



Welcome!

Walter Kukull, PhD, NACC Director

May 14, 2022 – ADRC Spring Meeting



UDSv4 – The Full Picture

Sarah Biber, PhD, NACC Program Director

May 14, 2022 – ADRC Spring Meeting

NACC Leadership Team



Bud Kukull, PhD
Director



Kari Stephens, PhD
Deputy Director



Sarah Biber, PhD
Program Director

MEET OUR TEAM

Research Team



Charles Mock, MD, PhD
Associate Director



Gary Chan, PhD
Associate Director



Dean Shibata, MD
Co-Investigator



Yen-Chi Chen, PhD
Co-Investigator



Melissa Lerch, PhD
Research Team Mgr



Zack Miller, BS
Research Consultant



Kathryn Gauthreaux, MS
Research Scientist



Jessica Culhane, MS
Research Scientist

Technology Team



Sean Mooney, PhD
Associate Director



Ben Keller, PhD
Tech Team Manager



Laura McLeod
Sr. REDCap Administrator



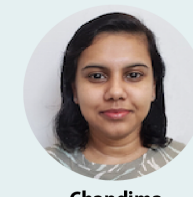
Joylee Wu, MS
Database Administrator



Brendan Smith
Web Developer



Zack Stark, BBA
Software Engineer



Chandima Hewanadungodage, PhD
Software Engineer



Janene Hubbard, BS
Research Consultant

Operations Team



Melissa Petty, PhD
Senior Project Mgr



Hannah Rosentreter
Mgr, Special Projects



Amy Young
Public Info Specialist



Theresa Barnhart
Grants & Finance Mgr



Valerie Hockens
Program Operations



Brittany Hale
Project Manager



Clair Cassidy
Admin Coordinator

UDS Data – Impact



45,000+ Participants with data at NACC



166,000+ Clinical assessments
(1-17 visits per participant; median =3)



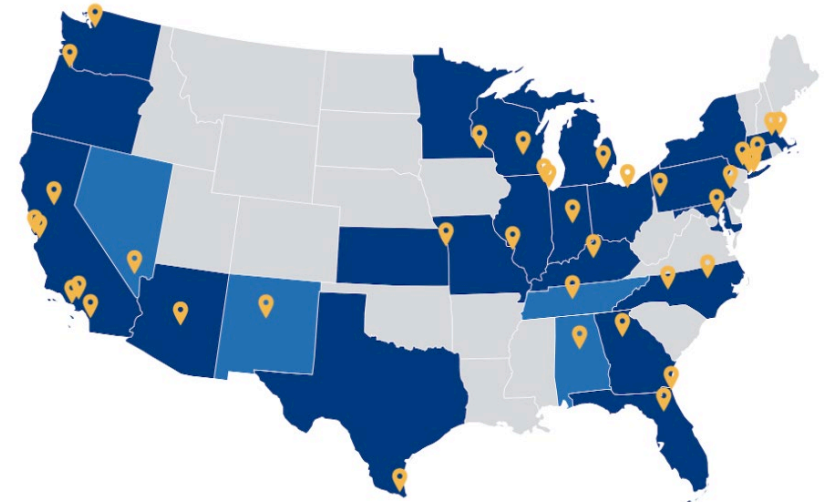
6,980+ Neuropathology datasets
(From 58% of deceased participants)



