



# NACC Session

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**Tuesday, May 2, 2023**  
**2023 Spring ADRC Meeting**

# Welcome to the NACC Session!

Topic	Speaker Name
<b>Progress Update: NACC Modernization and the New NACC Data Platform</b>	Sarah Biber, PhD - NACC
<b>Updates on Social Determinants Module for UDS4</b>	Lisa Barnes, PhD – RUSH ADRC
<b>NACC and ADRC Collaborative Neuroimaging Efforts</b>	Elizabeth Mormino, PhD - Stanford ADRC
<b>Electronic Data Capture Workgroup: A NACC-ADRC Collaborative Effort</b>	Sudeshna Das, PhD - Massachusetts ADRC
<b>ALZ-NET and NACC: Opportunities for Collaboration and Synergy</b>	Gil Rabinovici, MD - UCSF ADRC
<b>Multimodal Deep Learning for Dementia Assessment</b>	Vijaya Kolachalama, PhD - Boston University ADRC
<b>Generalizable Deep Learning Model for Early Alzheimer's Disease Detection from Structural MRIs</b>	Narges Razavian, PhD - NYU ADRC
<b>Genetic Drivers of Risk and Resilience</b>	Tim Hohman, PHD - Vanderbilt Exploratory ADRC
<b>Shared Q&amp;A</b>	All Speakers Above and Melissa Lerch, PhD - NACC Ben Keller, PhD – NACC



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



**SARAH BIBER, PHD**  
Program Director



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



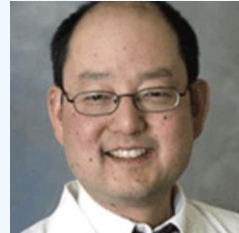
**KARI STEPHENS, PHD**  
Associate Director,  
NACC, Associate  
Professor, Family Medicine



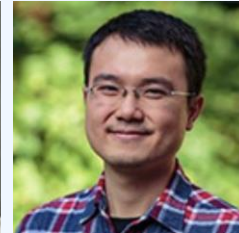
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**DEAN K. SHIBATA, MD**  
Co-investigator, NACC;  
Professor, Radiology



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



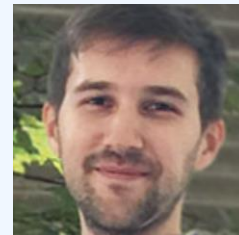
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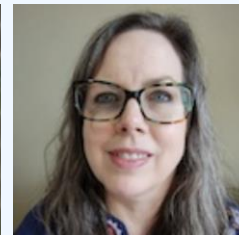
**BEN KELLER, PHD**  
Software Engineer 3



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



**ZACH STARK, BBA**  
Software Engineer 3



**LAURA MCLEOD**  
Senior REDCap  
Developer



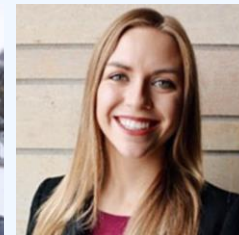
**JOYLEE WU**  
Database Administrator



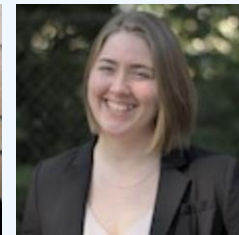
**JANENE  
HUBBARD, BS,** Research  
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**BRENDAN SMITH**  
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**HANNAH ROSENRETER**  
Manager of Special Projects



**BRITTANY HALE**  
Project Manager



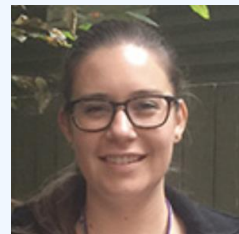
**FAITH BUCKLEY**  
Admin Specialist



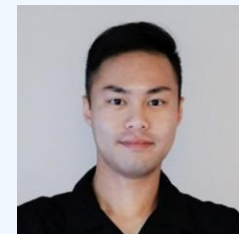
**MELISSA LERCH, PHD**  
Research Manager



**JESSICA CULHANE**  
Research Scientist 3



**KATHRYNN  
GAUTHREAUX**  
Research Scientist 3



**YUEQUAN WU, PHD**  
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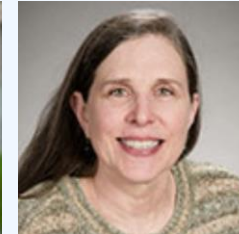
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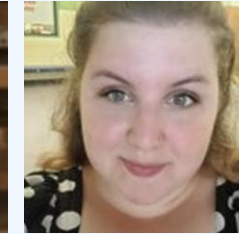
**JINGYAN XIA**  
Grants & Finance Manager



**VALERIE HOCKENS**  
Program Ops Specialist -  
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**AMY YOUNG**  
Public Information  
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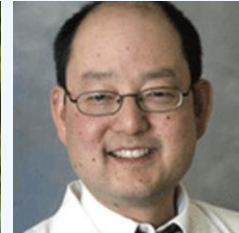
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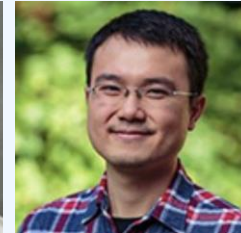
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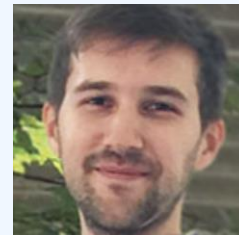
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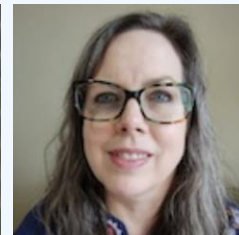
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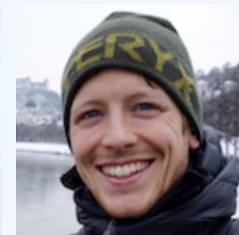
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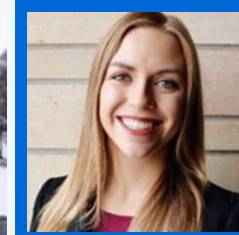
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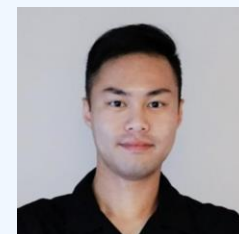
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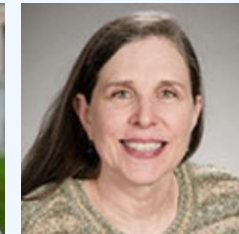
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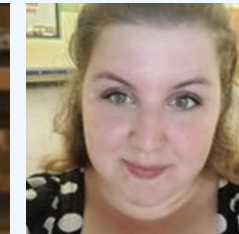
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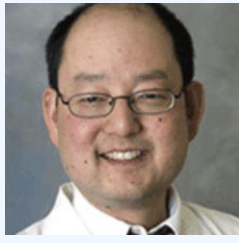
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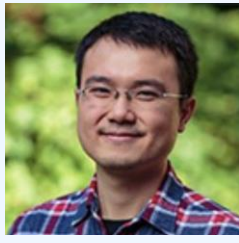
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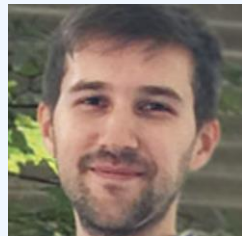
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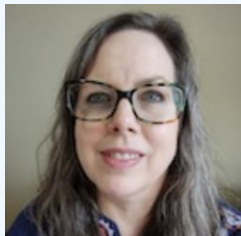
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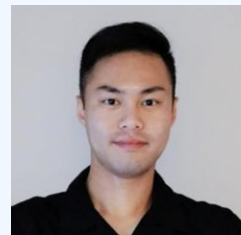
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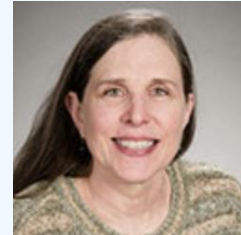
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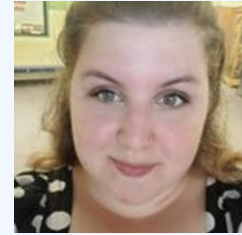
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# **Progress Update: NACC Modernization and the New NACC Data Platform**

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**Sarah Biber, PhD | NACC Program Director**

**May 1, 2023**

**2023 ADRC Spring Meeting**

# Overview of NACC's Expanded Mission and Role

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

## Data Coordination Hub

**F**indable 

**A**ccessible 

**I**nteroperable 

**R**eusable 

## Communication & Collaboration Hub



# UDS Impact

## UDS Updates



**47,777+**

Participants with data at NACC  
(17,000+ active participants)



**177,180+**

Clinical assessments  
(1-18 visits per participant; median =3.7)



**7,479+**

Neuropathology datasets  
(From 58% of deceased participants)



