



# Expanding NACC's Operational and Informatics Infrastructure to Amplify and Accelerate CLARiTI

**Sarah Biber, PhD, NACC Executive Director**

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**ADRC CLARiTI Session**

**October 17, 2024**

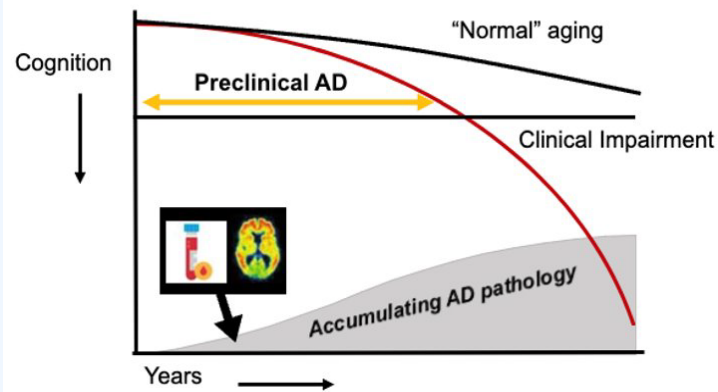
# NACC serves as the data coordination hub and centralized data repository for NIA's ADRC Program

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

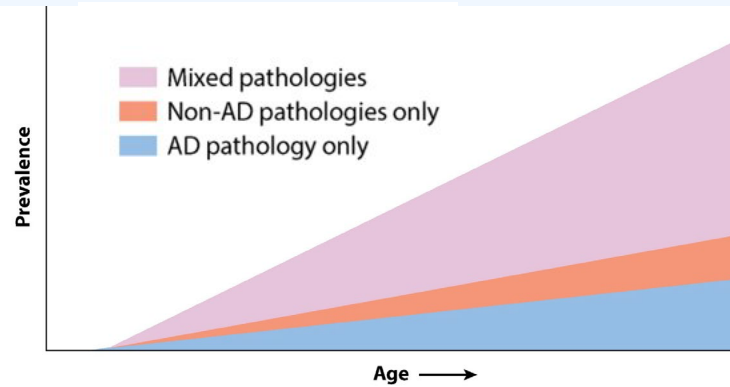


■ State with NIA-Designated Center(s)  
■ State with Exploratory Center

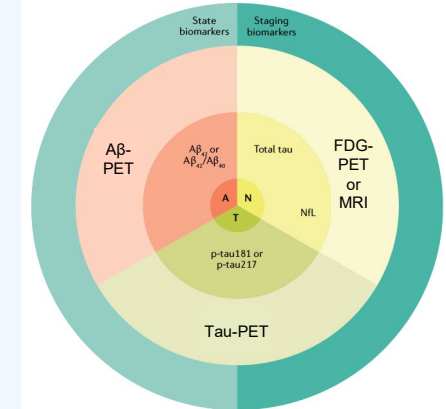
## Advance Early Detection



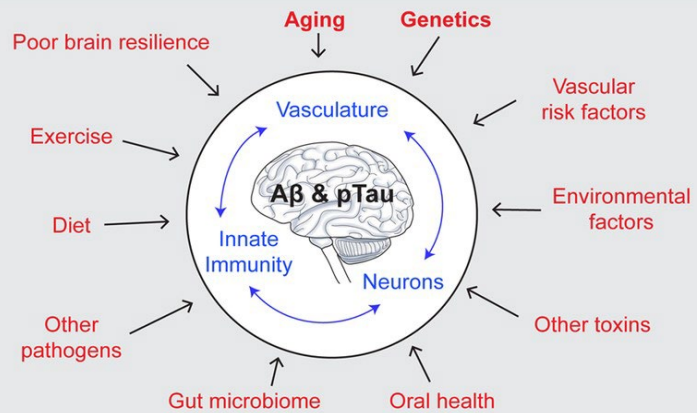
## Disentangle Heterogeneity



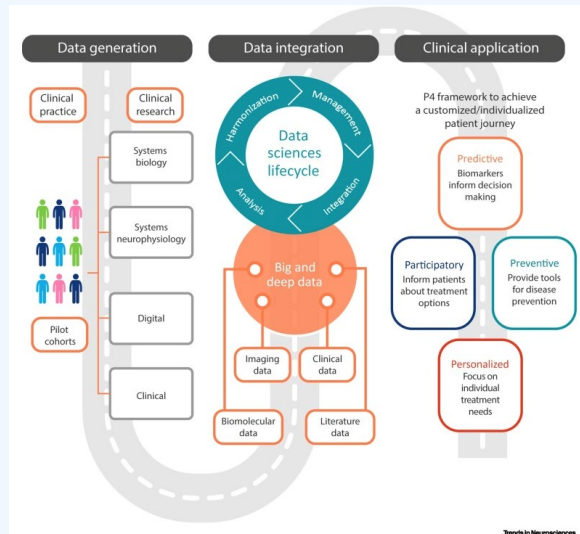
## Validate Blood Biomarkers



## Identify and Stratify Risk Factors and Protective Mechanisms



## Precision Medicine



## Improve Generalizability



## Requires More Multimodal Data!

**Researchers need to be able to readily access increasing amounts of multimodal data that are high-quality, harmonized, and integrated to advance the field**



**Socio-demographic**



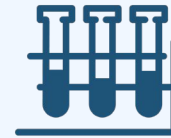
**Neurocognitive tests**



**Neuro-pathology**



**Imaging (MRI/PET)**



**Biomarker**



**Genetic & genomic**



**EHR & Claims**



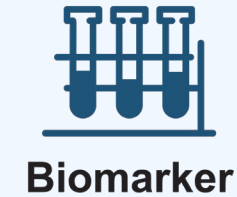
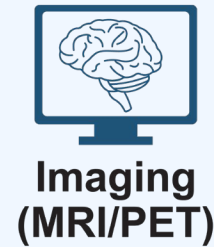
**Digital data**



**Multiomics data**



## Requires More Multimodal Data!



# NACC's Expanded Mission and Role

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

## Data Coordination & Centralized Repository

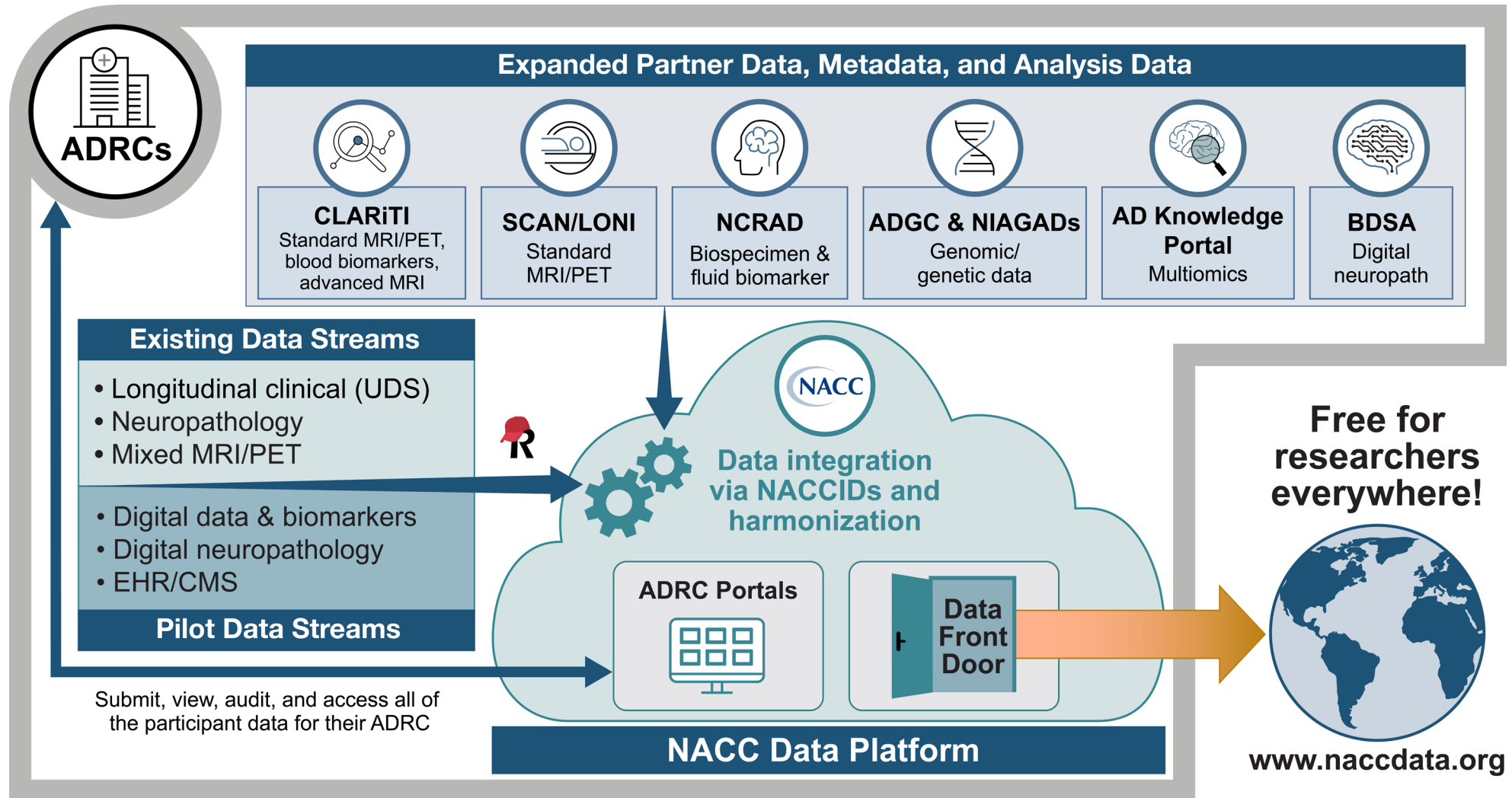
**F**indable   
**A**ccessible   
**I**nteroperable   
**R**eusable 

