



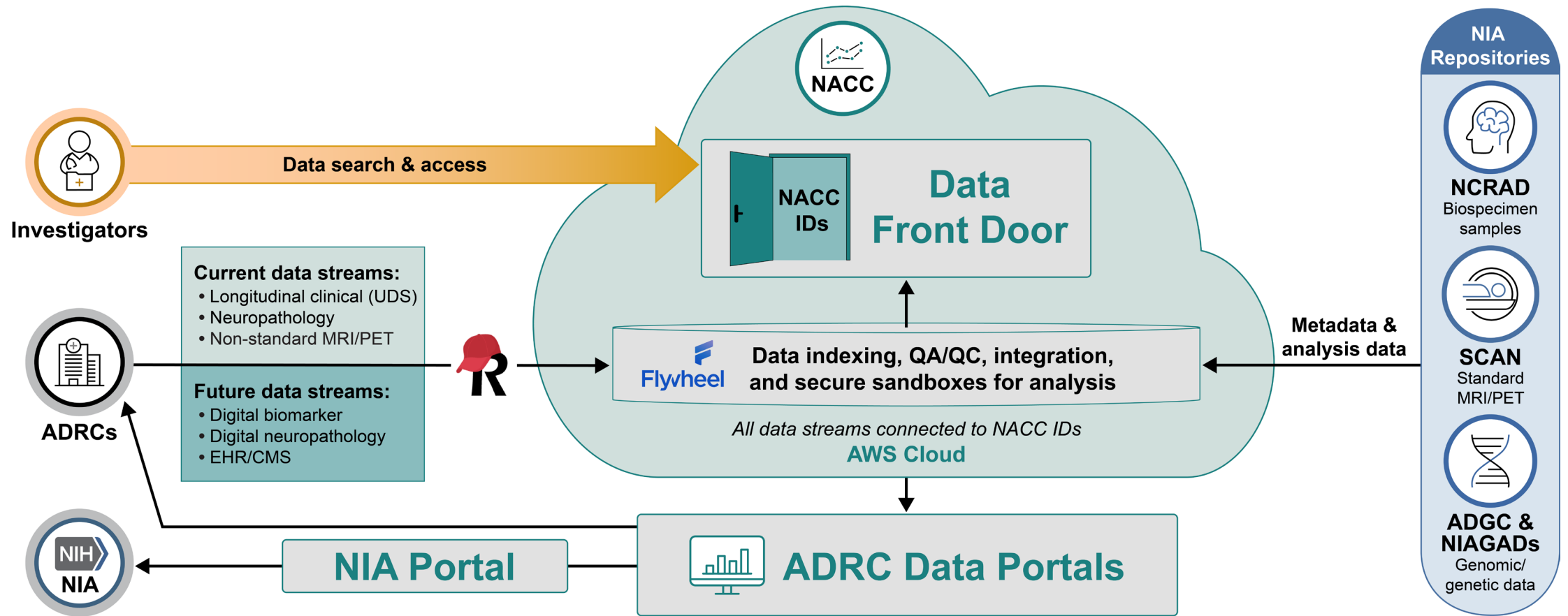
# New Ways to Access Your Data

**Sarah Biber, PhD**

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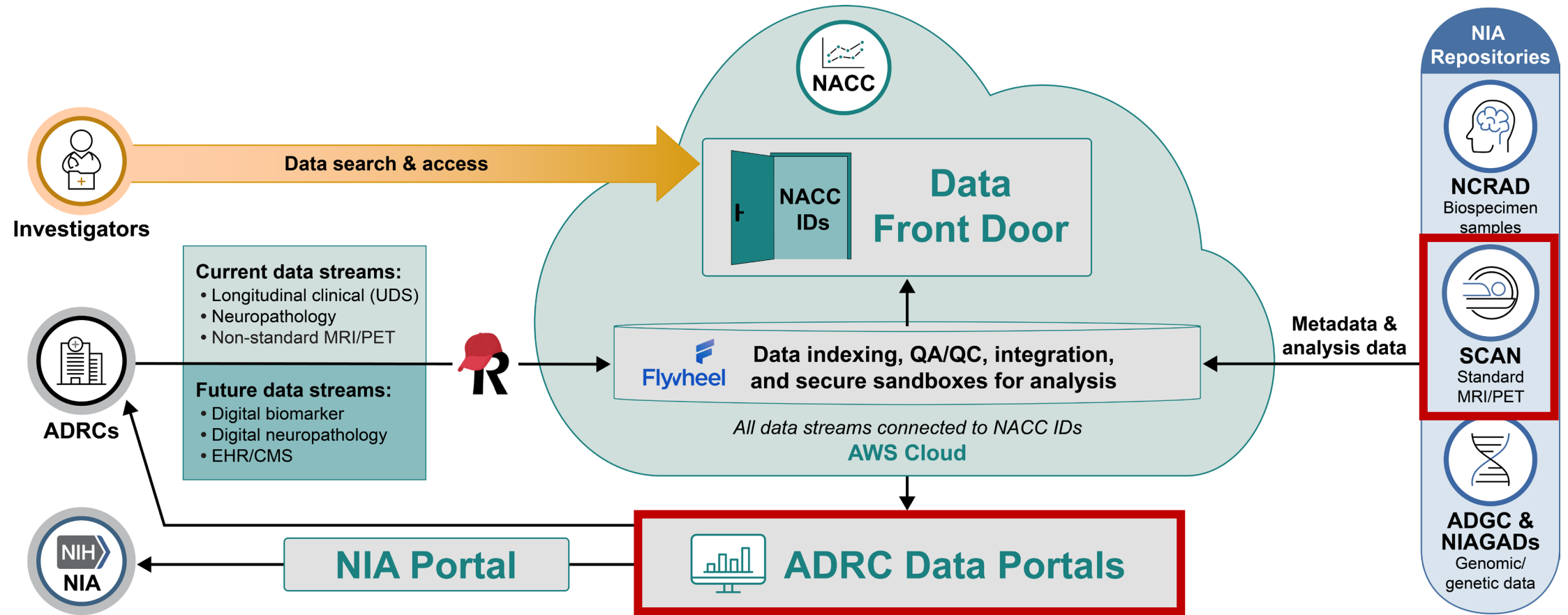
**NACC Session, October 20, Fall 2023 ADRC Meeting**