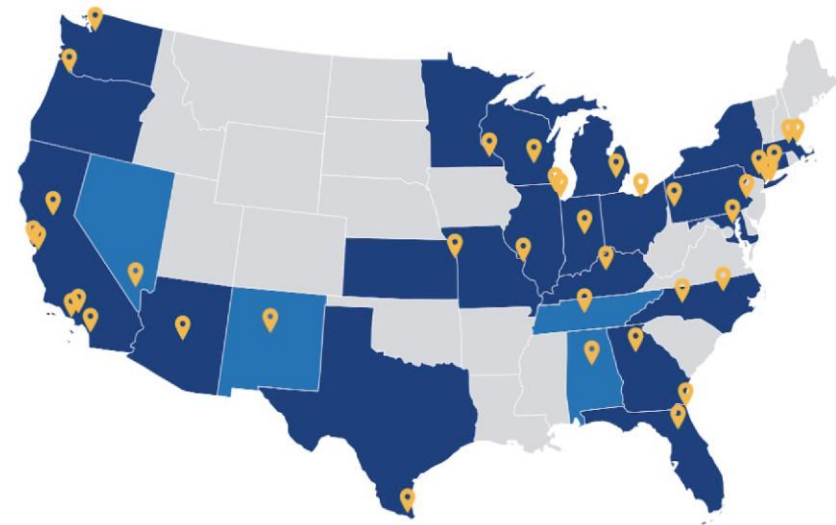
**1,141+**

Published studies using  
NACC data



**33**

ADRCs and 4 Exploratory  
Centers (Across 26 states)



- State with NIA-designated centers
- State with exploratory center



# The Power of NACC Data

Topic	Speaker Name
<b>Multimodal Deep Learning for Dementia Assessment</b>	Vijaya Kolachalama, PhD - Boston University ADRC
<b>Generalizable Deep Learning Model for Early Alzheimer's Disease Detection from Structural MRIs</b>	Narges Razavian, PhD - NYU ADRC
<b>Genetic Drivers of Risk and Resilience</b>	Tim Hohman, PHD - Vanderbilt Exploratory ADRC



# Access NACC Data Today!

Submit a data request (15 min)

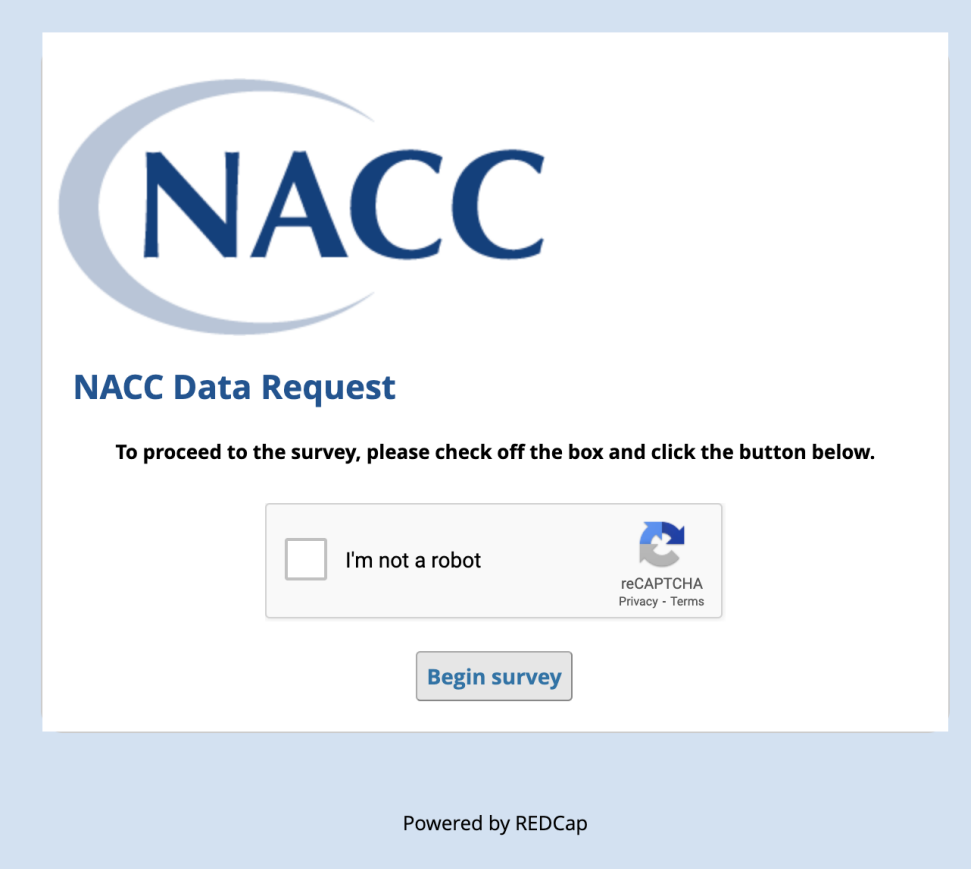
**Step 1.** Sign a Data Use Agreement and submit a title with specific aims.

**Step 2.** NACC reviews request.

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

***naccddata.org***

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



**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**

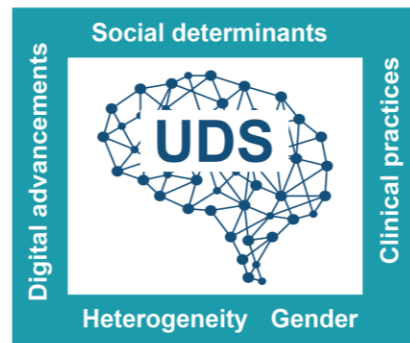
Powered by REDCap

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 page.

# **NACC Data is About to Get Even Better!**

# Aligning with NIH's Data Science Strategy

## Modernization



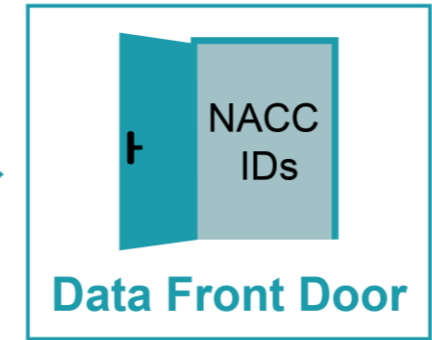
Updated UDS  
Content



Streamlined  
Electronic Data  
Capture

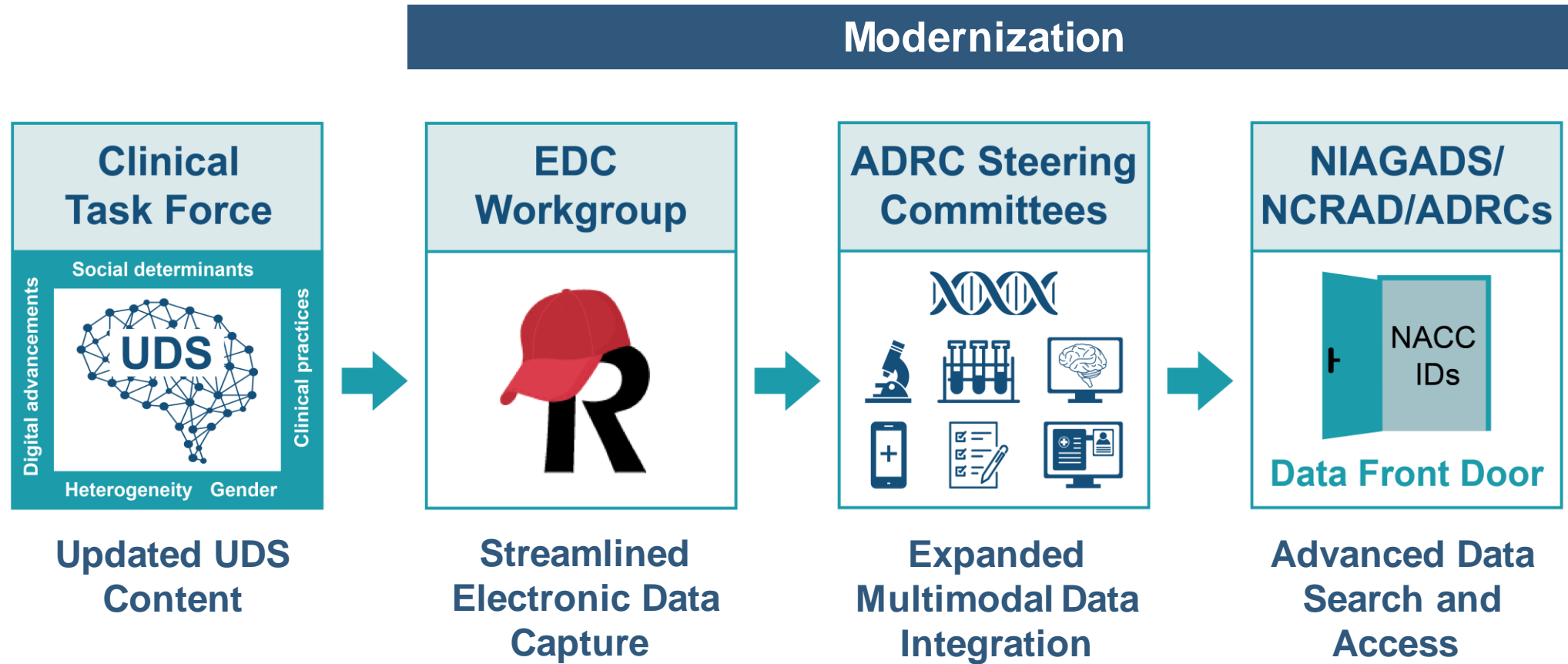


Expanded  
Multimodal Data  
Integration



Advanced Data  
Search and  
Access

# Aligning with NIH's Data Science Strategy



A decorative background consisting of a network 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 network is spread across the top and bottom of the slide, framing the central text.