## Communication & Collaboration Hub



## New Investigator Support

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





# Operational Advances

## Supporting ADRC groups and initiatives



Strategic Planning



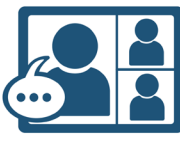
Project Management



Group Facilitation



Surveys & Analysis



Webinars & Forums

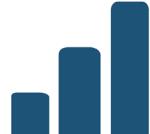
## Convening the ADRC Program through biannual meetings

# ADRC MEETING

## Sharing the value of NACC and the ADRC Program to key stakeholders



Dynamic Website



Reports



Newsletters



Social Media



Podcasts

## Facilitating collaboration through a real-time NACC Directory



Community Forum



NACC Directory

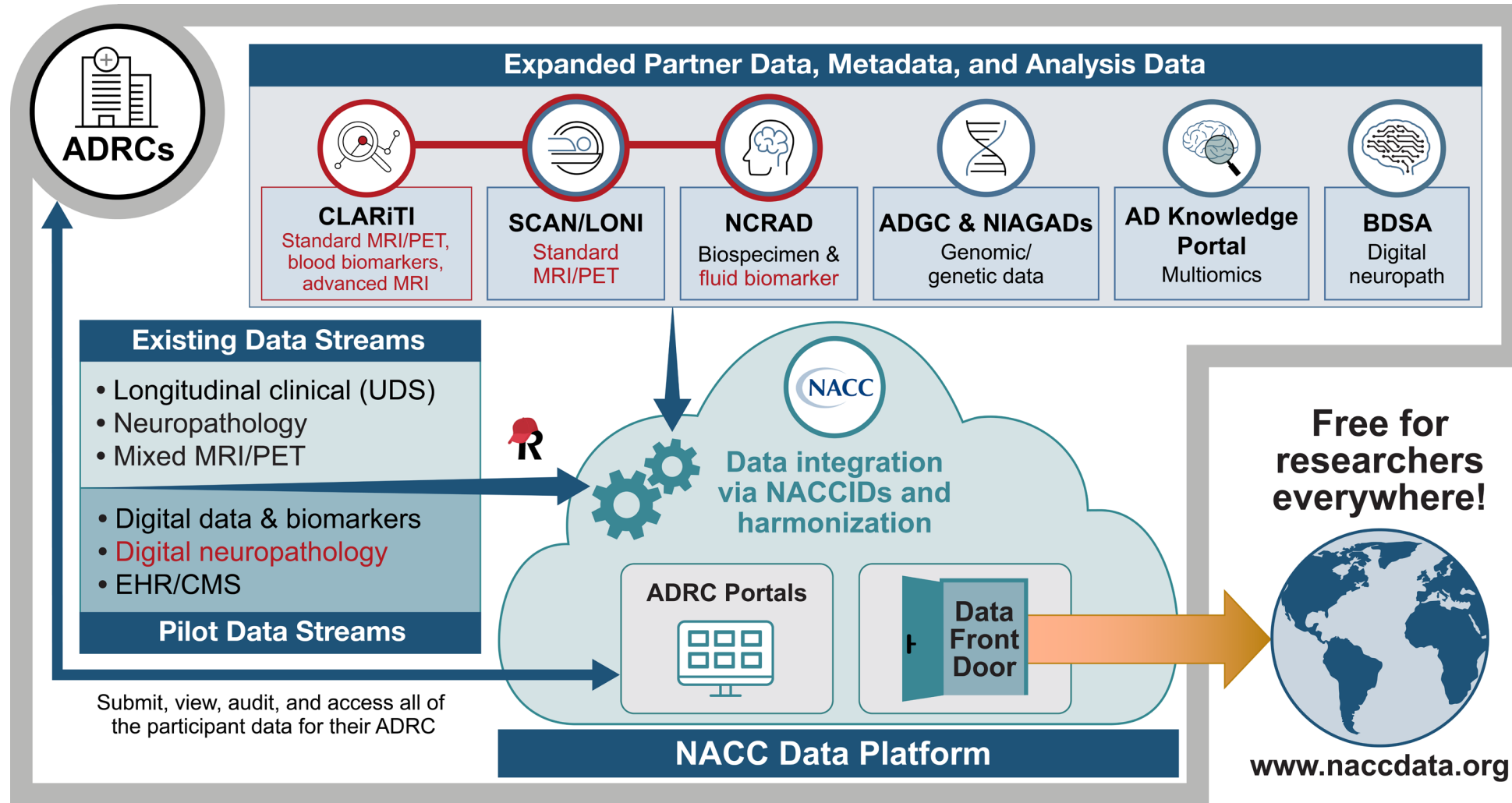




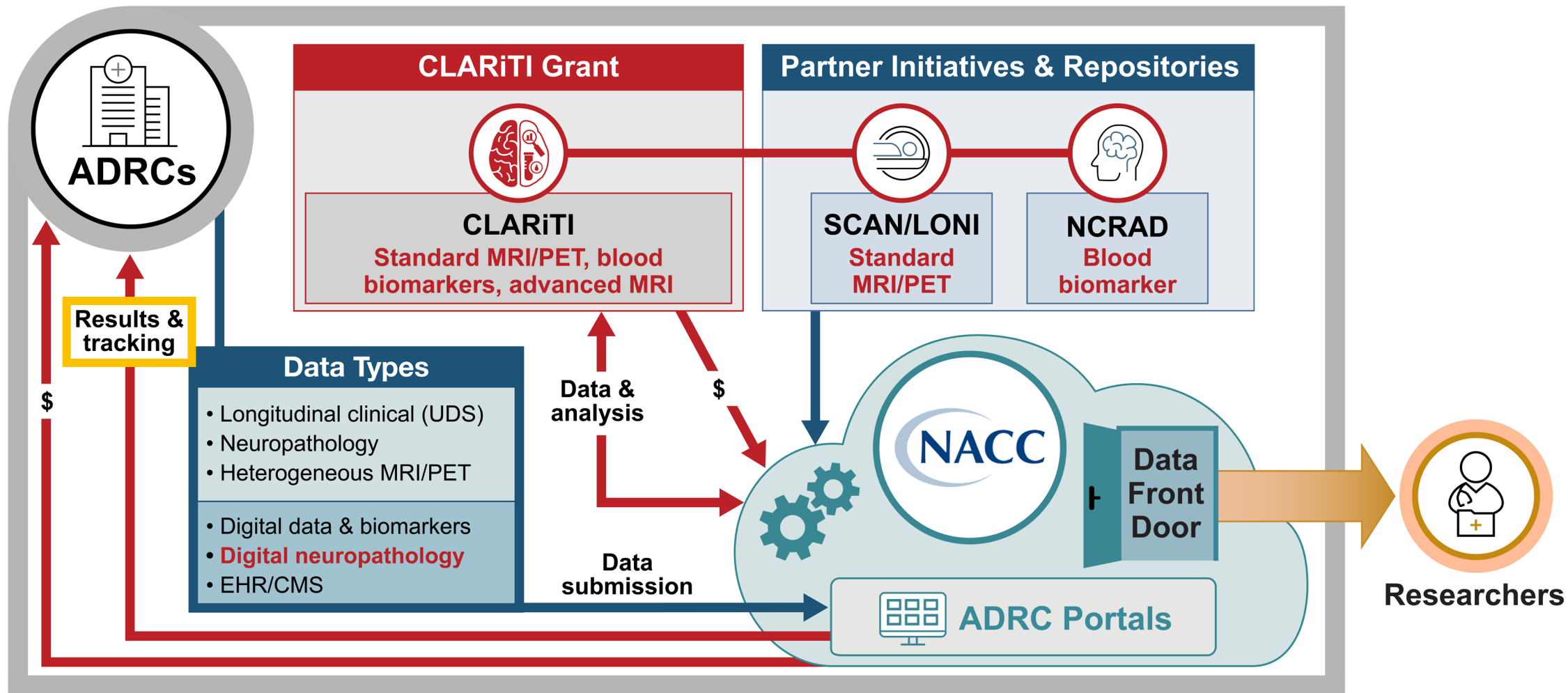
**CLARiTI**

**NACC**

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



# NACC Data Platform: CLARiTI



# NACC's Expanded Mission and Role

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

## Data Coordination & Centralized Repository

**F**indable



**A**ccessible



**I**nteroperable



**R**eusable



## Communication & Collaboration Hub



**New Investigator Support**



# Informatics Support

## Data Submission and Tracking

- Data submission interface
- EDC system with case report forms
- Site-level dashboards
- Program-wide dashboards

Electronic Data Capture



ADRC Portals



## Building key data pipelines

- MRI/PET
- Digital Neuropathology
- Fluid Biomarker
- Multimodal data integration via NACCID

Data Pipelines



Data Integration



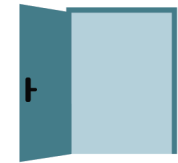
## Data Sharing

- Real-time form error checks
- Data Front Door: One-stop-shop for CLARiTI data

Data Integration



Data Front Door



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

# Data Submission and Tracking

# NACC ADRC Portals

ADRCs can submit, view, audit, access,  
and manage their CLARiTI participant data

## ADRC Portals

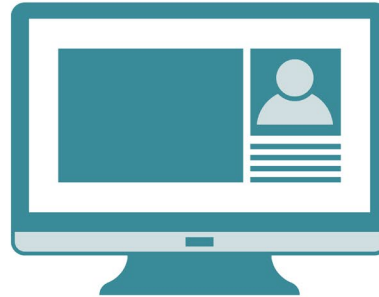


# CLARiTI

Submit Data



View, Audit, Track, and  
Access Participant Data



Program-Wide  
Dashboards and Reports



# NACC ADRC Portals

ADRCs can submit, view, audit, access,  
and manage their CLARiTI participant data

## ADRC Portals

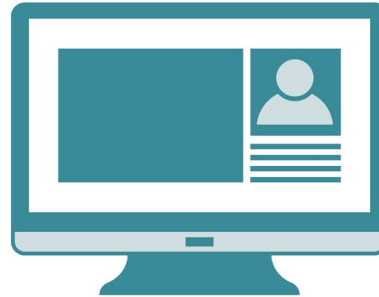


## CLARiTI

Submit Data



View, Audit, Track, and  
Access Participant Data



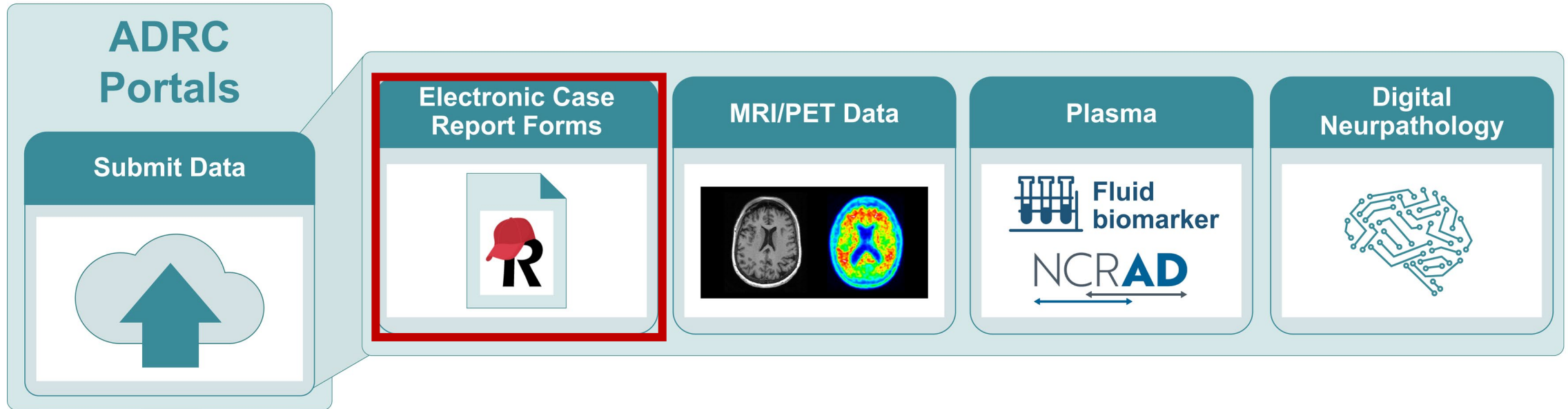
Program-Wide  
Dashboards and Reports