900+ Published studies using NACC data



37 ADRCs are contributing data (Across 26 states)

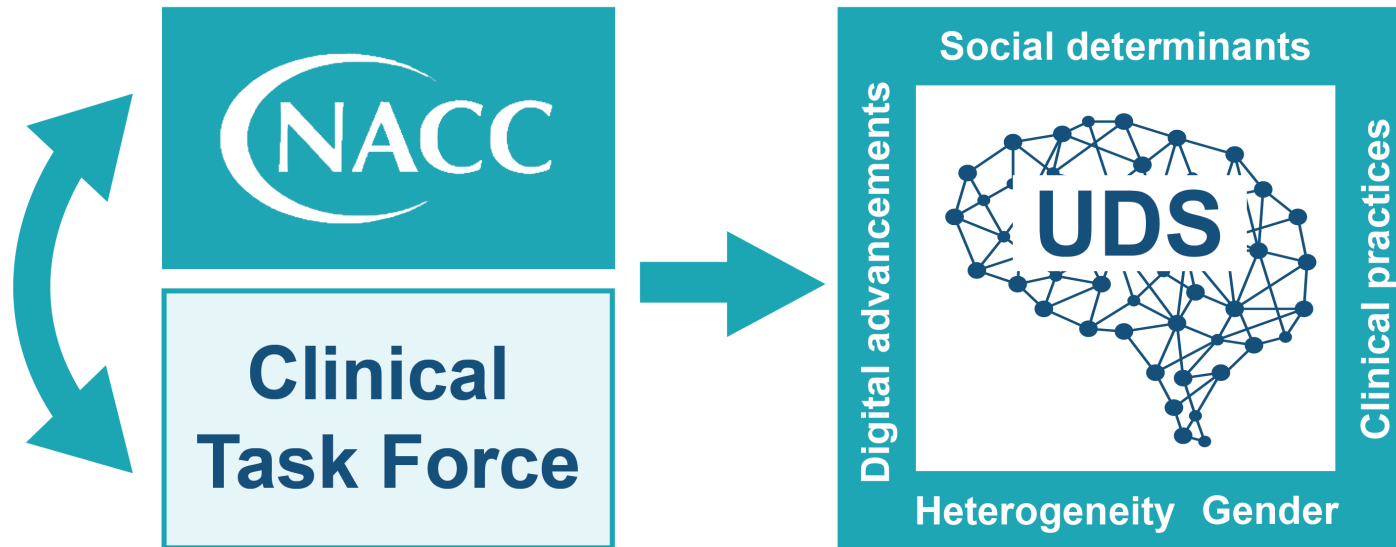


■ State with NIA-Designated Center(s)

■ State with Exploratory Center

UDSv4 – Content Update

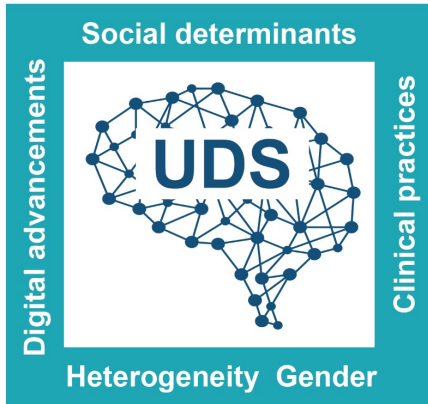
- **Expand UDS participation** (Currently > 45,000 participants)
- **Streamline and reduce participant burden**
- **Reflect advances in science, technology, clinical practice, and our understanding of social determinants**



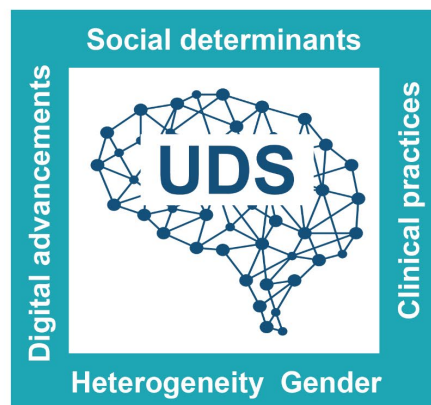
UDSv4 – Collaboration with the CTF

Collaboration with the Clinical Task Force (CTF)	Lead: Allen Levey, MD, PhD
Technology Workgroup	Lead: Rhoda Au, PhD
Clinical Measures and Diagnosis Workgroup	Co-leads: Cindy Carlsson, MD, MS and Greg Jicha, MD, PhD
Behavioral Workgroup	Lead: Howie Rosen, MD
Cognitive Workgroup	Co-leads: Andy Saykin, PsyD and Lisa Barnes, PhD
Social Determinants of Health Workgroup	Co-lead: Lisa Barnes, PhD and Megan Zuelsdorff, PhD