# UDSv4

# Advancing the ADRD Field with UDSv4

## ADRD-Disease Modifying Drugs

### Form A4a: ADRD-Specific Treatments



## Social Determinants of Health

### A1a: Social Determinants of Health

One-time mandatory form



## New Concepts

- **Subjective Cognitive Decline**
- **Mild Behavioral Impairment**
- **Addition of the new verbal learning test**

## More Inclusive

- **More inclusive gender and sexual orientation questions**
- **Captures multi-racial identity**

# Fostering Inclusion

## UDSv4 Chinese and Spanish translations



## Promote best practices for engaging Indigenous populations

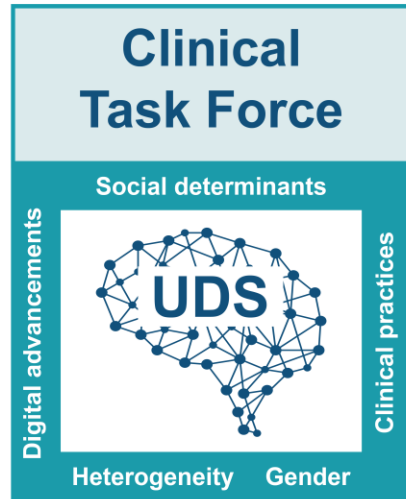


## Expand UDS participant access via electronic data capture





# Thank you to the CTF!



**ALLAN LEVEY, MD, PHD**  
Emory ADRC



**RHODA AU, PHD**  
Boston U ADRC



**LISA BARNES, PHD**  
Rush U ADRC



**CINDY CARLSSON, MD, MS**  
UW Madison ADRC



**GREG JICHA, MD, PHD**  
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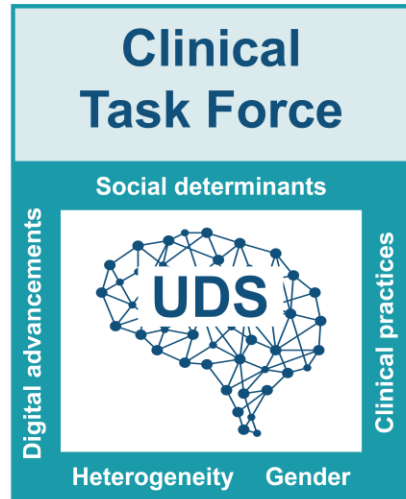


**HOWIE ROSEN, MD**  
UCSF ADRC



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John Hopkins ADRC

# Thank you to the CTF and Dr. Lerch!



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Manager



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UCSF ADRC



**KOSTAS LYKETSOS MD**  
John Hopkins ADRC

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.

# Electronic Data Capture

# Building Transparent QC Processes for UDSv4



**Kathryn Gauthreaux**  
NACC Research  
Scientist 3



**Chandima  
HewaNadungodage, PhD**  
NACC Software Engineer 3

## Approved by CTF

- Form A1
- Form A1a: SDOH
- Form A2
- Form A3
- Form A4
- Form A4a: ADRD-Specific Drugs
- Form A5/D2
- Form B1
- Form B3: UPDRS
- \* Form B4
- \* Form B5
- \* Form B6
- \* Form B7
- Form B8
- Form B9

*\* Phase 1 QC Complete (missingness and conformity)*

## Final Revisions by CTF

- Form D1a
- Form D1b
- Form C2/C2T
- Form Z1X



<https://github.com/naccdata/uniform-data-set>  
<https://github.com/naccdata/redcap-data-transfer>

**Rules Engine Task Force Forming Soon!**

Go to the UDSv4 / EDC Booth to learn more

Category	Task	Q2 2023	Q3 2023	Q4 2023	Q1 2024	FUTURE
<b>UDSv4 Implementation</b>	UDSv4 Forms content finalized	Anticipated Completion				
	UDSv4 Coding Guidebooks	Anticipated Completion	Anticipated Completion			
	UDSv4 pilot at select centers		Anticipated Completion			
	UDSv4 Data Harmonization UDSv3 for RDD		Anticipated Completion	Anticipated Completion		
<b>UDSv4 Training</b>	UDSv4 Training Developed: (UPDRS video produced if Admin sup funded)		Anticipated Completion			
	UDSv4 training: clinicians and data managers			Anticipated Completion		
<b>EDC System</b>	UDSv4 REDCap Forms Developed		Anticipated Completion			
	REDCap Pilot at select centers			Anticipated Completion		
	Data quality implementation			Anticipated Completion		
	EDC Training and Documentation Complete			Anticipated Completion		
	Submission system activated for Downs Syndrome and COVID modules				Anticipated Completion	
<b>UDSv4 Initiation</b>	Centers start using and submitting UDSv4 (REDCap and PDF)				Anticipated Completion	
	Stop date for UDSv3 submission				Anticipated Completion	
<b>Translations</b>	Chinese Translations (Validation study- R01 grant with high score)					Dependent on Supplement Funding
	Spanish Translation (NACC Admin Supplement dependent)					Dependent on Supplement Funding