# NACC ADRC Portals: Submit Data

## Data Submission



# NACC ADRC Portals

## Submit CLARiTI Protocol Data via REDCap EDC CRFs

**CLARiTI EDC** PID 25

**Record Status Dashboard (all records)**

Displayed below is a table listing all existing records/responses and their status for every data collection instrument (and if longitudinal, for every event). You may click any of the colored buttons in the table to open a new tab/window in your browser to view that record on that particular data collection instrument. Please note that if your form-level user privileges are restricted for certain data collection instruments, you will only be able to view those instruments, and if you belong to a Data Access Group, you will only be able to view records that belong to your group.

**Legend for status icons:**

- Incomplete
- Incomplete (no data saved) ?
- Unverified
- Complete
- ● ● Many statuses (all same)
- Many statuses (mixed)

Dashboard displayed: [Default dashboard] [Create custom dashboard](#)

Displaying Data Access Group: -- ALL --

Displaying record: Page 1 of 2: "CL33\_1" through "CL37\_50" of 200 records 100 records per page

[+ Add new record](#)

Displaying: Instrument status only | [Lock status only](#) | [All status types](#)

Record ID	Identifiers			Study Participation		Baseline							Return of Results			Follow-up Visit				
	A - CLARiTI Identifiers CRF	B1 - CLARiTI Eligibility Screening CRF	B2 - CLARiTI Participant Consent Status CRF	C1 - CLARiTI ADCFB Bio-Sample Collection CRF	C2 - CLARiTI Amyloid PET Scan CRF	C3 - CLARiTI Tau PET CRF	C4 - CLARiTI FDG PET CRF	C5 - CLARiTI MRI and Advanced MRI CRF	C6 - CLARiTI Amyloid PET Visual Read CRF	C7 - CLARiTI MR Visual Read CRF	E1 - CLARiTI PET Results of Pre-Visit CRF	E2 - CLARiTI PET Results of Return of Visit CRF	E3 - CLARiTI Post-Visit Results of Follow-up CRF	C1 - CLARiTI ADCFB Bio-Sample Collection CRF	C2 - CLARiTI Amyloid PET Scan CRF	C3 - CLARiTI Tau PET CRF	C4 - CLARiTI FDG PET CRF	C5 - CLARiTI MRI and Advanced MRI CRF		
<a href="#">CL33_1</a> Center: Arizona NACCID:	<span style="color: red;">●</span>	<span style="color: green;">●</span>	<span style="color: green;">●</span>	<span style="color: grey;">●</span>	<span style="color: green;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>		
<a href="#">CL33_2</a> Center: Arizona NACCID:	<span style="color: red;">●</span>	<span style="color: grey;">●</span>	<span style="color: red;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>		
<a href="#">CL33_3</a> Center: Arizona NACCID:	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: red;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>		
<a href="#">CL33_4</a> Center: Arizona NACCID: Rock	<span style="color: green;">●</span>	<span style="color: red;">●</span>	<span style="color: red;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>		
<a href="#">CL33_5</a> Center: Arizona NACCID:	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>	<span style="color: grey;">●</span>		