**Collaborate on meeting agendas, setting strategic goals,
and tracking deliverables**



**Update UDS
Content**



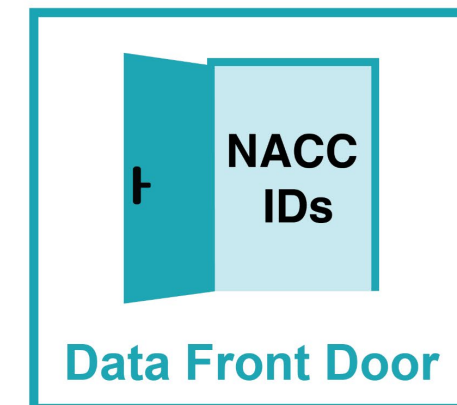
**Updated UDS
Content**



**Streamlined
Submission
System**



**Integrated
Pipeline and
Database**



**Expanded Search
and Access
Portal**

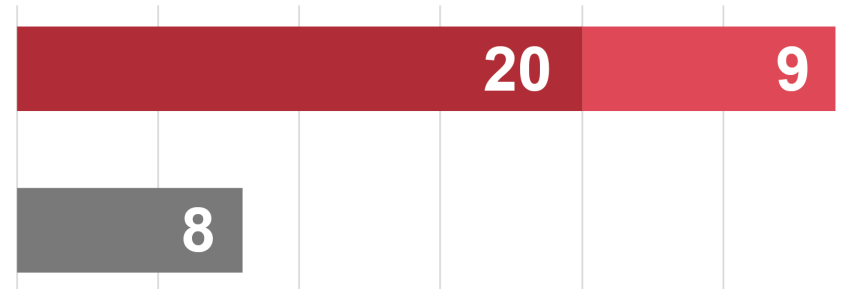
UDSv4 – New Submission System

- Existing system is 20 years old and needs to be updated to be more cloud friendly and virtualized
- **Goals:**
 - Streamline UDS data collection for the ADRC program
 - NACC will continue to host a range of options
- **Why are we starting with REDCap?**
 - Canonical tool for forms data capture



20 centers already using REDCap
with 9 more interested

Not interested



UDSv4 – New Submission System

All data will go through REDCap at NACC in the future via one of these options:



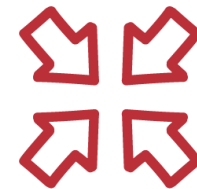
**Direct data entry into
NACC REDCap**



**Synchronize local ADRC
REDCap instances through
REDCap APIs**



**Bulk upload of .csv files into
NACC REDCap**



UDSv4 – Electronic Data Capture (EDC) Workgroup

- **Electronic Data Capture Working Group:**
 - Launched January 24th, 2022 in collaboration with the Data Core Steering Committee
- **45 people across 17 ADRCs that are collaborating with us to:**

Define Requirements



Develop Submission Forms



Create Training and Education



UDSv4 – Electronic Data Capture (EDC) Workgroup

- **Thank you EDC Workgroup members!**
 - **Co-Leads:** Sudeshna Das, PhD and Sarah Biber, PhD
 - **Development Co-Leads:** Jon Reader, MS and Ben Keller, PhD
 - **Requirements Co-Leads:** Meredith Zozus, PhD and Kari Stephens, PhD
 - **Documentation and Training Co-Leads:** Alice Spalitta, Leah Reuter, and Laura McLeod

Scan QR code and
fill out the form to join!

