NACC Modernization and UDSv4 Updates

Sarah Biber, PhD

Tuesday, May 7, 2024

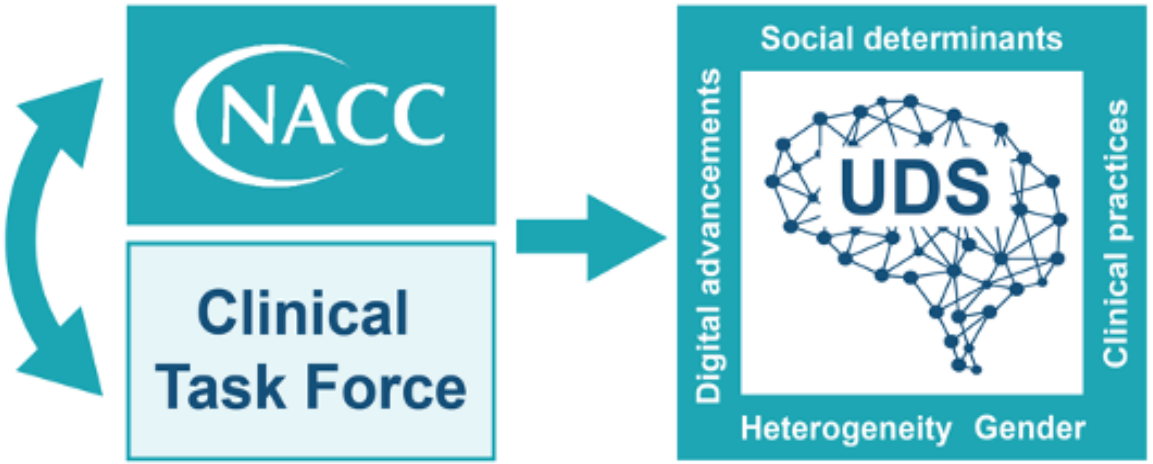
2024 Spring ADRC Meeting

NACC Data is FAIR

NACC sets data standards for the field

NACC Data is FAIR

Defining Standards for the Field



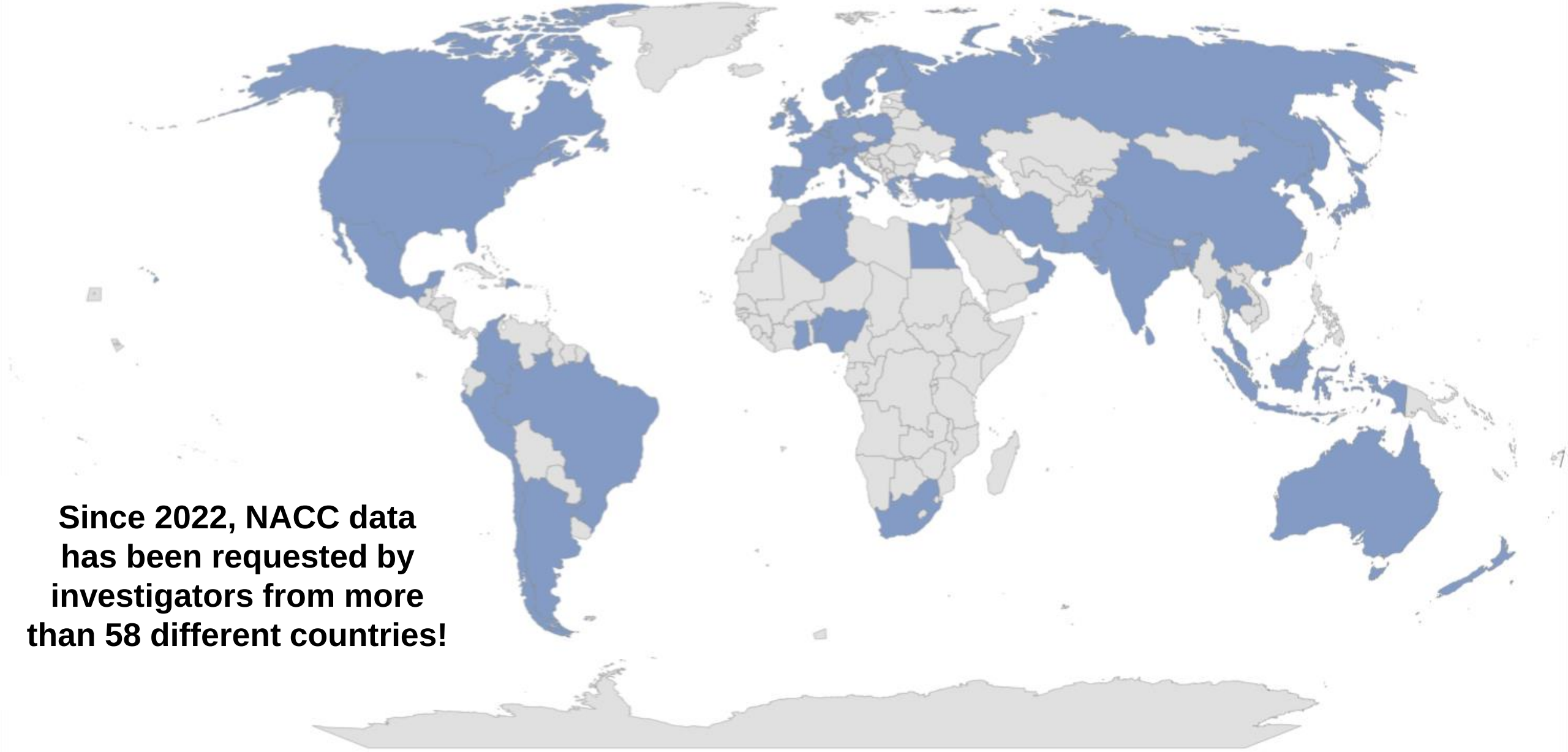
- Our consortium sets clinical research data standards for AD/ADRD data
- Data is standardized before it is submitted to NACC

- Gold-standard for how clinical phenotypic neurocognitive data should be collected for ADRD

NACC UDS Translations

UDSv3 has been translated into a total of 33 languages for use in 147 different international studies!

NACC Data is Used All Over the World



Since 2022, NACC data has been requested by investigators from more than 58 different countries!

NACC Data Has Enabled Major Breakthroughs in the ADRD Field

Article | Open access | Published: 20 June 2022

Multimodal deep learning for Alzheimer's disease dementia assessment

Shangran Qiu, Matthew I. Miller, Prajakta S. Joshi, Joyce C. Lee, Chonghua Xue, Yunruo Ni, Yuwei Wang, Ileana De Anda-Duran, Phillip H. Hwang, Justin A. Cramer, Brigid C. Dwyer, Honglin Hao, Michelle C. Kaku, Sachin Kedar, Peter H. Lee, Asim Z. Mian, Daniel L. Murman, Sarah O'Shea, Aaron B. Paul, Marie-Helene Saint-Hilaire, E. Alton Sartor, Aneeta R. Saxena, Ludy C. Shih, Juan E. Small, ... Vijaya B. Kolachalama + Show authors

Nature Communications **13**, Article number: 3404 (2022) | Cite this article

35k Accesses | **59** Citations | **104** Altmetric | Metrics

Original Investigation

May 23, 2022

FREE

Clinical Manifestations of Early-Onset Dementia With Lewy Bodies Compared With Late-Onset Dementia With Lewy Bodies and Early-Onset Alzheimer Disease

Jingwei Sim, MRCP[1]; Huihua Li, PhD[2]; Shahul Hameed, MD[1]; et al

Author Affiliations | Article Information

JAMA Neurol. 2022;79(7):702-709. doi:10.1001/jamaneurol.2022.1133

BRAIN
ORIGINAL ARTICLE

Proposed research criteria for prodromal behavioural variant frontotemporal dementia

Megan S. Barker,[1] Reena T. Gottesman,[2] Masood Manoochehri,[1] Silvia Chapman,[1] Brian S. Appleby,[3] Danielle Brushaber,[4] Katrina L. Devick,[4] Bradford C. Dickerson,[5] Kimiko Domoto-Reilly,[6] Julie A. Fields,[7] Leah K. Forsberg,[8] Douglas R. Galasko,[9] Nupur Ghoshal,[10] Jill Goldman,[1,2] Neill R. Graff-Radford,[11] Murray Grossman,[12] Hilary W. Heuer,[13] Ging-Yuek Hsiung,[14] David S. Knopman,[8] John Kornak,[15] Irene Litvan,[9] Ian R. Mackenzie,[16] Joseph C. Masdeu,[17] Mario F. Mendez,[18,19] Belen Pascual,[17] Adam M. Staffaroni,[13] Maria Carmela Tartaglia,[20] Bradley F. Boeve,[8] Adam L. Boxer,[13] Howard J. Rosen,[13] Katherine P. Rankin,[13] Stephanie Cosentino,[1,2,21] Katya Rascovsky[12] and Edward D. Huey[1,2,22] on behalf of the ALLFTD Consortium

ALZHEIMER'S ASSOCIATION | Alzheimer's & Dementia®
THE JOURNAL OF THE ALZHEIMER'S ASSOCIATION

RESEARCH ARTICLE

Prediction of neuropathologic lesions from clinical data

Thanaphong Phongpreecha, Brenna Cholerton, Syed Bukhari, Alan L. Chang, Davide De Francesco, Melan Thuraiappah, Dana Godrich, Amalia Perna, Martin G. Becker, Neal G. Ravindra ... See all authors

First published: 21 January 2023 | https://doi.org/10.1002/alz.12921 | Citations: 1

Thomas J. Montine and Nima Aghaeepour contributed equally to this work.
[Correction added on January 26, 2023, after first online publication: The last name of the author Syed Bukhari was misspelled and has been corrected now.]

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ARTICLES

RESEARCH ARTICLE | February 4, 2022

Limbic-Predominant Age-Related TDP-43 Encephalopathy

Medical and Pathologic Factors Associated With Comorbid Hippocampal Sclerosis

Kathryn M. Gauthreaux, MS, Merilee A. Teylan, MPH, Yuriko Katsumata, PhD, Charles Mock, MD, Jessica E. Culhane, MS, Yen-Chi Chen, PhD, Kwun C.G. Chan, PhD, ... SHOW ALL ..., and Peter T. Nelson, MD, PhD AUTHORS INFO & AFFILIATIONS

April 5, 2022 issue • 98 (14) e1422-e1433 • https://doi.org/10.1212/WNL.0000000000200001

scientific reports

OPEN

Generalizable deep learning model for early Alzheimer's disease detection from structural MRIs

Sheng Liu, Arjun V. Masurkar, Henry Rusinek, Jingyun Chen, Ben Zhang, Weicheng Zhu, Carlos Fernandez-Granda & Narges Razavian

Scientific Reports **12**, Article number: 17106 (2022) | Cite this article

24k Accesses | **24** Citations | **93** Altmetric | Metrics

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THE JOURNAL OF THE ALZHEIMER'S ASSOCIATION

RESEARCH ARTICLE | Open Access

Different cohort, disparate results: Selection bias is a key factor in autopsy cohorts

Kathryn Gauthreaux, Walter A. Kukull, Karin B. Nelson, Charles Mock, Yen-Chi Chen, Kwun C. G. Chan, David W. Fardo, Yuriko Katsumata, Erin L. Abner, Peter T. Nelson

First published: 17 August 2023 | https://doi.org/10.1002/alz.13422 | Citations: 2

ELSEVIER
Neurobiology of Disease
Volume 191, February 2024, 106412

Pathologic correlates of aging-related tau astrogliopathy: ARTAG is associated with LATE-NC and cerebrovascular pathologies, but not with ADNC

Yuriko Katsumata [a b], Xian Wu [a b], Khine Zin Aung [a b], Kathryn Gauthreaux [c], Charles Mock [c], Shelley L. Forrest [d e], Gabor G. Kovacs [d e], Peter T. Nelson [a f]

Original Investigation

July 17, 2023

Associations of Sex, Race, and Apolipoprotein E Alleles With Multiple Domains of Cognition Among Older Adults

Skylar Walters, MS[1,2]; Alex G. Contreras, BS[1,2]; Jaclyn M. Eissman, BS[1,2]; et al

Author Affiliations | Article Information

JAMA Neurol. 2023;80(9):929-939. doi:10.1001/jamaneurol.2023.2169

Research | Open access | Published: 06 November 2023

Quantitative estimate of cognitive resilience and its medical and genetic associations

Thanaphong Phongpreecha, Dana Godrich, Eloise Berson, Camilo Espinosa, Yeasul Kim, Brenna Cholerton, Alan L. Chang, Samson Mataraso, Syed A. Bukhari, Amalia Perna, Koya Yakabi, Kathleen S. Montine, Kathleen L. Poston, Elizabeth Mormino, Lon White, Gary Beecham, Nima Aghaeepour & Thomas J. Montine

Alzheimer's Research & Therapy **15**, Article number: 192 (2023) | Cite this article

1292 Accesses | **1** Citations | **10** Altmetric | Metrics

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THE JOURNAL OF THE ALZHEIMER'S ASSOCIATION

FEATURED ARTICLE

ARMADA: Assessing reliable measurement in Alzheimer's disease and cognitive aging project methods

Sandra Weintraub, Tatiana Karpouzian-Rogers, John Devin Peipert, Cindy Nowinski, Jerry Slotkin, Katy Wortman, Emily Ho, Emily Rogalski, Cynthia Carlsson, Bruno Giordani ... See all authors

First published: 17 November 2021 | https://doi.org/10.1002/alz.12497 | Citations: 4

medRxiv
THE PREPRINT SERVER FOR HEALTH SCIENCES

CSH Cold Spring Harbor Laboratory | BMJ | Yale

Multi-ancestry genome-wide meta-analysis of 56,241 individuals identifies *LRRC4C*, *LHX5-AS1* and nominates ancestry-specific loci *PTPRK*, *GRB14*, and *KIAA0825* as novel risk loci for Alzheimer's disease: the Alzheimer's Disease Genetics Consortium

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THE JOURNAL OF THE ALZHEIMER'S ASSOCIATION

FEATURED ARTICLE | Full Access

Black and White individuals differ in dementia prevalence, risk factors, and symptomatic presentation

Jack C. Lennon, Stephen L. Aita, Victor A. Del Bene, Tasha Rhoads, Zachary J. Resch, Janelle M. Eloi, Keenan A. Walker

First published: 02 December 2021 | https://doi-org.offcampus.lib.washington.edu/10.1002/alz.12509 | Citations: 32

iScience

Volume 26, Issue 9, 15 September 2023, 107522

CellPress

Article

Deep learning for risk-based stratification of cognitively impaired individuals

Michael F. Romano [1 2 18], Xiao Zhou [1 3 18], Akshara R. Balachandra [1 4 18], Michalina F. Jadick [1], Shangran Qiu [1], Diya A. Nijhawan [1], Prajakta S. Joshi [5 6 7], Shariq Mohammad [8], Peter H. Lee [9], Maximilian J. Smith [9], Aaron B. Paul [10], Asim Z. Mian [11], Juan E. Small [9], Sang P. Chin [3 12 13], Rhoda Au [5 7 14 15 16], Vijaya B. Kolachalama [1 3 14 17 19]

ARTICLE

https://doi.org/10.1038/s41467-022-31037-5 OPEN

Multimodal deep learning for Alzheimer's disease dementia assessment

Shangran Qiu, Matthew I. Miller, Prajakta S. Joshi, Joyce C. Lee, Chonghua Xue, Yunruo Ni, Yuwei Wang, Ileana De Anda-Duran, Phillip H. Hwang, Justin A. Cramer, Brigid C. Dwyer, Honglin Hao, Michelle C. Kaku, Sachin Kedar, Peter H. Lee, Asim Z. Mian, Daniel L. Murman, Sarah O'Shea, Aaron B. Paul, Marie-Helene Saint-Hilaire, E. Alton Sartor, Aneeta R. Saxena, Ludy C. Shih, Juan E. Small, ... Vijaya B. Kolachalama + Show authors