**CLARiTI EDC** PID 25

Actions: [Modify instrument](#) [Download PDF of instrument\(s\)](#) [Video: Basic data entry](#)

**B1 - CLARiTI Eligibility Screening CRF** Data Access Group: Arizona

Editing existing Record ID **CL33\_1**. Center: Arizona NACCID:

Event: Study Participation

Record ID: CL33\_1

**CLARiTI Research Program**  
**Screening and Eligibility Case Report Form**

0. Name of staff filling out this form:

Participant ADRC ID# (PTID): 987654321

Participant NACCID # (if available):

ADC Name: Arizona ADRC

ADC Site ID#: 33

0a. Date of Screening:  Today M-D-Y

0b. Select the UDS form version you will be using to complete the participant's CLARiTI Eligibility and Screening Case Report Form:  
 UDSv3  
 UDSv4

**Attention Research Staff:** Please fill out this form using information from the participant's most recently completed NACC Uniform Data Set (UDS) form.

For guidance on where to find the questions in UDSv3 please refer to the CLARiTI Screening and Eligibility Case Report Form UDSv3 Appendix in Box: <https://uwmadison.box.com/s/p9ifxp7cx5gqzr18ztop15sgpd42jgw>

**Cognitive Decline**

1a. Does the participant have normal cognition (global CDR=0 and/or neuropsychological testing within normal range) and normal behavior (i.e., the participant does not exhibit behavior sufficient to diagnose MCI or dementia due to FTLD or LBD)?  
 No, cognitively impaired  
 Yes, cognitively unimpaired

1b. Does the participant meet the criteria for dementia?  
 No  
 Yes

1c. Does the participant meet the criteria for MCI?  
 No  
 Yes

# NACC ADRC Portals

ADRCs can submit, view, audit, access,  
and manage their CLARiTI participant data

## ADRC Portals



## CLARiTI

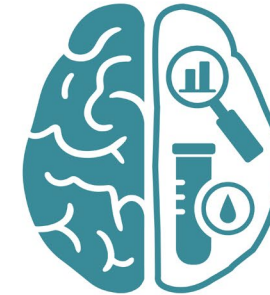
Submit Data



View, Audit, Track, and  
Access Participant Data

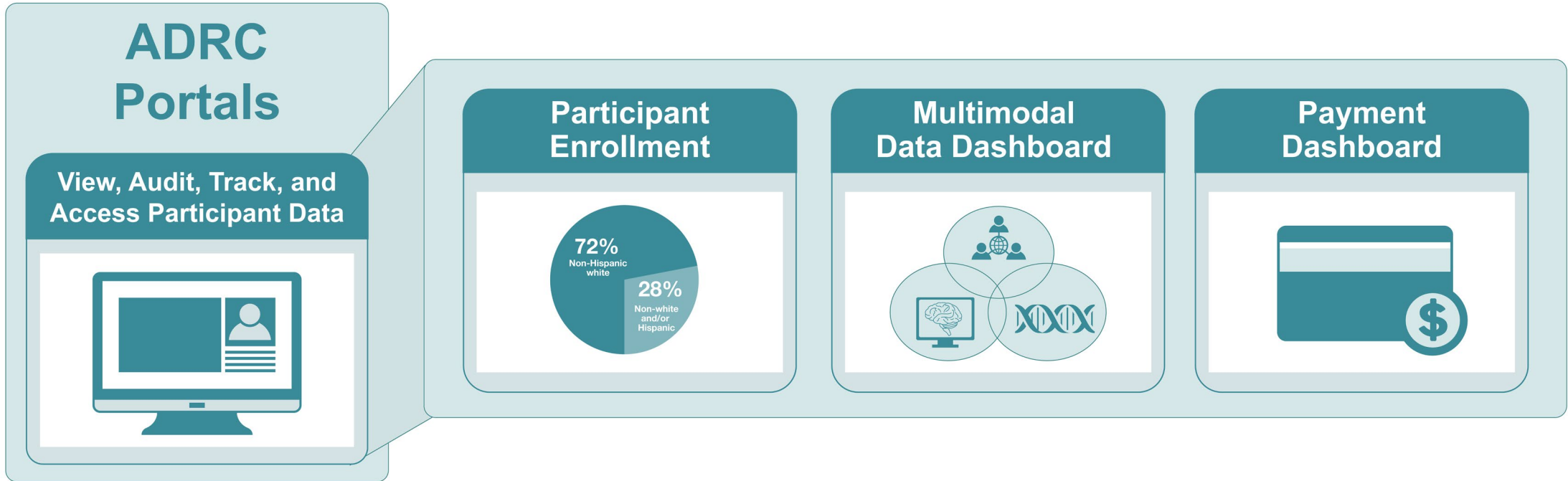


Program-Wide  
Dashboards and Reports



# NACC ADRC Portals

## Site-Level View, Audit, and Access





# NACC ADRC Portals

ADRCs can view and download  
Program-Wide Dashboards and Reports

ADRC Portals

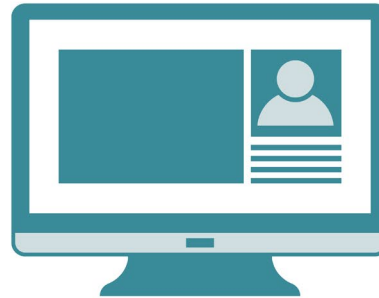


CLARiTi

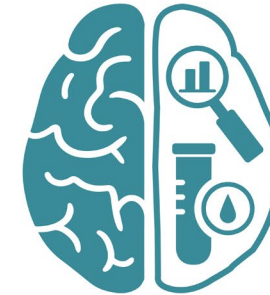
Submit Data



View, Audit, Track, and  
Access Participant Data



Program-Wide  
Dashboards and Reports



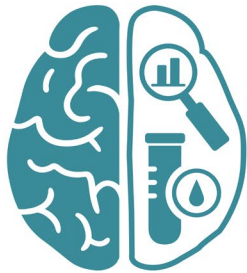


# NACC ADRC Portals: Program-Wide Dashboards

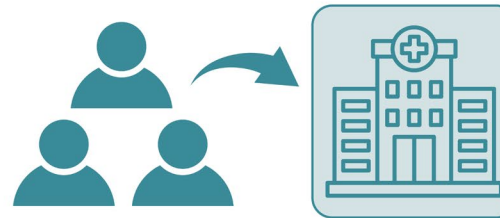


## ADRC Portals

Program-Wide Dashboards & Reports



## CLARiTI Recruitment and Enrollment



## Multimodal Data Dashboard



A decorative background featuring a network diagram with light blue lines connecting various nodes. Some nodes are highlighted with larger, darker blue circles, while others are smaller and lighter. The network is spread across the top and bottom of the slide, framing the central text.