# NACC Data Platform





# NACC Data Platform – The SCAN Story



# ADRC Data Portals



Alzheimer's Disease  
Research Centers  
(ADRCs)

Current  
Data  
Streams

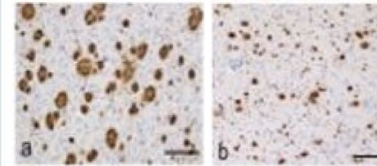
New  
Data  
Streams

## ADRC Data Portals

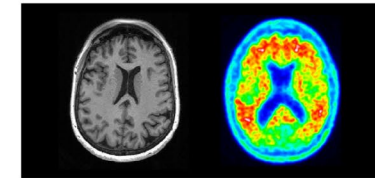
### Harmonized Phenotypic Data (UDS)

	Initial Visit (IVV)	Follow-up Visit (FVV)	Ttl. Initial Visit (TIFV)	Ttl. Follow-up (TFFV)
A1: Subject Demographics				
A2: Co-participant Demographics				
A3: Subject Family History				
A4: Subject Medications				

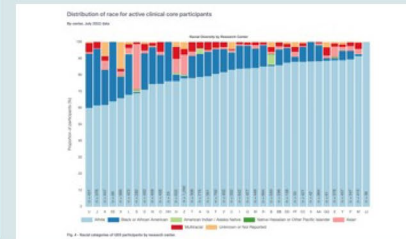
### Neuropathology Reports



### Non-Standard MRI/PET



### Participant Diversity Dashboard



### ADRC SCAN MRI/PET QC Dashboards

NACC Site-Specific Dashboard > Western Iowa PET Data

Review PET Data

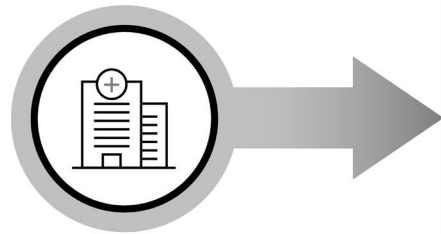
ADRC	NACC ID	PTV ID	Study Date and Time	Image Voxel	Scanner Model	PET Radionuclide	QC Status	Validated
Western Iowa	NACC00007	108	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC14002	128	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC12803	728	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC12804	728	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC04008	400	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC04009	400	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC04010	400	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC04011	400	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC04012	400	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC04013	400	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC04014	400	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC04015	400	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC04016	400	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC04017	400	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC04018	400	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC04019	400	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	
Western Iowa	NACC04020	400	03/01/2015 0:00	00000000	Siemens Pretec	18F-FDG	Passed	

### Specimen / Marker / Genetic Metadata





# ADRC Portals - The SCAN Story



Alzheimer's Disease  
Research Centers  
(ADRCs)

Current  
Data  
Streams

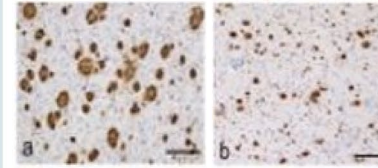
New  
Data  
Streams

## ADRC Data Portals

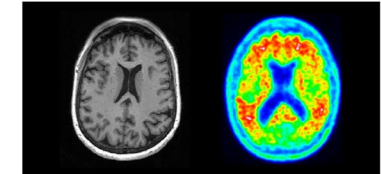
### Harmonized Phenotypic Data (UDS)

	Initial Visit (I1P)	Follow-up Visit (F1P)	Tel. Initial Visit (I1P)	Tel. Follow-up (F1P)
A1: Subject Demographics				
A2: Co-participant Demographics				
A3: Subject Family History				
A4: Subject Medications				

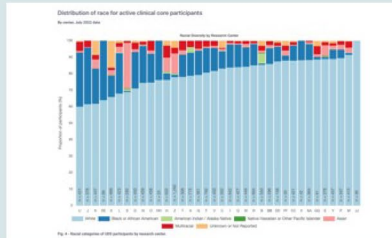
### Neuropathology Reports



### Non-Standard MRI/PET



### Participant Diversity Dashboard



### ADRC SCAN MRI/PET QC Dashboards

Site-Specific Dashboard - Western Iowa PET Data

Review PET Data

Study	Image ID	Scanner Model	PET calibration	QC Status	Final QC
Western Iowa - 1445314902	1445314902	Biograph Horizon	Passed	Passed	Passed
Western Iowa - 1445314903	1445314903	Biograph Horizon	Passed	Passed	Passed
Western Iowa - 1445314904	1445314904	Biograph Horizon	Passed	Passed	Passed
Western Iowa - 1445314905	1445314905	Biograph Horizon	Passed	Passed	Passed
Western Iowa - 1445314906	1445314906	Biograph Horizon	Passed	Passed	Passed
Western Iowa - 1445314907	1445314907	Biograph Horizon	Passed	Passed	Passed
Western Iowa - 1445314908	1445314908	Biograph Horizon	Passed	Passed	Passed
Western Iowa - 1445314909	1445314909	Biograph Horizon	Passed	Passed	Passed
Western Iowa - 1445314910	1445314910	Biograph Horizon	Passed	Passed	Passed

### Specimen / Marker / Genetic Metadata



# ADRC Portals Demo – The SCAN Story



**BRENDAN  
SMITH**  
Database  
Administrator

A screenshot of a web dashboard titled "Alpha University ADRC Portal". The dashboard features a navigation bar with "About", "Impact", "ADRC Portal", and "Research" menus. The main content area is a grid of data cards. The top row shows summary statistics: "Participants 1,234", "MRI Scans 5,678", "PET Scans 9,012", and "NP Forms 34,567". Below these are four data visualization cards: "Harmonized Phenotypic Data (UDS)", "Neuropathology Reports", "Non-Standard (Legacy) MRI/PET", and "SCAN Data" (which features the SCAN logo). The bottom row contains four more cards: "Biomarker and Biospecimen Data" (with NCRAD logo), "Genetic and Genomic Data" (with NIAGADS logo), "View Available Data Modalities for All Participants" (describing a high-level overview), and "Individual Participant Data" (describing direct access to UDS, SCAN, and NP data).

**ADRC Data Portals are Live & Accessible!**

# Provide Input on the ADRC Portal!

Go to  
<https://redcap.link/x4rqgmp4>

or scan this QR code!





# ADRC Directory – Authorization

34/37 ADRCs have completed this task!



