



NACC Update

Sarah Biber, PhD, NACC Executive Director
Monday, May 6, 2024
ADRC Spring Meeting

NACC's 25th Anniversary!



National
Alzheimer's
Coordinating
Center

HAPPY ANNIVERSARY
25

UDS Impact



50,000+

Participants with UDS data
(18,000+ active participants)



188,000+

Clinical assessments
(1-19 visits per participant; median =3)



7,900+

Neuropathology datasets
(From 58% of deceased participants)



1,300+

Published studies using
NACC data



37

ADRCs are contributing data
(Across 26 states)

MDS Impact



71,000+

Participants with MDS data



11,000+

Neuropathology datasets

Special Issue of the Journal of Alzheimer's and Dementia

Celebrating
the ADRC
Program's
40th and
NACC's 25th
Anniversary
!

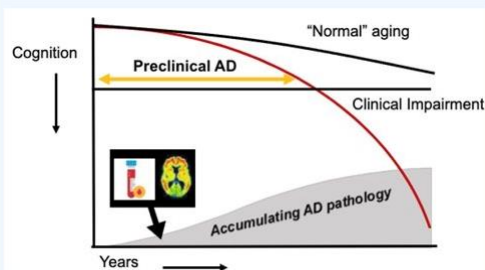
Call for proposals can be
viewed at:

[bit.ly/NACC Special Issue](https://bit.ly/NACC_Special_Issue)

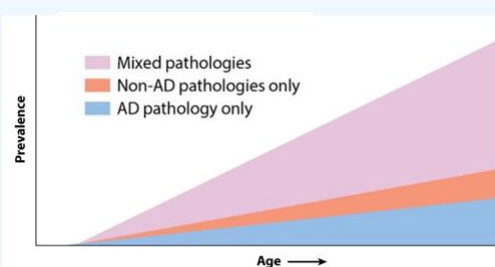
Submission Deadline:
December 31, 2024

GOAL: Highlight the impact these programs have had on advancing ADRD translation and discovery and their ongoing and critical role in tackling the most pressing challenges in the field

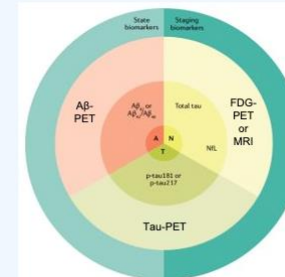
Advance Early Detection



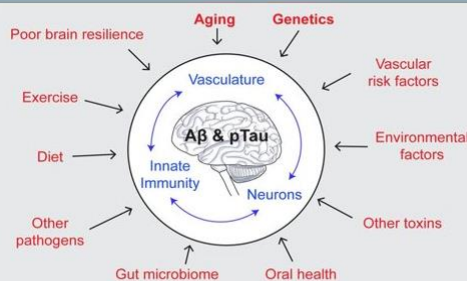
Disentangle Heterogeneity



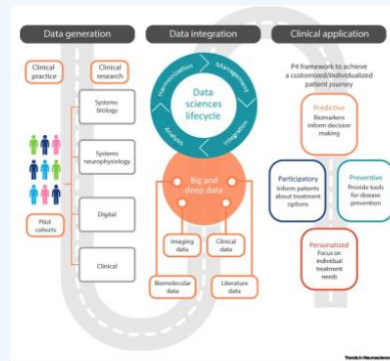
Validate Blood Biomarkers



Identify and Stratify Risk Factors and Protective Mechanisms



Precision Medicine



Improve Generalizability





2.5

YEARS

NACC is rapidly evolving and leveraging its' unique strengths to meet the emergent needs of the ADRD field and the ADRC Program