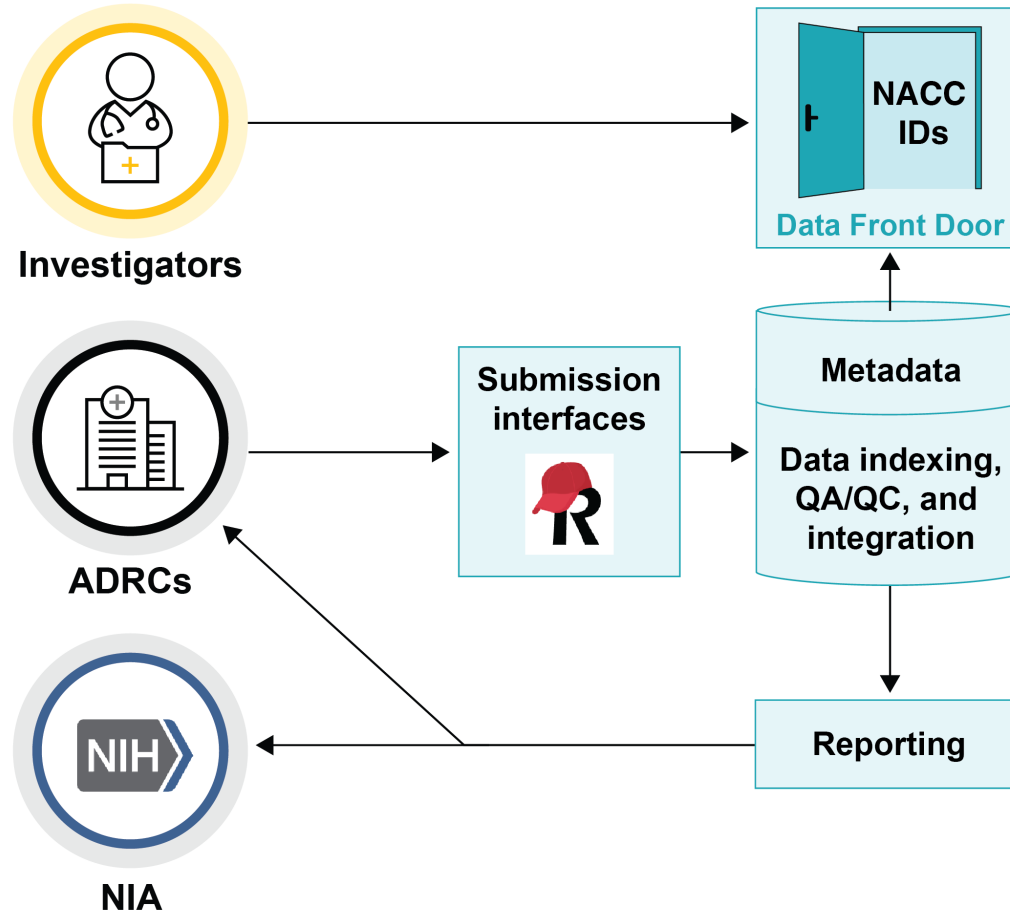


Link [Here](#)