Nature Communications **13**, Article number: 3404 (2022) | Cite this article

34k Accesses | **53** Citations | **104** Altmetric | Metrics

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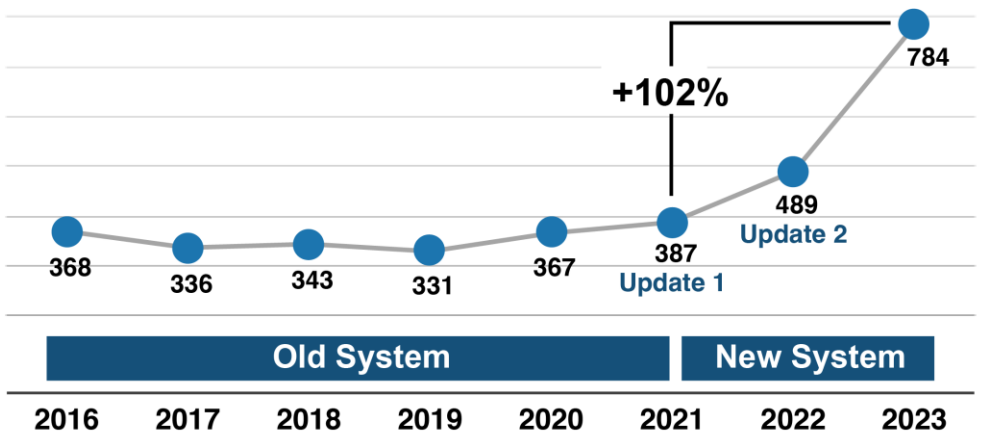
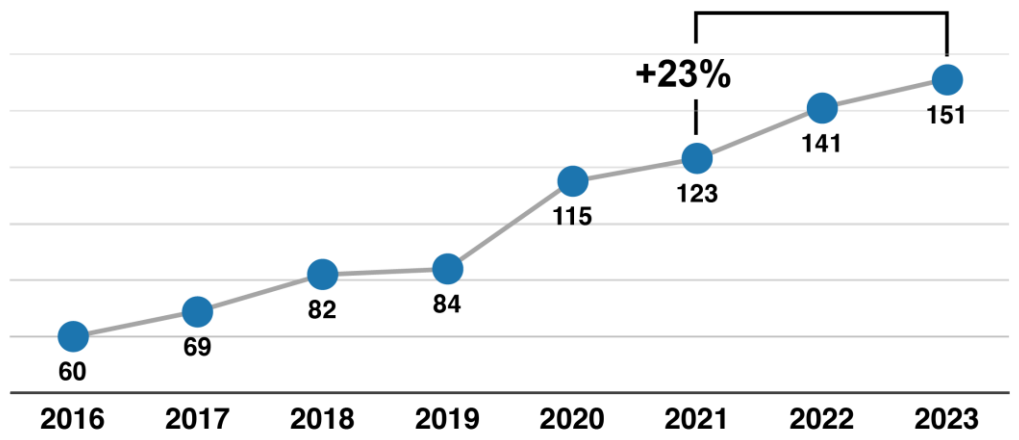
Increased Utilization of NACC Data

102% increase in the number of data requests



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



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

UDSv4 Updates & Timeline

Thank you to the CTF!

Clinical Task Force

ALLAN LEVEY, MD, PHD
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Rush U ADRC

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Mayo Clinic ADRC

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WashU Knight ADRC

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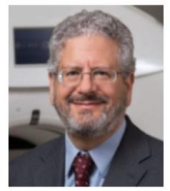
UW Madison ADRC

GREG JICHA, MD, PHD
U of Kentucky ADRC



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John Hopkins ADRC

TERESA GOMEZ-ISLA, MD, PHD
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AIMEE PIERCE, MD
OHSU ADRC

LIANA APOSTOLOVA, MD, MS
Indiana ADRC

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Critical New Content to Align with Advances in the Field

ADRD-Disease Modifying Drugs

Form A4a: ADRD-Specific Treatments

Social Determinants of Health

A1a: Social Determinants of Health

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

Completed UDSv4 Content, PDFs, and REDCap Forms

100% UDSv4 content complete!

Approved by CTF

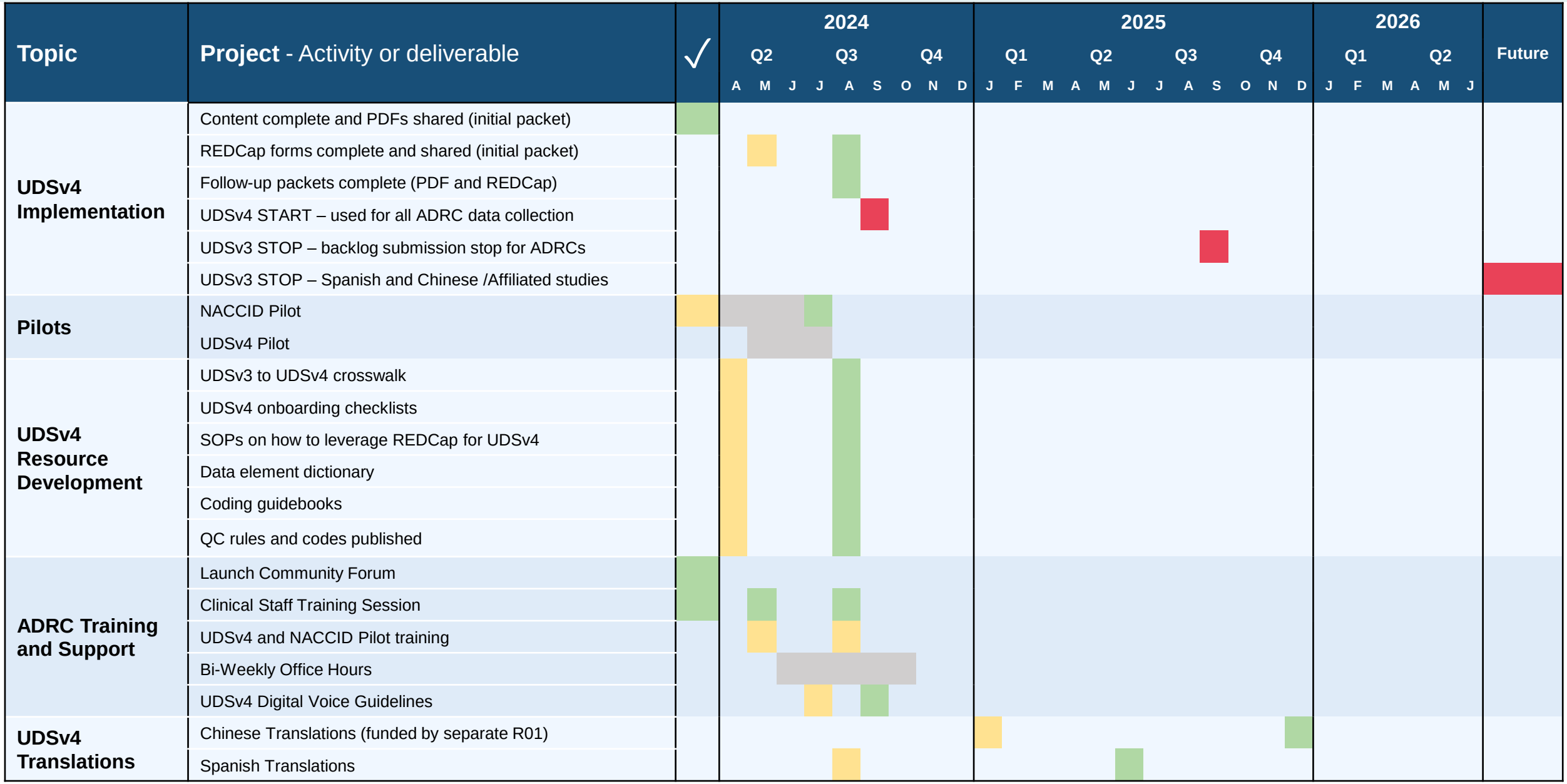
- Form A1
- ***Form A1a: SDOH***
- Form A2
- Form A3
- Form A4
- ***Form A4a: ADRD-Specific Drugs***
- Form A5/D2
- Form B1
- ***Form B3: UPDRS***
- *Form B4
- *Form B5
- *Form B6
- *Form B7
- Form B8
- Form B9
- Form D1a
- Form D1b
- Form C2/C2t

New forms

**No changes from UDSv3*

100% of UDSv4 REDCap forms developed

UDSv4 and EDC Timeline

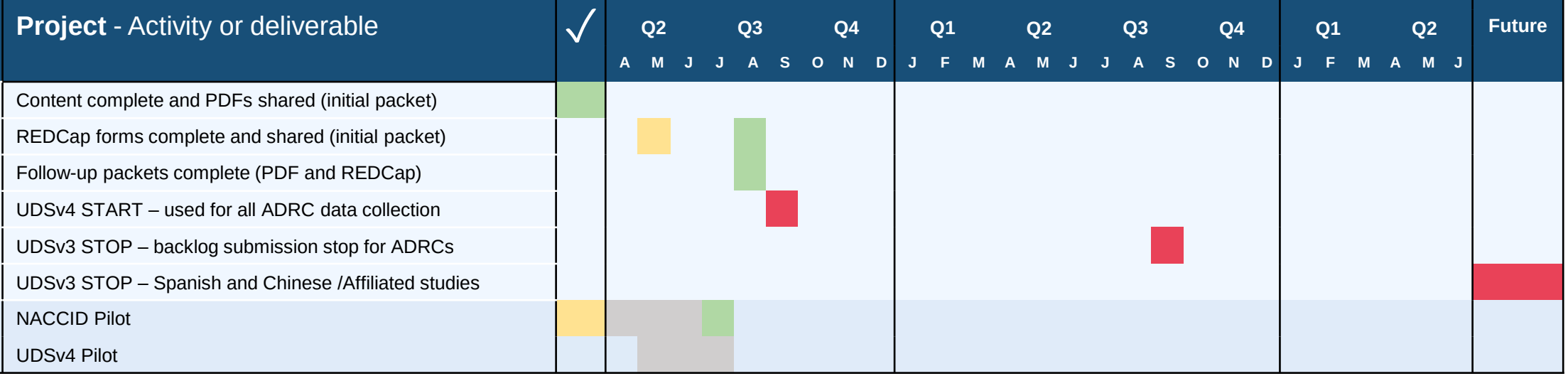


UDSv4 and EDC Timeline

Topic	Project - Activity or deliverable	✓	2024 Q2 A	2024 Q2 M	2024 Q2 J	2024 Q3 J	2024 Q3 A	2024 Q3 S	2024 Q4 O	2024 Q4 N	2024 Q4 D	2025 Q1 J	2025 Q1 F	2025 Q1 M	2025 Q2 A	2025 Q2 M	2025 Q2 J	2025 Q3 J	2025 Q3 A	2025 Q3 S	2025 Q4 O	2025 Q4 N	2025 Q4 D	2026 Q1 J	2026 Q1 F	2026 Q1 M	2026 Q2 A	2026 Q2 M	2026 Q2 J	Future
UDSv4 Implementation	Content complete and PDFs shared (initial packet)																												
	REDCap forms complete and shared (initial packet)																												
	Follow-up packets complete (PDF and REDCap)																												
	UDSv4 START – used for all ADRC data collection																												
	UDSv3 STOP – backlog submission stop for ADRCs																												
	UDSv3 STOP – Spanish and Chinese /Affiliated studies																												

✓ Current Status	Activity Duration	Draft	Complete	Deadline

UDSv4 and EDC Timeline



Topic	Project - Activity or deliverable	✓
UDSv4 Implementation	Content complete and PDFs shared (initial packet)	
	REDCap forms complete and shared (initial packet)	
	Follow-up packets complete (PDF and REDCap)	
	UDSv4 START – used for all ADRC data collection	
	UDSv3 STOP – backlog submission stop for ADRCs	
	UDSv3 STOP – Spanish and Chinese /Affiliated studies	
Pilots	NACCID Pilot	
	UDSv4 Pilot	

✓ Current Status | Activity Duration | Draft | Complete | Deadline

UDSv4 and EDC Timeline

Topic	Project - Activity or deliverable	✓	2024 Q2 A	2024 Q2 M	2024 Q2 J	2024 Q3 J	2024 Q3 A	2024 Q3 S	2024 Q4 O	2024 Q4 N	2024 Q4 D	2025 Q1 J	2025 Q1 F	2025 Q1 M	2025 Q2 A	2025 Q2 M	2025 Q2 J	2025 Q3 J	2025 Q3 A	2025 Q3 S	2025 Q4 O	2025 Q4 N	2025 Q4 D	2026 Q1 J	2026 Q1 F	2026 Q1 M	2026 Q2 A	2026 Q2 M	2026 Q2 J	Future
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	UDSv4 onboarding checklists																												
	SOPs on how to leverage REDCap for UDSv4																												
	Data element dictionary																												
	Coding guidebooks																												
	QC rules and codes published																												

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UDSv4 and EDC Timeline

Topic	Project - Activity or deliverable	✓	2024 Q2 A	2024 Q2 M	2024 Q2 J	2024 Q3 J	2024 Q3 A	2024 Q3 S	2024 Q4 O	2024 Q4 N	2024 Q4 D	2025 Q1 J	2025 Q1 F	2025 Q1 M	2025 Q2 A	2025 Q2 M	2025 Q2 J	2025 Q3 J	2025 Q3 A	2025 Q3 S	2025 Q4 O	2025 Q4 N	2025 Q4 D	2026 Q1 J	2026 Q1 F	2026 Q1 M	2026 Q2 A	2026 Q2 M	2026 Q2 J	Future
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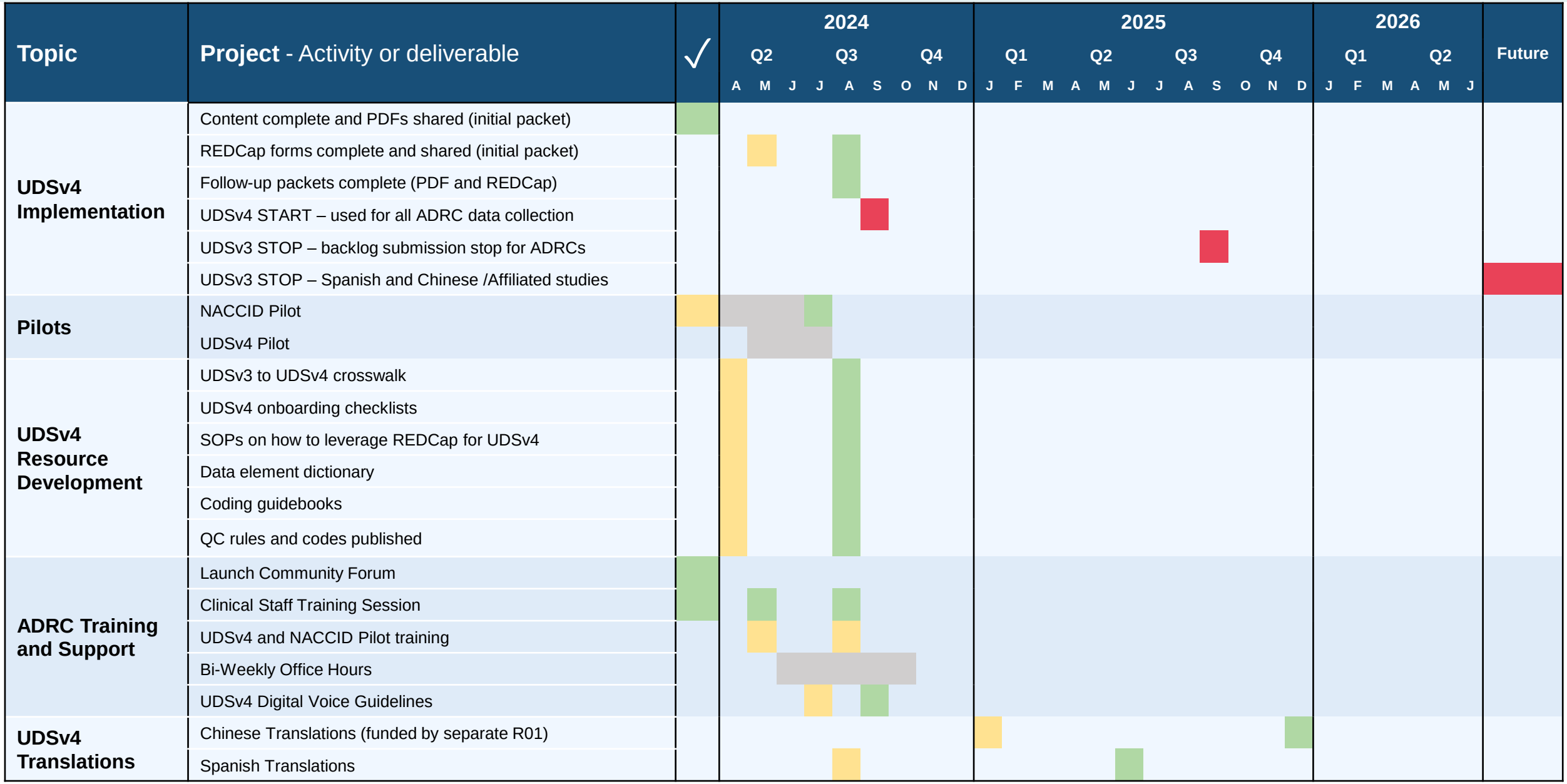
	QC rules and codes published																												
ADRC Training and Support	Launch Community Forum																												
	Clinical Staff Training Session																												
	UDSv4 and NACCID Pilot training																												
	Bi-Weekly Office Hours																												
	UDSv4 Digital Voice Guidelines																												