**Ben Keller**  
Software  
Engineer 3



**Laura McLeod**  
Senior REDCap  
Administrator



**Amy Young**  
Public Information  
Specialist



Link for administrators to  
authorize access to Flywheel:

<https://bit.ly/NaccDirectoryAdmin>

**NACC Directory** PID 78

**Data Exports, Reports, and Stats** VIDEO: How to use Data Exports, Reports, a

+ Create New Report My Reports & Exports Other Export Options View Report: All Individual ADRC contacts

Number of results returned: **1551**  
Total number of records queried: 1818  
Report execution time: 0.4 seconds

Stats & Charts Export Data Print Page Edit Report

Live filters: [ADRC Affiliation] [NACC Data Platform] [REC Scholar]

### All Individual ADRC contacts

Center Admins - please click on the Live Filter for 'ADRC Affiliation' above and select your Center. You will then see a list that only contains entries related to your Center. To watch a video introduction of this page, [please click here](#).

Next, review the list of entries associated with your Center:

This report also includes two additional "live filters" to sort and identify quickly who has:

- Data Access Privileges
- REC Scholar of REC Scholar Alumnus Status

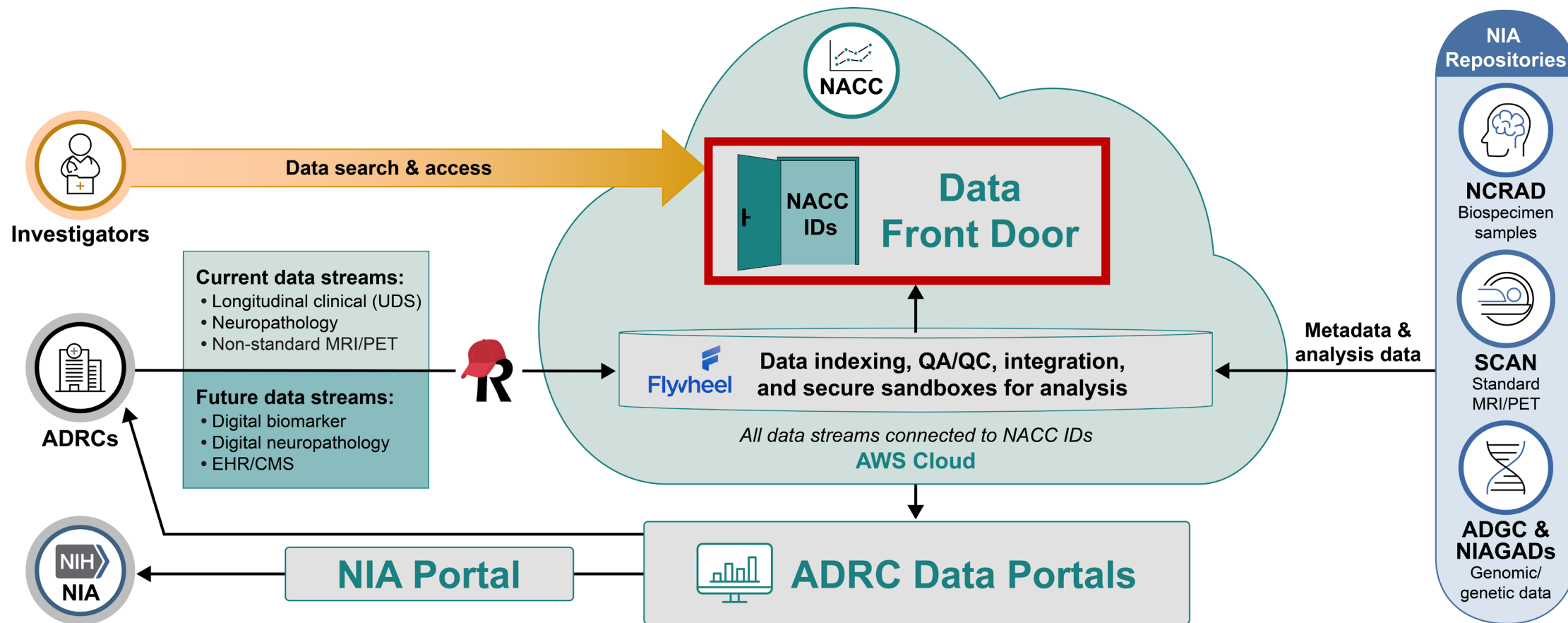
Once you have found the contact you want to update, click on the "Record ID Number" or "Contact" link to open their individual contact record. Identify the fields that require updating and then click "Save" at the bottom of the contact record form.

While you're reviewing your ADRC contacts, please check to see...

