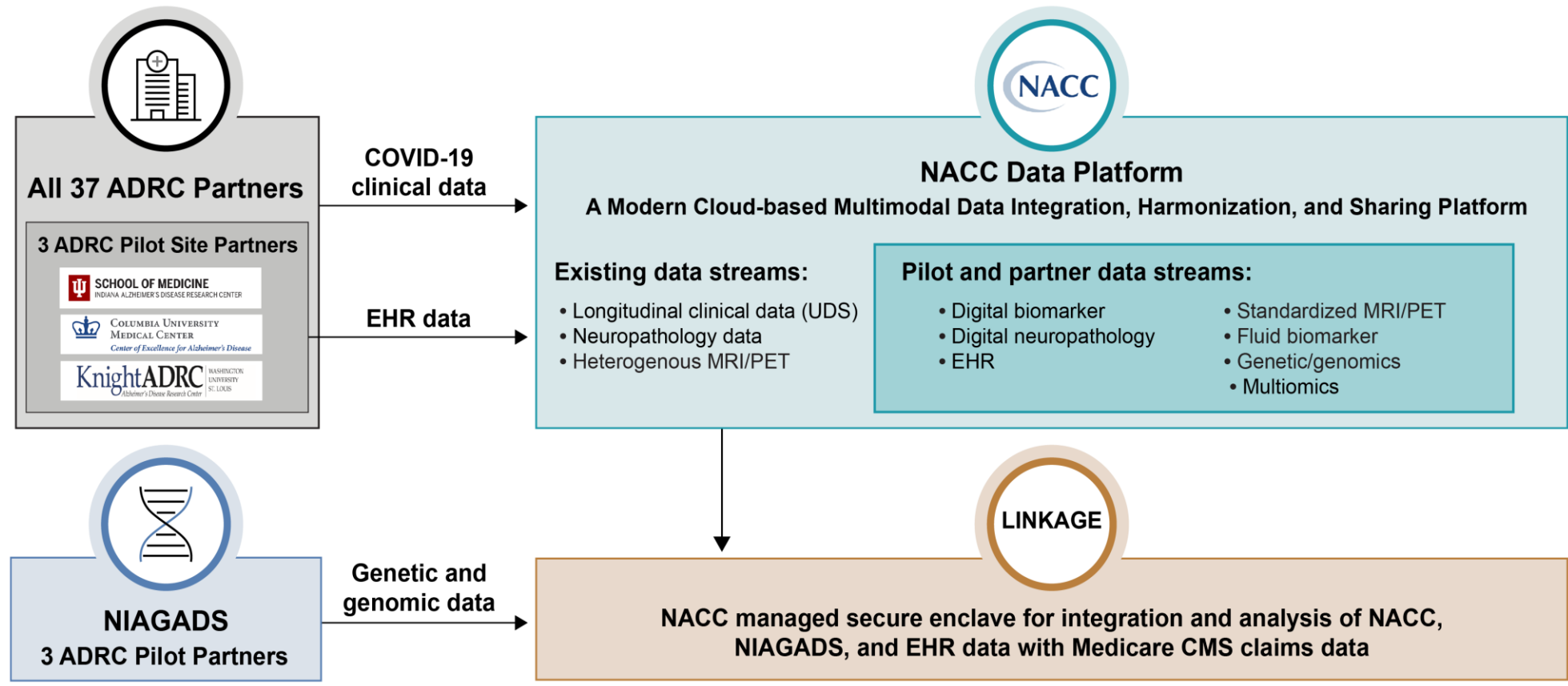




# Data Front Door: NACC's COVID-19/RWD Pilot Platform

## One-Stop-Shop for All ADRC Data

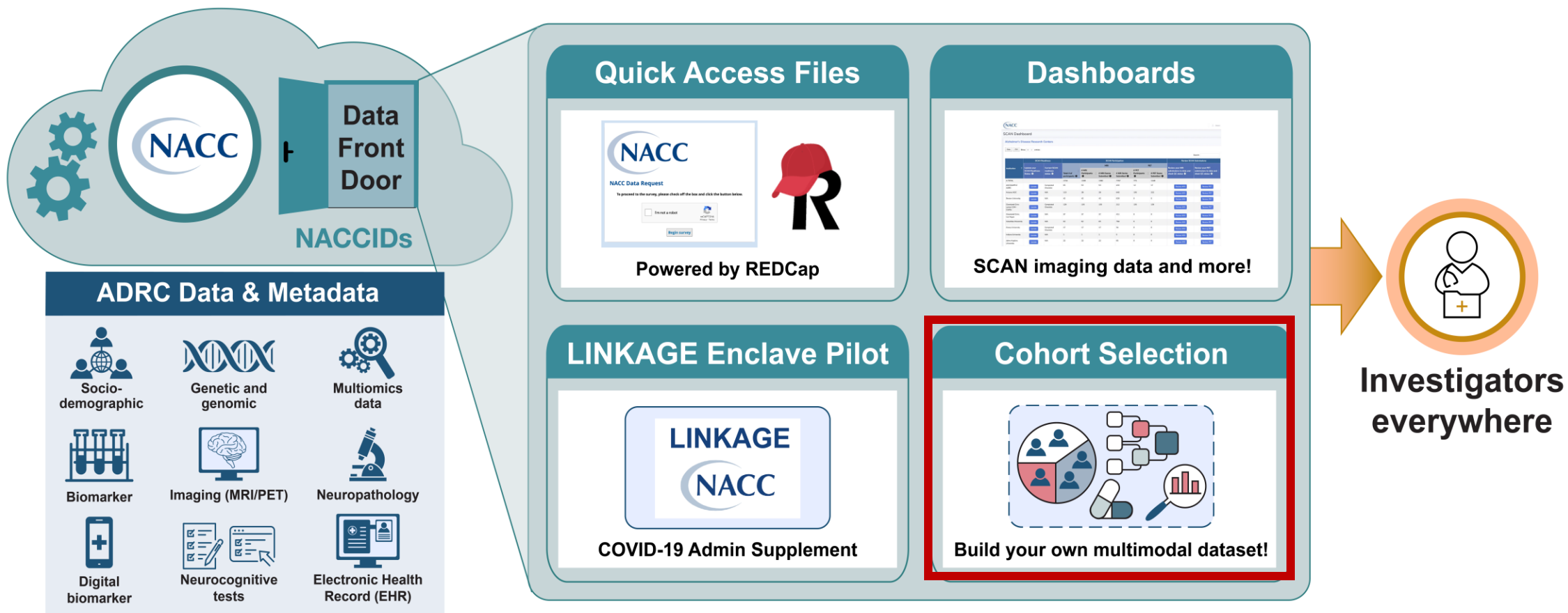
NACC has deployed a platform and governance strategy to link clinical (EHR), genetic/genomic (NIAGADS/ADSP), and phenotypic (NACC) data with claims data for consented ADRC participants within a secure LINKAGE enclave.





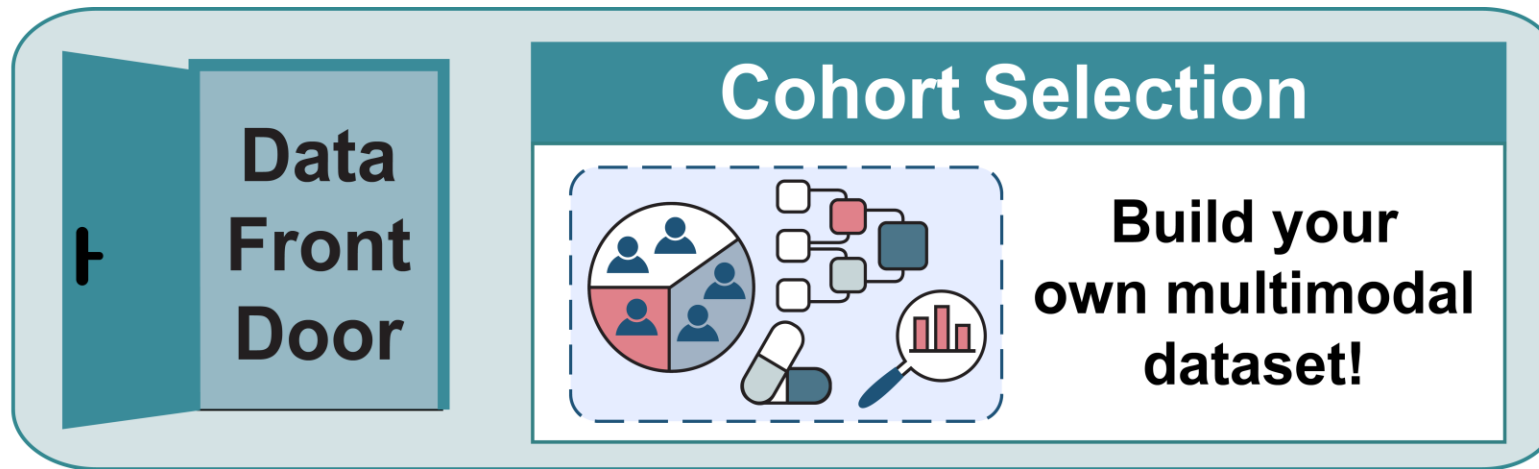
# Data Front Door: Advanced Data Search, Visualization, & Access