NACC's Expanded Mission and Role

Data Coordination & Centralized Repository

Findable 
Accessible 
Interoperable 
Reusable 

Communication & Collaboration Hub

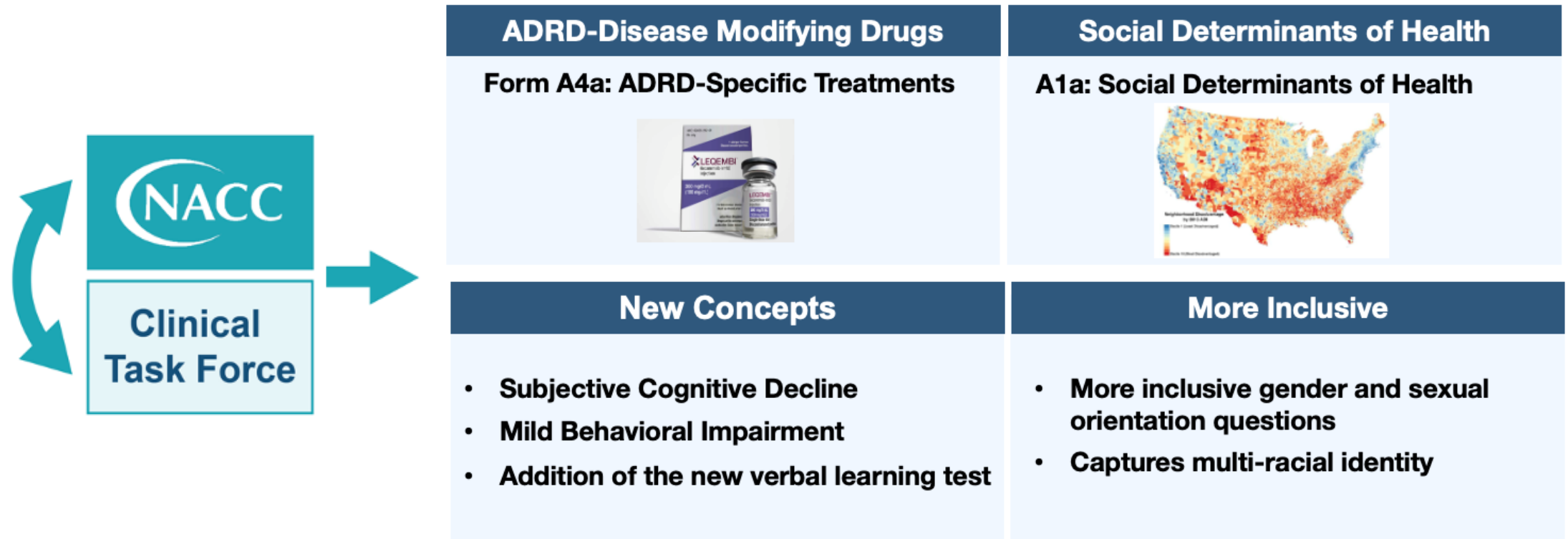


A network diagram background consisting of a complex web of light blue lines connecting various nodes. Some nodes are represented by solid teal circles, while others are smaller, semi-transparent grey circles. The lines are thin and create a dense, interconnected pattern across the entire slide.

UDSv4: Establishing new data standards for the field

Launching UDSv4

Defining New Standards for the Field



Completed UDSv4 Content, PDFs, and REDCap Forms

100% UDSv4 content complete!

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
- Form D1a
- Form D1b
- Form C2/C2t