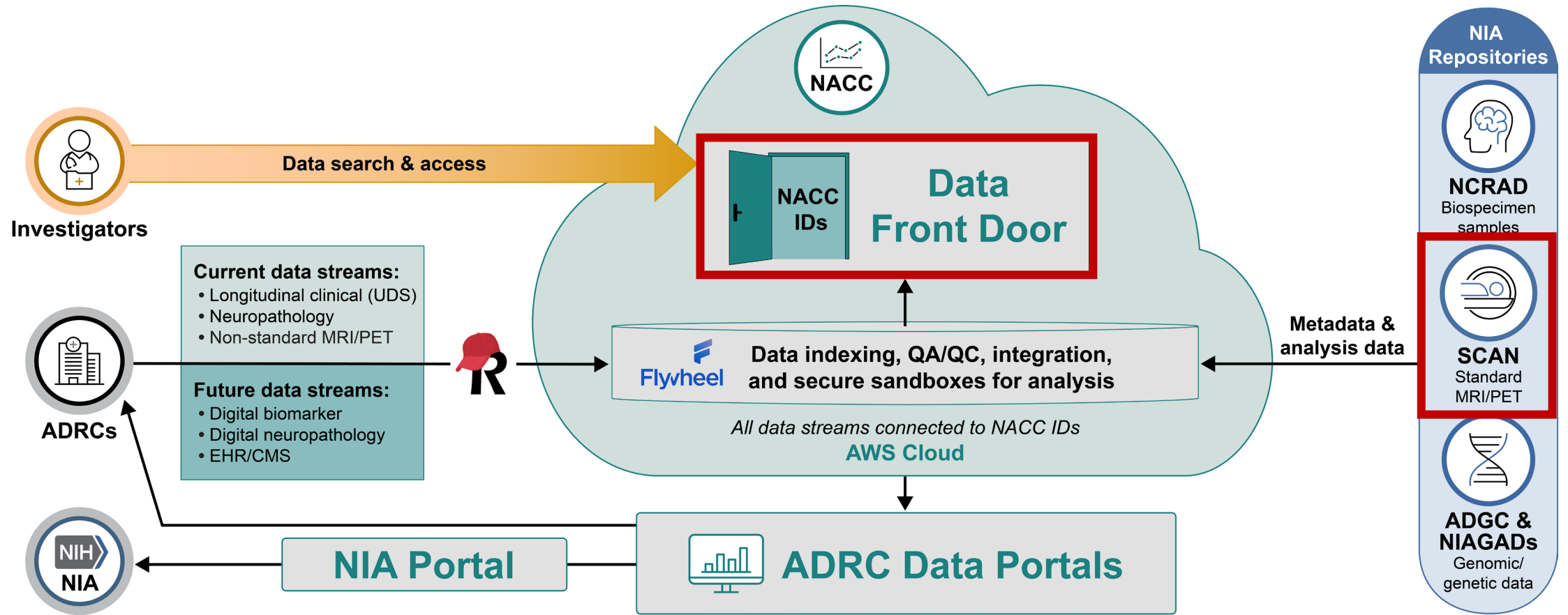
- Is everyone on the list still with the ADRC?
  - [click here](#) to learn how to **archive** someone from your list
- Is there anyone missing from the list?
  - [click here](#) to learn how to **add** a contact to your list
- Are the email addresses correct?
  - the primary email address should be an institutional email address
  - [click here](#) to learn how to **edit** an email address
- Update contacts for **access to the NACC Data Platform**
  - [click here](#) to learn how to update a contact that should have a Flywheel account (and, therefore, access to the NACC Data Platform)
  - *Individuals at your Center should have access to a Flywheel account if they are involved in submission, curation, audits and approval of data at NACC, as well as viewing summary center data reports. This would include Center Directors or anyone that now receives monthly reports.*
- Other important updates for ADRC Members:
  - Identify REC Scholars and Alumni at your ADRC
  - Administrator Mentor/Mentee status
  - Update your ADRC logo, social media, and other ADRC information: [Company and Leadership Form](#)

Please email Amy Young at [ayoung1@uw.edu](mailto:ayoung1@uw.edu) with any questions.