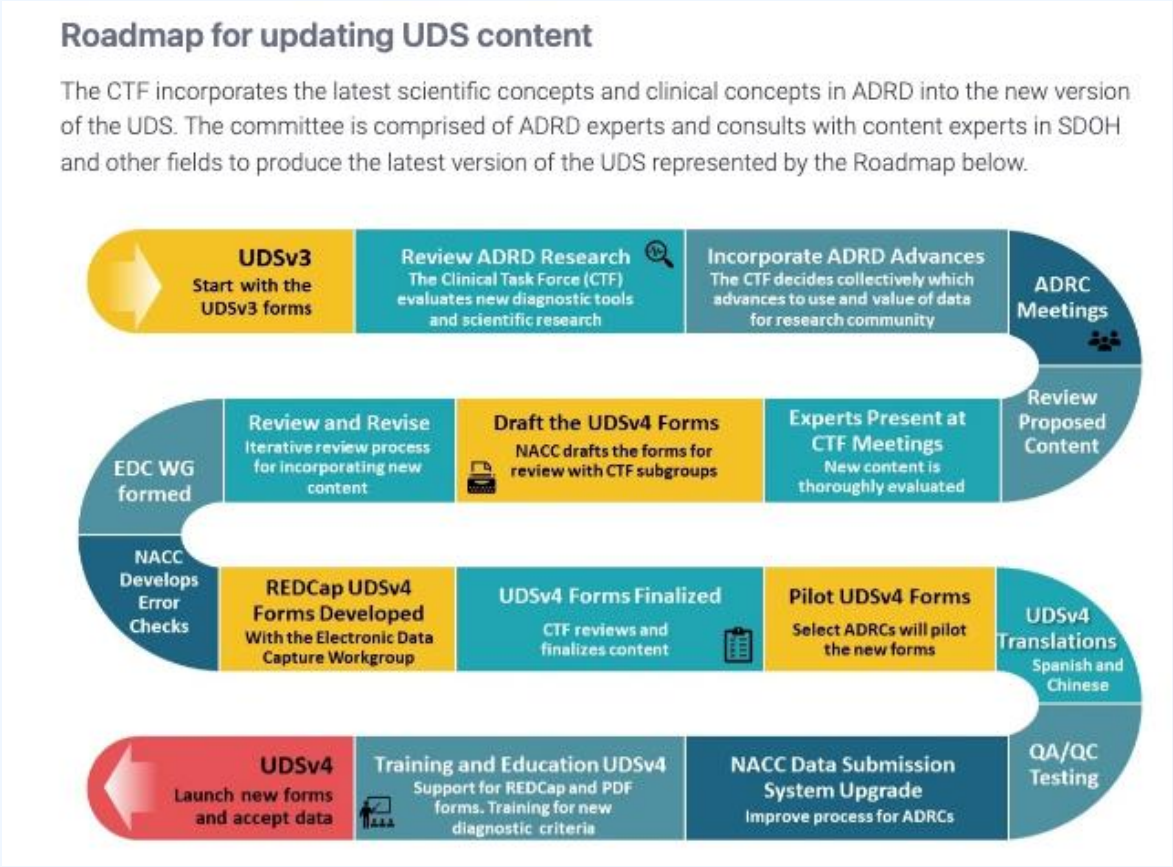
✓ Current Status | Activity Duration | Draft | Complete | Deadline

UDSv4 and EDC Timeline



Keeping You in the Loop!

UDSv4 Resources

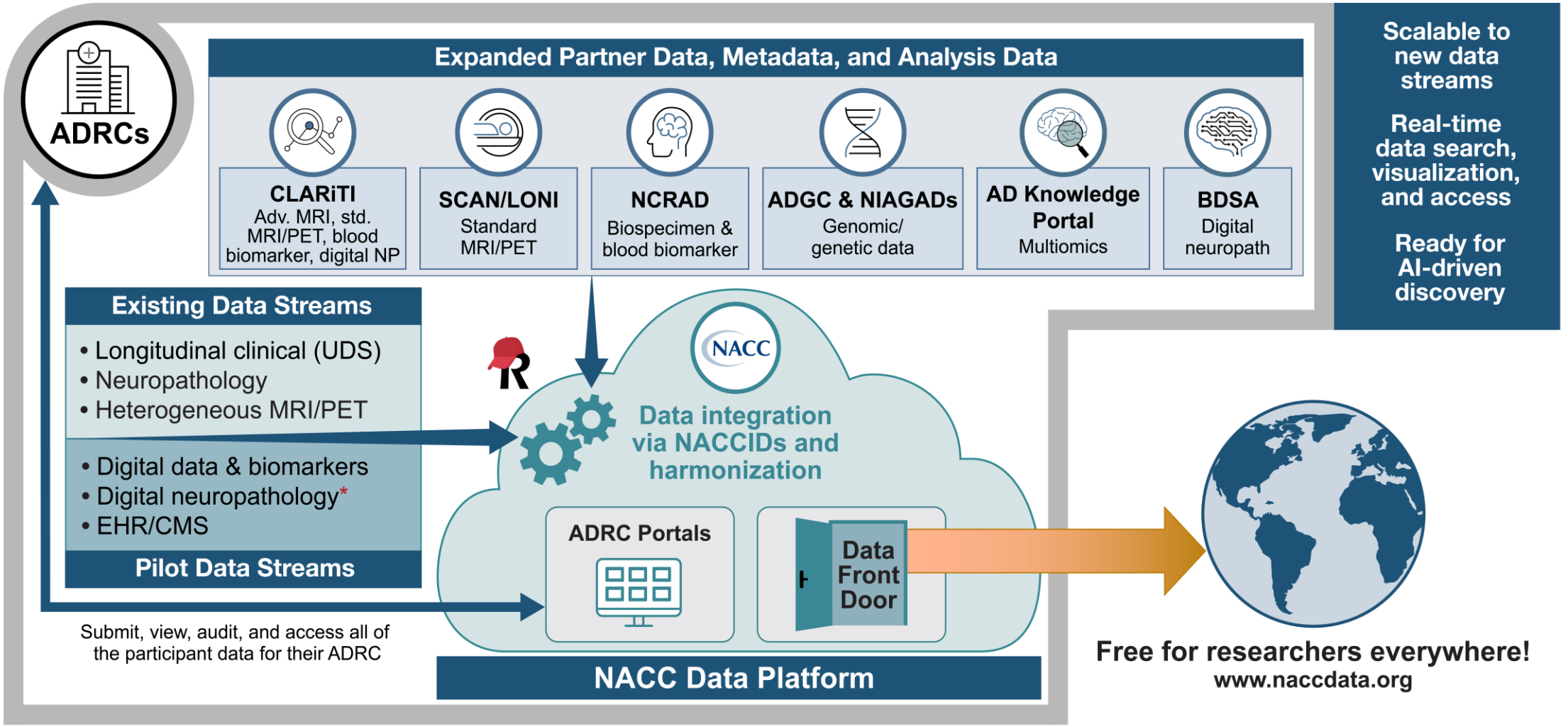


Stay tuned for USDv4 implementation strategies in the Q&A Panel at the end of today's session!

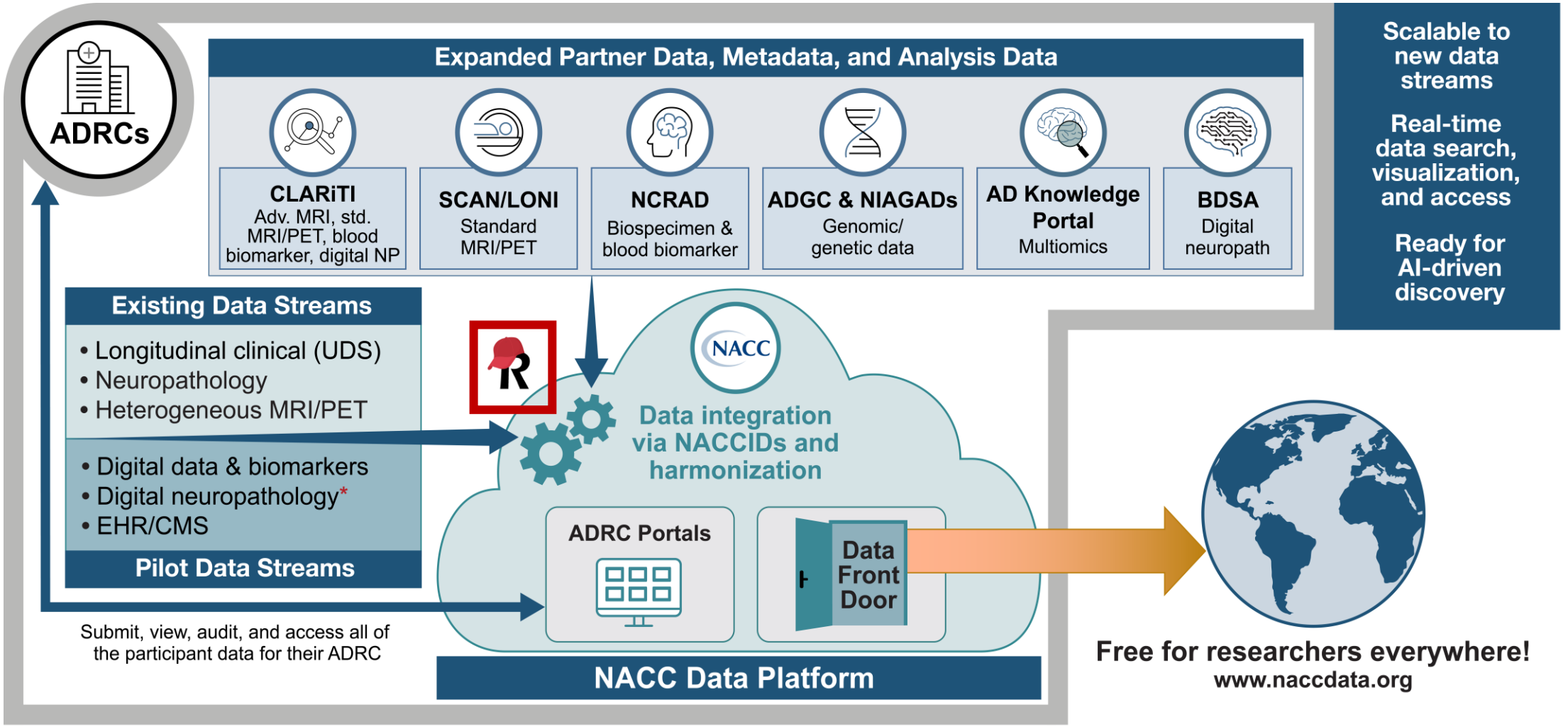
View latest updates on the NACC website:
bit.ly/UDSv4Updates

Providing Next Generation Informatics Infrastructure

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



New NACC Data Platform Features That ADRCs Will Interact With Via UDSv4



Modern and Streamlined Electronic Data Capture System

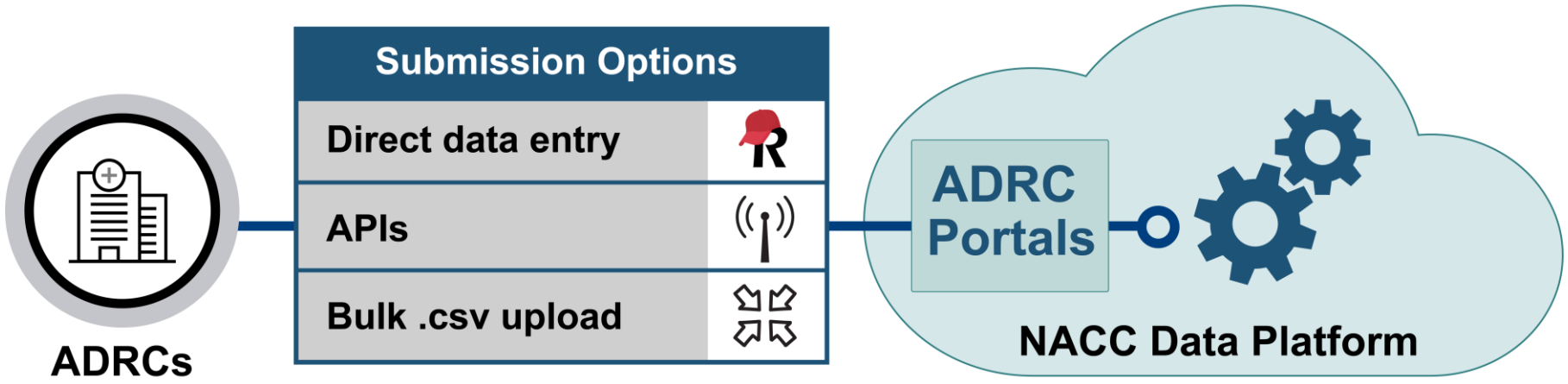
Built a Modern Electronic Data Capture System

Electronic Data Capture Workgroup

- Launched in January 2022
- 97 people across 33 ADRCs

Requirements	Development	Documentation and Training

Saves time, enhances sharing, and improves data quality



Go to naccdata.org/edc to learn more!