New forms

**No changes from UDSv3*



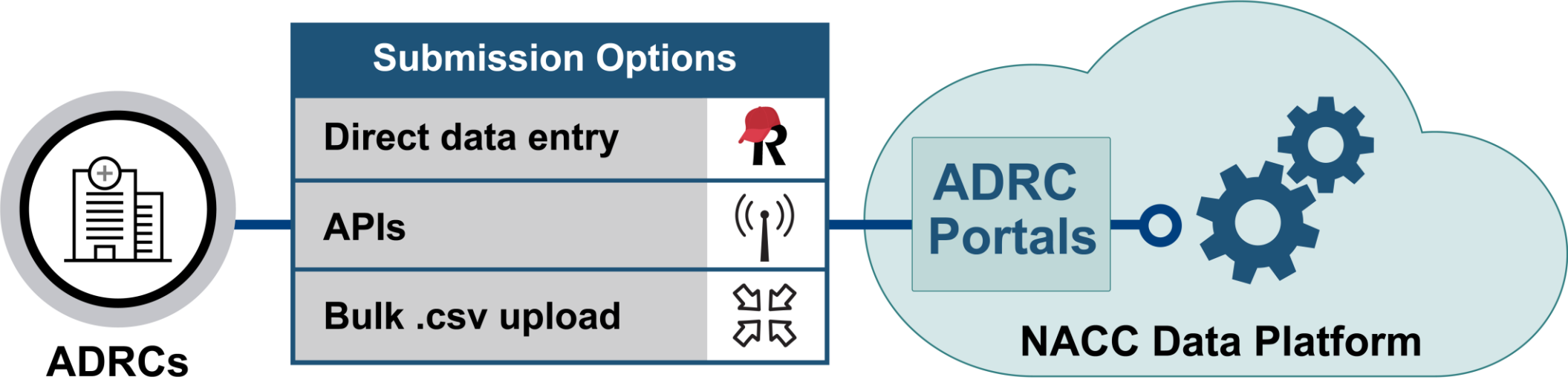
100% of UDSv4 REDCap forms developed

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

Making it easier for ADRCs to collect, submit, manage, and access participant data

Built a Modern Electronic Data Capture System

Saves time, enhances sharing, and improves data quality



Launched ADRC Portals

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

ADRC Portals

Manage Participants



Assign
NACC
IDs and
more!