Anticipated Completion



Dependent on Supplement Funding

## UDSv4 Webpage

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

## EDC Workgroup Webpage

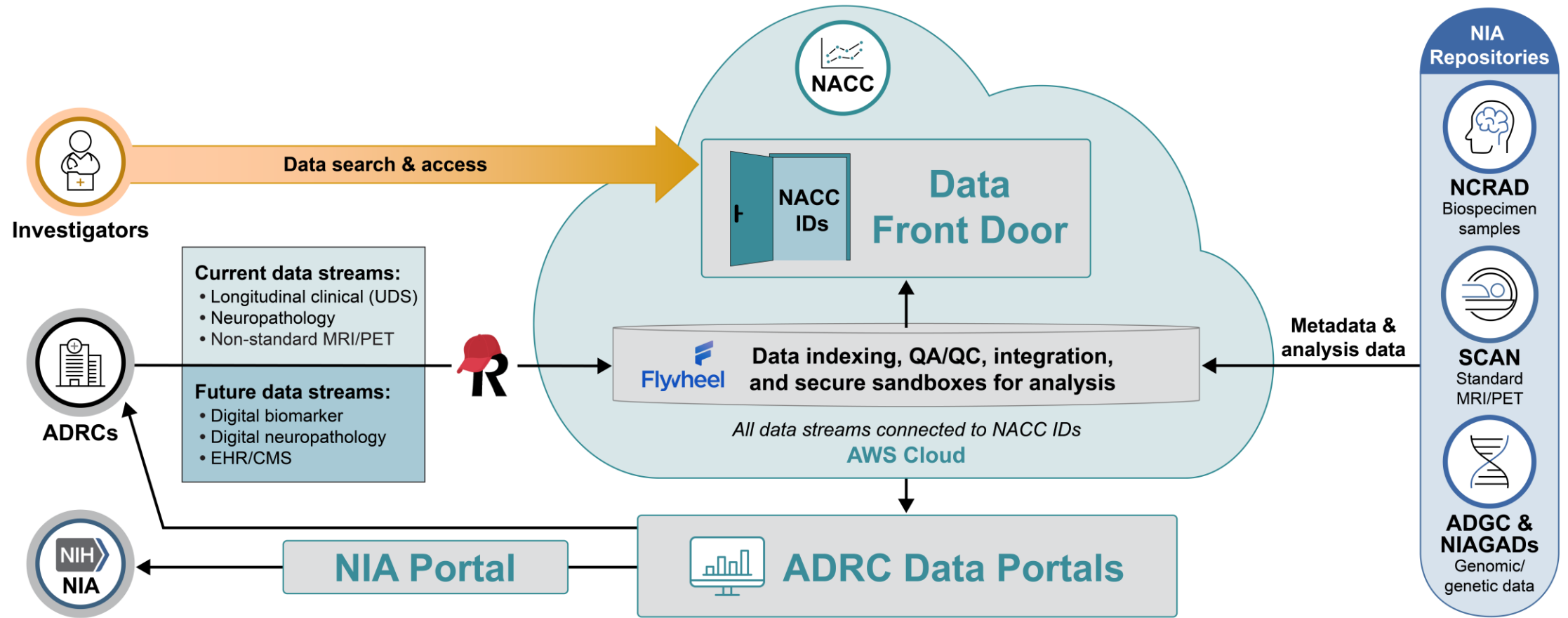
<https://nacccdata.org/edc>

**UDSv4 Email Updates: [bit.ly/nacc-stay-connected](https://bit.ly/nacc-stay-connected)**

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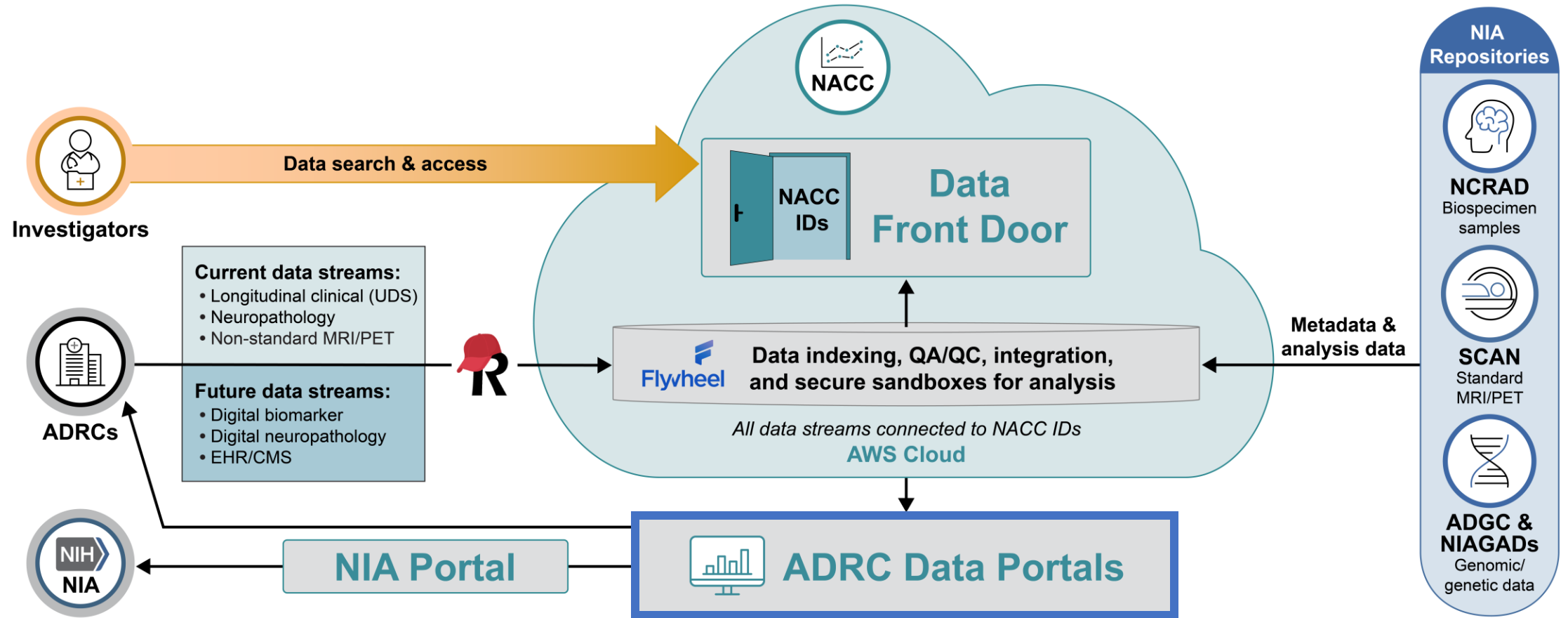
# The New NACC Data Platform and Data Front Door

# The New NACC Data Platform





# The New NACC Data Platform



# Welcome to your ADRC Data Portal!

On-demand reports available for download



Alzheimer's Disease  
Research Centers  
(ADRCs)

Current  
Data  
Streams

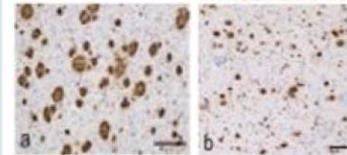
New  
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Streams

## ADRC Data Portals

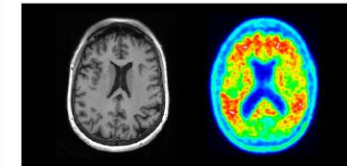
### Harmonized Phenotypic Data (UDS)

	Initial Visit (IV1)	Follow-up Visit (FV1)	Tx. Initial Visit (IV2)	Tx. Follow-up (FV2)
A1: Subject Demographics				
A2: Co-participant Demographics				
A3: Subject Family History				
A4: Subject Medications				

### Neuropathology Reports



### Non-Standard MRI/PET



### Participant Diversity Dashboard



### ADRC Standard MRI/PET (SCAN) Dashboards

### Specimen / Marker / Genetic Metadata



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Alzheimer's Disease  
Research Centers  
(ADRCs)



**BEN KELLER, PHD**  
NACC Software  
Engineer 3

## ADRC Data Portals

**Current Data Streams**

- Harmonized Phenotypic Data (UDS)**
- Neuropathology Reports**
- Non-Standard MRI/PET**

**New Data Streams**

- Participant Diversity Dashboard**
- ADRC Standard MRI/PET (SCAN) Dashboards**
- Specimen / Marker / Genetic Metadata**

# Welcome to your ADRC Data Portal!

On-demand reports available for download



Alzheimer's Disease  
Research Centers  
(ADRCs)

Current  
Data  
Streams

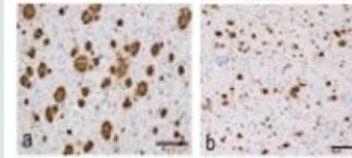
New  
Data  
Streams

## ADRC Data Portals

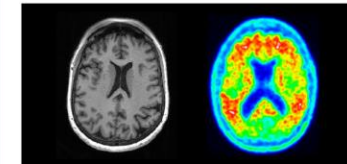
### Harmonized Phenotypic Data (UDS)

	Initial Visit (IV)	Follow-up Visit (FV)	Tx. Initial Visit (TIV)	Tx. Follow-up (TFV)
A1: Subject Demographics				
A2: Co-participant Demographics				
A3: Subject Family History				
A4: Subject Medications				

### Neuropathology Reports



### Non-Standard MRI/PET



### Participant Diversity Dashboard



### ADRC Standard MRI/PET (SCAN) Dashboards

### Specimen / Marker / Genetic Metadata



Beth Morimino, PhD


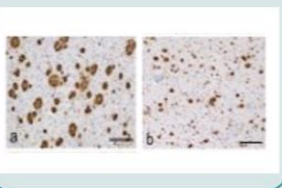
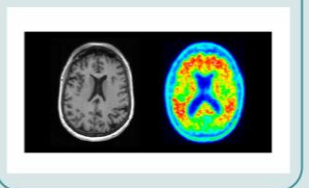
# Welcome to your ADRC Data Portal!

## Coming this summer!


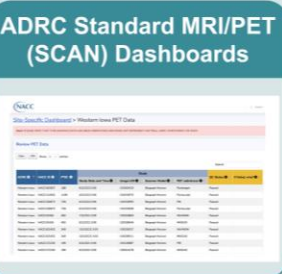
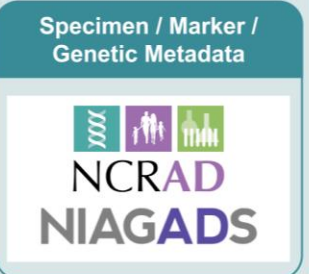
- **Prototype demo webinar**
- **Data managers invited to view, audit, and access data and provide feedback**
- **On-demand report feature activated for feedback**