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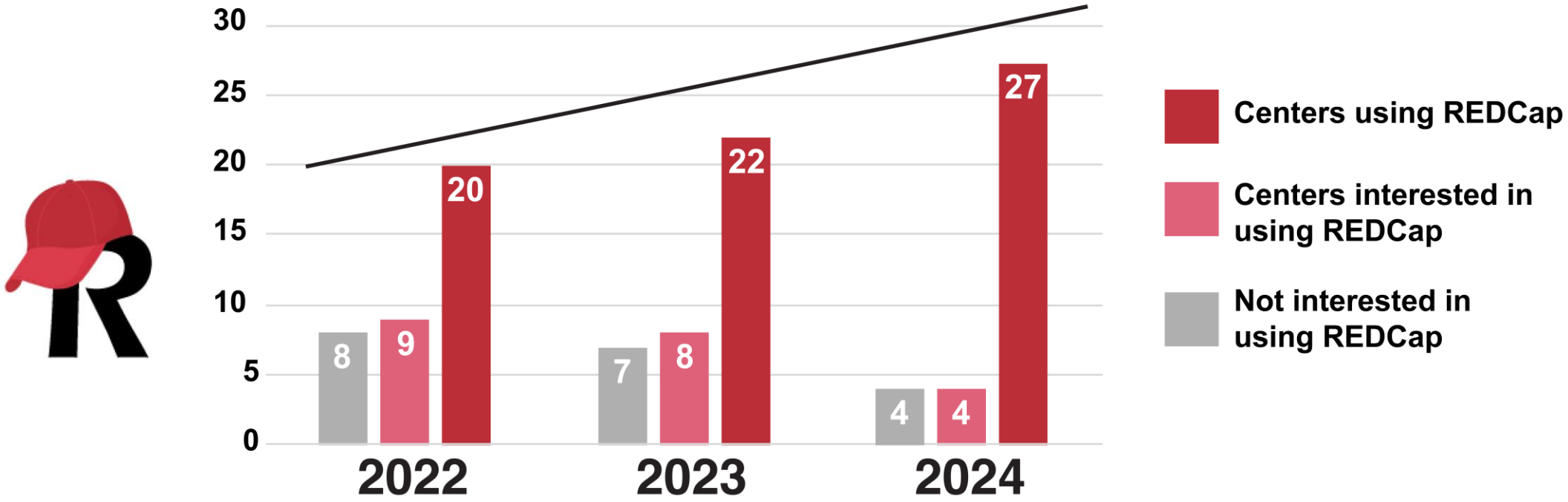
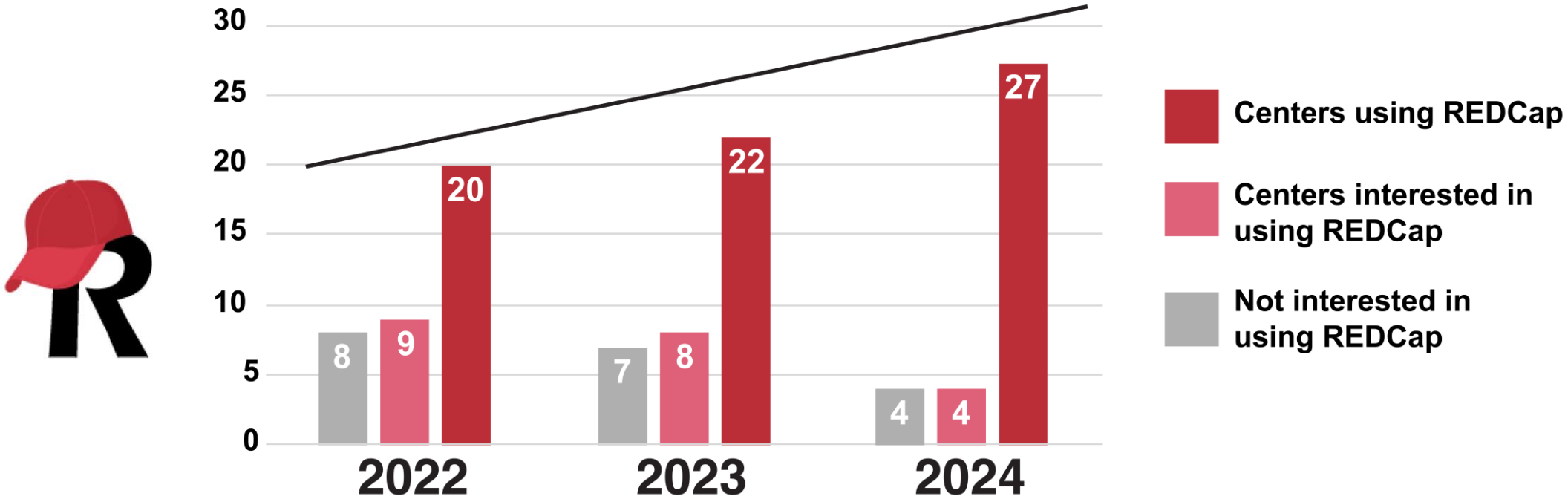
Driving REDCap and EDC Adoption



Driving REDCap and EDC Adoption



PDFs and any EDC will still work!

Thank you EDC Workgroup Leads & Co-leads!

Workgroup Leads:

Leads the EDC Workgroup All Hands Meetings and oversees the EDC Workgroup leads meetings with the subgroup co-leads.

Sudeshna Das, PhD
Massachusetts ADRC

Sarah Biber, PhD
NACC

Development Subgroup:

Design, build and test EDC technologies including data quality validation.

Jon Reader, MS
Michigan ADRC

Kathryn Gauthreaux, MS
NACC

Requirements Subgroup:

Identify and recommend best practices for EDC/REDCap data capture and requirements for data collection, data quality checking and data transformation from ADRC's to NACC.

Meredith Zozus, PhD
South Texas ADRC

Chad Murchison, PhD
Alabama Exploratory ADRC

Kari Stephens, PhD
NACC

Documentation and Training Subgroup:

Design and develop training materials and SOPs for EDC (REDCap, in particular) at ADRCs as well as make existing resources more readily available to the community.

Sarah Gothard, BS
OHSU ADRC

Laura McLeod, BBA
NACC

Coordination

Hannah Rosentreter
NACC

Jessica Welsch, MBA
NACC

Thank you EDC Workgroup Requirements Subgroup members!

- Ari Bhaumik
- Ashley Wilson
- Ben Keller
- Bill Sanns
- Carolyn Zhu
- Chad Murchison
- Christopher Barnes
- Donald Saner
- Fangfang Shi
- Hernis De La Cruz
- Jessica Welsch
- Jimmy Akrivos
- Justin Barber
- Kari Stephens
- Kathryn Gauthreaux
- Kei Cheung
- Kim Pechman
- Kirsten Dunn
- Lingyi Lu
- Meredith Zozus
- Niranjana Shashikumar
- Panpan Zhang
- Ricardo Amador
- Robert Bauer Robin
- Stillwell-Minear Sade
- Agboola Sara Farmer
- Sarah Farias
- Sarah Biber
- Sarah Gaussoin
- Sarah Gothard
- Shelley Ferson
- Sudeshna Das
- Sudha Seshadri
- Talia Seshaiah
- Tiffany Kollah
- Timothy Shannon
- Tung Le
- Vijaya Kolachalama
- Will Affleck-Asch
- Zac Kasper

Thank you EDC Workgroup Development Subgroup members!

- Alok Vedvyas
- Aron Kuch
- Ashley Wilson
- Ben Keller
- Bill Sanns
- CeeCee Manzanares
- Cesar Hernandez
- Chad Murchison
- Chandima HewaNadungodage
- Christopher Barnes
- Dan Hoang David Merle
- Deborah Zemlock
- Diane Dixon
- Donald Saner
- Eric Fischer
- Gaurav Vedvyas
- Haseena Rajeevan
- Helen Foster
- Hernis De La Cruz
- Janet Hwang
- Jeffrey Phillips
- Jessica Welsch
- Jimmy Akrivos
- John Hepler
- Jon Reader
- Kate Rankin
- Kathryn Gauthreaux
- Laura McLeod
- Lingyi Lu
- Marilyn Williams
- Melissa Moreno
- Panpan Zhang
- Philip Chase
- Ricardo Amador
- Robert Bauer
- Robin Stillwell-Minear
- Rodney Jones
- Ruijin Lu
- Samantha Emerson
- Sara Farmer
- Sarah Biber
- Sarah Gaussoin
- Sarah Gothard
- Stacy Oswald
- Steven Brown
- Sudeshna Das
- Suzanne Hunt Talia
- Seshaiah Tiffany
- Kollah Timothy
- Shannon Tung Le
- Will Affleck-Asch
- Zac Kasper

Thank You EDC Workgroup, Documentation & Training Subgroup members!

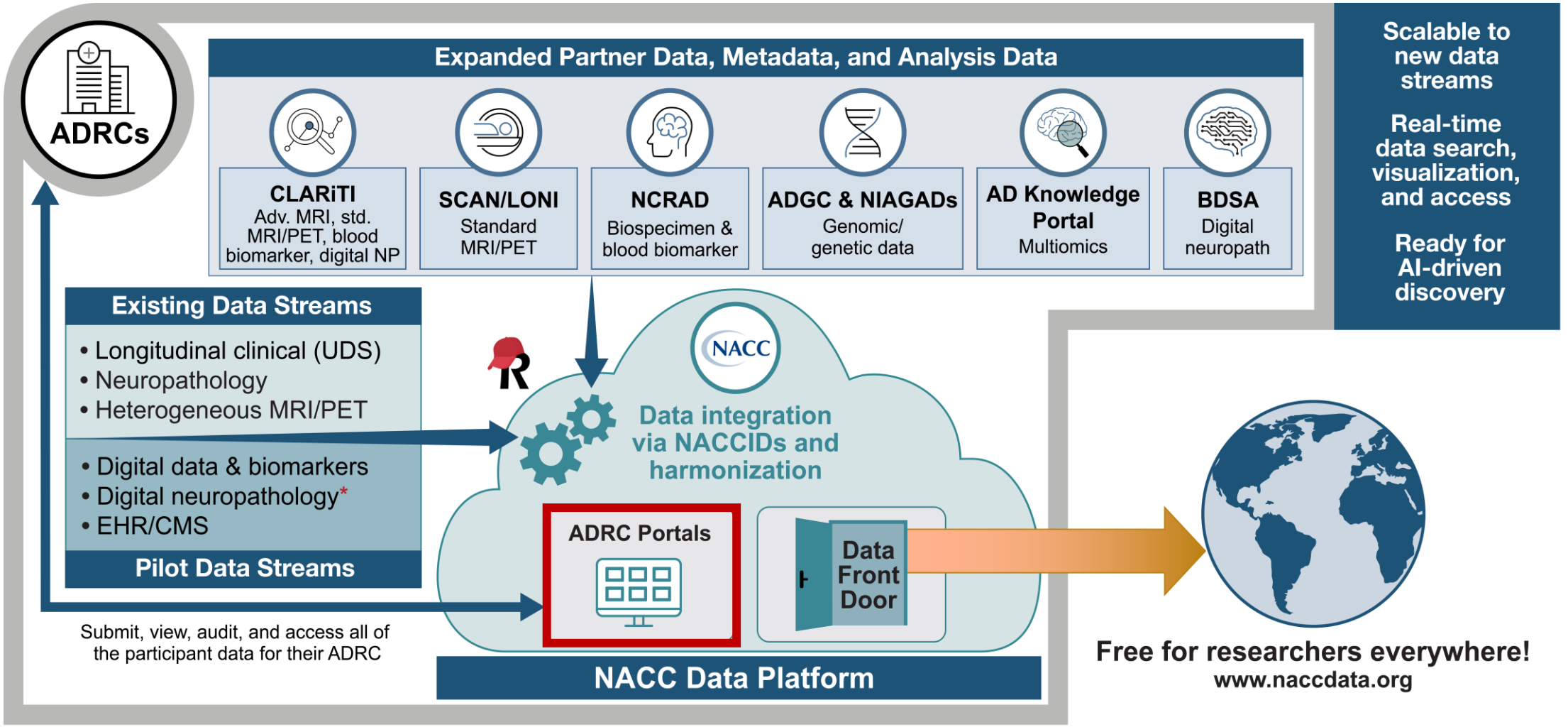
- Alok Vedvyas
- Anne Buffington
- Ashley LaRoche
- Beata-Gabriela Simpson
- Brittany Fair
- Eric Fischer
- Gina Morris
- Helen Foster
- Hernis De La Cruz
- Jessica Welsch
- Jill Prestopnik
- Jimmy Akrivos
- Laura McLeod
- Lingyi Lu
- Michelle Quirke
- Niranjana Shashikumar
- Robin Stillwell-Minear
- Ruijin Lu
- Samantha Emerson
- Sara Farmer
- Sarah Biber
- Sarah Gothard
- Shelley Ferson
- Talia Seshaiah
- Taryn Stoffs
- Tiffany Kollah
- Veronica Ramirez
- Will Affleck-Asch
- Zac Kasper

Join the EDC team!

Join our 97 members across 33 ADRCs!

Go to naccdata.org/edc to learn more and sign-up!

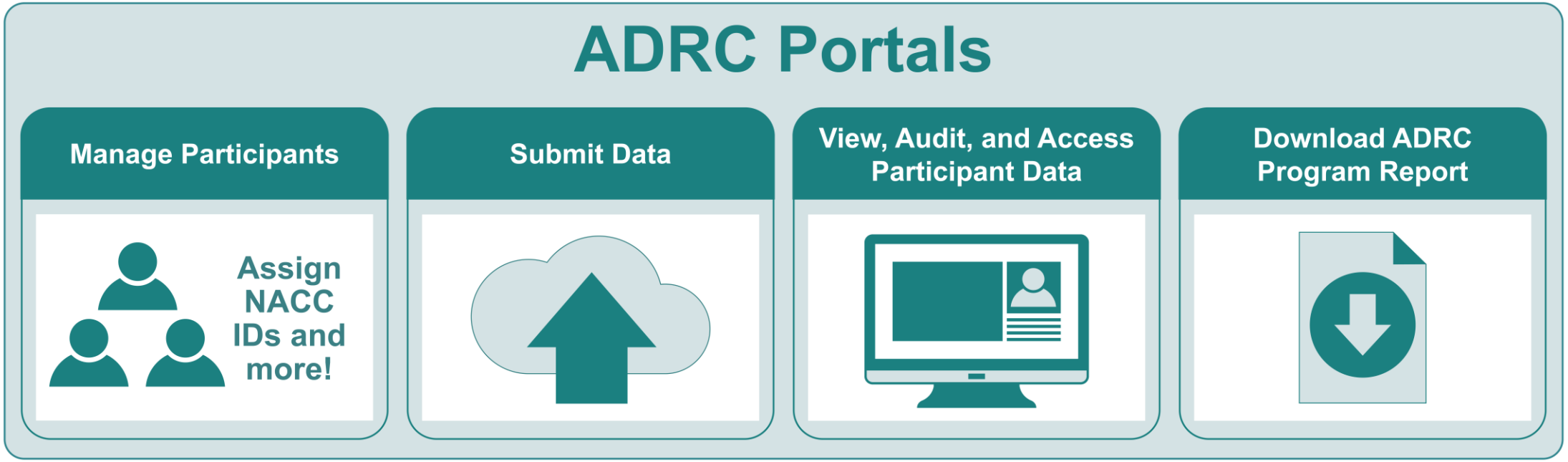
New NACC Data Platform Features That ADRCs Will Interact With Via UDSv4