# NACC Data Platform

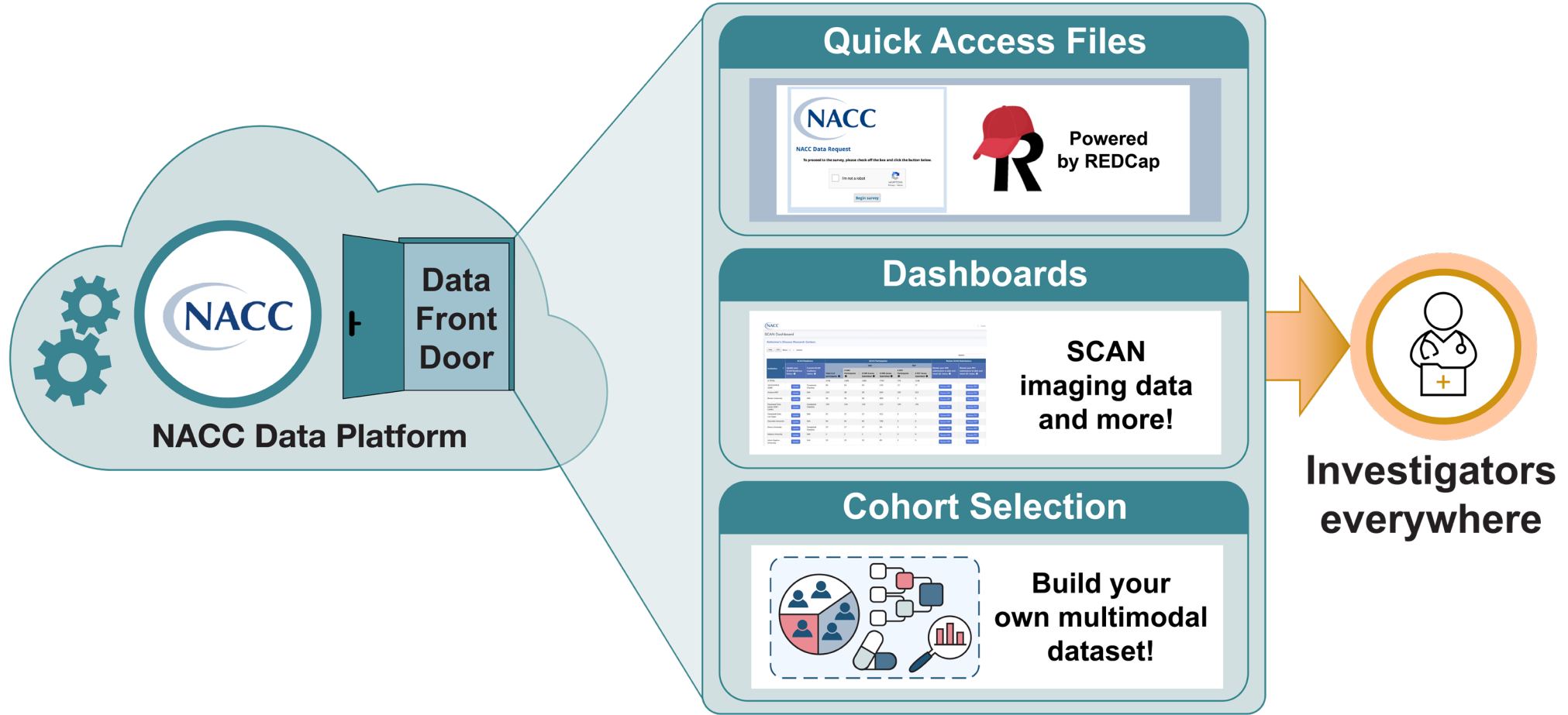


# NACC Data Platform – The SCAN Story



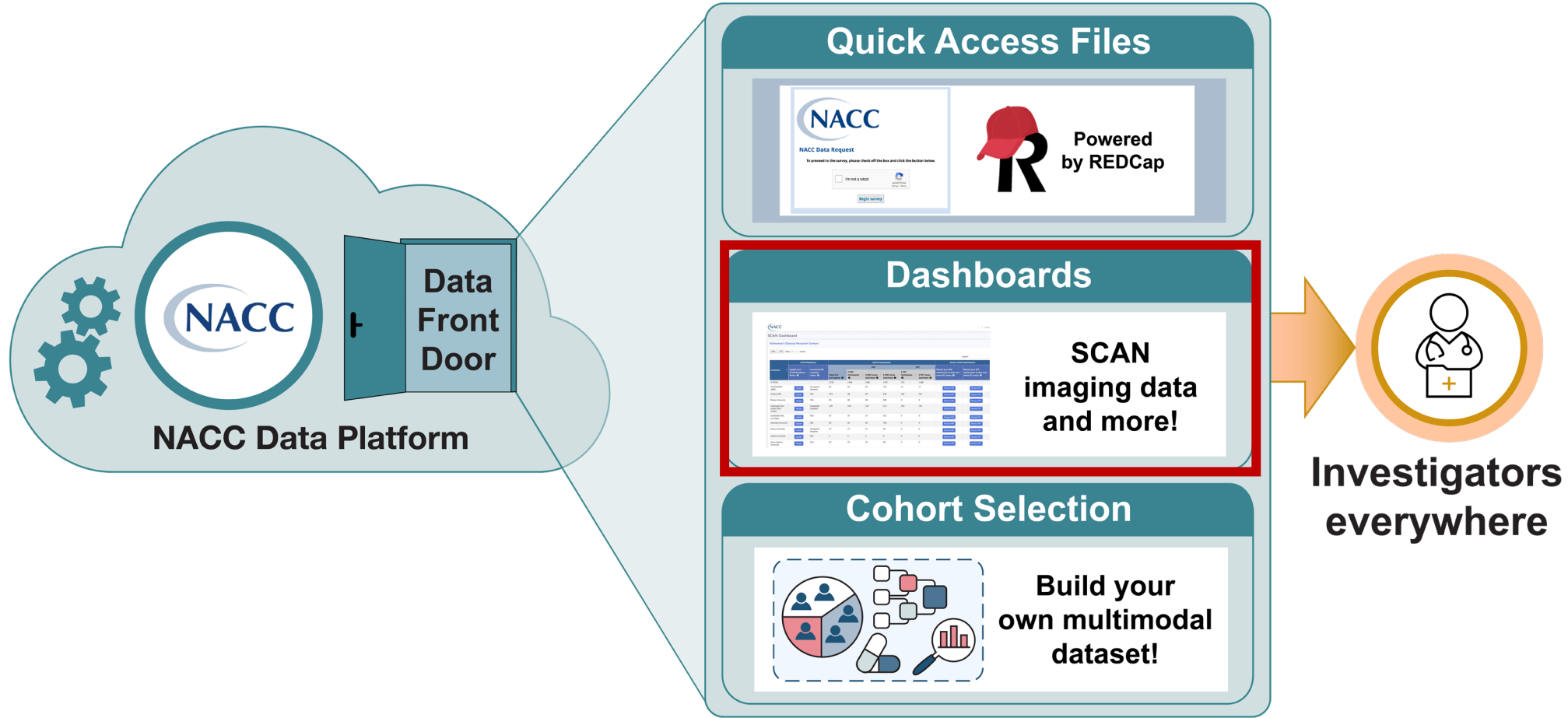
# Data Front Door - Advanced Data Search and Access

One-Stop-Shop for All ADRC Data



# Data Front Door - Advanced Data Search and Access

One-Stop-Shop for All ADRC Data





# SCAN Public Dashboard Demo



**BRENDAN SMITH**  
Database Administrator

SCAN Public Dashboard

This dashboard tracks the number of SCAN-compliant MRI/PET images and the number of participants that images have been submitted for by each Alzheimer's Disease Research Center to LONI/NACC. [Learn more about the Dashboard.](#)

Have feedback on the SCAN dashboard? [Submit it here!](#)

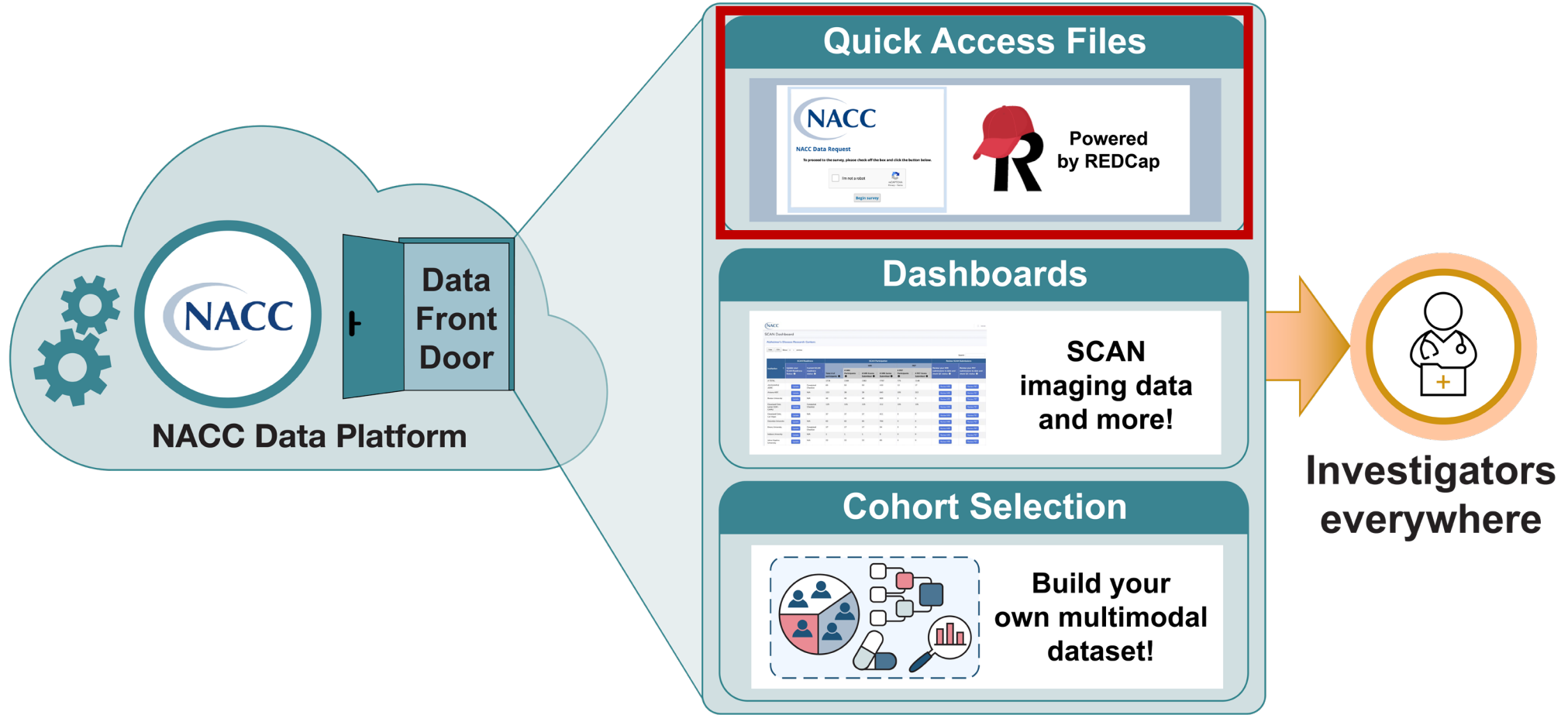
Alzheimer's Disease Research Centers COPY CSV