# Building Key Data Processing Pipelines



**scan**

*Imaging Analysis*



*Data Integration and Distribution*

**Researchers everywhere**

*SCAN Compliant Acquisitions*

**SCAN non-P30  
2021—Ongoing**

- SCAN Supplements
- Affiliated R01s
- Site specific scanning schedules & eligibility

**SCAN P30  
2023—Ongoing**

- ADRC P30 Budget
- Site specific scanning schedules & eligibility
- 24 ATN sets required
- Expect 600 participants/year



**CLARiTI**

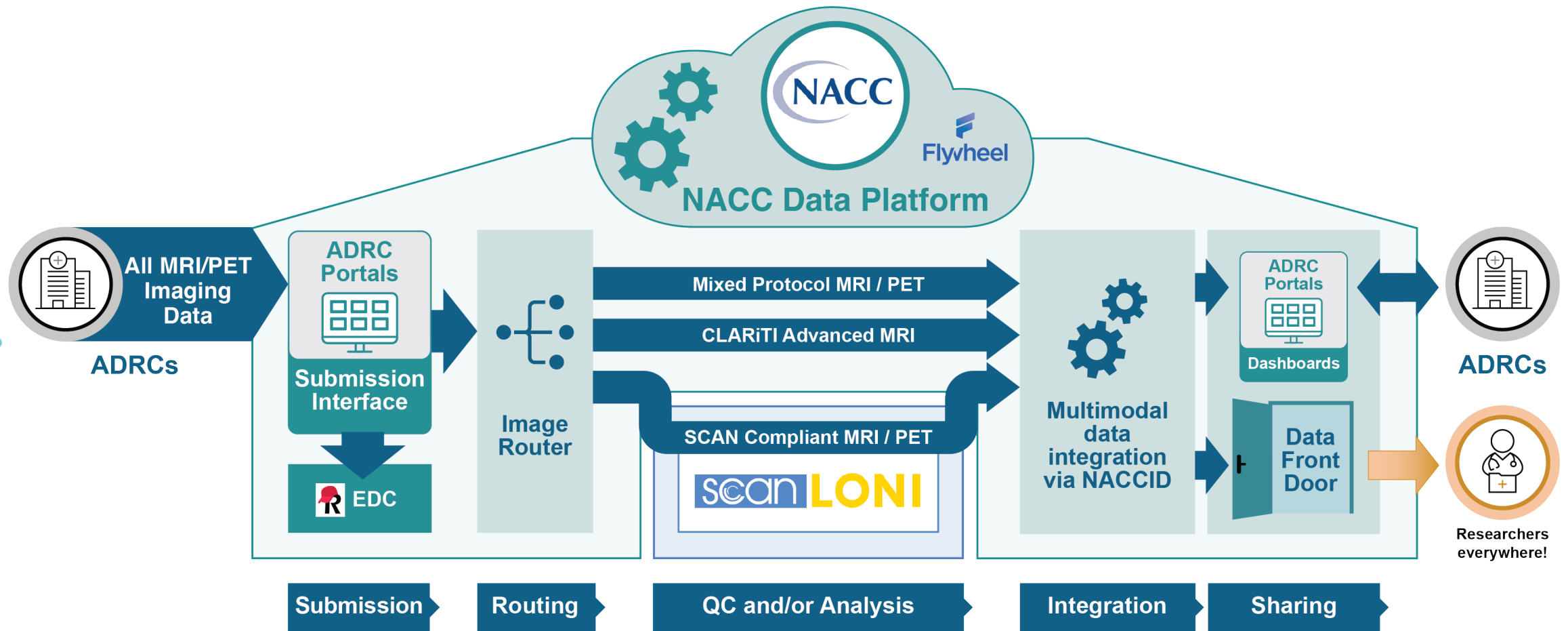
**CLARiTI  
2023—Ongoing**

- CLARiTI Performance Site Budget
- CLARiTI scanning schedule and eligibility
- 2000 participants over 5 years