ADRC Portals

New ADRC Portals

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



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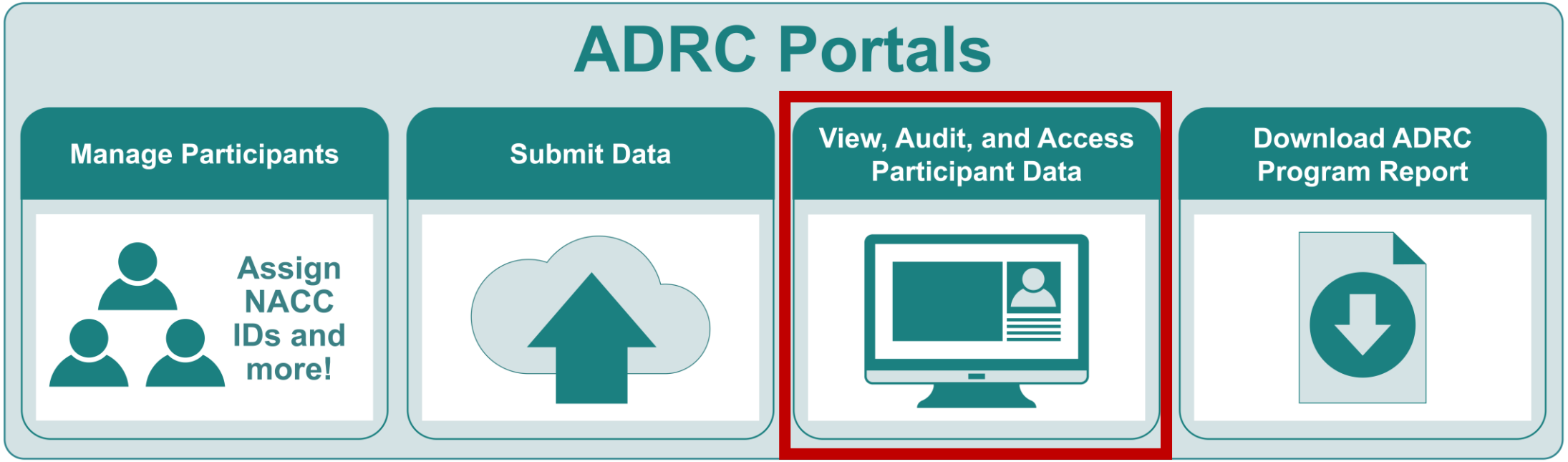


New ADRC Portals

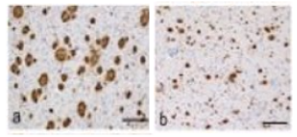
ADRCs can submit, view, audit, and access their participant data

ADRC Portals

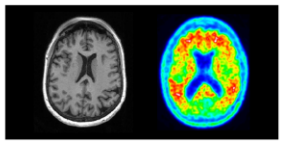
View, Audit, and Access Participant Data

Harmonized Phenotypic Data (UDS)

Neuropathology Reports



Heterogeneous MRI/PET



SCAN

scan

- SCAN QC Dashboard
- All data variables

ADGC & NIAGADS (Genetic/Genomic)

NIAGADS

ADGC Alzheimer's Disease Genetics Consortium

NCRAD (Liquid Biomarker/Biospecimen)

NCRAD

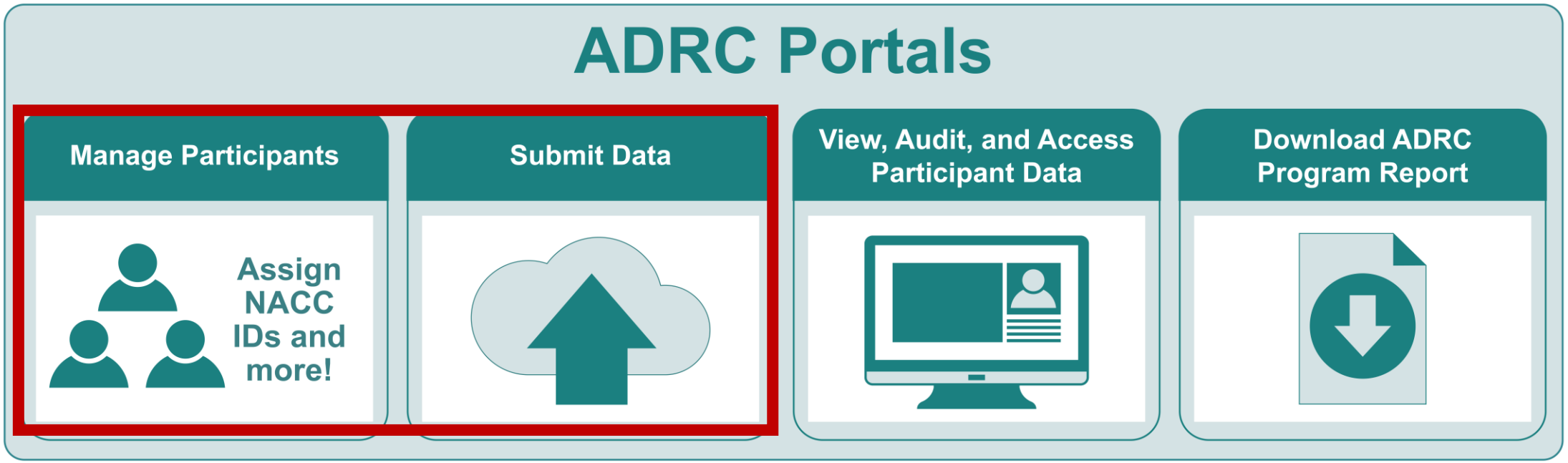
CLARiTI

CLARiTI

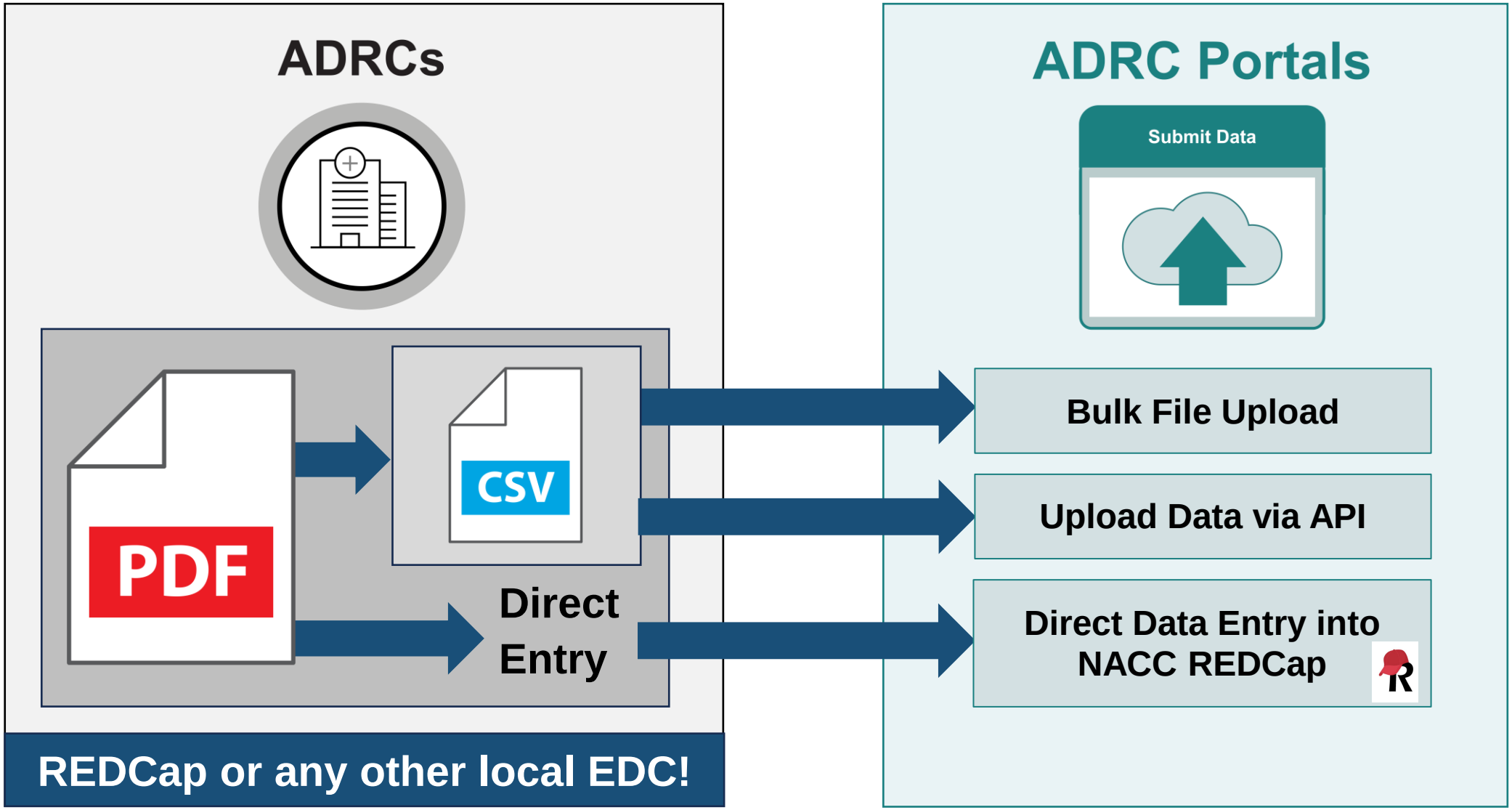
Participant Diversity Dashboard

ADRC Portals and the Upcoming Pilots!

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

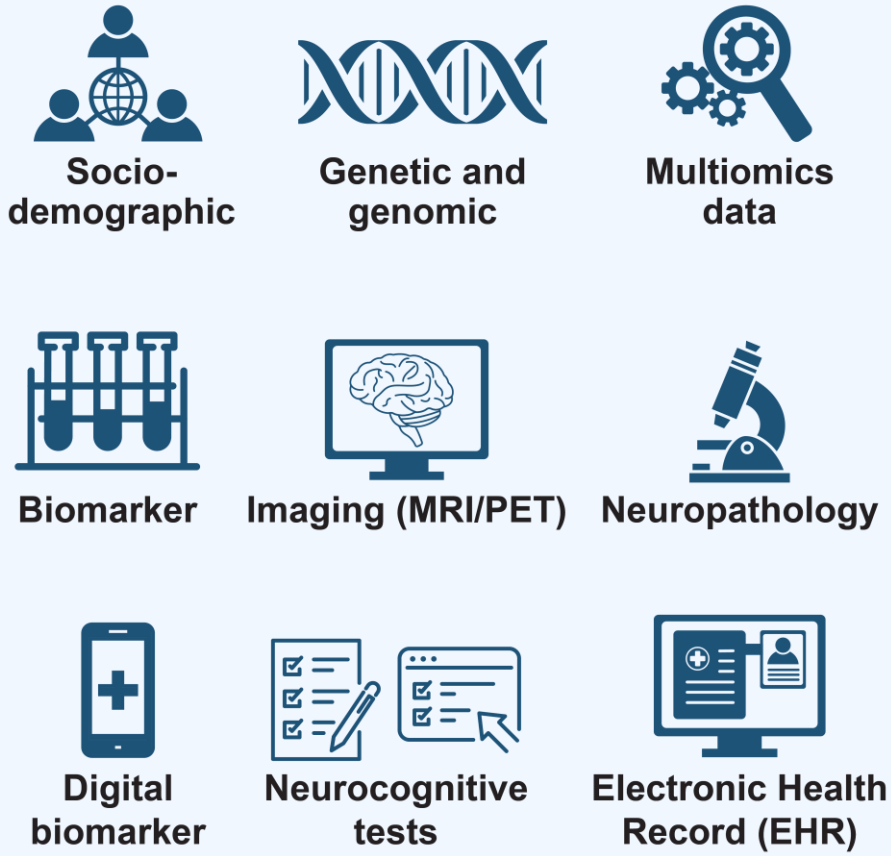


Flexible UDSv4 Collection and Submission



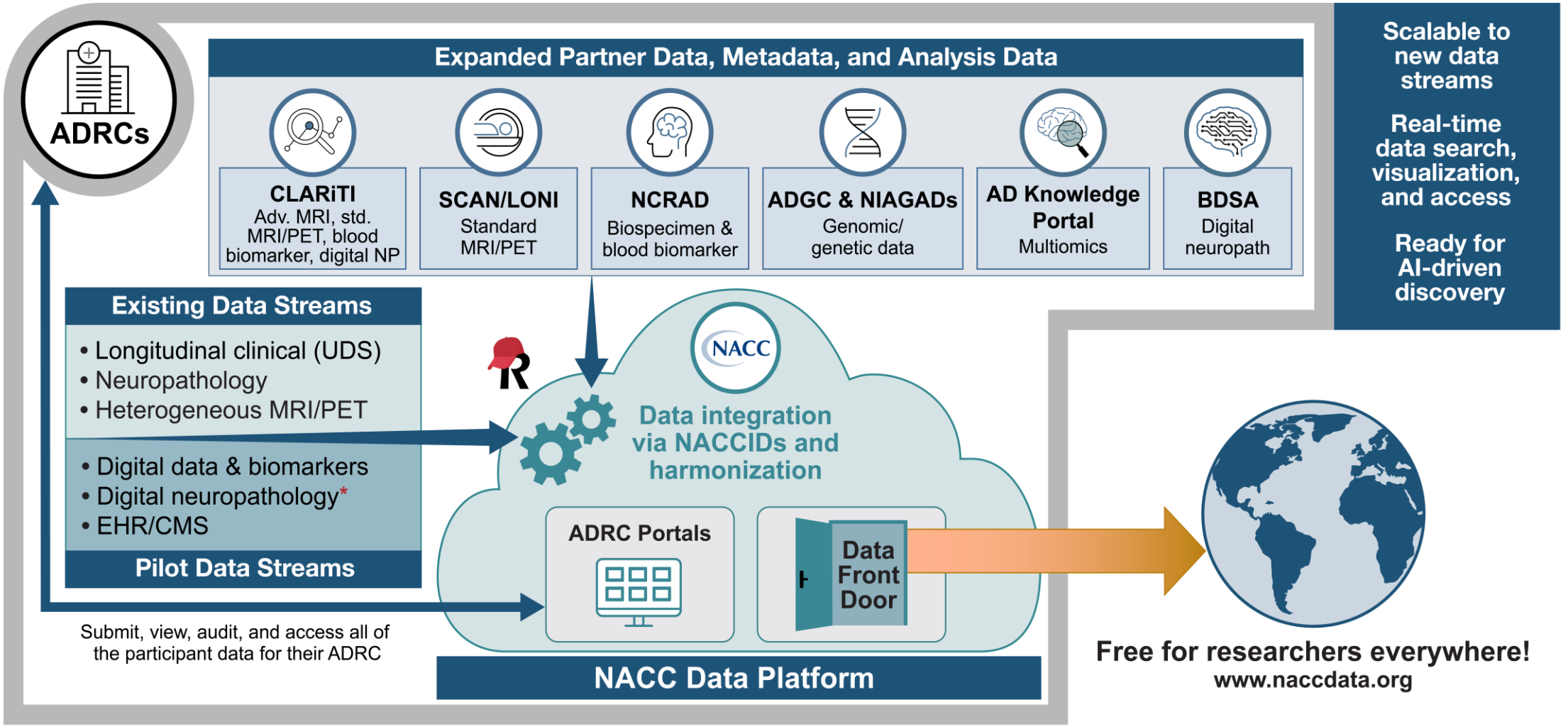
Becoming More Multimodal

Expanding Multimodal Data Integration and Interoperability



To tackle the most pressing challenges in the field, researchers need to be able to readily access increasing amounts of multimodal data that are high-quality, harmonized, and integrated