Submit Data



View, Audit, and Access
Participant Data



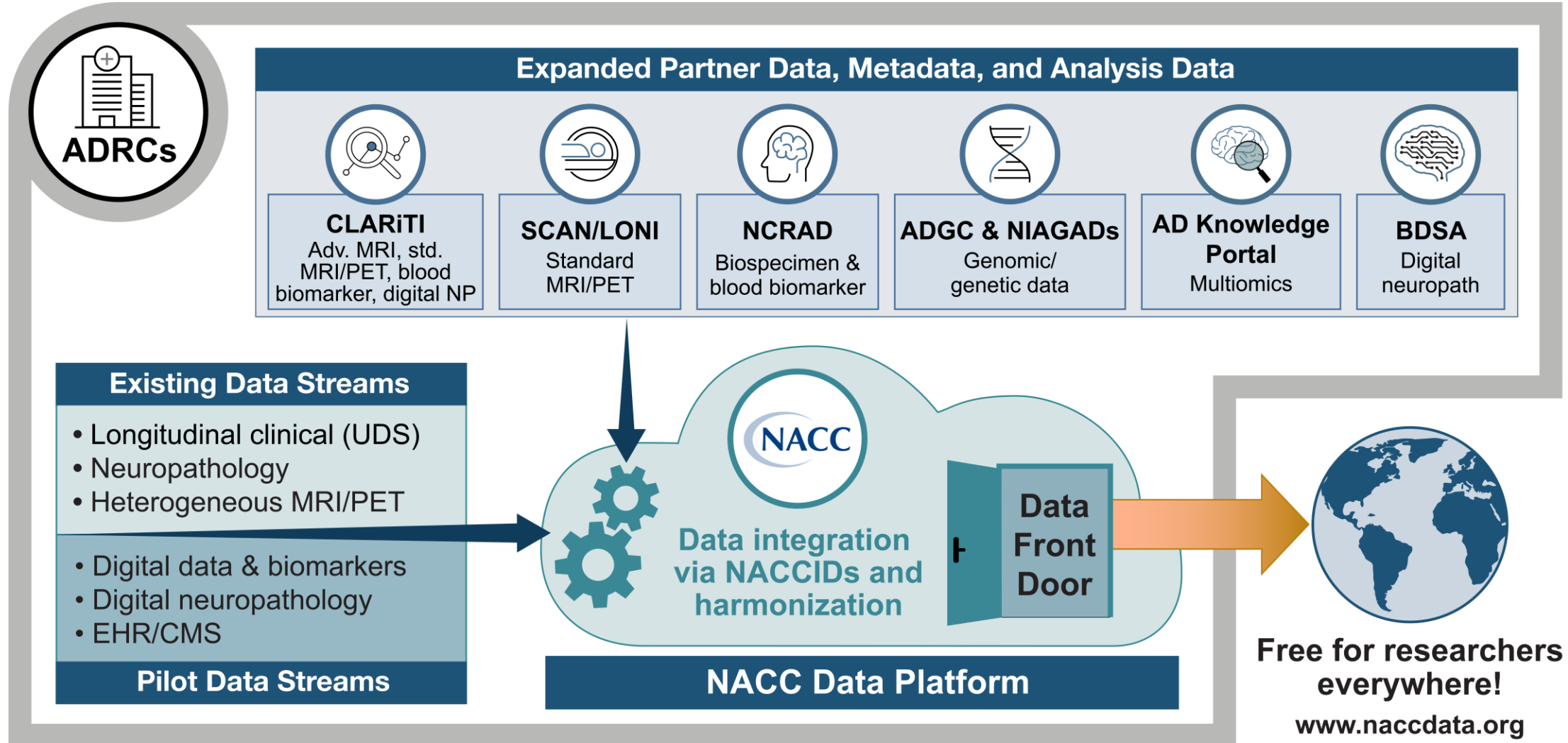
Download ADRC
Program Report



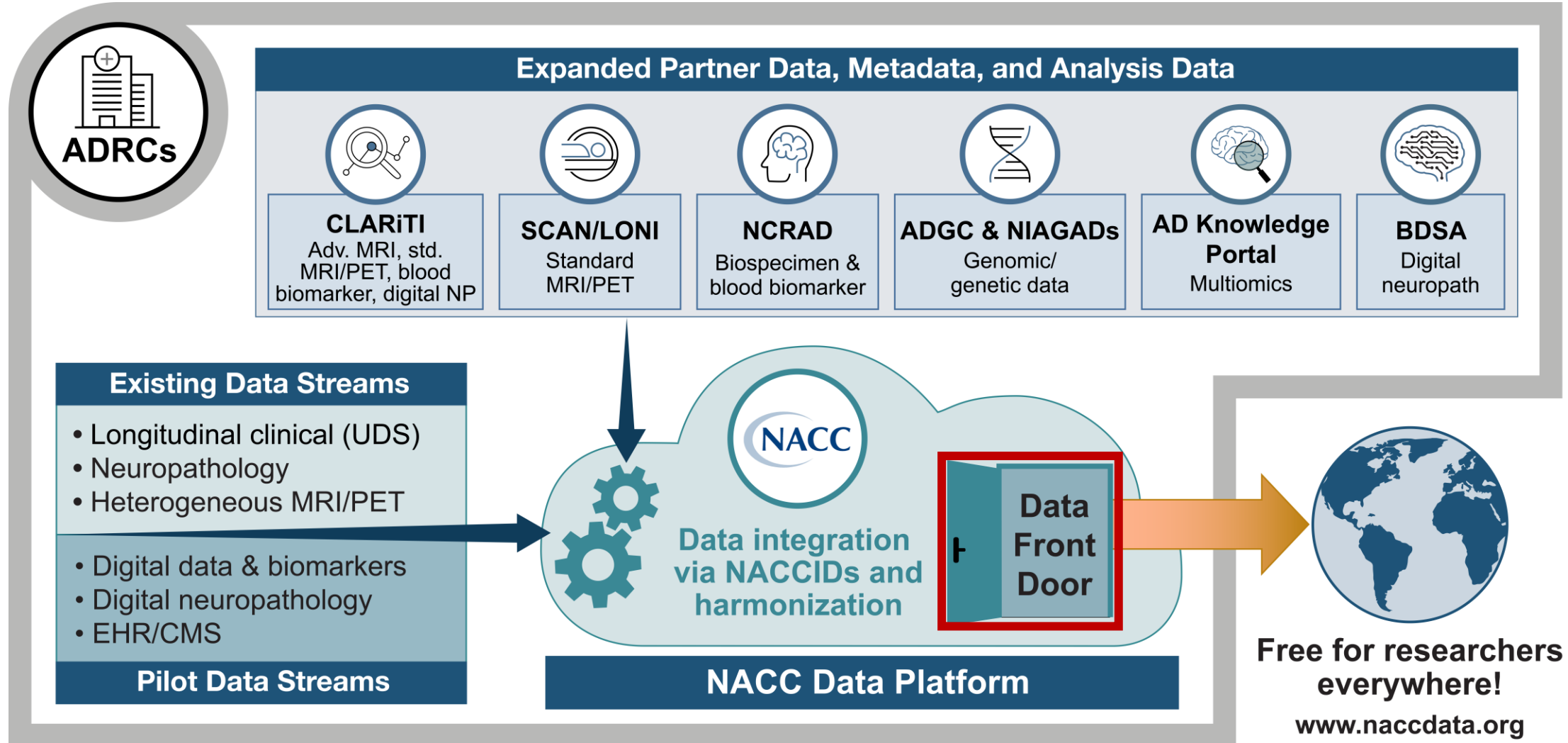
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Providing next generation informatics infrastructure to advance ADRD discovery and translation