### ADRC Data Portals

**Current Data Streams**

- Harmonized Phenotypic Data (UDS)**  

- Neuropathology Reports**  

- Non-Standard MRI/PET**  


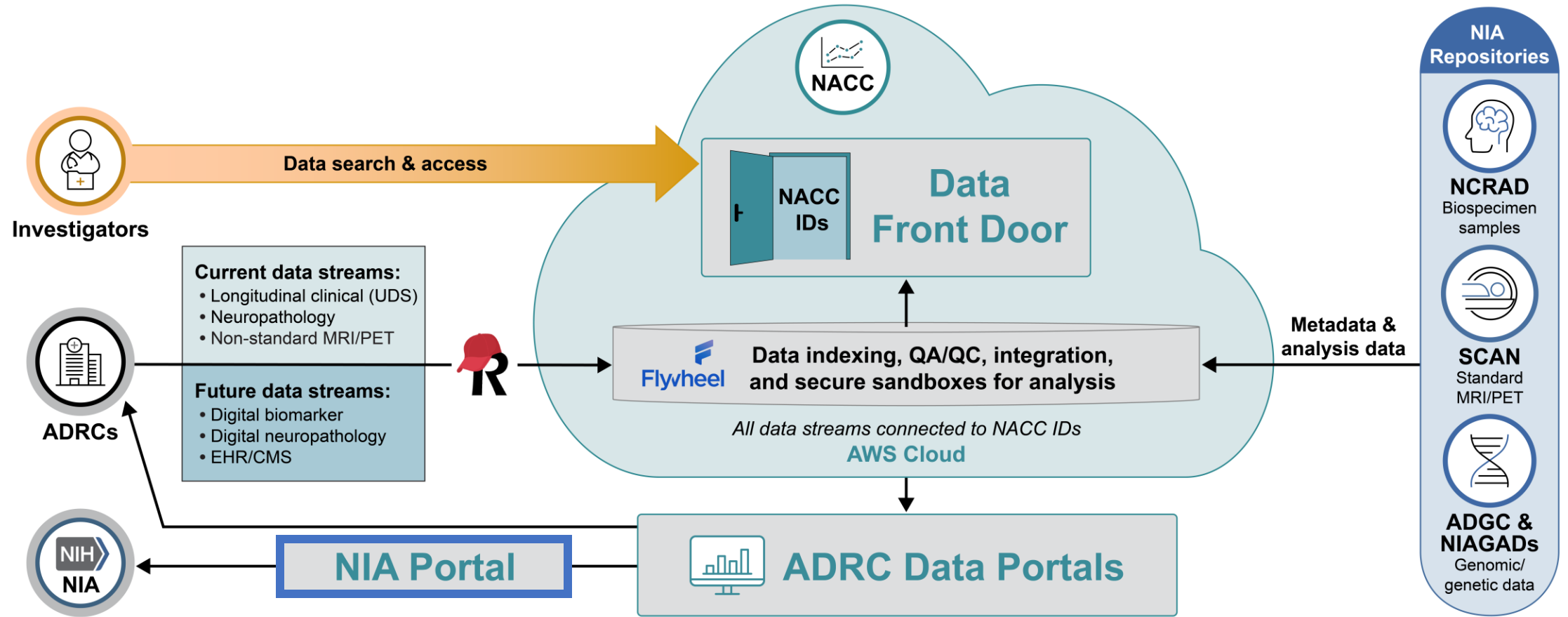
**New Data Streams**

- Participant Diversity Dashboard**  

- ADRC Standard MRI/PET (SCAN) Dashboards**  

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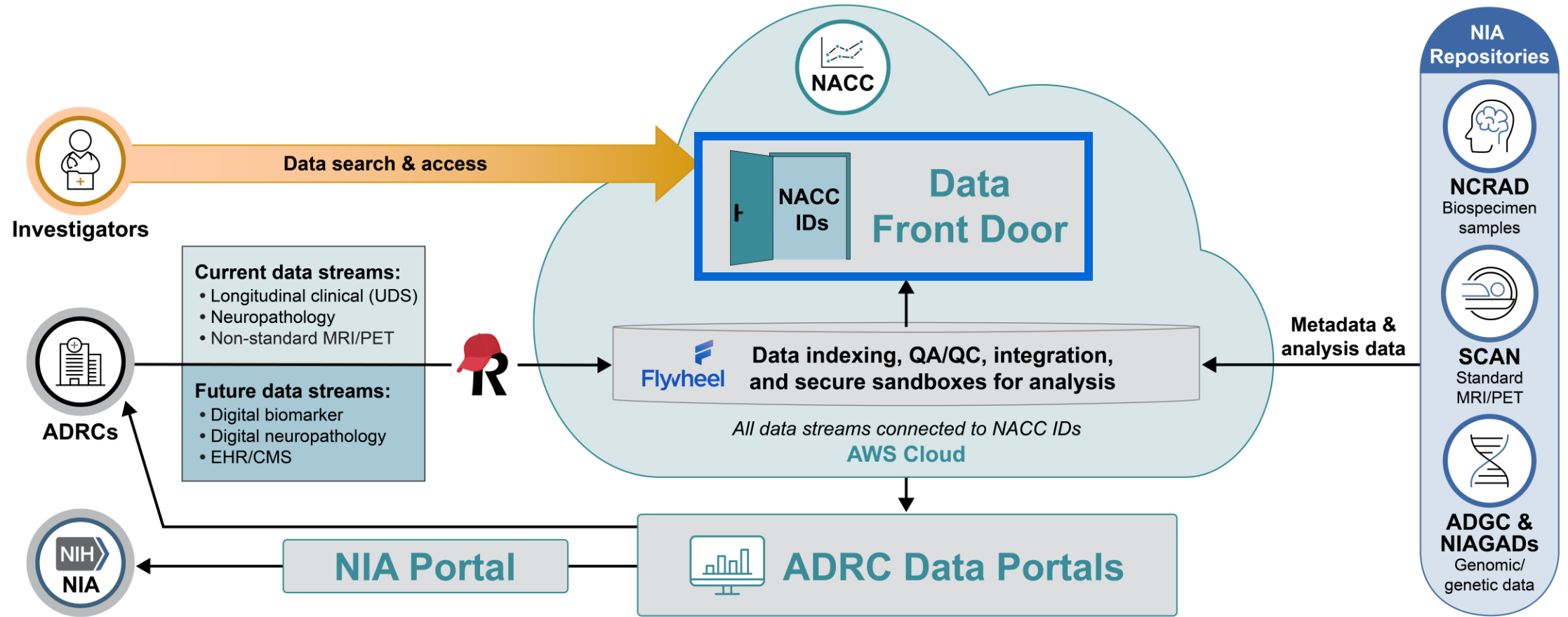
## Provide feedback today!

Visit the NACC Data Platform Booth to test our prototype  
Learn how to get access permissions for the ADRC data portal

# The New NACC Data Platform



# The New NACC Data Platform



# Advanced Data Sharing Through Data Front Door

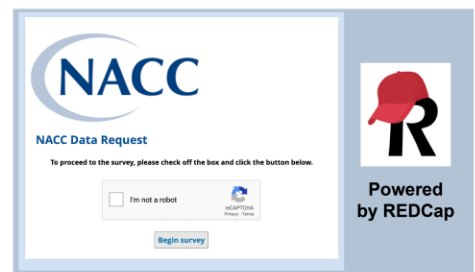
One-Stop-Shop for All ADRC Data Modalities

## Data Front Door



Researchers  
Everywhere

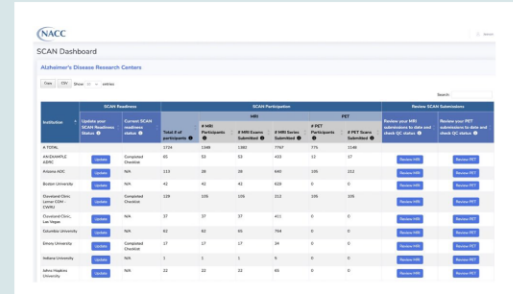
### Quick Access Files



### Cohort Selection



### SCAN Public Dashboard



Site	Study Year	Study Type	Study ID	SCAN Participation						Recent SCAN Connections		
				Total # of Participants	# MCI Participants	# PET Participants	# PET + MCI Participants	# PET + MCI + CSF Participants	# PET + MCI + CSF + APOE ε4 Participants	Number of MCI Connections	Number of PET Connections	
ADRC	2014	Longitudinal	ADRC-2014	2724	1488	1288	1176	1176	1176	1176	1176	1176
ADRC	2015	Longitudinal	ADRC-2015	2724	1488	1288	1176	1176	1176	1176	1176	1176
ADRC	2016	Longitudinal	ADRC-2016	2724	1488	1288	1176	1176	1176	1176	1176	1176
ADRC	2017	Longitudinal	ADRC-2017	2724	1488	1288	1176	1176	1176	1176	1176	1176
ADRC	2018	Longitudinal	ADRC-2018	2724	1488	1288	1176	1176	1176	1176	1176	1176
ADRC	2019	Longitudinal	ADRC-2019	2724	1488	1288	1176	1176	1176	1176	1176	1176
ADRC	2020	Longitudinal	ADRC-2020	2724	1488	1288	1176	1176	1176	1176	1176	1176
ADRC	2021	Longitudinal	ADRC-2021	2724	1488	1288	1176	1176	1176	1176	1176	1176
ADRC	2022	Longitudinal	ADRC-2022	2724	1488	1288	1176	1176	1176	1176	1176	1176
ADRC	2023	Longitudinal	ADRC-2023	2724	1488	1288	1176	1176	1176	1176	1176	1176
ADRC	2024	Longitudinal	ADRC-2024	2724	1488	1288	1176	1176	1176	1176	1176	1176



# Advanced Data Sharing Through Data Front Door

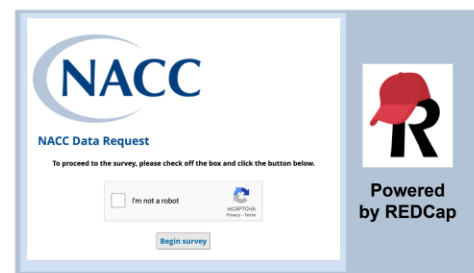
One-Stop-Shop for All ADRC Data Modalities

## Data Front Door



Researchers  
Everywhere

### Quick Access Files

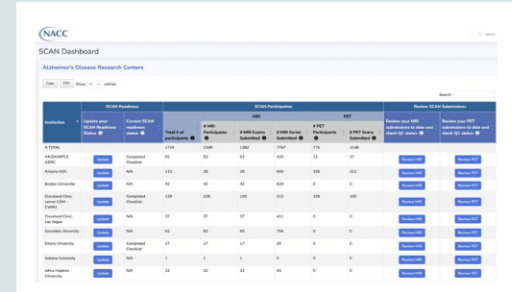


### Cohort Selection



Build your own  
multimodal dataset!