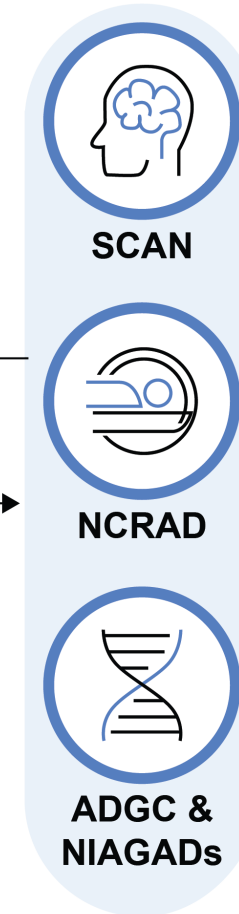


UDSv4 – Pipeline and Database

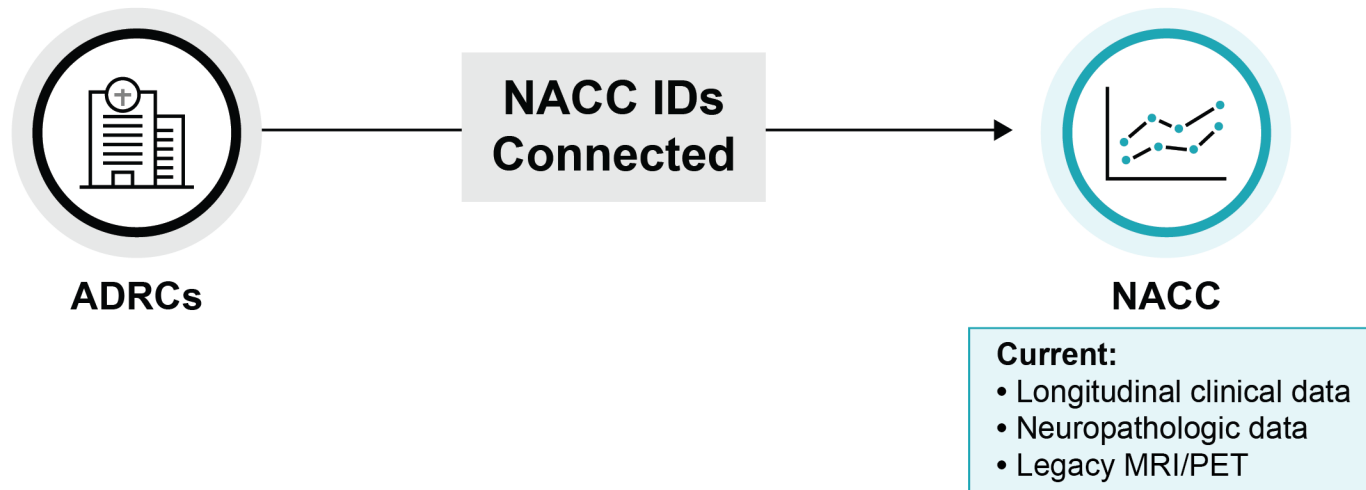
Stakeholders



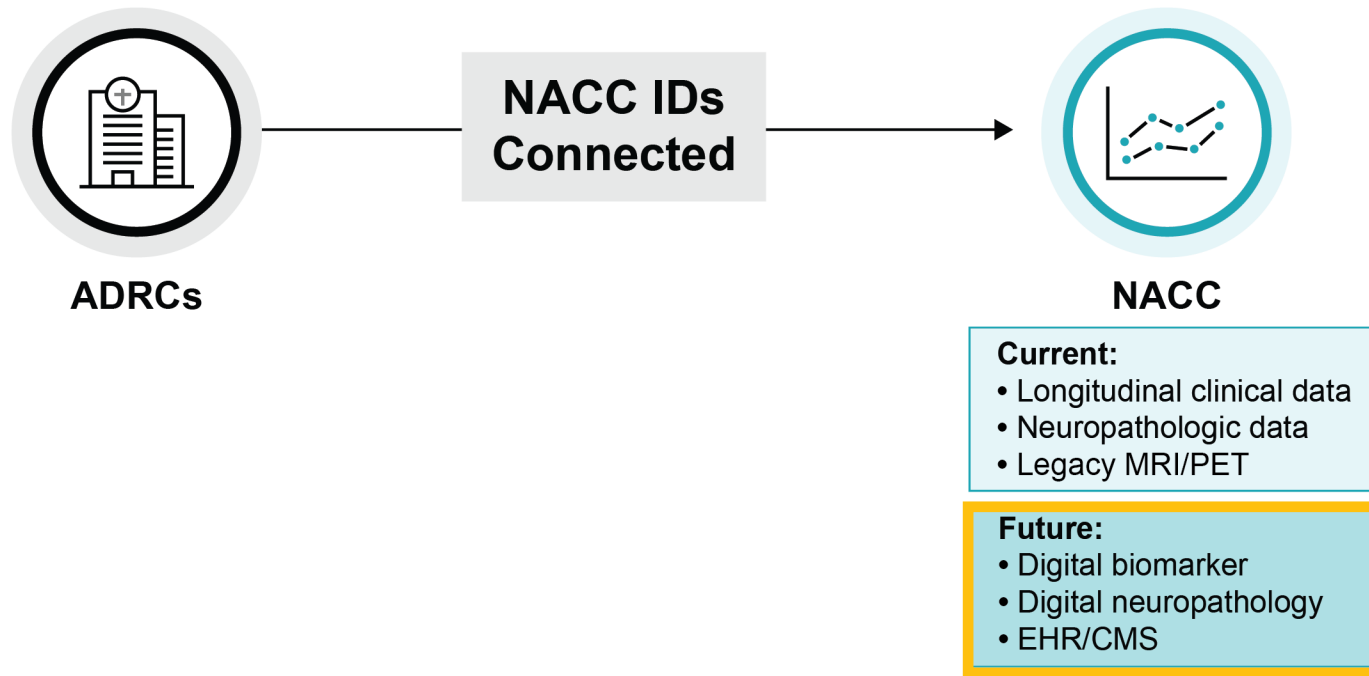
Coordinators



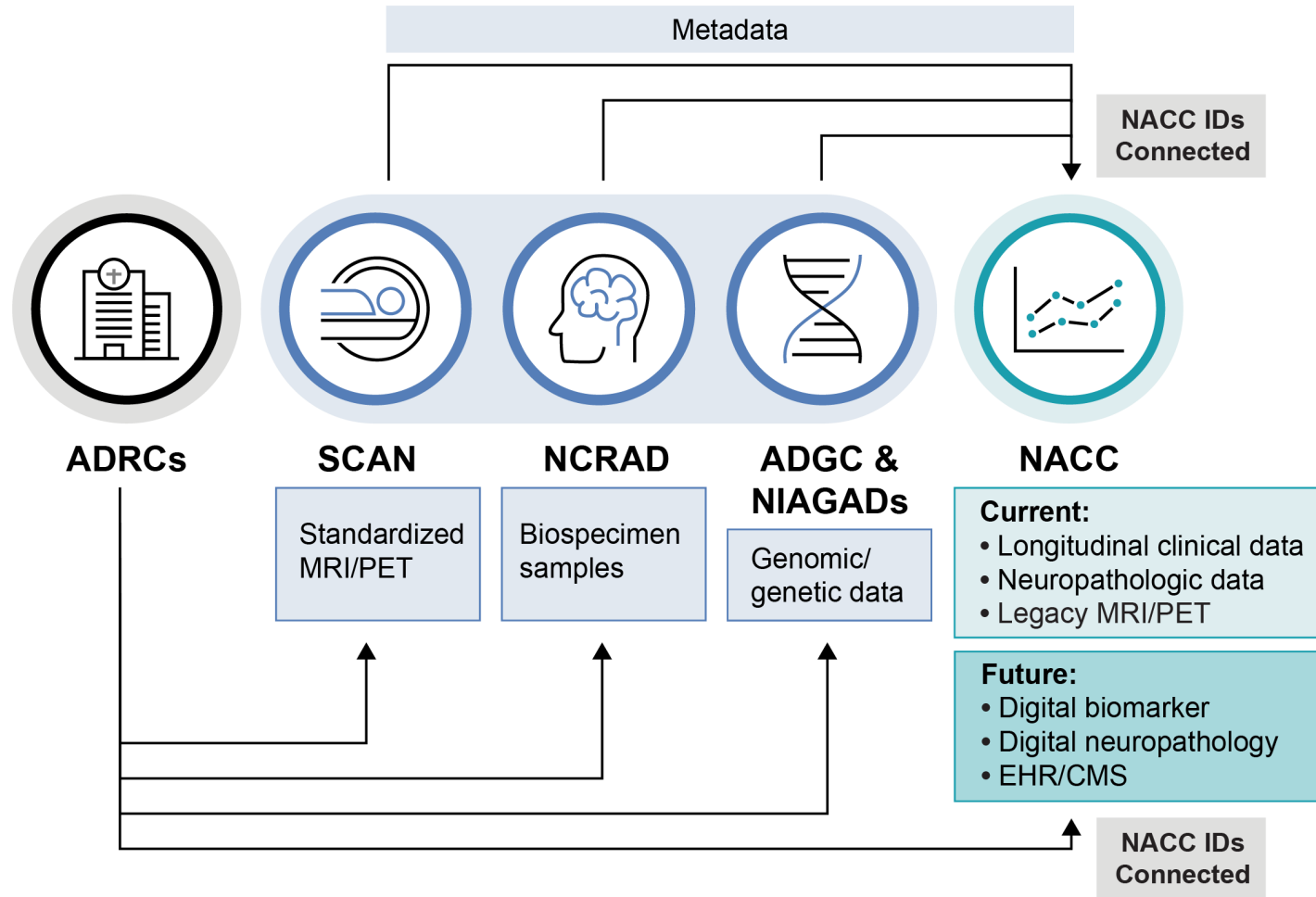