Institution	SCAN Participation						Private Dashboard
	Total # of Participants	MRI			PET		
		# MRI participants	# MRI exams submitted	# MRI series submitted	# PET participants	# PET scans submitted	
<b>Total</b>	3,405	2,888	3,264	16,885	1,600	2,858	
Mayo Clinic	352	235	295	878	325	805	PRIVATE DASH
Wake Forest University	335	272	281	728	174	271	PRIVATE DASH
University of Wisconsin	297	271	321	745	150	318	PRIVATE DASH
University of Pittsburgh	217	136	136	406	85	168	PRIVATE DASH
New York University	191	189	278	427	72	98	PRIVATE DASH
University of California, San Francisco	177	148	145	860	45	86	PRIVATE DASH
Arizona ADC	161	74	75	1,619	153	316	PRIVATE DASH

**SCAN Public Dashboards are Live & Accessible!**

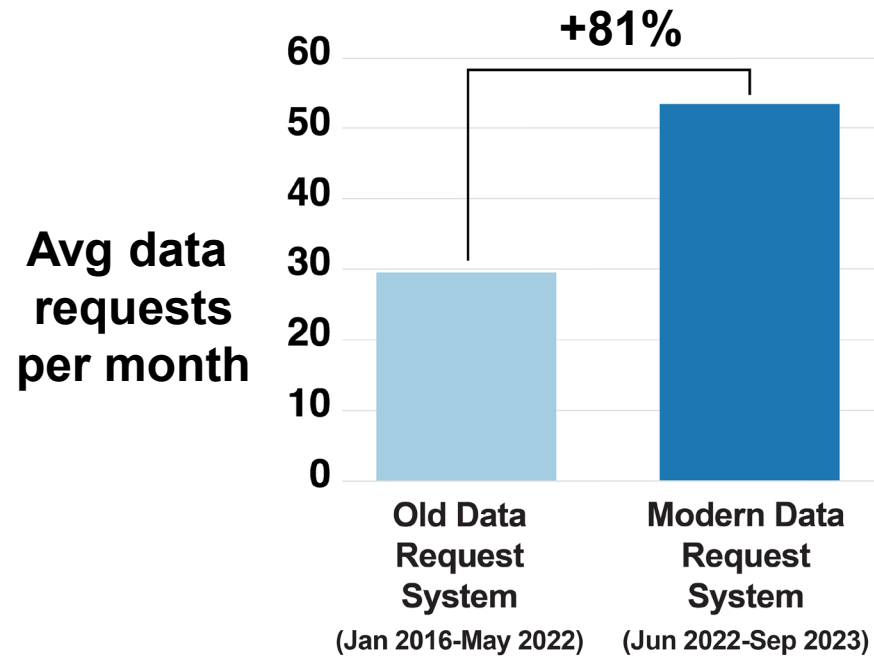
# Data Front Door - Advanced Data Search and Access

One-Stop-Shop for All ADRC Data

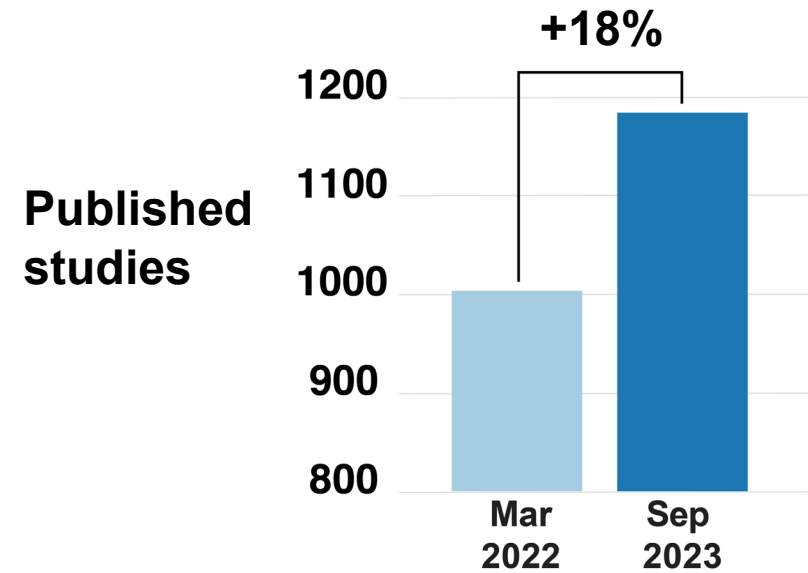


# Modern Quick Access File → Increases Data Utilization

81% increase in the average number of data requests



18% increase in the number of published studies using NACC data



# Access NACC Data Today

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.



**NACC**

**NACC Data Request**

To proceed to the survey, please check off the box and click the button below.