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



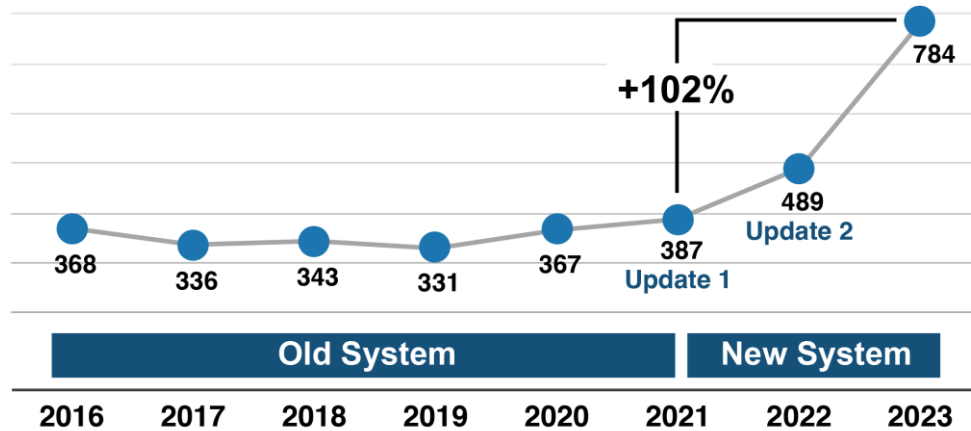
New NACC Data Platform: A Modern Cloud-based Multimodal Data Integration, Harmonization, and Sharing Platform



Enabled Increased NACC Data Utilization

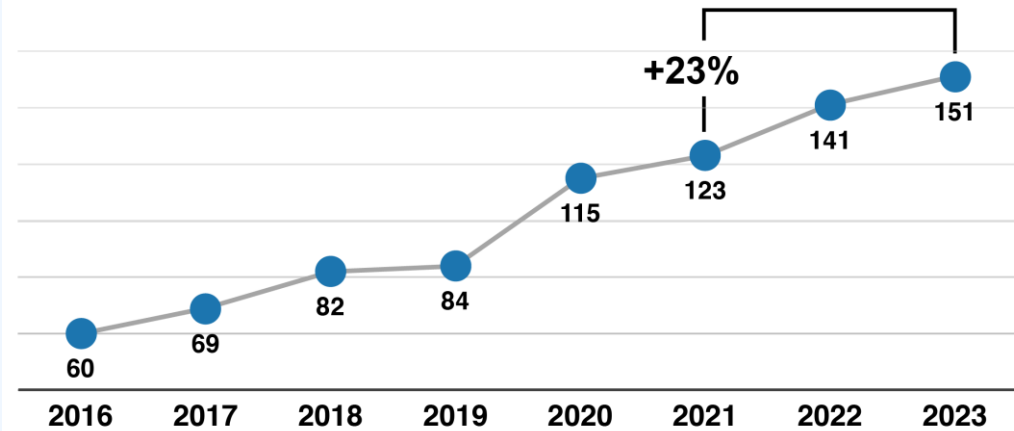
102% increase in the average number of data requests