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



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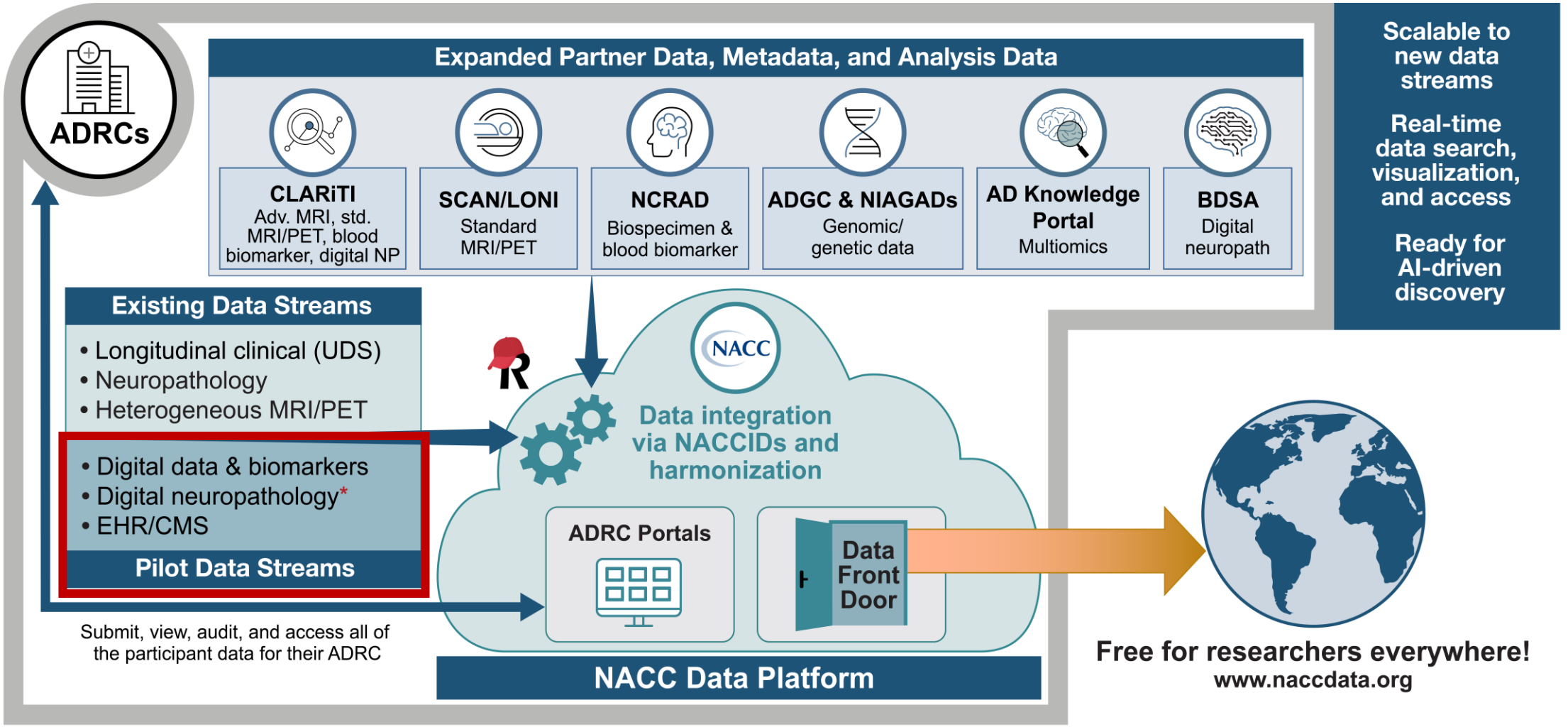

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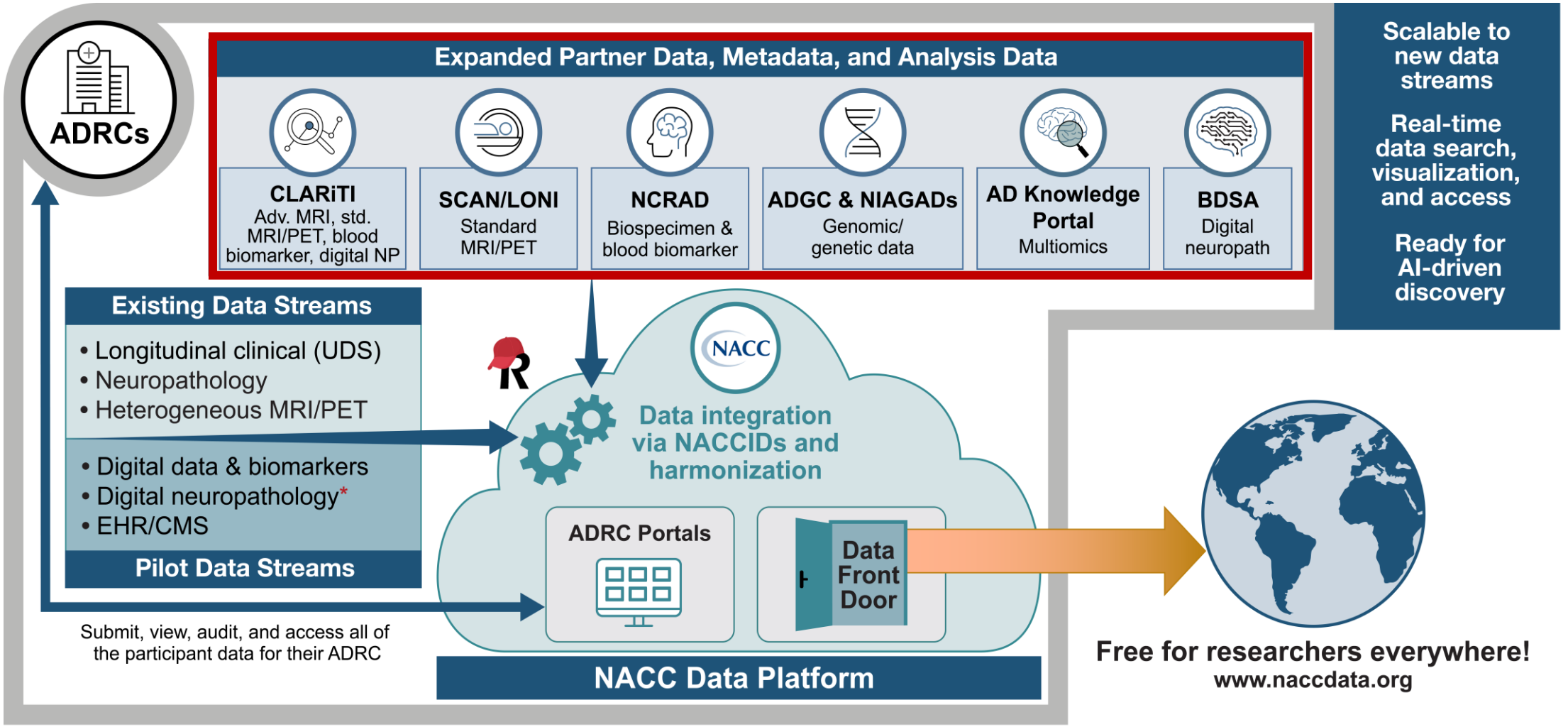

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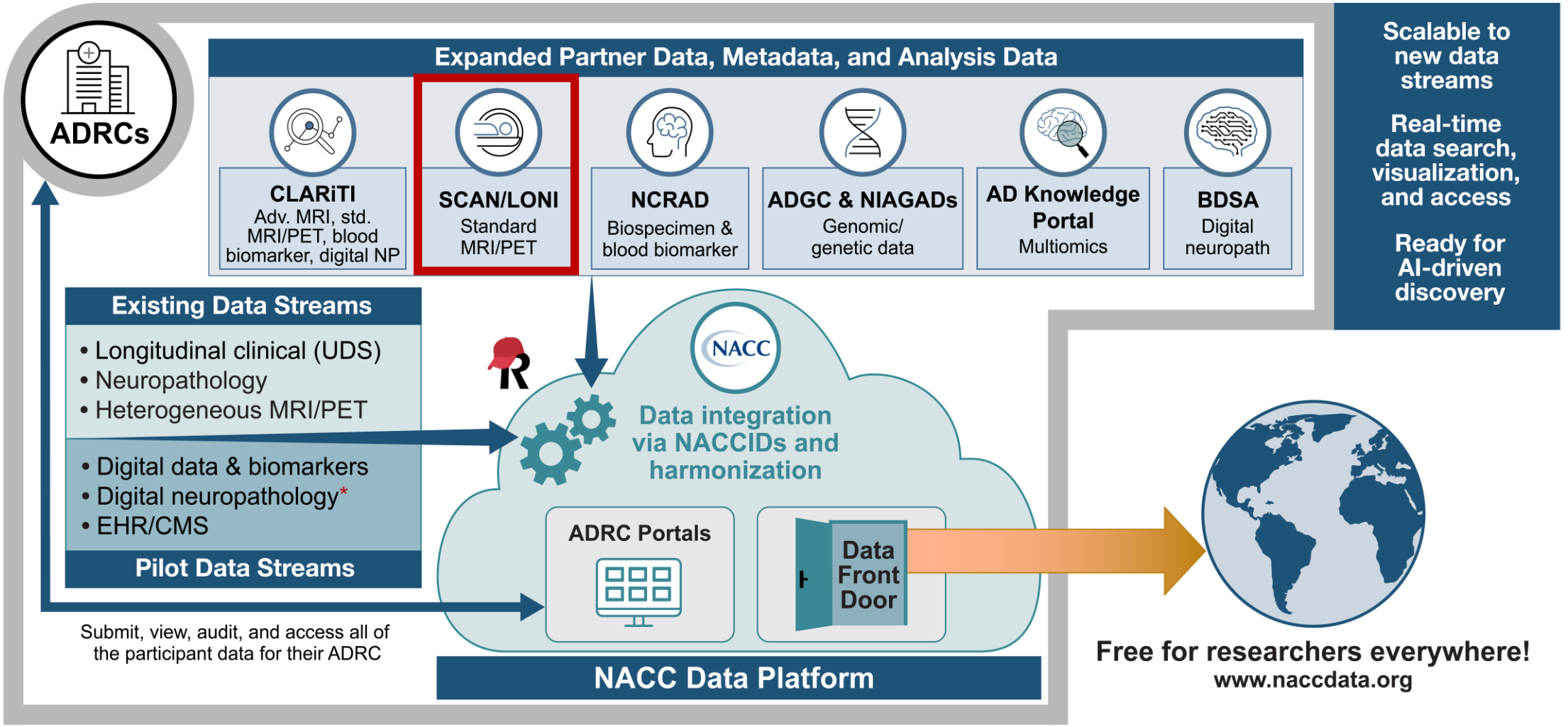
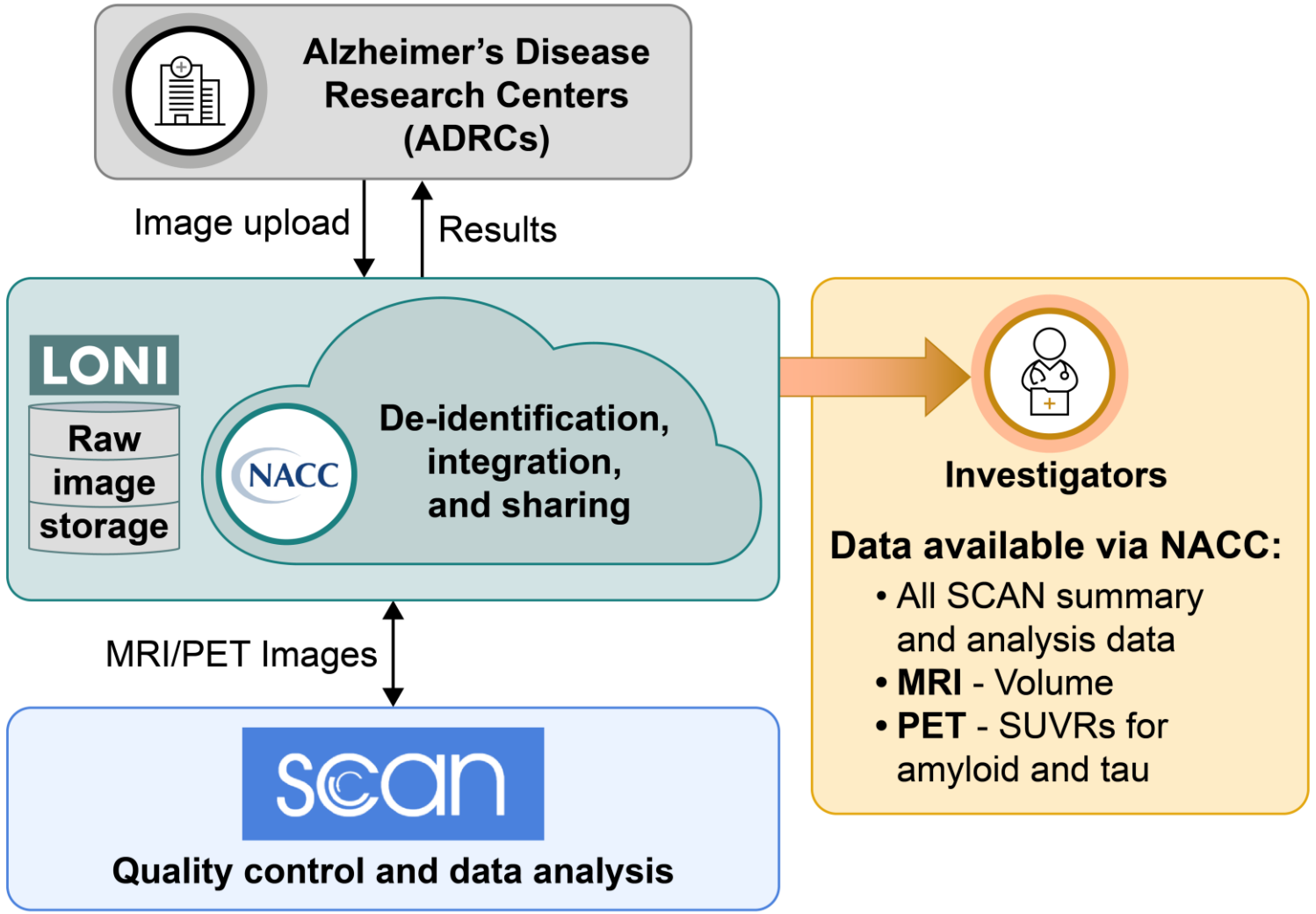


Standardized MRI/PET Data

Mission: Collect large quantities of standardized imaging data, integrate it with other data modalities available via NACC, and share it with researchers around the world to advance the field.

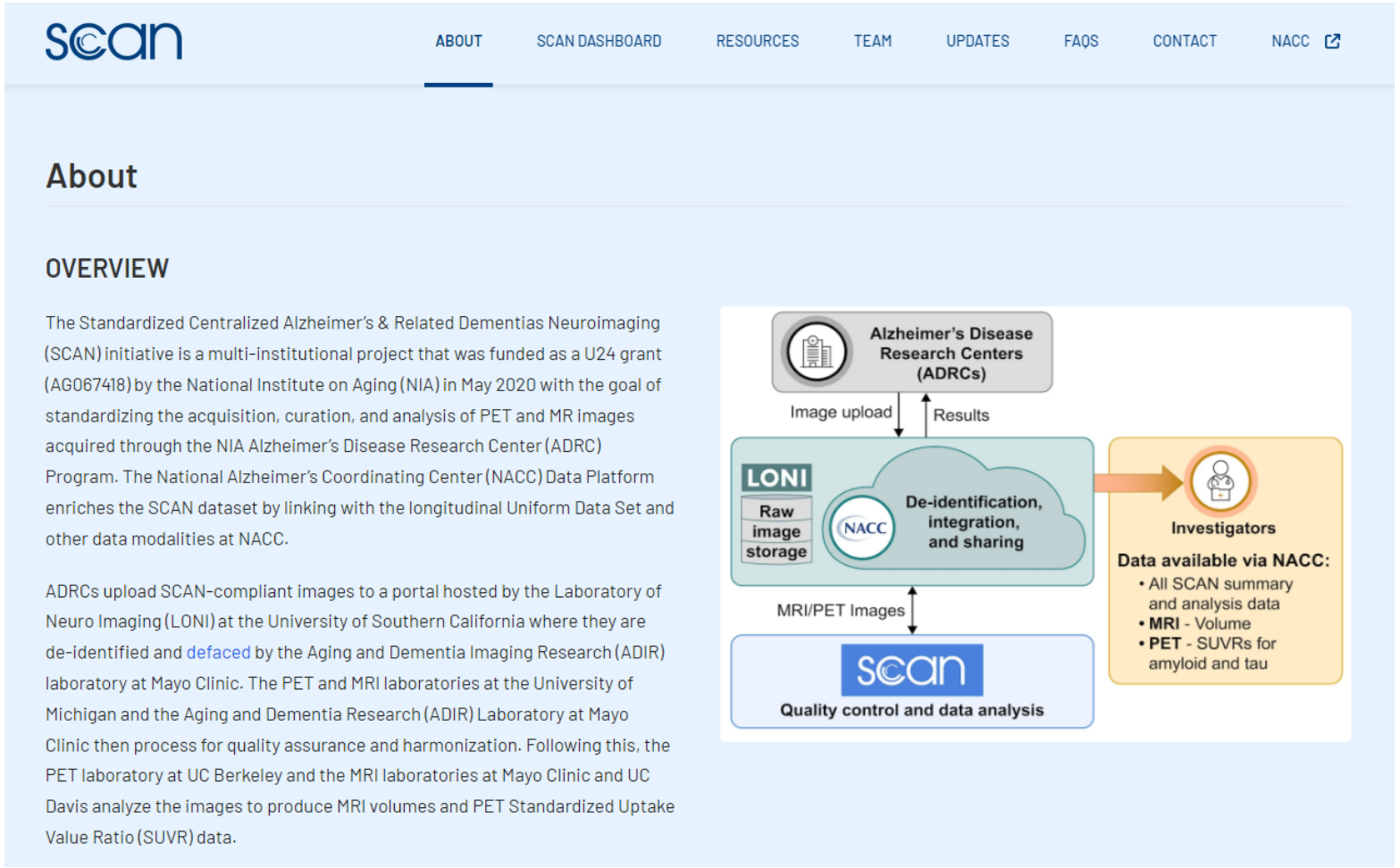


NACC's ROLE

1) Facilitate ADRC participation
2) Support data quality
3) Provide data access

Goal 1. Facilitate ADRC Participation

New SCAN Website!