UDSv4 – Pipeline and Database



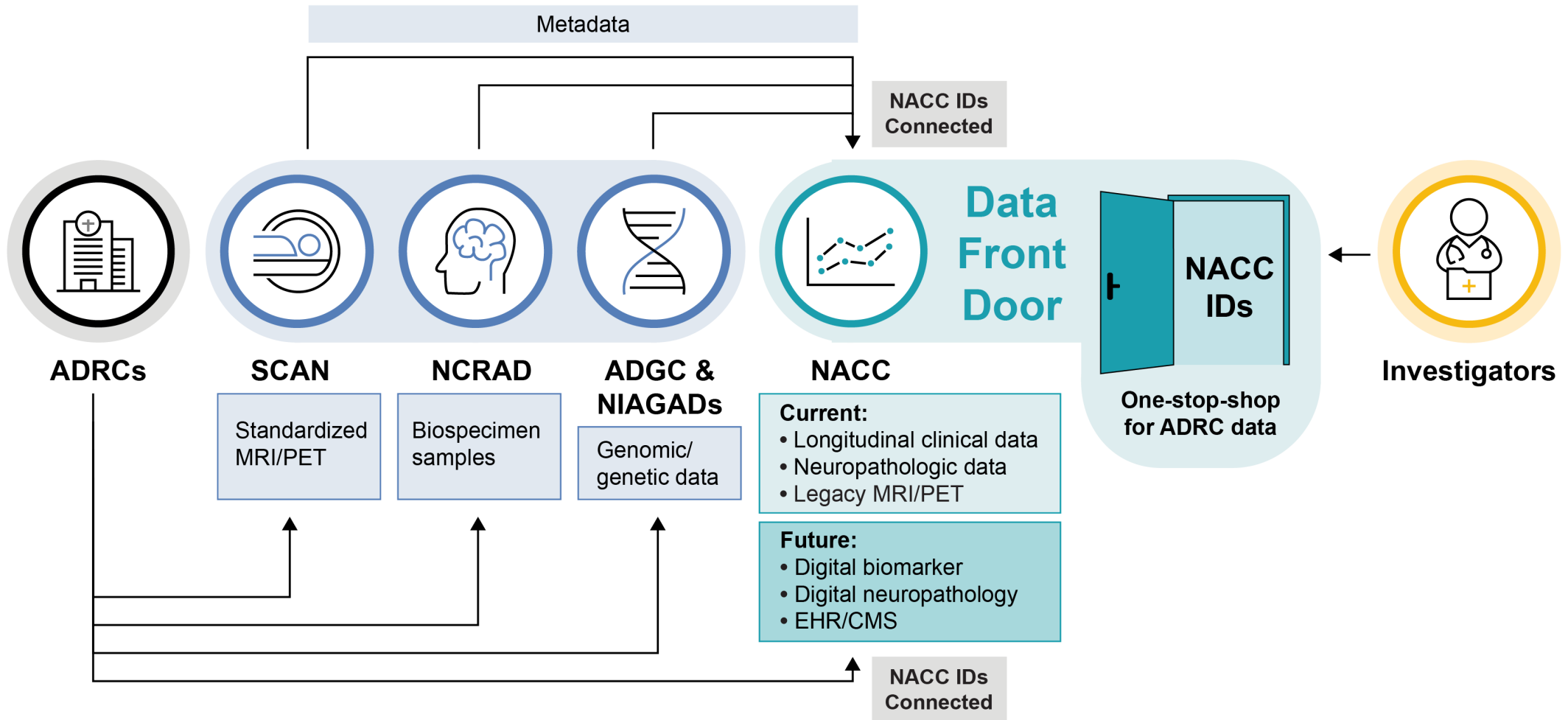
UDSv4 – Pipeline and Database



UDSv4 – Pipeline and Database

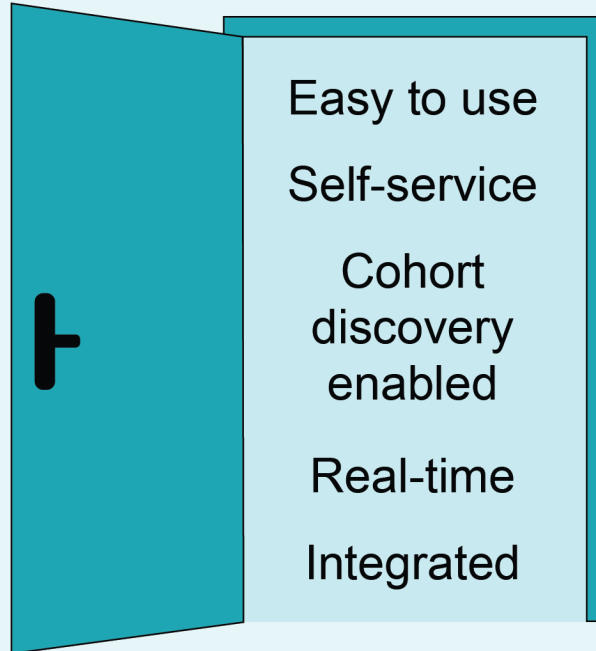


UDSv4 – Pipeline and Database



UDSv4 – Search and Access Portal

Data Front Door



**One-stop-shop
for ADRC data**

Requirements Pilot Project

- Collaboration between NACC, NCRAD, and NIAGADS

Provide input!

- Visit our interactive DFD station to provide input on your needs – Solano Room, noon – 1:30pm