### SCAN Public Dashboard



Study	Study Type	Current SCAN Enrollment	SCAN Participation				Recent SCAN Connections	
			Total # of Participants	# MCI Participants	# PET Participants	# PET + MCI Participants	Participants in SCAN PET	Participants in SCAN MCI
ADRC	Longitudinal	2774	104	104	171	104		
ADRC-Gen	Genetic	85	10	10	10	10		
ADRC-Genetic	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen-PET	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen-PET-MCI	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen-PET-MCI-Gen	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen-PET-MCI-Gen-PET	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen-PET-MCI-Gen-PET-Gen	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen-PET-MCI-Gen-PET-Gen-PET	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen-PET-MCI-Gen-PET-Gen-PET-Gen	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen-PET-MCI-Gen-PET-Gen-PET-Gen-PET	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen-PET-MCI-Gen-PET-Gen-PET-Gen-PET-Gen	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen-PET-MCI-Gen-PET-Gen-PET-Gen-PET-Gen-PET	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen-PET-MCI-Gen-PET-Gen-PET-Gen-PET-Gen-PET-Gen	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen-PET-MCI-Gen-PET-Gen-PET-Gen-PET-Gen-PET-Gen-PET	Genetic	111	10	10	10	10		
ADRC-Genetic-Gen-PET-MCI-Gen-PET-Gen-PET-Gen-PET-Gen-PET-Gen-PET-Gen	Genetic	111	10	10	10	10		

# Data Front Door: Quick Access File

**New Variables!**

**Coming this summer!**

## **SCAN Data**

### **Data Available via NACC**

All SCAN Summary and Analysis Data:


**MRI - Volume**

**PET - SUVRs**



### **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>

# Advanced Data Sharing Through Data Front Door

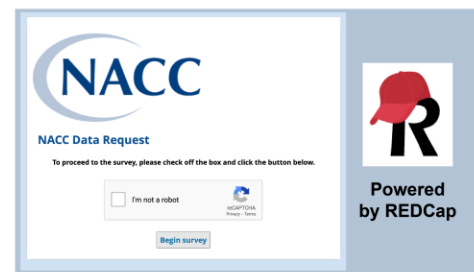
One-Stop-Shop for All ADRC Data Modalities

## Data Front Door



Researchers  
Everywhere

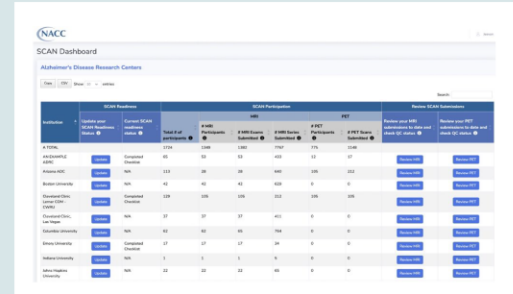
### Quick Access Files



### Cohort Selection



### SCAN Public Dashboard



SCAN Public Dashboard

Site	Study Year	Study Modality	Study Period	SCAN Participation				Recent SCAN Connections	
				Total # of Participants	# MRI Scans	# PET Scans	# PET Tracers	Participants in SCAN	Participants in SCAN
ADRC	2014	ADRC	2014	100	100	100	100	100	100
ADRC	2015	ADRC	2015	100	100	100	100	100	100
ADRC	2016	ADRC	2016	100	100	100	100	100	100
ADRC	2017	ADRC	2017	100	100	100	100	100	100
ADRC	2018	ADRC	2018	100	100	100	100	100	100
ADRC	2019	ADRC	2019	100	100	100	100	100	100
ADRC	2020	ADRC	2020	100	100	100	100	100	100
ADRC	2021	ADRC	2021	100	100	100	100	100	100
ADRC	2022	ADRC	2022	100	100	100	100	100	100

# Advanced Data Sharing Through Data Front Door

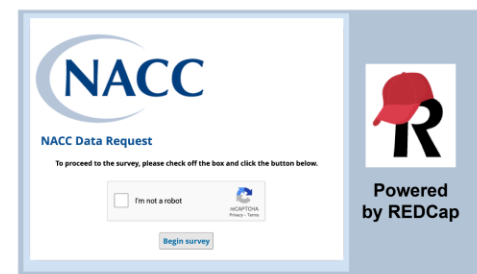
One-Stop-Shop for All ADRC Data Modalities

## Data Front Door



Researchers  
Everywhere

### Quick Access Files



### Cohort Selection

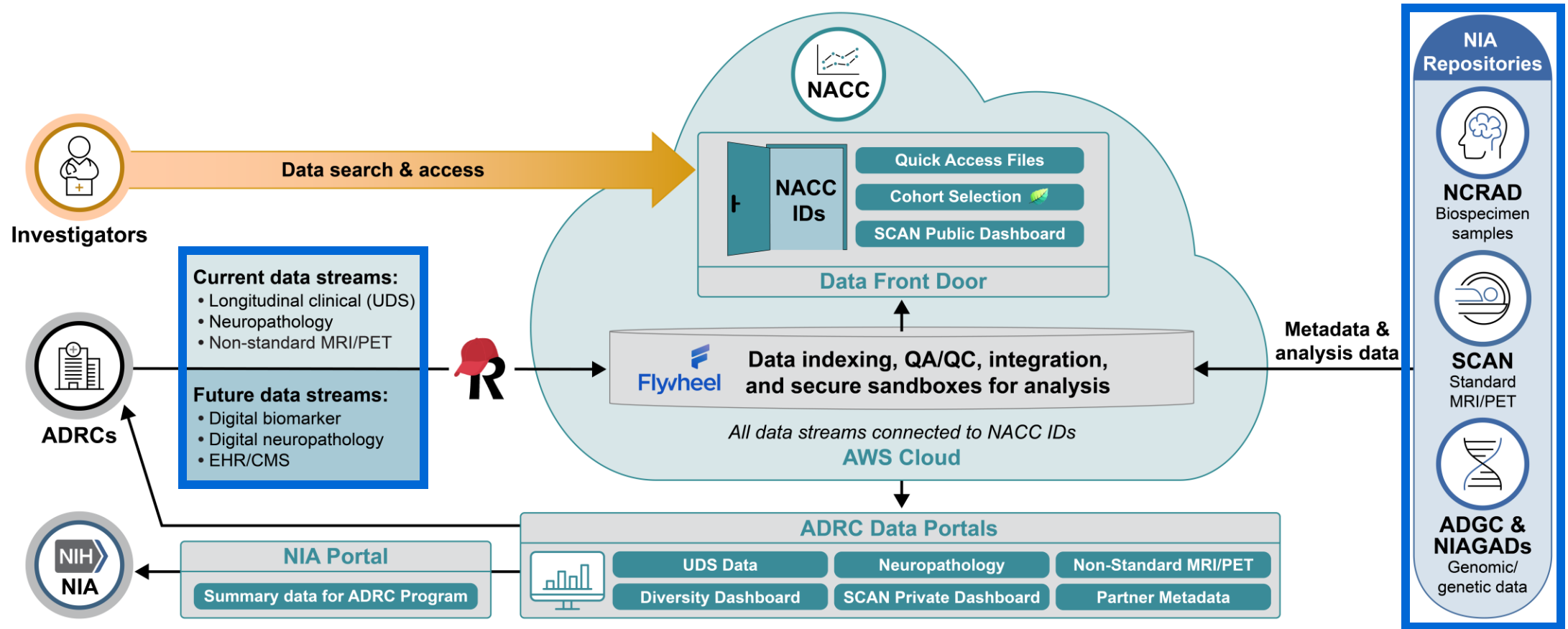


### SCAN Public Dashboard

Cohort	Status	NACC	ADRC	ADRC Population		PPT		Recent ADRC Connections	
				#ADRC	#ADRC	#ADRC	#ADRC	#ADRC	#ADRC
ADRC	Completed	2775	1000	1000	1000	1000	1000	1000	1000
ADRC	Completed	100	100	100	100	100	100	100	100
ADRC	Completed	100	100	100	100	100	100	100	100
ADRC	Completed	100	100	100	100	100	100	100	100
ADRC	Completed	100	100	100	100	100	100	100	100
ADRC	Completed	100	100	100	100	100	100	100	100
ADRC	Completed	100	100	100	100	100	100	100	100
ADRC	Completed	100	100	100	100	100	100	100	100
ADRC	Completed	100	100	100	100	100	100	100	100