Total Number of Data Requests Per Year



23% increase in the number of published studies using NACC data

Total Number of Published Studies Per Year

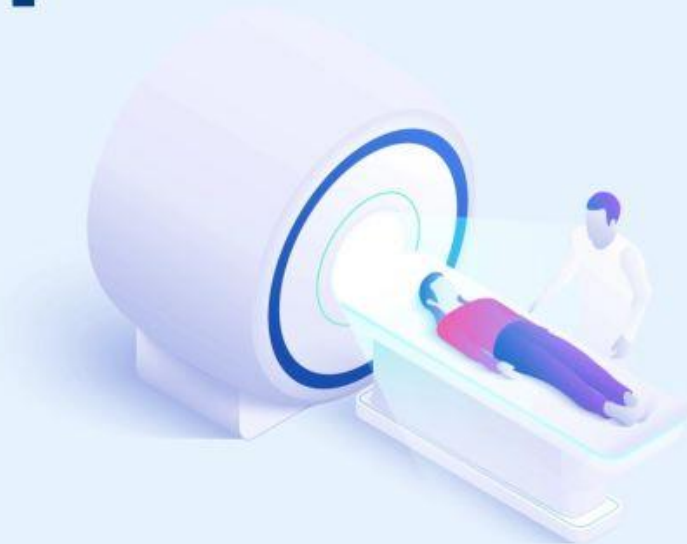


System update 1: Expanded Quick-Access file types (FTLD, LBD, CSF, MRI, PET, scans)
System update 2: Data request survey through REDCap

Advanced Multimodal Data Search and Access

NACC's Data Front Door: A One-Stop-Shop for All ADRC Data

scan
data is
available
at NACC!



Visit
scan.naccdata.org/

Berkeley
UNIVERSITY OF CALIFORNIA



UNIVERSITY OF MICHIGAN



UC DAVIS



Tackling Complex ADRD Challenges Requires Multimodal Data



Socio-demographic



Genetic and genomic



Multiomics data



Biomarker



Imaging (MRI/PET)



Neuropathology



Digital biomarker



Neurocognitive tests



Electronic Health Record (EHR)



AD Knowledge Portal

LONI

NIAGADS

NCRAD



Alzheimer's Disease Center



Goizueta Alzheimer's Disease Research Center

Leveraging Multimodal AD/ADRD Data to Advance Discovery

AD/ADRD Multimodal Data Workshop

Friday, July 26th | 1-5pm ET

Learning objectives:

- Discover the multimodal data resources that are available from some of the leading ADRD data centers
- Pitch ideas and form teams for deciphering how multimodal data can best be leveraged to address the most pressing ADRD research questions
- Identify multimodal data infrastructure needs, gaps, and solutions

Register today!

ALZHEIMER'S ASSOCIATION®
AAIC > 24



Thank you to our partners!

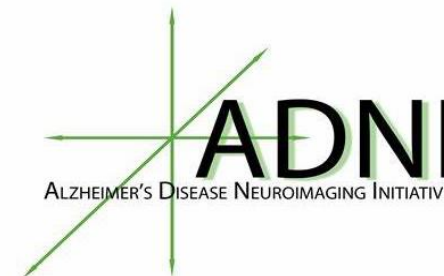


AD Knowledge Portal



NIAGADS

NCRAD



Tuesday, May 7th @ 10:00 – 11:30am CT (Zilker 1-2)

Topic	Speaker Name
Welcome and Introduction	Sarah Biber, PhD
NACC Data Platform	Sarah Biber, PhD
UDSv4 and NACC ID Updates	
<ul style="list-style-type: none"> UDSv4 Timeline 	Sarah Biber, PhD
<ul style="list-style-type: none"> UDSv4 and NACCID Pilots 	Jess Welsch, MBA
UDSv4 Onboarding and Training Resources	Sarah Gothard
UDSv4 Transition Strategy – Panel and Q&A	Greg Jicha, MD, PhD; Ari Bhaumik; Jeffery M. Burns, MD, MS; Sudeshna Das, PhD; Sarah Tomaszewski Farias, PhD <i>Moderator: Sarah Biber, PhD</i>

A decorative network graphic consisting of light blue lines connecting various nodes. Some nodes are solid teal circles, while others are light gray circles. The network is spread across the top and bottom of the slide, framing the central text.