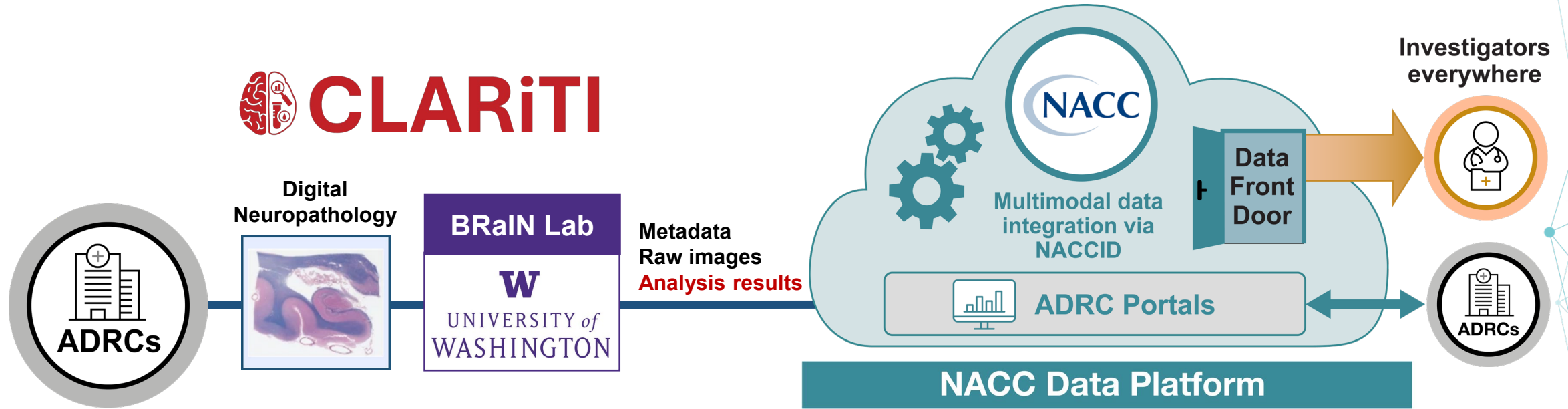
**Mixed Protocol  
<2021**

- Site-specific protocols

# MRI / PET Pipeline



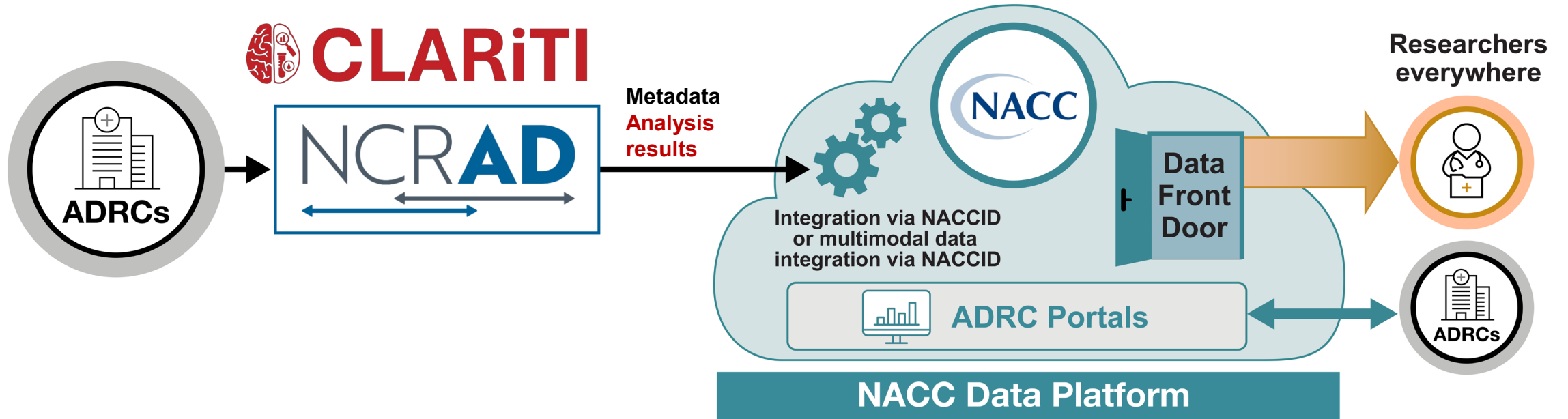
# Digital Neuropathology Pipeline



**Dirk Keene, MD, PhD**  
CLARiTI Neuropathology Lead  
Chair of Neuropathology,  
University of Washington



# Fluid Biomarker Pipeline



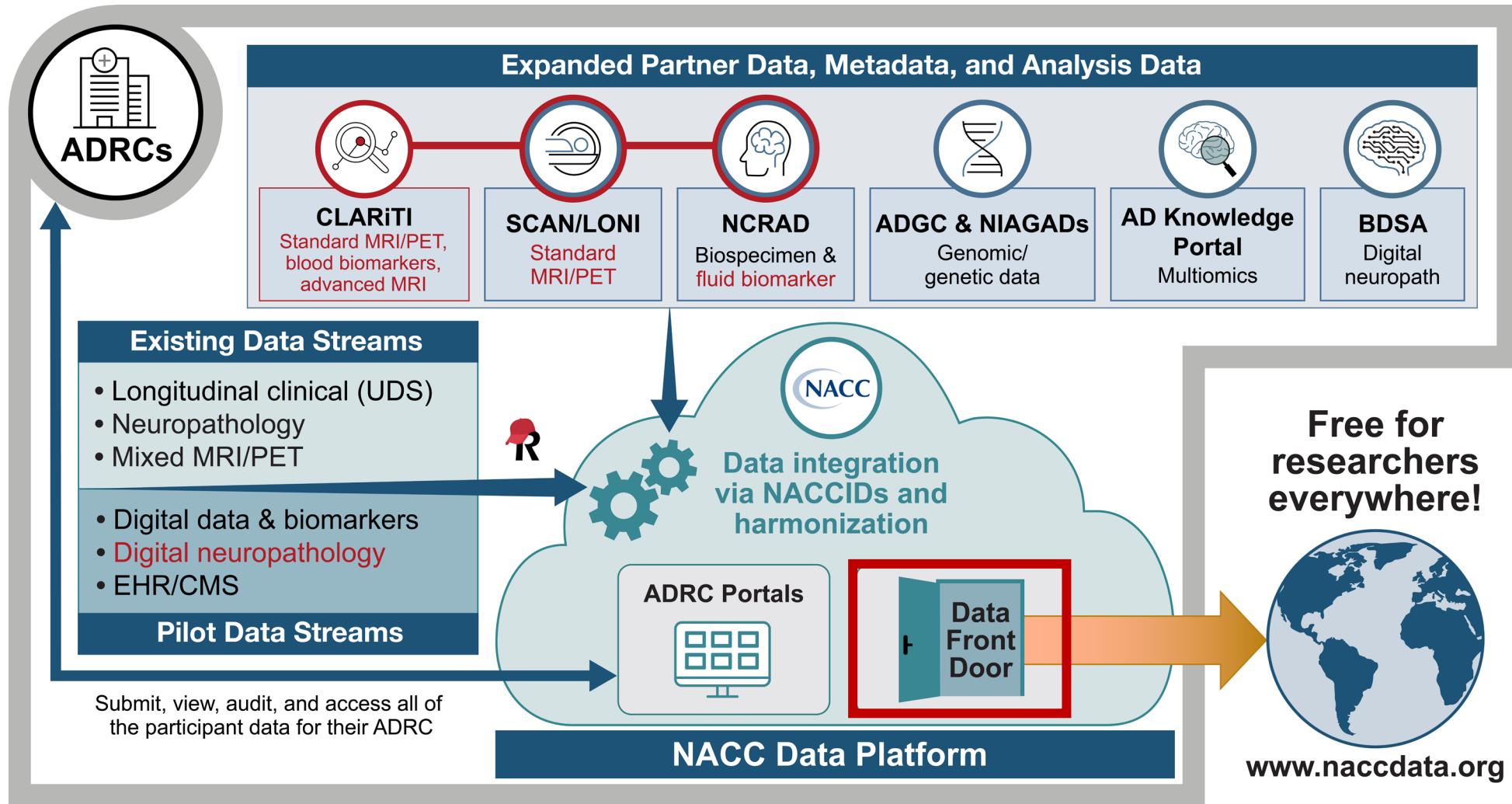
**Tatiana Foroud, PhD**

CLARiTI Plasma Biomarkers Lead  
Executive Associate Dean for Research Affairs,  
Indiana University School of Medicine

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.

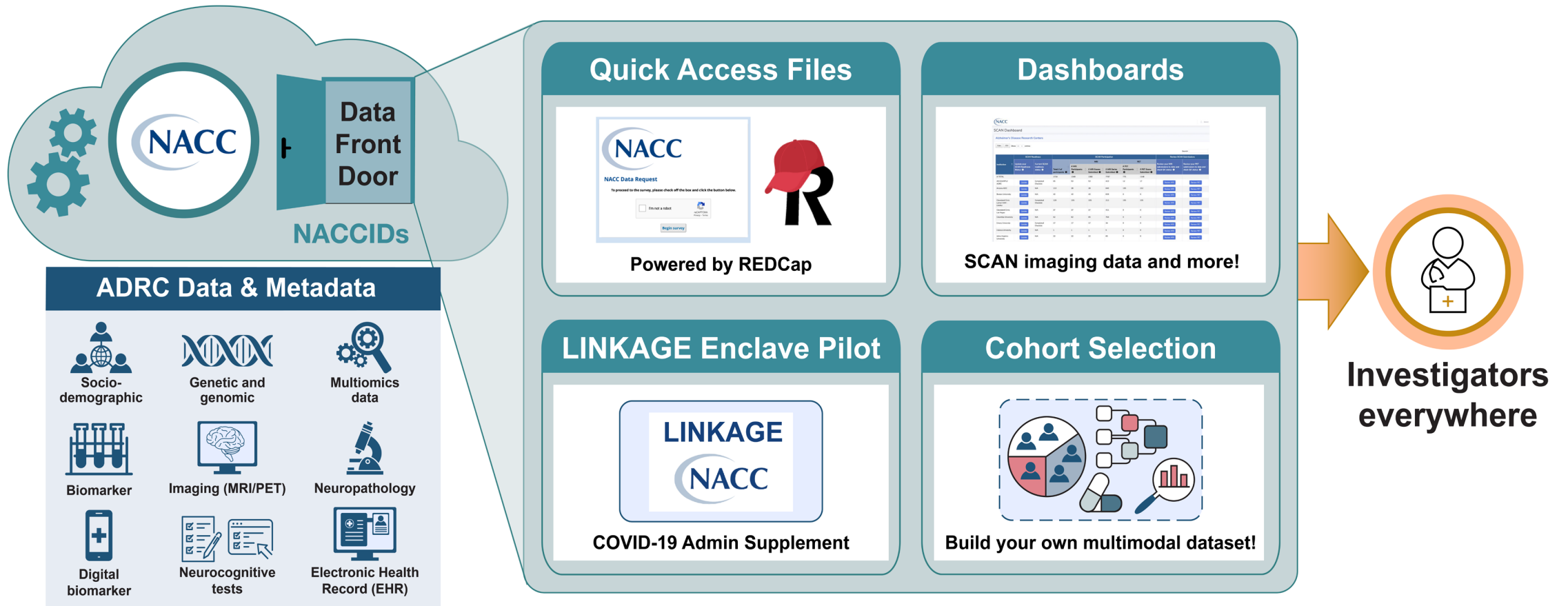
# **NACC Data Front Door: A One-Stop-Shop for CLARiTI Study Data**

# 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



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## Data Coordination & Centralized Repository



## Communication & Collaboration Hub



**New Investigator Support**



# Operations Support

## Study Start-up Support

- Surveys for data informed decisions
- Study start-up dashboard (public)
- CLARiTI-specific directory
- Study Handbook

Data Exports, Reports, and Stats

Number of results returned: 30

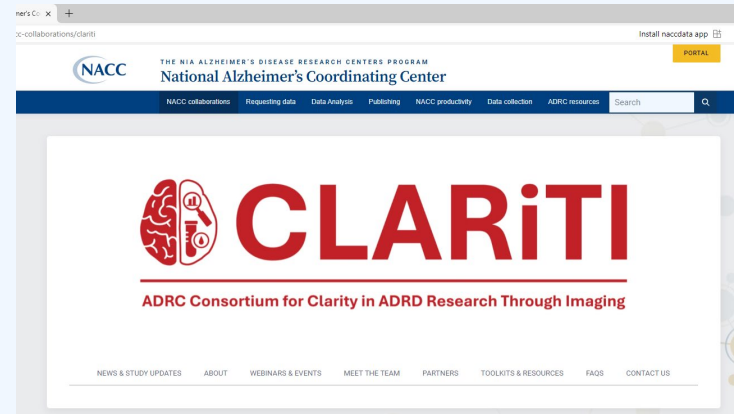
Not under review sorted 31

CLARiTI Study Start-up Dashboard - ranked by points

Site	Site Type	Site Status	Site Points	Site Name	Site Address	Site Contact	Site Phone	Site Email	Site Website	Site Description	Site URL
University of Washington	Site	In Progress	100	University of Washington	1959 University Avenue	Dr. David Holtzman	206 616 7160	david.holtzman@uw.edu	www.washington.edu	University of Washington	www.washington.edu
University of Washington	Site	In Progress	100	University of Washington	1959 University Avenue	Dr. David Holtzman	206 616 7160	david.holtzman@uw.edu	www.washington.edu	University of Washington	www.washington.edu
University of Washington	Site	In Progress	100	University of Washington	1959 University Avenue	Dr. David Holtzman	206 616 7160	david.holtzman@uw.edu	www.washington.edu	University of Washington	www.washington.edu
University of Washington	Site	In Progress	100	University of Washington	1959 University Avenue	Dr. David Holtzman	206 616 7160	david.holtzman@uw.edu	www.washington.edu	University of Washington	www.washington.edu
University of Washington	Site	In Progress	100	University of Washington	1959 University Avenue	Dr. David Holtzman	206 616 7160	david.holtzman@uw.edu	www.washington.edu	University of Washington	www.washington.edu