Beth Morimino, PhD

# The New NACC Data Platform: Progress Highlights



# Accelerating AD/ADRD Research and Discovery



Socio-demographic



Neurocognitive tests



Neuropathology



Imaging (MRI/PET)



Biomarker



Genetic and genomic



Electronic Health Record (EHR)



Digital biomarker

## New Discoveries!

**Researchers will be able to ask and answer new questions in AD/ADRD**

# Accelerating AD/ADRD Research and Discovery



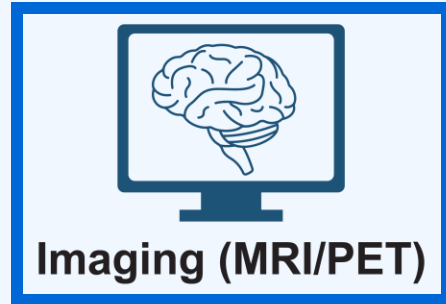
Socio-demographic



Neurocognitive tests



Neuropathology



Imaging (MRI/PET)



Biomarker



Genetic and genomic



Electronic Health Record (EHR)



Digital biomarker

Standard MRI/PET

scan

# Accelerating AD/ADRD Research and Discovery



Socio-demographic



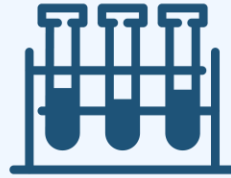
Neurocognitive tests



Neuropathology



Imaging (MRI/PET)



Biomarker



Genetic and genomic

COVID  
Supplement



Electronic Health  
Record (EHR)



Digital  
biomarker

## ADRC Pilot Sites



**SCHOOL OF MEDICINE**  
INDIANA ALZHEIMER'S DISEASE RESEARCH CENTER

**KnightADRC** | WASHINGTON  
UNIVERSITY  
ST. LOUIS  
*Alzheimer's Disease Research Center*



**COLUMBIA UNIVERSITY  
MEDICAL CENTER**  
*Center of Excellence for Alzheimer's Disease*



# Accelerating AD/ADRD Research and Discovery



Socio-demographic



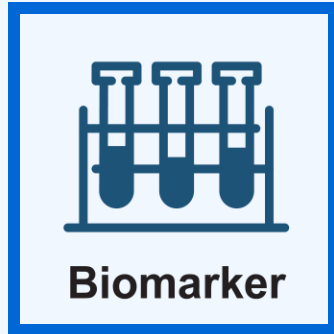
Neurocognitive tests



Neuropathology



Imaging (MRI/PET)



Biomarker



Genetic and genomic



Electronic Health Record (EHR)



Digital biomarker

ADRC Data

# NCRAD

Metadata and Analysis Data

# Accelerating AD/ADRD Research and Discovery



Socio-demographic



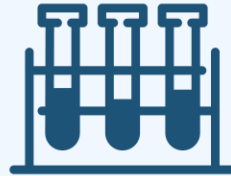
Neurocognitive tests



Neuropathology



Imaging (MRI/PET)



Biomarker



Genetic and genomic



Electronic Health Record (EHR)



Digital biomarker

ADRC Data

NIAGADS

Metadata and Analysis Data

# Accelerating AD/ADRD Research and Discovery



Socio-demographic



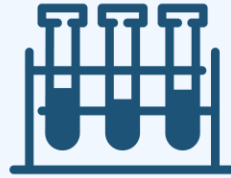
Neurocognitive tests



Neuropathology



Imaging (MRI/PET)



Biomarker



Genetic and genomic



Electronic Health Record (EHR)



Digital biomarker

## Technology Workgroup

**The restructured  
technology WG  
will be relaunched  
soon**

[Rhodaau@bu.edu](mailto:Rhodaau@bu.edu)



- **Goals:**
  - Accelerate innovative digital biomarker collection and sharing across the ADRC Program to advance ADRD research and discovery
  - Leverage technology to capture more data with less burden for participants and ADRCs
- **Budget:** 1-3 pilots ranging from \$250K to \$1M
- **Pilot length:** 1-2 years
- **Eligibility:** Open to any ADRC or non-ADRC groups or companies. They must have multiple ADRC collaborators.
- **Funding will be channeled through NACC and will support:**
  - **Partners:** Provide digital instruments
  - **ADRCs:** Data collection with innovative digital instruments
  - **NACC:** Integrating this data into the NACC Data Platform and sharing it with the ADRD researchers through the Data Front Door
- **Selection Committee:** TBA



## Pilot Requirements:

- Adds research value and enhances metrics
- Reduces burden
- Expands and addresses diversity
- Involves multiple ADRCs
- Demonstrate scalability to all ADRCs in future
- Amenable to a data challenge down the line
- Partnering companies must provide the raw digital files to NACC

**Modalities:** Sleep, movement, gait (phone gyroscope measures), fall detection, voice, video, language, eye tracking, digitized UDS, non-UDS, mood, diet, biological measures, driving, keystrokes

**Tools:** Wearables, sensors, multi-sensor, smart phone apps, algorithms

## Proposed Timeline for Pilot Launch :

- **May 2nd, 2023:** Announce at the ADRC meeting
- **Fall 2023:** Release the RFA and select winners
- **Winter 2023:** Launch pilots

## Potential Follow-Up Support :

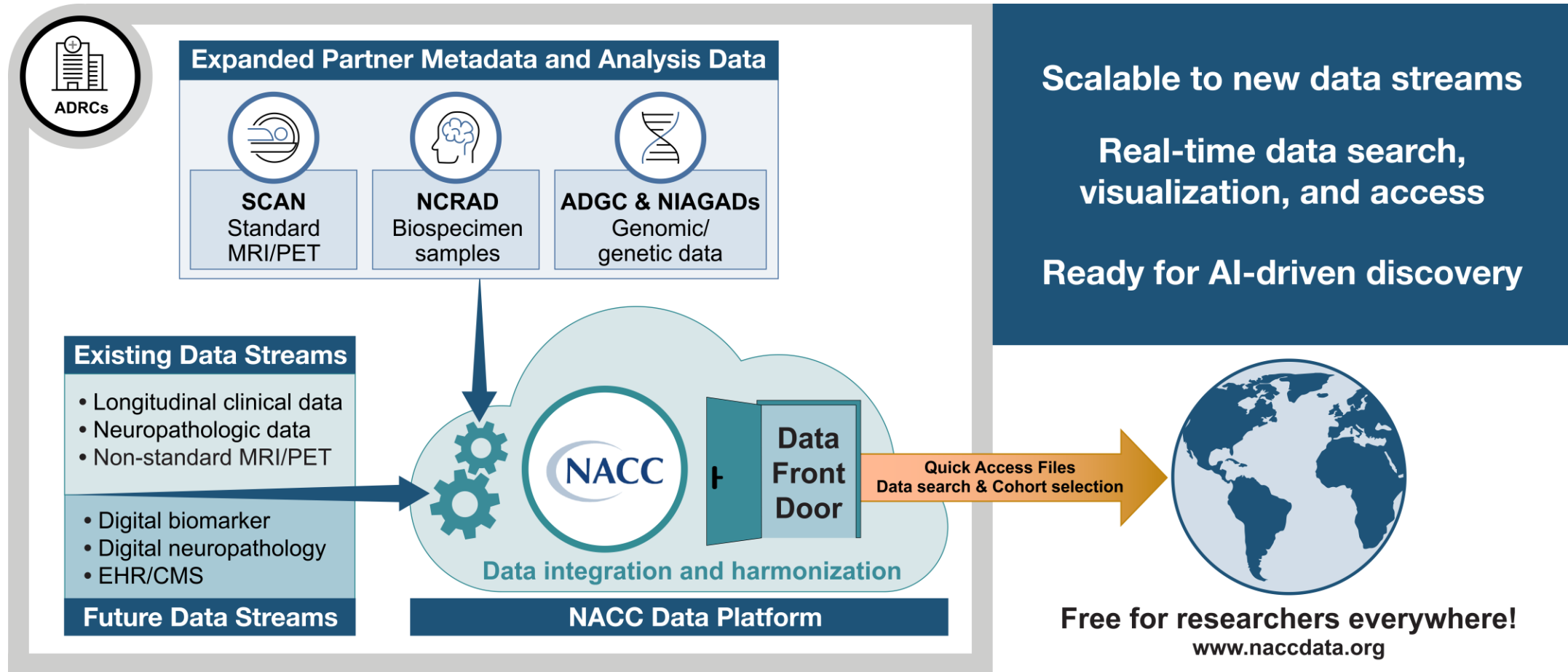
- Funded Data Challenge using data collected from the pilot
- Promising digital pilots may be scaled to the full ADRC Program via NACC's U24 renewal
- SBIR/STTR