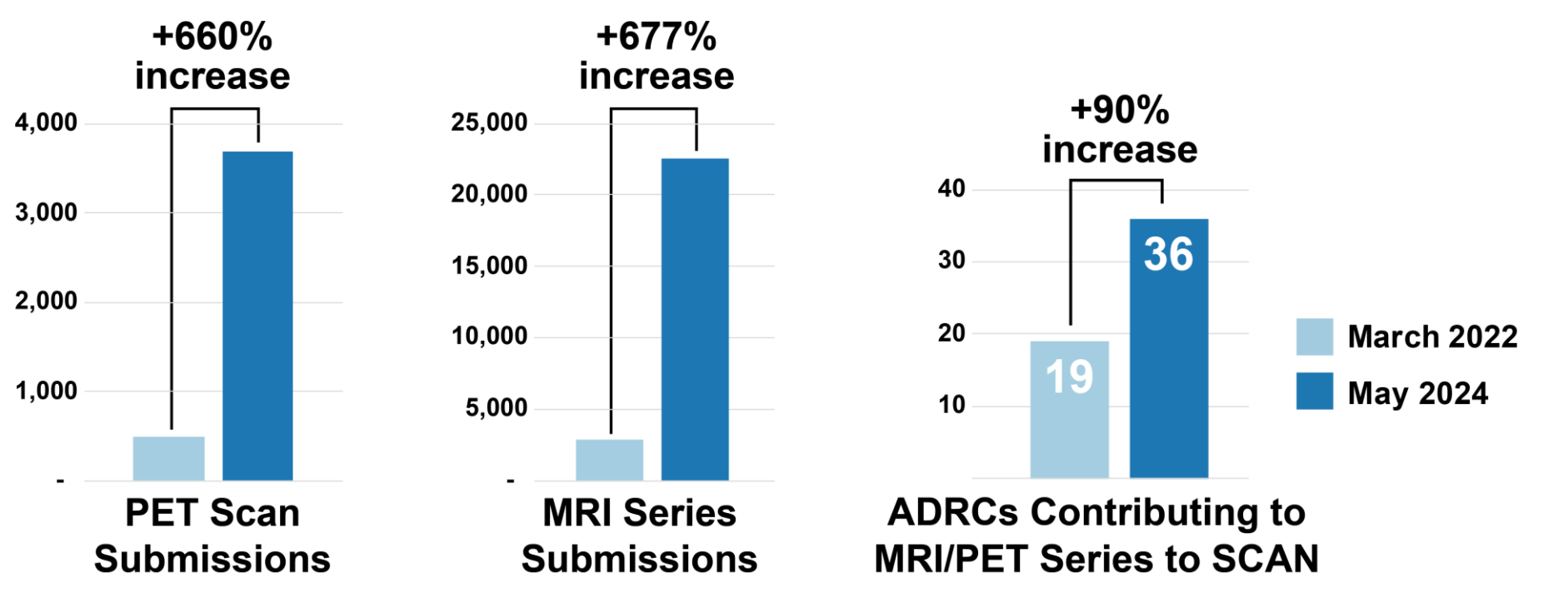


Visit scan.naccdata.org/

Standardized MRI/PET Data

A dramatic increase in SCAN submissions

- **PET:** 3,689 PET scans
- **MRI:** 22,589 MRI series
- **ADRCs:** 36 ADRCs

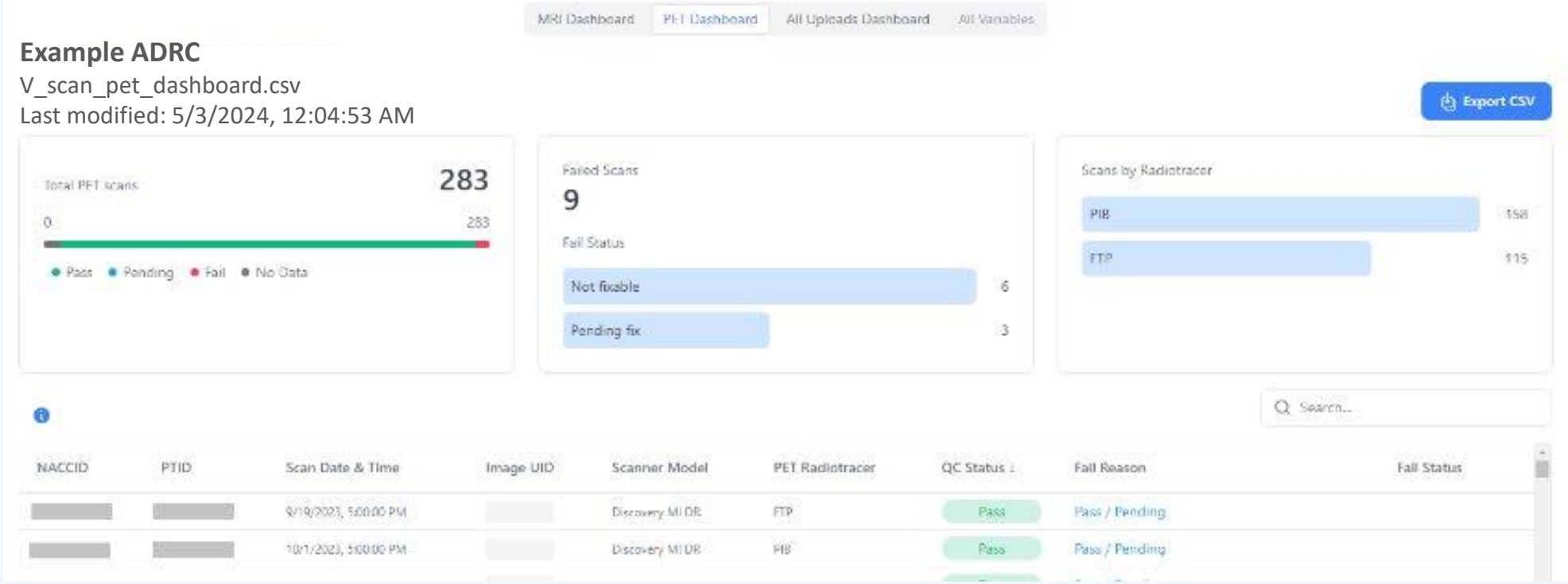


Goal 2. Support Data Quality

SCAN QC Dashboards (MRI and PET)

- **Available via ADRC Portals within the NACC Data Platform**
  - Sites can track the QC status of their MRI and PET submissions, allowing them to rapidly address errors
  - Serves as an auditable record of all SCAN MRI and PET data submitted to date, downloadable as a csv file

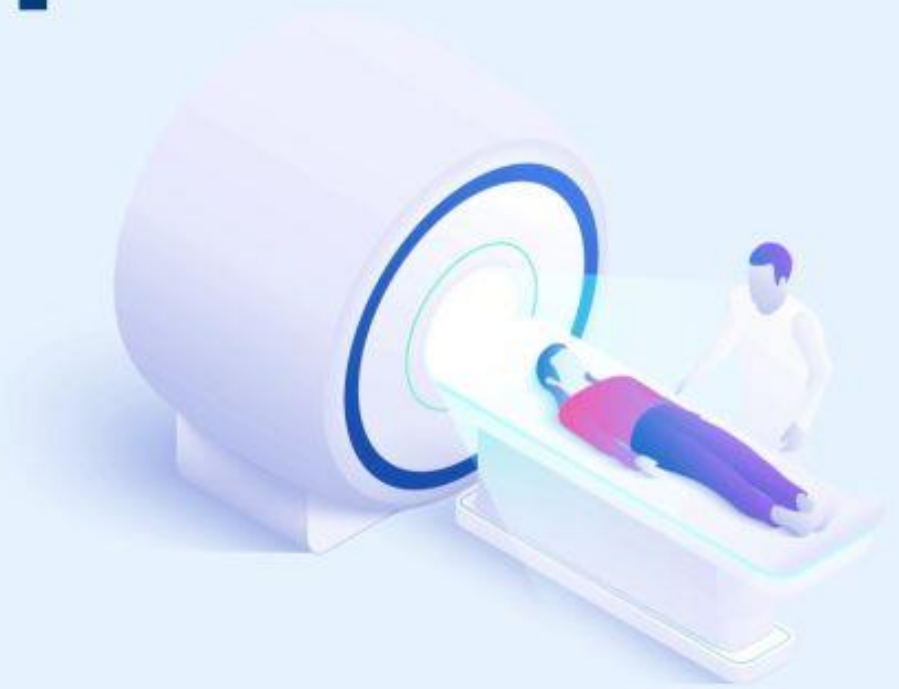
PET Example



Goal 3. Provide Data Access

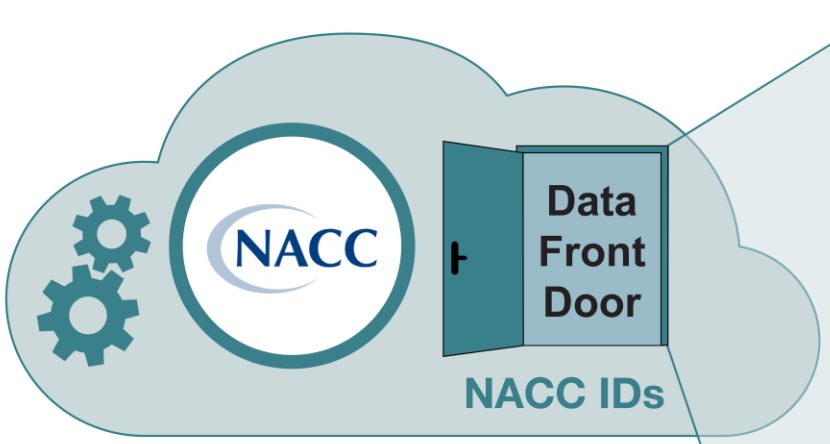
Data Front Door: One-Stop-Shop for All ADRC Data

scan data is available at NACC!



Data Front Door: Advanced Data Search, Visualization, and Access

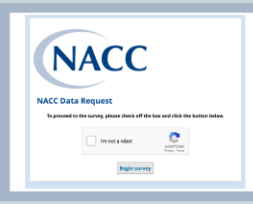
One-Stop-Shop for All ADRC Data



ADRC Data & Metadata

- Socio-demographic
- Genetic and genomic
- Multiomics data
- Biomarker
- Imaging (MRI/PET)
- Neuropathology
- Digital biomarker
- Neurocognitive tests
- Electronic Health Record (EHR)

Quick Access Files

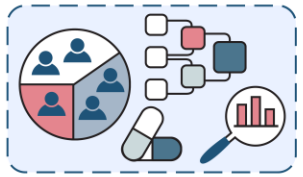


Powered by REDCap

Dashboards

SCAN imaging data and more!

Cohort Selection



Build your own multimodal dataset!

Investigators everywhere

Data Front Door – SCAN Dashboards

SCAN Public Real-time Dashboard

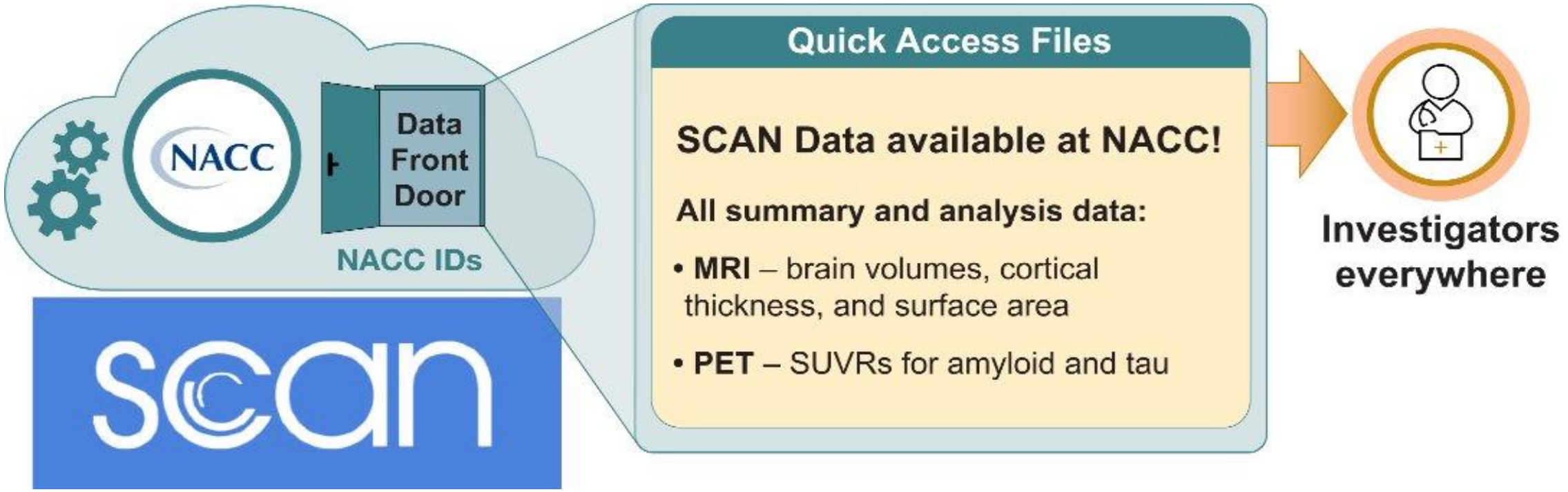
Real-time numbers on how much MRI/PET data was provided by each ADRC and available to the research community. Visit scan.naccdata.org

ALZHEIMER'S DISEASE RESEARCH CENTERS

COPY CSV | Search

Institution	SCAN Participation						ADRC-specific SCAN QC Dashboards
		MRI			PET		
	Total # of Participants	# MRI participants	# MRI exams submitted	# MRI series submitted	# PET participants	# PET scans submitted	
Total	**4,742**	**4,208**	**4,832**	**23,466**	**1,887**	**2,845**	
Wake Forest University	402	357	391	870	196	310	PRIVATE DASH
University of Wisconsin	348	316	393	865	185	393	PRIVATE DASH
University of Michigan	240	240	246	491	0	0	PRIVATE DASH
Mayo Clinic	235	235	294	878	0	0	PRIVATE DASH