## Communications & Events Support

- CLARiTI Connect newsletter and webinars to drive engagement
- Launched website for CLARiTI sites
- Building a public-facing recruitment website



## Established Subaward process

- Initiated execution - documentation collected from all sites
- Building a payment dashboard for ADRCs

Sample Center Portal

View, Audit, and Access Data > CLARiTI Dashboard > Payment Tracker

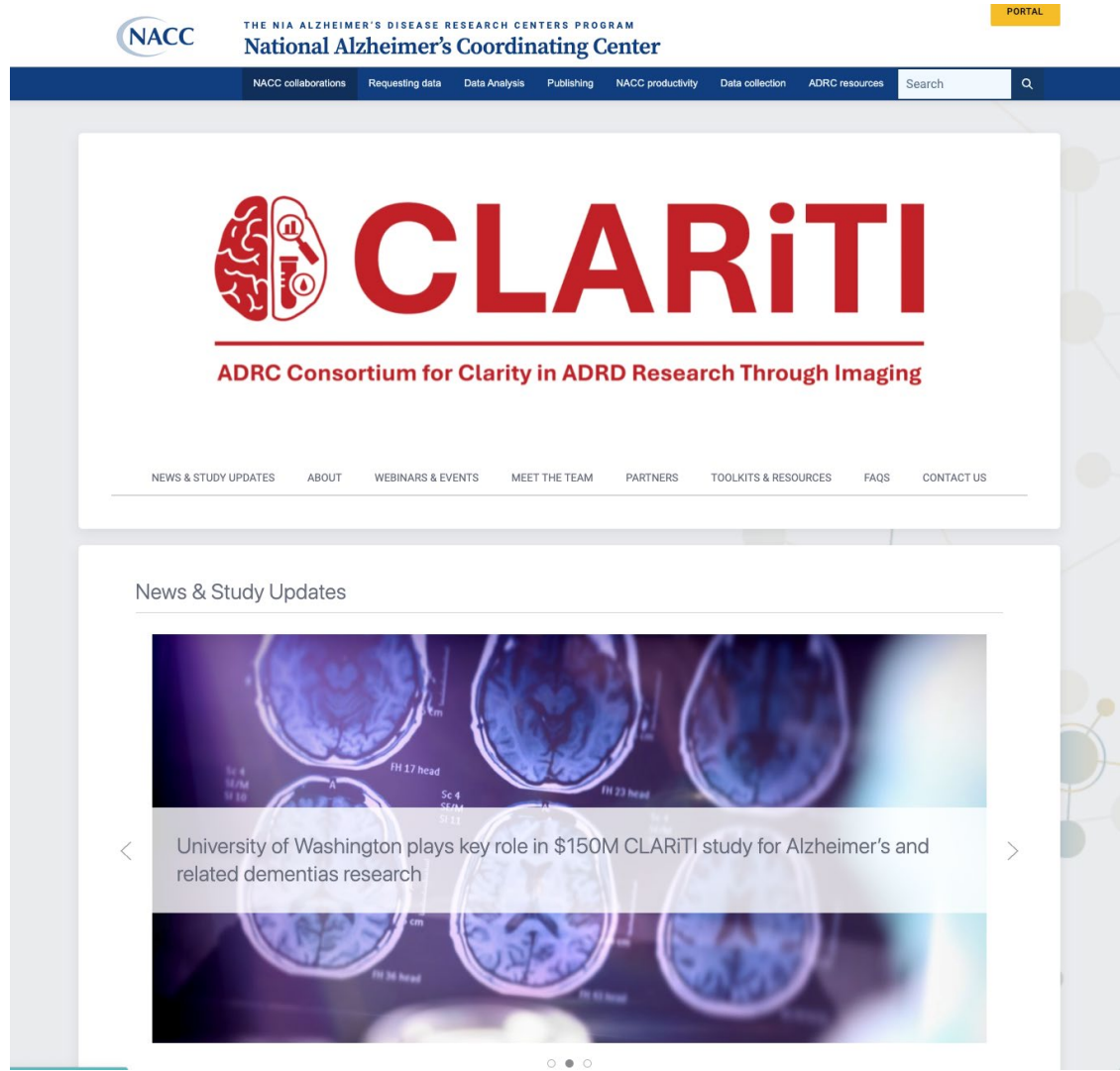
**CLARiTI Payments**

Subawardee Alpha University  
BPO # 12345  
UW ID UWSC12345  
Subaward Amount \$100,000.00

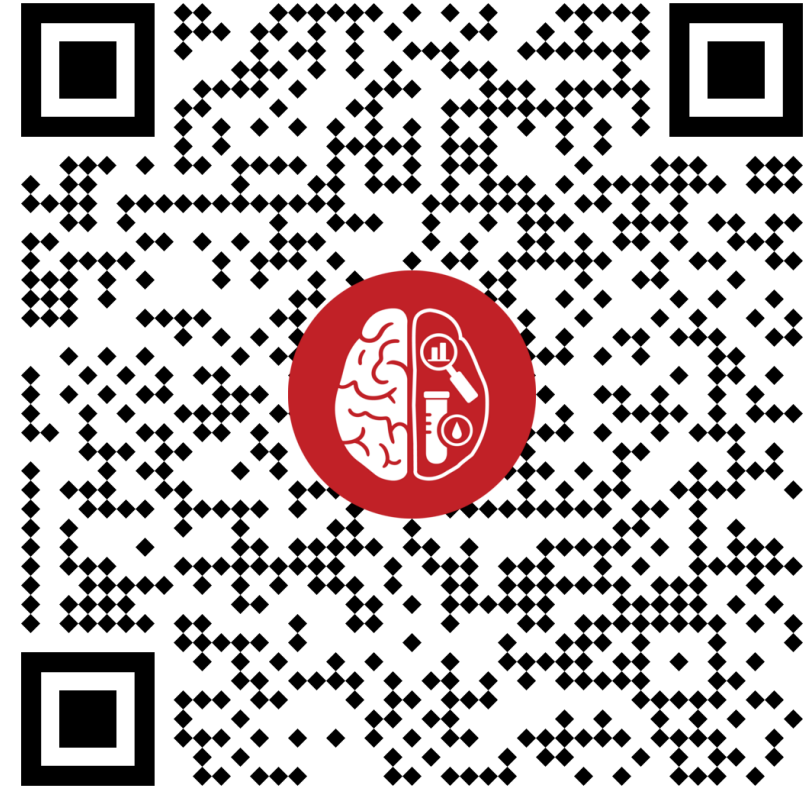
ADRC	NACCID	Procedure Type	Procedure Date	Eligible for Payment	Eligible Payment Amount	Invoice Received Date	Payment Processed Date
Sample ADRC	NACC123456	Advanced MRI	2021-10-01	yes	\$1,000.00	2021-10-15	2021-10-20
Beta Research Center	NACC654321	Amyloid PET	2021-11-01	pending_docs	\$1,500.00	2021-11-15	2021-11-20
Gamma Medical Institute	NACC789012	Tau PET	2021-12-01	no	\$2,000.00	2021-12-15	2021-12-20
Delta Health Center	NACC345678	FDG PET	2022-01-01	paid	\$2,500.00	2022-01-15	2022-01-20

4 rows Rows per page Page 1 of 1

# Operations Support: NACC-hosted website

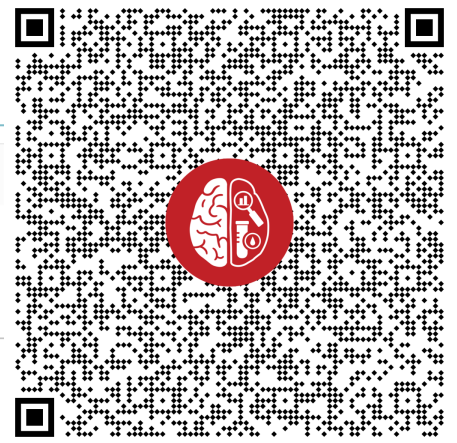


The screenshot shows the homepage of the CLARiTI website. At the top left is the NACC logo and the text "THE NIA ALZHEIMER'S DISEASE RESEARCH CENTERS PROGRAM National Alzheimer's Coordinating Center". A yellow "PORTAL" button is in the top right. Below is a navigation bar with links: "NACC collaborations", "Requesting data", "Data Analysis", "Publishing", "NACC productivity", "Data collection", "ADRC resources", and a search box. The main header features the CLARiTI logo (a brain with a microscope) and the text "CLARiTI" in large red letters, with "ADRC Consortium for Clarity in ADRC Research Through Imaging" below it. A horizontal menu contains: "NEWS & STUDY UPDATES", "ABOUT", "WEBINARS & EVENTS", "MEET THE TEAM", "PARTNERS", "TOOLKITS & RESOURCES", "FAQS", and "CONTACT US". The "News & Study Updates" section is active, showing a carousel of brain scan images with the text "University of Washington plays key role in \$150M CLARiTI study for Alzheimer's and related dementias research".