I'm not a robot

reCAPTCHA  
Privacy - Terms

**Begin survey**

Powered by REDCap

**Login into the existing data request system:**  
<https://naccddata.org/requesting-data/data-request-process>

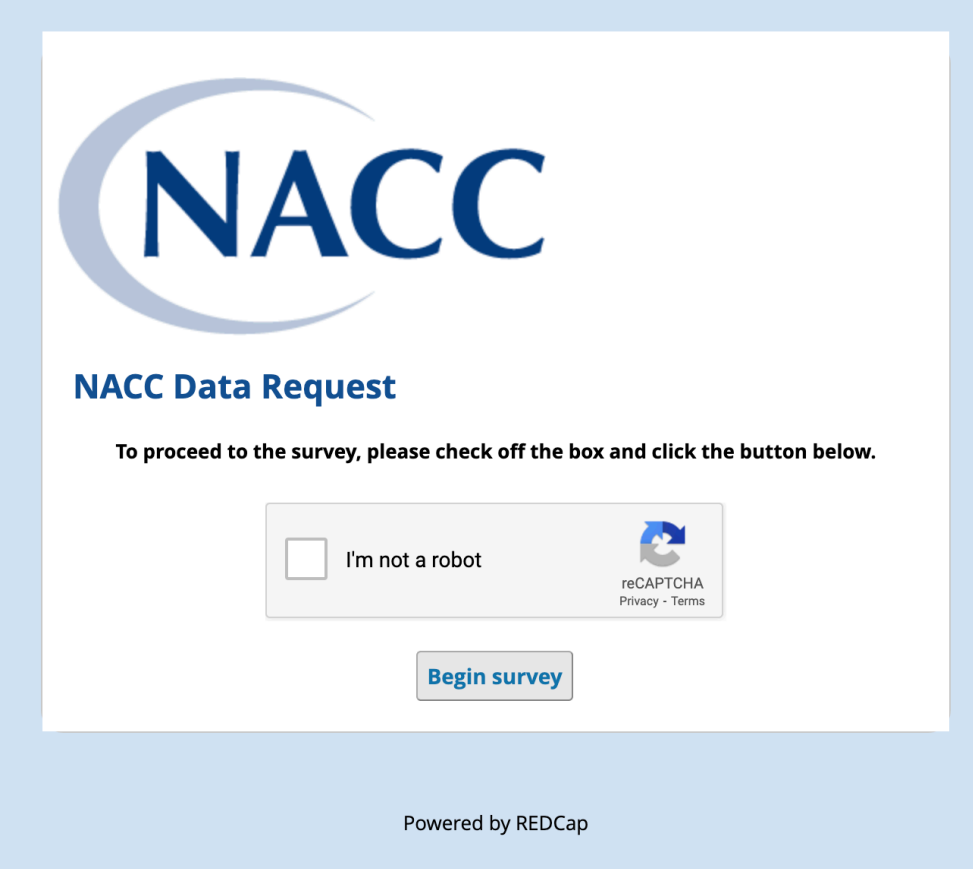
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I'm not a robot

reCAPTCHA  
Privacy - Terms

[Begin survey](#)

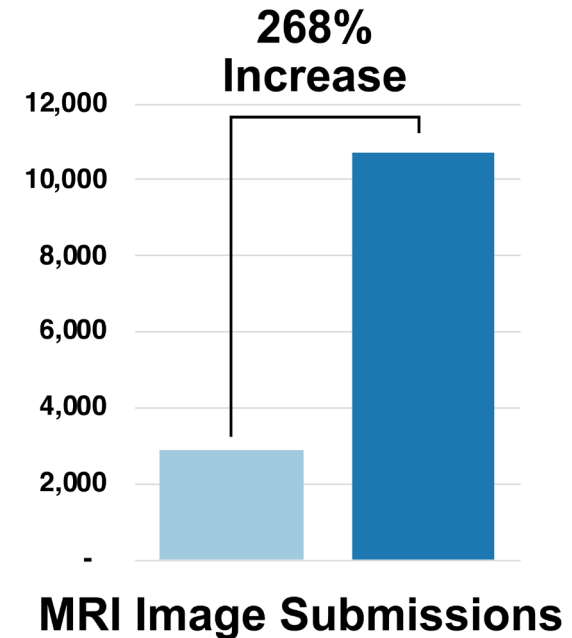
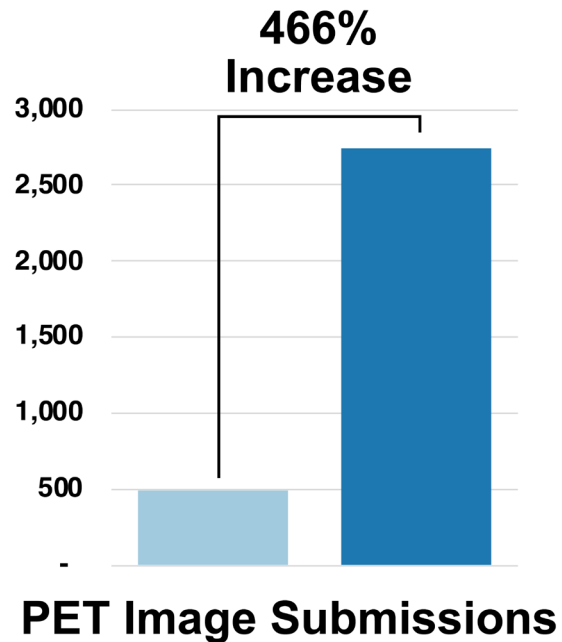
Powered by REDCap

**All SCAN variables will be available in November 2023!**

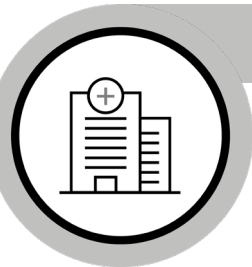


# Facilitating ADRC Participation

- **NACC's support has contributed to a dramatic increase in SCAN submissions between March 2022 and October 2023**
  - 2,746 PET scans from 20 sites
  - 10,690 MRI scans collected from 30 sites



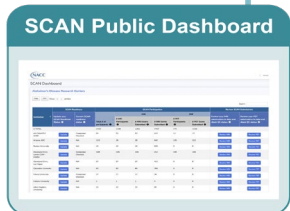
## ADRCs Access



**ADRC Portals:**

- SCAN QC Dashboards (MRI/PET)

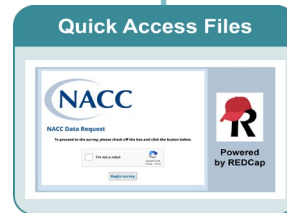
**Oct  
2023**



**NACC Data Front Door**

- SCAN Dashboard (Public)