### NIA Small Business Programs (SBIR & STTR)

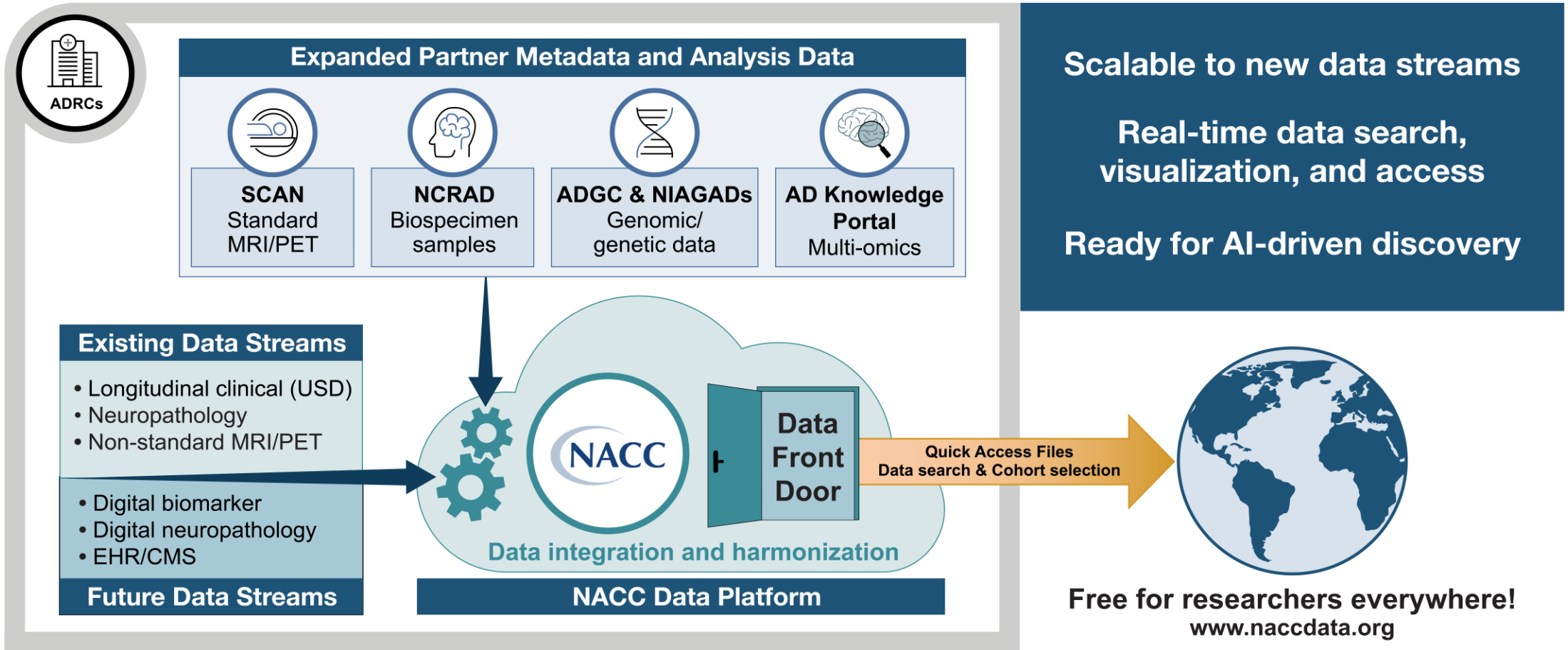
<https://www.nia.nih.gov/research/sbir>

Non-dilutive Funding for Healthy Aging Innovations

# Expanded Multimodal Data Integration



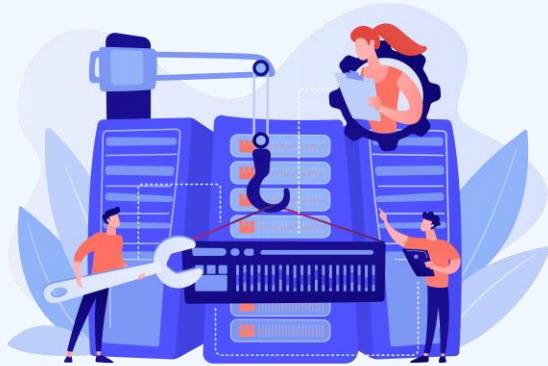
# Expanded Multimodal Data Integration



# Challenges Associated with Adding New Data Streams

## Challenges

- **Create governance**
- **Update process by which unique identifiers are assigned**
- **Build pipelines to collect, integrate, and share new data streams**
- **Optimizing search**
- **Building interoperability with other repositories**

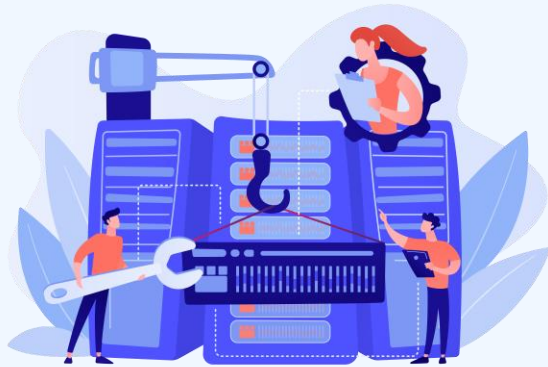




# Next Steps

## Challenges

- **Create governance**
- **Update process by which unique identifiers are assigned**
- **Build pipelines to collect, integrate, and share new data streams**
- **Optimizing search**
- **Building interoperability with other repositories**



## Future Opportunities!

- **Integrate more real-world data**
- **Build seamless interoperability with other platforms**
- **Digital health: more data with less burden via digital tools**
- **More languages, more diversity, more access**
- **Reduce barriers to data access and analysis by providing secure enclaves**

Category	Task	Q2 2023	Q3 2023	Q4 2023	Q1 2024	FUTURE
<b>Platform Establishment</b>	Existing NACC data (UDS/Neuropath forms) transferred to the cloud	Complete				
	Authorization system deployed leveraging NACC Directory	Anticipated Completion				
	Centers start using new participant registration process				Anticipated Completion	
<b>ADRC Data Portals</b>	UDS/Neuropath forms data available and	Anticipated Completion				
	SCAN MRI/PET QC Dashboards live		Timing Dependent on Admin Supplement Funding			
	All SCAN variables		Timing Dependent on Admin Supplement Funding			
	Non-standard MRI/PET		Anticipated Completion			
	NCRAD (Top 5 biomarkers) and NIAGADS (GWAS download feature) live				Timing Dependent on Admin Supplement Funding	
	Diversity dashboard			Timing Dependent on Admin Supplement Funding		
	On-demand ADRC reports available (to replace static monthly reports)			Anticipated Completion		
<b>Data Front Door</b>	SCAN Public Dashboard live		Timing Dependent on Admin Supplement Funding			
	SCAN metadata and analysis available via Quick Access File		Timing Dependent on Admin Supplement Funding			
	NCRAD/NIAGADS metadata and analysis data pilots					Timing Dependent on Admin Supplement Funding
	Cohort selection: Flywheel connected to Leaf for data queries/access					Timing Dependent on Admin Supplement Funding
<b>Multimodal Data Integration</b>	EHR/CMS pilot data					Anticipated Completion
	Digital Neuropathology pilot				Timing Dependent on Admin Supplement Funding	
	Digital Biomarker		Timing Dependent on Admin Supplement Funding			
<b>Affiliated Projects</b>	Project data available via NACC DP for DVCID, VCOG, LEADS, NAPS2			Anticipated Completion		



# NACC Collaborations and Communication Hub

## Provide Feedback at Our Interactive Booths!

### NACC Website

Test the new website features  
Provide input

### NACC Data Platform

Learn more about the NACC Data Platform  
Provide input on the ADRC Portal prototype  
View the SCAN Public Dashboard

### UDSv4 / EDC

Review printed UDSv4 forms  
Learn how REDCap will improve UDSv4  
Participate in a REDCap forms demo

### NACC Directory

Learn about:  
Data access privileges  
How to keep your ADRC up to date

# Thank you!



# Connect with NACC

Sarah Biber, PhD, Program Director

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