Awards!

Expanded New Investigator Award Program!

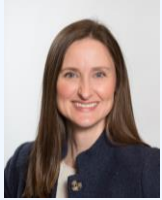
Program Highlights:

- ❑ Expanded from 2 to 13 awards!
- ❑ Doubled the award amount – now \$135K (Direct Costs) per project
- ❑ 156 applications from across 36 ADRCs



Congratulations to our 2024 Awardees!

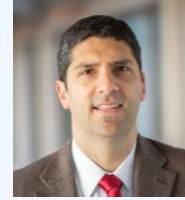
Each will receive \$135K (Direct Costs) for their Projects



Claire Clelland, MD, PhD
UC San Francisco ADRC



Daniel Fisher, MD, PhD
U of Washington ADRC



Brian Gordon, PhD
Washington U in St. Louis ADRC



Abbi Hernandez, PhD
U of Alabama at Birmingham ADRC



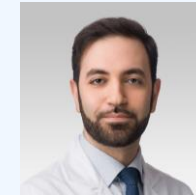
Annie Lee, PhD
Columbia U ADRC



Wonjae Lee, PhD
Duke U of North Carolina ADRC



Liang Ma, PhD
South Texas AD Center (STAC)



Malik Nassan, MD
Northwestern U ADRC



Chris Rodgers, PhD
Emory University ADRC



Jessica Schwarz, PhD
Mount Sinai SoM ADRC



Yuto Uchida, MD, PhD
Johns Hopkins U ADRC



Xian Wu, PhD
U of Kentucky ADRC



Emma Zang, PhD
Yale University ADRC

New Mentorship Program

Providing value for all New Investigator Award applicants

NACC partnered with the REC to launch a companion mentorship program

- **77% of applicants** participated in the program
- **80.2% of applicants** strongly agreed that this mentorship strengthened their NI Award applications
- **92.2% of applicants** are confident that they will apply this guidance to future grant applications
- **95.4% of mentors** expressed interest in continuing their mentor role in future award cycles.



2024 New Investigator Award Program

THANK YOU!



Heather Synder, PhD
Alzheimer's Association
Vice President of Medical & Scientific Relations



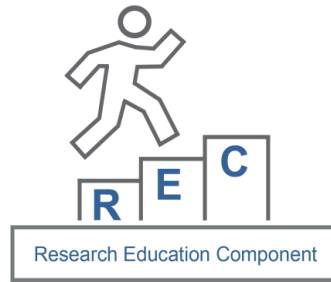
Stephania Forner, PhD
Alzheimer's Association
Director of Medical & Scientific Relations



Katie Donlin
Alzheimer's Association
Award Grant Specialist

2024 New Investigator Award Program

THANK YOU!



Elizabeth Head, MA, PhD

Hussein Yassine, MD

Jose Cavazos, MD, PhD

REC Steering Committee

Claire Ghazal Nelson

ALZHEIMER'S DISEASE AND RELATED DEMENTIAS DIGITAL PILOT PROGRAM

Virtual Pitch Competition

 **May 31, 2024**



Join us at the

AD/ADRD Digital Pilot Program *Pitch Competition*

- Top applicants will pitch their proposals in front of a live audience
- Winners (1 to 3) will each be awarded \$250K-\$1M in funding (direct cost)

REGISTER TODAY!

[BIT.LY/NACC-DIGITAL-PILOTS](https://bit.ly/nacc-digital-pilots)

This virtual event is open to all!



AD/ADRD DIGITAL PILOT PROGRAM PITCH COMPETITION

AND THE FINALIST TEAMS ARE...