Goal 3. Provide Data Access

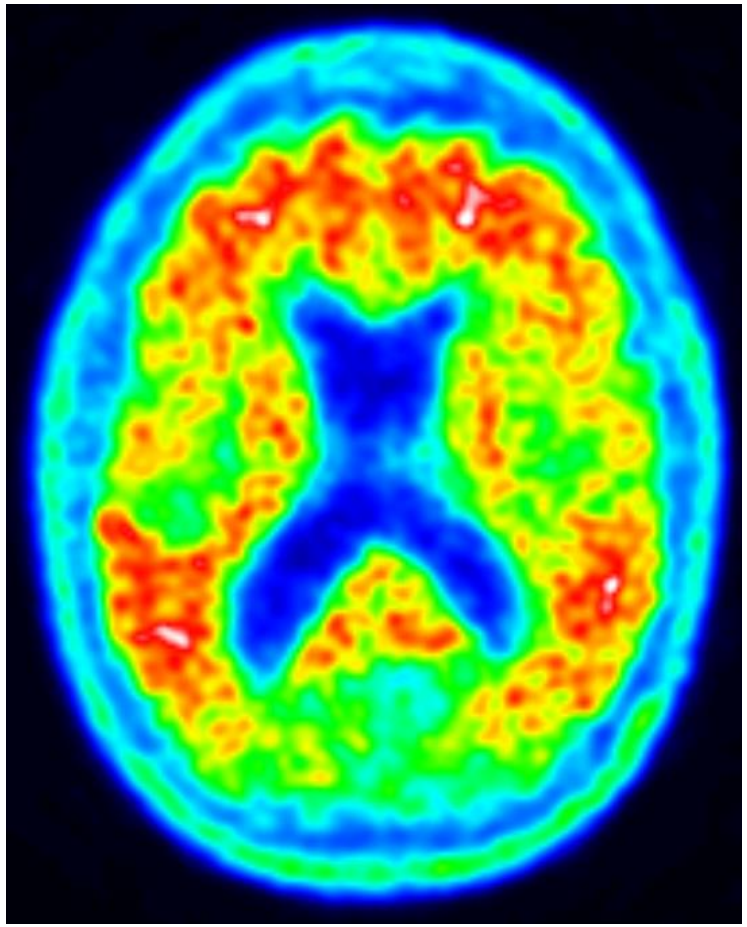


Goal 3. Provide Data Access

PET Data Received by SCAN: 3,689 scans (from 22 ADRCs)

SUVR (amyloid, tau) data available to researchers via NACC: 2,801 scans

Data available at NACC for researchers	
Scan tracer type	Total #
PIB	728
Florbetapir	139
Florbetaben	444
NAV4694	123
Total Amyloid	**1,434**
Flortaucipir	578
MK6240	331
PI2620	0
Total tau	**909**
FDG (Fluorodeoxyglucose)	**458**

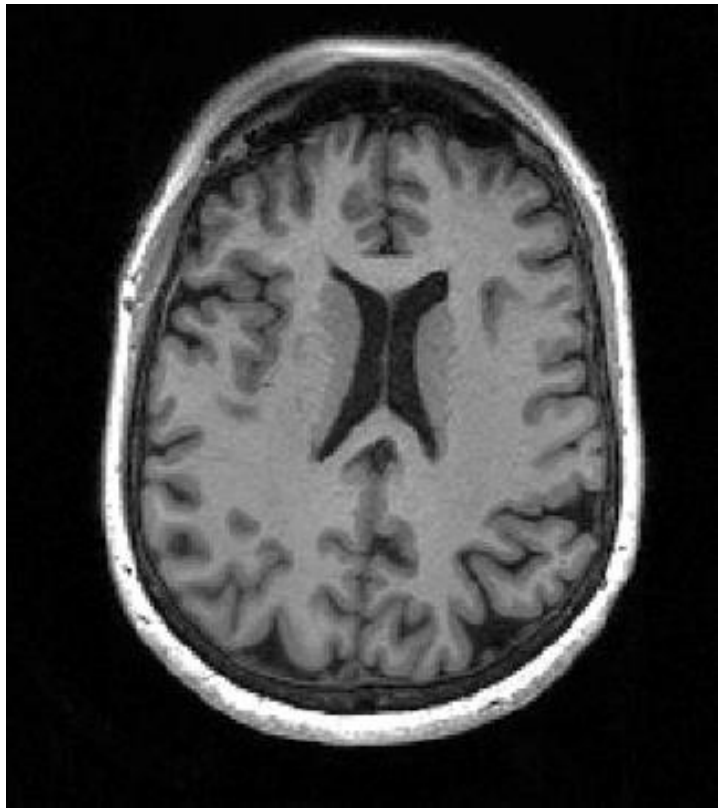


Goal 3. Provide Data Access

MRI Date Received by SCAN: 22,589 MRI series (from 35 ADRCs)

FreeSurfer volume/thickness MRI available to researchers via NACC: 1,326 series

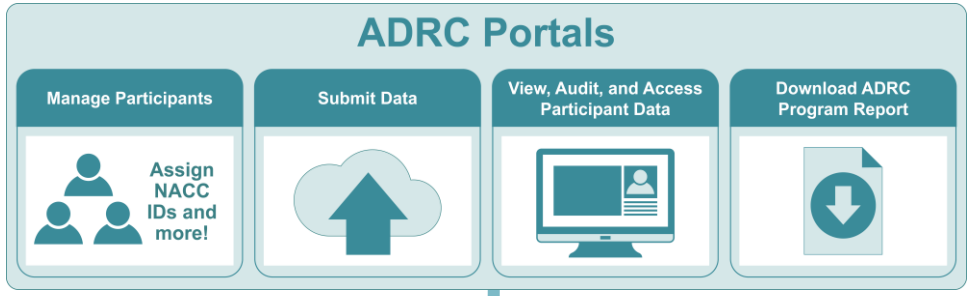
Data that will be available at NACC soon	
Series Type	**Total #**
T1	2,909
FLAIR	2,699
T2	233
GRE/T2*	543
dMRI	573
ASL	0
HRH	583
fMRI	344

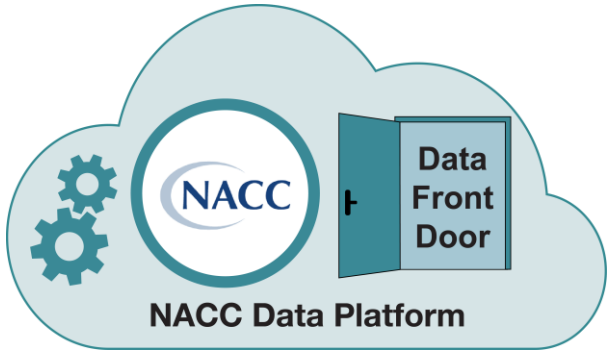


SCAN Data Availability

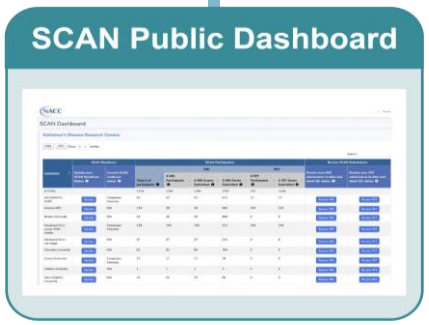
ADRC Access

ADRC Portals
SCAN MRI/PET QC Dashboards





Oct 2023



NACC Data Front Door
SCAN Public Dashboard

Apr 2024

NACC Data Front Door
SCAN summary and analysis data available via the NACC Quick Access File Data Request System

July 2024

ADRC Portals
All SCAN data variables available including summary and analysis data

Future

NACC Data Front Door

Raw Image Availability: via NACC and LONI

Cohort Selection Tool: Build your own multimodal dataset!

Secure Enclave: Download your dataset into a secure enclave for analysis

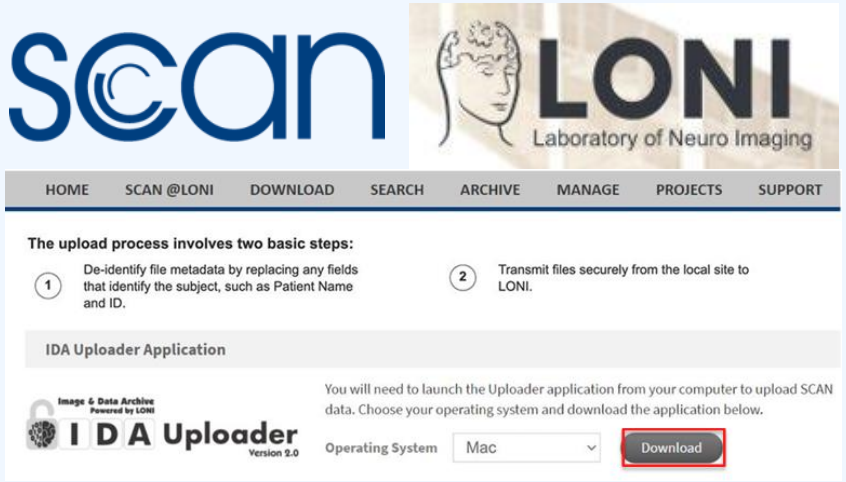
Free for Researchers Everywhere

Help keep the data flowing!

ONLY Submit SCAN-Compliant MRI and PET Images to SCAN/LONI

Submit SCAN-Compliant Data Here:

https://ida.loni.usc.edu/



Submit Non-SCAN-Compliant MRI and PET Images to NACC

Submit Non-SCAN-Compliant Data:

https://scan.naccdata.org/

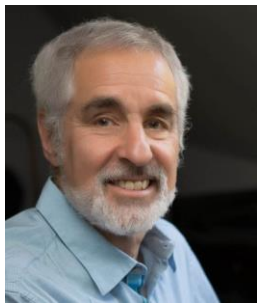
NACC

SCAN compliance details: https://scan.naccdata.org/

Expanded SCAN Team

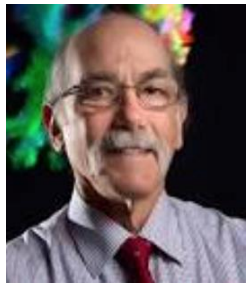
SCAN MRI Team

Clifford Jack (PI)
Charles DeCarli
Chadwick Ward
Pauline Maillard
Christopher Schwarz
Denise Reyes
Bret Borowski
John Moore-Weiss
Leonard Matoush
Robert Reid
Anne Effron
Gregory Preboske
Jeffrey Gunter
Matthew Senjem
Colin Hortman
Kejal Kantarci
Oliver Martinez



SCAN PET Team

William Jagust (PI)
Bob Koeppe
Susan Landau
Suzanne Baker
Tessa Harrison
Trevor Chadwick



LONI Team

Arthur Toga
Karen Crawford

NACC Team

Sarah Biber
Bud Kukull
Brittany Hale
Brendan Smith
Zach Stark
Jessica Culhane

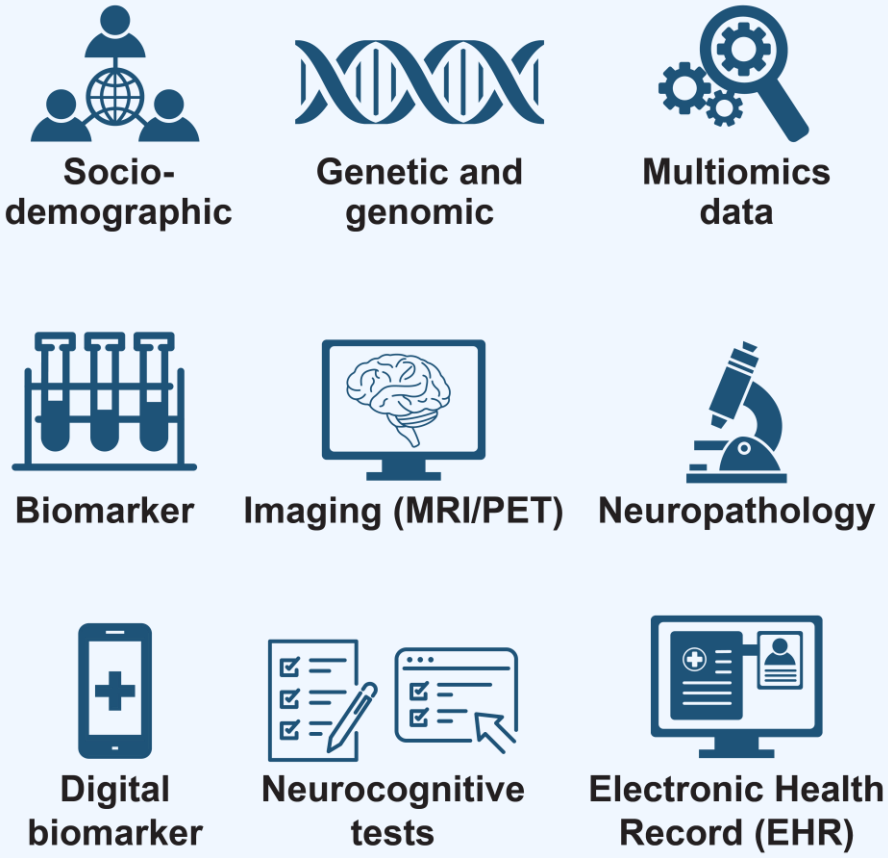
Imaging Core SC

Emily Rogalski
Annie Cohen
Trey Hedden
John Detre
Renaud La Joie
Mark Lowe
Beth Mormino
Sterling Johnson

Imaging Core Steering Committee

Making it Easier to Access Multimodal Data

Expanding Multimodal Data Integration and Interoperability



scan

CLARiTI

Gates Ventures

ALZHEIMER'S NETWORK

AD Knowledge Portal

LONI NIAGADS NCRAD

KnightADRC Alzheimer's Disease Research Center | Washington University St. Louis

A·D·R·C for healthy brain aging

BU Alzheimer's Disease Center

SCHOOL OF MEDICINE
INDIANA ALZHEIMER'S DISEASE RESEARCH CENTER

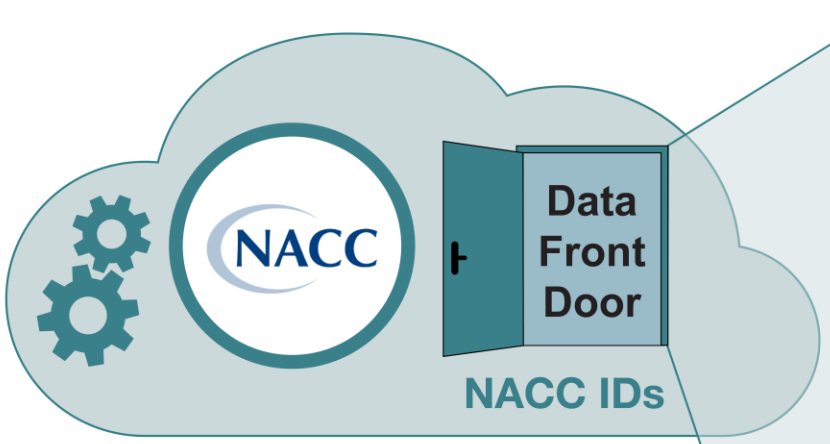
Columbia University Medical Center
Center of Excellence for Alzheimer's Disease

UCDAVIS ALZHEIMER'S DISEASE CENTER

Emory University
Goizueta Alzheimer's Disease Research Center

Data Front Door: Advanced Data Search, Visualization, and Access

One-Stop-Shop for All ADRC Data



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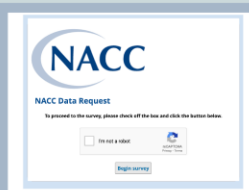

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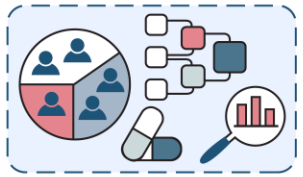

Build your own multimodal dataset!

Investigators everywhere

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

NACC

NIAGADS

NCRAD

ADNI
Alzheimer's Disease Neuroimaging Initiative

Thank You!