**Join a thought leader
focus group session**

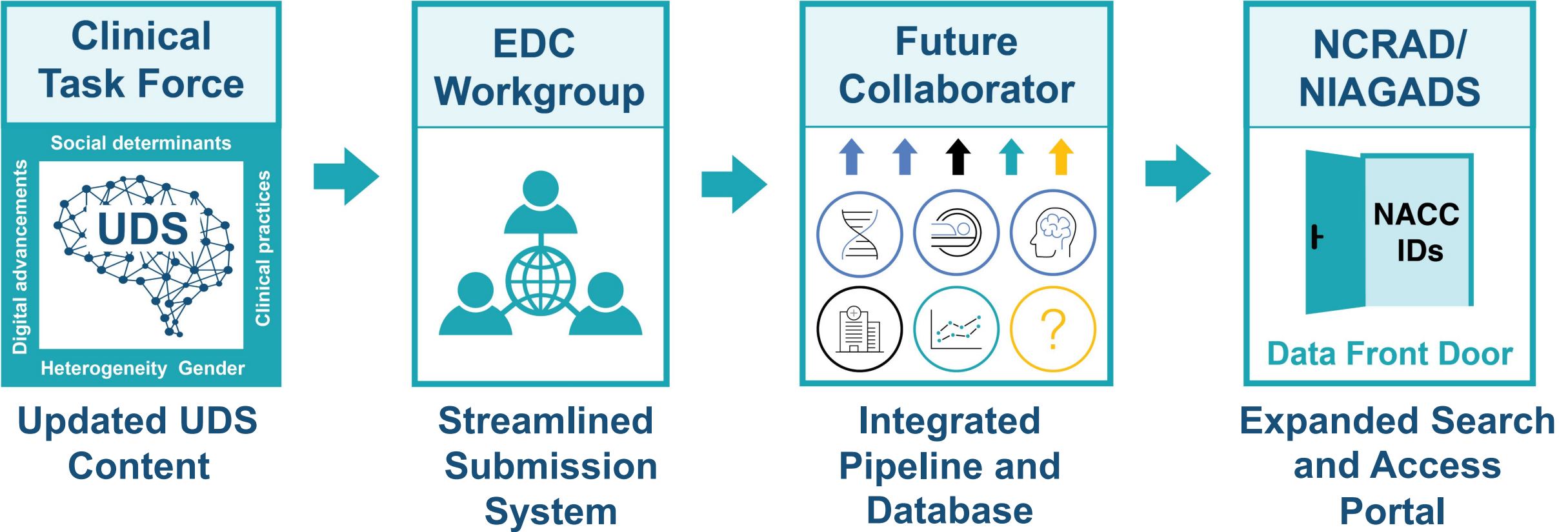


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**Provide input
via a survey**

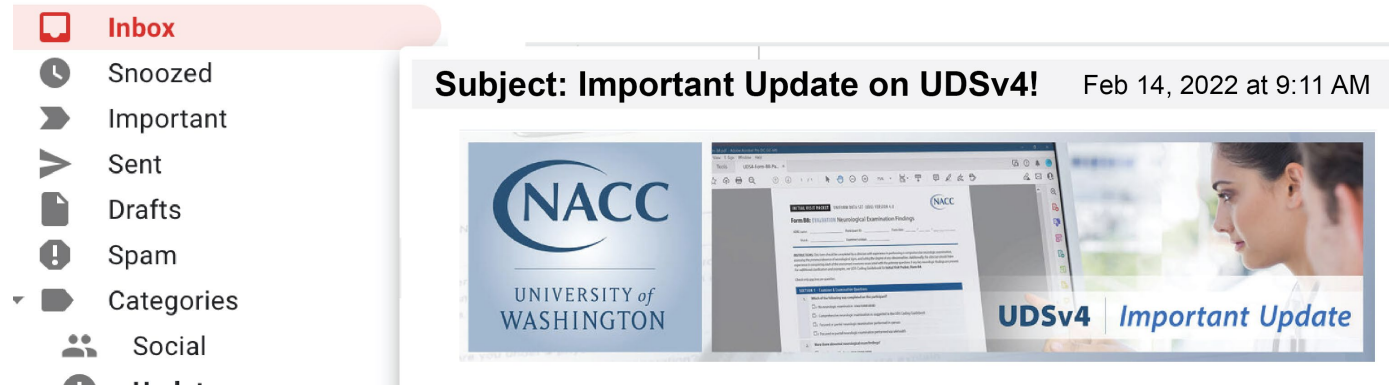


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So, when will all of this be available?

- **Timing constraints**
 - CTF content update
 - Architecture design and build
- **We're committed to keeping you in the loop!**
 - Regular progress updates to the ADRC community
 - Transparent tracking (shared CTF tracker and forms tracker)
 - Email, newsletters, website updates
 - Early forms access for testing with your systems



How do you want to receive updates?

Fill out the survey!



Link [Here](#)

UDSv4 Forms Status Update: Webinar on June 3rd at 8-10 am PT

Hosted by CTF and NACC

Learn all about the new UDSv4 forms!

- New content added for assessing:
 - Subjective cognitive decline
 - Mild behavioral impairment
- COVID-19 Forms
- Potential participant burden

Scan here to sign up
for a calendar invite



Link [Here](#)

Thank you!



Thank you!



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Thank you!



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Connect with NACC

Sarah Biber – Program Director

biber@uw.edu



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