



NACC Update

Bud Kukull, PhD, NACC Director
Monday, May 1, 2023
ADRC Spring Meeting

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)



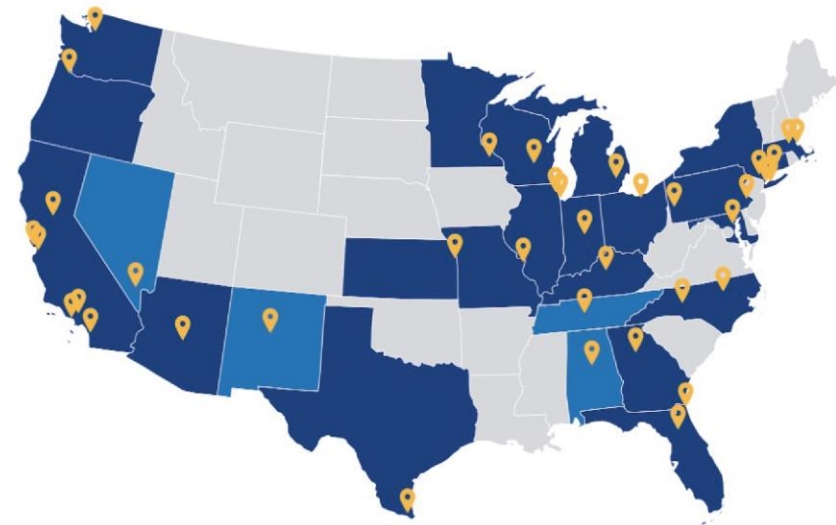
1,141+

Published studies using
NACC data



33

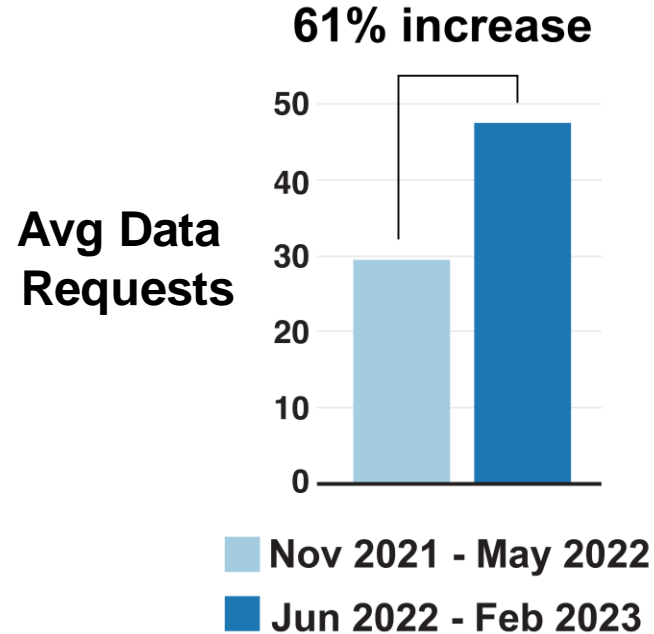
ADRCs and 4 Exploratory
Centers (Across 26 states)



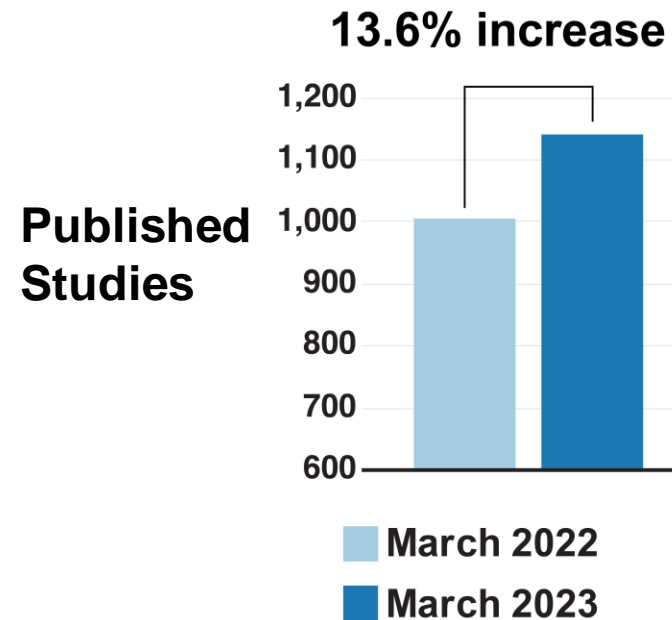
- State with NIA-designated centers
- State with exploratory center