## One-Stop-Shop for All ADRC Data



# Data Front Door: Cohort Selection Tools

One-Stop-Shop for All ADRC Data



- Cohort-discovery enabled
- Easy to use
- Self-service
- Real-time
- Integrated

# NACC Cohort Browser

Researchers can discover/search, build, and visualize multimodal cohorts using facets (search fields)

## Cohort Browser Tools

### Data Types



Socio-demographic



Genetic and genomic



Multiomics data



Biomarker



Imaging (MRI/PET)



Neuropathology



Digital biomarker



Neurocognitive tests



Electronic Health Record (EHR)

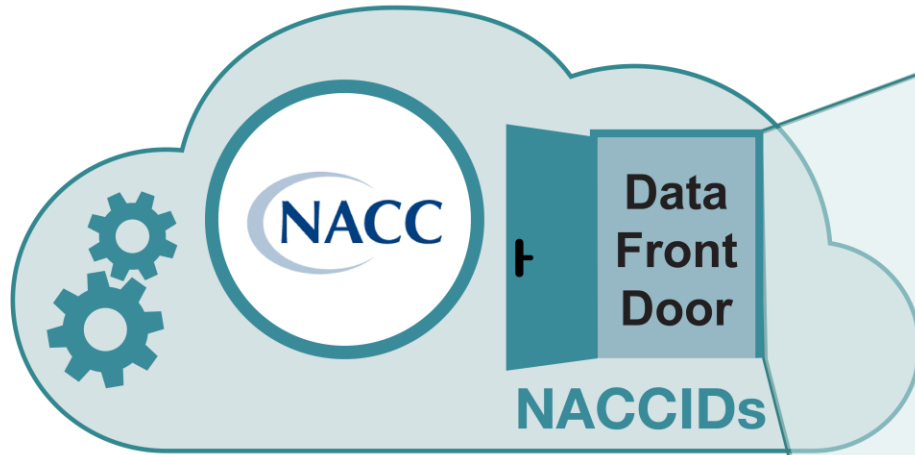
### Example Facets

- Age at visit
- Sex
- Years of education
- NIH race categories
- Hispanic ethnicity
- Primary language
- Series acquisition type (SCAN)
- Radiotracer (SCAN)

Researchers everywhere



Quick Access File for data retrieval from NACC and partner repositories



## NACC Data Platform

Socio-demographic

Neurocognitive tests

Neuro-pathology

Imaging (MRI/PET)

Biomarker

Genetic & genomic

EHR & Claims

Digital data

Multiomics data

## Key AD/ADRD Challenges & Opportunities

Advancing Early Detection

Disentangling Heterogeneity

Validating Blood Biomarkers

Identifying & Stratifying Risk Factors & Protective Mechanisms

Providing Precision Medicine

Improving Generalizability





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



**SARAH BIBER, PHD**  
Executive Director



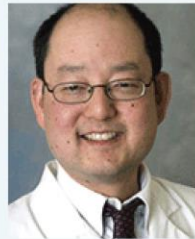
**KARI STEPHENS, PHD**  
Associate Director,  
NACC,  
Professor, Family  
Medicine



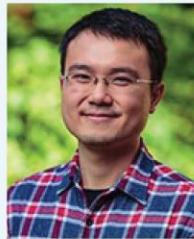
**CHARLES  
MOCK, MD, PHD, FACS**  
Associate Director,  
NACC Professor,  
Epidemiology  
and Surgery



**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



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