**Nov  
2023**



**NACC Data Front Door**

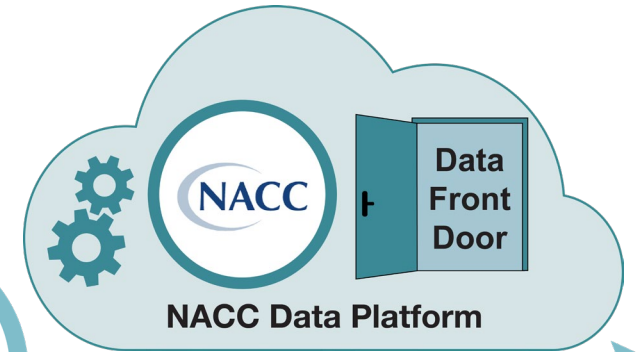
- All SCAN data available via Quick Access File: SCAN metadata and analysis (connected to NACC IDs)

**ADRC Portals:**

- All SCAN data variables available

- MRI: Volume
- PET: SUVR for amyloid & tau

**Future**



### NACC Data Front Door

- **Cohort Selection Tool:** Build your own multimodal dataset!
- **Secure Enclave:** Download your dataset into a secure enclave for analysis

**LONI Data Request:** Request raw images



**Free for Researchers Everywhere**

# SCAN Quick Start Guide

## Learn how to:

- Access the SCAN Public Dashboard
- Access your ADRC's SCAN MRI and PET QC Dashboards




**Brittany Hale**  
NACC Project  
Manager


The cover page of the 'SCAN Dashboard Quick Guide'. It features a blue and white color scheme. At the top, the title 'SCAN DASHBOARD QUICK GUIDE' is written in large, bold, blue letters. Below the title, the word 'CONTENTS' is written in white on a dark blue background, followed by a bulleted list of topics: 'Overview', 'Accessing the SCAN Dashboards', 'Navigating the SCAN Dashboards', and 'Where to go for Help & Questions'. A QR code is located in the bottom right corner, with a small 'b' logo in the center. Below the QR code is a button that says 'SCAN ME' with a mobile phone icon. At the bottom left of the cover is the NACC logo, and at the bottom right is the URL 'bit.ly/scan\_dashboard'.


**SCAN DASHBOARD  
QUICK GUIDE**

**CONTENTS**

- Overview
- Accessing the SCAN Dashboards
- Navigating the SCAN Dashboards
- Where to go for Help & Questions







[bit.ly/scan\\_dashboard](https://bit.ly/scan_dashboard)

# Goal: Identify and Address Barriers

## Interviewed 20 ADRCs

- Interviews conducted in May and June of 2022
- Identified needed solutions
  - SCAN Dashboard
  - Rapid QC feedback loop
  - Submission interface with verification step



**Brittany Hale**  
NACC Project Manager



**Cerise Elliott, PhD**  
NIA Program Director



**Sterling Johnson, PhD**  
Imaging SC Chair



**Sarah Biber, PhD**  
NACC Program Director

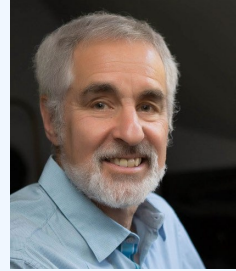
Institution	SCAN Connection
UNIVERSITY OF CALIFORNIA AT DAVIS	SCAN Collaborator, Imaging Steering Committee
MAYO CLINIC ROCHESTER	SCAN Co-I, Imaging Steering Committee
UNIVERSITY OF MICHIGAN AT ANN ARBOR	SCAN Collaborator
UNIVERSITY OF SOUTHERN CALIFORNIA	SCAN Collaborator, Supplement
UNIVERSITY OF WISCONSIN-MADISON	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





## SCAN MRI team

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



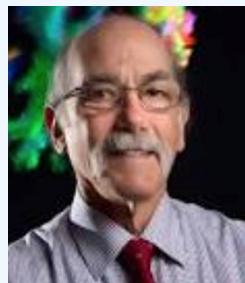
## SCAN PET team

- William Jagust MD (PI)
- Bob Koeppe, PhD
- Susan Landau, PhD
- Tessa Harrison
- Suzanne Baker
- JiaQie Lee
- Trevor Chadwick
- Pablo Aguilar



## NACC Team

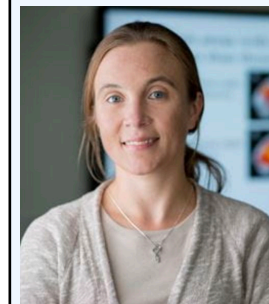
- Bud Kukull, PhD
- Sarah Biber PhD
- Brittany Hale
- Brendan Smith
- Ben Keller
- Zach Stark
- Jess Welsch
- Jessica Culhane



## LONI

- Arthur Toga, PhD
- Karen Crawford, MLIS

## Imaging Core Steering Committee







## SCAN MRI team

- Clifford Jack MD (PI)
- Charles DeCarli, MD
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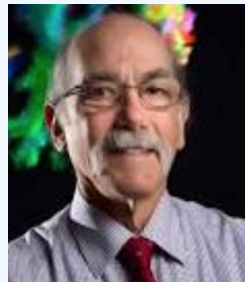
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## NACC Team

- Bud Kukull, PhD
- Sarah Biber PhD
- **Brittany Hale**
- **Brendan Smith**
- **Ben Keller**
- **Zach Stark**
- **Jessica Culhane**



## LONI

- Arthur Toga, PhD
- Karen Crawford, MLIS

## Key NACC Team Members



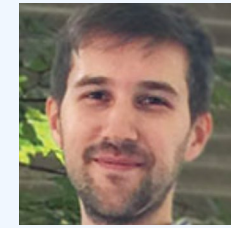
**Brittany Hale**  
Project  
Manager



**Brendan Smith**  
Database  
Administrator



**Ben Keller**  
Software  
Engineer 3



**Zach Stark**  
Software  
Engineer 3



**Jessica Culhane**  
Research  
Scientist 3

# Provide Input on the SCAN Dashboards!

Go to

<https://nacc.redcap.rit.uw.edu/surveys/?s=Y7YKAWWDCJHYHJCT>

or scan this QR code!



**Thank you!**



# Connect with Dr. Biber

**Sarah Biber, Ph.D.**

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