PI: Jeffrey Kaye, PhD

EFFECT-AD: Everyday Frequent Functional Evaluation with Crosscutting Technology for AD



PI: Joseph Winer, PhD

Characterizing sleep-wake activity patterns across the spectrum of AD/ADRD



PI: Raeanne Moore, PhD

CLARIFY- speeCh analysis And keystRoke tracking For early AD detection



PI: Ehsan Adeli, PhD

Scalable Next-Generation Smartphone Gait Assessment for Early Detection of AD/ADRD



PI: Kayci Vickers, PhD

Pilot Study to Evaluate VisMET on the Linus Health Platform at Multiple ADRCs



PI: Emma Rhodes, PhD

Remote Digital Monitoring to Detect Behavioral & Neuropsychiatric Symptoms in ADRD





2.5
YEARS

This progress has been made possible through our collaboration with the ADRC Program, CTF, EDC Workgroup, our partners,

and the team at NACC



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



SARAH BIBER, PHD
Executive Director



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



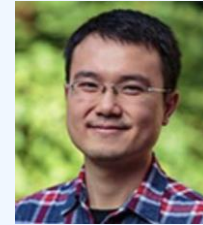
CHARLES MOCK, MD, PHD, FACS
Associate Director,
NACC Professor,
Epidemiology and Surgery



KWUN CHUEN GARY CHAN, PHD
Associate Director
Professor, Biostatistics,
Health Systems
and Population Health



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



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



KYLE ORMSBY, PHD
Co-Investigator
Visiting Associate
Professor, Mathematics



SHILPA ALLIMATTI, MA, MBA
Tech Team Manager



BEN KELLER, PHD
Software Engineer 3



JANENE HUBBARD, BS
Research
Consultant



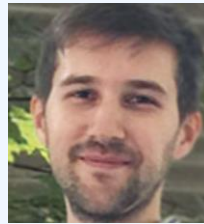
CHANDIMA HEWA-ADUNGODAGE, PHD
Software Engineer 3



JOYLEE WU
Database Administrator



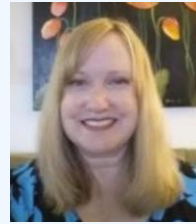
BRENDAN SMITH
Web Developer



ZACH STARK, BBA
Software
Engineer 3



LAURA MCLEOD, BBA
REDCap Developer



STACY OSWALD, MHS
Research Team
Manager



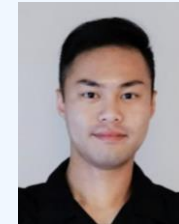
JESSICA CULHANE, MS
Research Scientist 3



KATHRYNN GAUTHREAU, MS
Research Scientist 3



ZACK MILLER
Research
Consultant



YUEXUAN WU, PHD
Post-Doc



SARAH YASUDA
Research
Assistant



HEATHER O'CONNELL
CLARiTi Program
Manager



JESS WELSCH, MBA
Senior Project
Manager



ELISE GRUBER
Project Manager



BRITTANY HALE
Project Manager



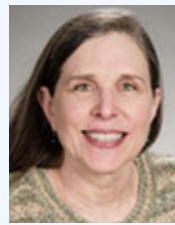
JULIE GORDON
Administrative
Assistant



JINGYAN XIA
Grants & Finance
Manager



EMILY ALMADA
Administrative
Coordinator



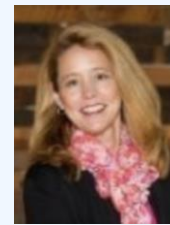
VALERIE HOCKENS
Program Ops
Specialist - Finance



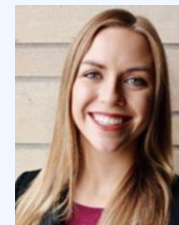
BRITTANY FAIR, MS
Communications
Manager



AILEEN IDA, MA
Communication
Specialist



AMY YOUNG
Public
Information
Specialist



HANNAH ROSENTRETER
Manager of Special
Projects



FAITH BUCKLEY, MBA
Admin Specialist



TINA MONROE
HR Specialist

A decorative background graphic consisting of a network of light blue lines connecting various circular nodes. Some nodes are solid dark blue, while others are light blue or grey. The network is spread across the top and bottom of the slide, framing the central text.

Thank You!