<https://bit.ly/CLARiTI>

# Operational Support: Study Start-up Dashboard



<https://bit.ly/CLARiTI-Startup-Dashboard>

CLARiTI Study Start-up PID 237

## Data Exports, Reports, and Stats

[VIDEO: How to use Data Exports, Reports, and Stats](#)

[+ Create New Report](#)
[My Reports & Exports](#)
[Other Export Options](#)

Number of results returned: **36**

Total number of records queried: 37

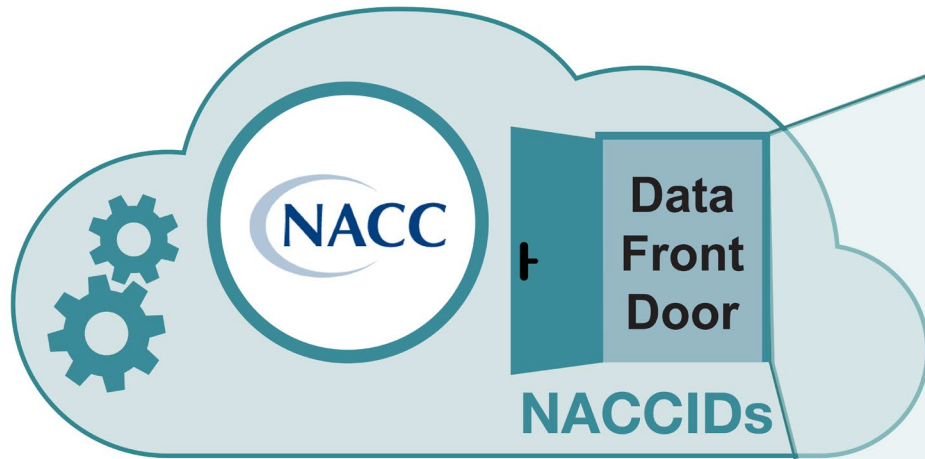
Report execution time: 0.1 seconds

[Public](#)
[Stats & Charts](#)
[Export Data](#)
[Print Page](#)

Live filters: [ADRC Affiliation]

## CLARiTI Study Start-up Dashboard - ranked by points

ADRC Affiliation	Site Initiation Meeting Completed	Site CLARiTI Study Coordinator Designated	Site CLARiTI Outreach Specialist Designated	NACC Subaward Executed	IRB Review Ceded To WCG	WCG Approval	SCAN Qualified Site for CLARiTI	Radiotracers Selected	Manufacturer SOW Filed	Regulatory Documents Completed	UWisc Central Monitoring SIV	LONI Access	ADCFB Protocol Training With NCRAD	Blood Collection Kits Ordered	Site Recr Strat Final
Wisconsin ADRC	Complete	Complete	Complete	Complete	Complete	Complete	Complete	Complete	Complete	Complete	Complete	Complete	Complete	Complete	Complete
Boston University ADRC	Complete	Complete	Complete	In Progress	Complete	Complete	Complete	Complete	Not Started	Complete	In Progress	Complete	Complete	Not Started	In Progress
Mayo Clinic ADRC	Complete	Complete	Complete	In Progress	Complete	Complete	Complete	Complete	In Progress	Not Started	In Progress	Complete	Not Started	Not Started	Not Started
1Florida ADRC	Complete	Complete	Complete	In Progress	Complete	Complete	In Progress	Complete	In Progress	Not Started	In Progress	Complete	Not Started	Not Started	Not Started
South Texas ADRC	Complete	Complete	Complete	In Progress	Complete	Complete	In Progress	Complete	Not Started	Not Started	In Progress	Complete	Not Started	Not Started	Not Started
University of Kansas ADRC	Complete	Complete	Complete	In Progress	Complete	Complete	Not Started	Complete	In Progress	Not Started	In Progress	Complete	Not Started	Not Started	Not Started
Wake Forest University, ADRC	Complete	Complete	Complete	In Progress	Complete	Not Started	Complete	Complete	In Progress	Not Started	Not Started	Complete	Not Started	Not Started	Not Started
Rush University Alzheimer's Disease Center	Complete	Complete	Not Designated	In Progress	In Progress	Not Started	Complete	Complete	In Progress	Not Started	Not Started	Complete	Not Started	Not Started	Not Started
Stanford ADRC	Complete	Complete	Not Designated	In Progress	Complete	Complete	Complete	Complete	Not Started	Not Started	In Progress	Complete	Not Started	Not Started	Not Started
University of Michigan ADRC	Complete	Complete	Not Designated	In Progress	Not Started	Not Started	Not Started	Complete	Not Started	Complete	Not Started	Complete	Complete	Not Started	Not Started
University of Washington ADRC	Complete	Complete	Not Designated	In Progress	Complete	Not Started	Not Started	Complete	Not Started	Not Started	Not Started	Complete	Complete	Not Started	Not Started



## Key AD/ADRD Challenges & Opportunities

Advancing Early Detection

Disentangling Heterogeneity

Validating Blood Biomarkers

Identifying & Stratifying Risk Factors & Protective Mechanisms

Providing Precision Medicine

Improving Generalizability

## NACC Data Platform

Socio-demographic

Neurocognitive tests

Neuro-pathology

Imaging (MRI/PET)

Biomarker

Genetic & genomic

EHR & Claims

Digital data

Multiomics data



# NACC's CLARiTI Team

## CLARiTI Leadership (mPIs)



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



**SARAH BIBER, PHD**  
Executive Director

## CLARiTI Management & Operations Support



**HEATHER O'CONNELL**  
CLARiTI  
Program Manager

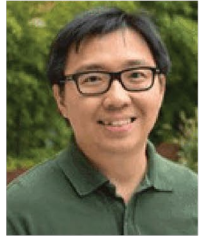


**HANNAH KOENIG**  
CLARiTI Data Manager

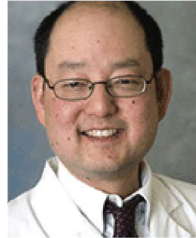


**BRITTANY HALE**  
Project Manager

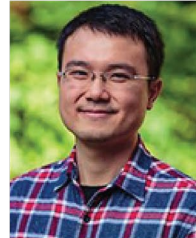
## Co-Investigators



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



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



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



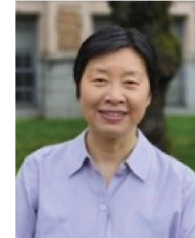
**MARK BAUER, EDD**  
Manager of  
Communications



**AILEEN IDA, MA**  
Communications  
Specialist



**HANNAH  
ROSENTRETER**  
Events & Collaborations  
Manager



**JANE XIA, MHA**  
Grants & Finance  
Manager



**VALERIE HOCKENS**  
Program Operations  
Specialist



**EMILY ALMEDA**  
Administrative  
Coordinator

## Communications & Events Support

## Grants & Finance Support

## CLARiTI Technical Support



**SHILPA  
ALLIMATTI, MS, MBA**  
Technology Lead



**DAN PETERSON**  
Software Engineer



**EMILY CHENG, BS**  
Software Engineer



**LAURA MCLEOD**  
Senior REDCap  
Administrator



**ZACH STARK, BBA**  
Software Engineer



**BEN KELLER, PHD**  
Software Engineer



**JANENE HUBBARD, BS**  
Research Consultant



**BRENDAN SMITH, BS**  
Software Developer