Increase in NACC Data Utilization

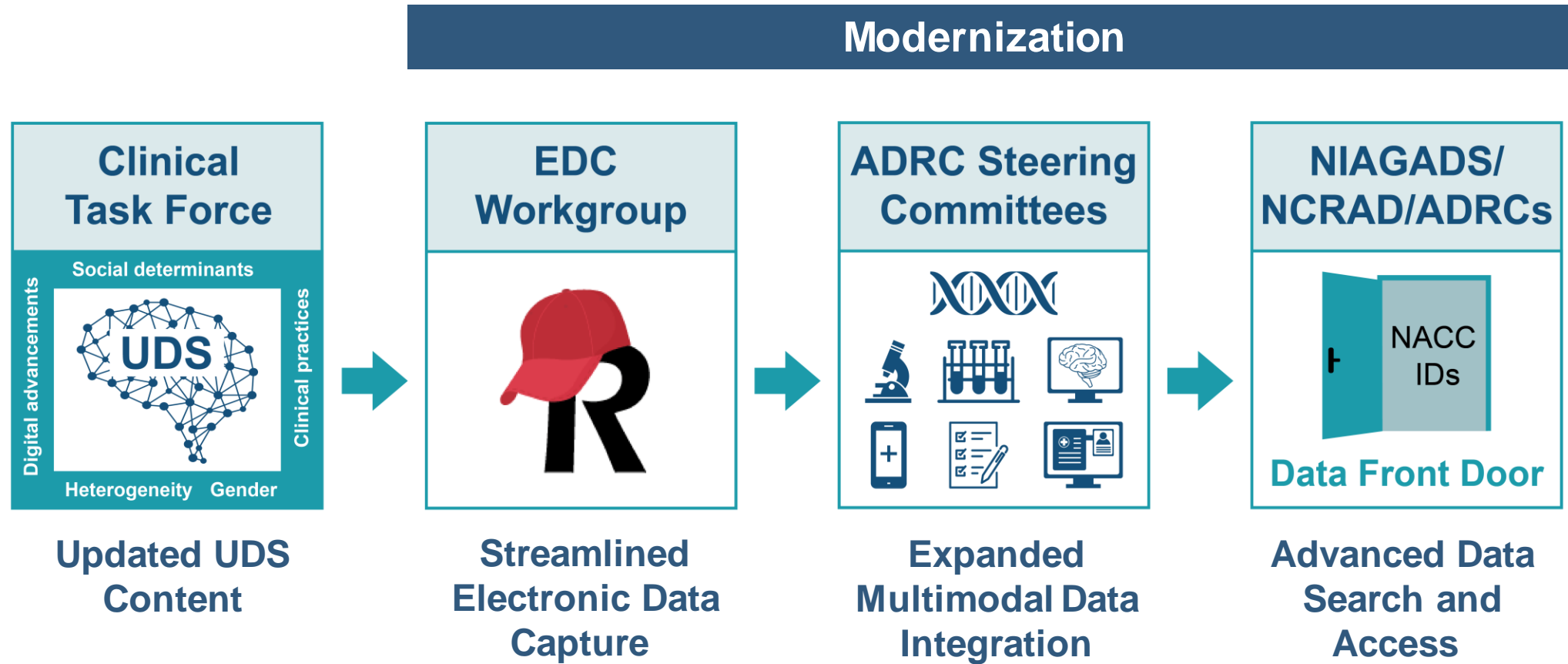
61% increase in the average number of data requests filled per month



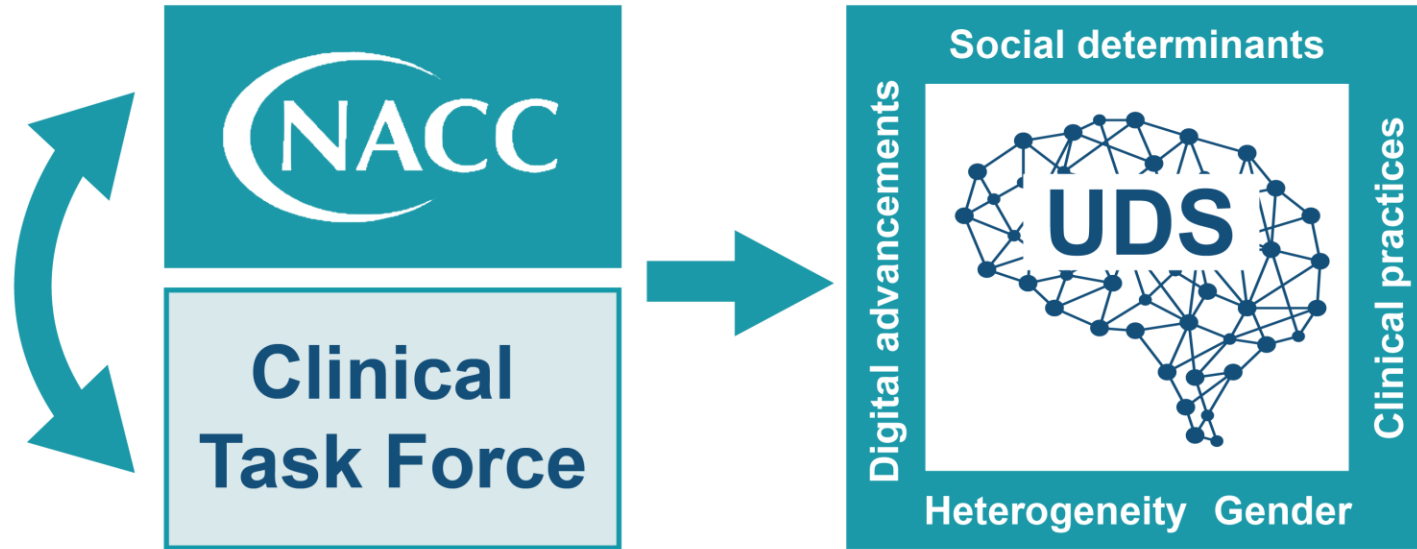
~14% increase in the number of published studies using NACC data



Aligning with NIH's Data Science Strategy



Modernizing UDSv4 Content



CTF UDSv4 Status of Form Content

95% of content is 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

New forms *No changes from UDSv3

Final Revisions by CTF

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

Advancing the ADRD Field with UDSv4

ADRD-Disease Modifying Drugs

Form A4a: ADRD-Specific Treatments



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



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**

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**
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More Inclusive

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

UDSv4 – Collaboration with the CTF

Thank you to the CTF for their collaboration on this effort!

Collaboration with the Clinical Task Force (CTF)

Lead: Allan 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, Kostas Lyketsos MD

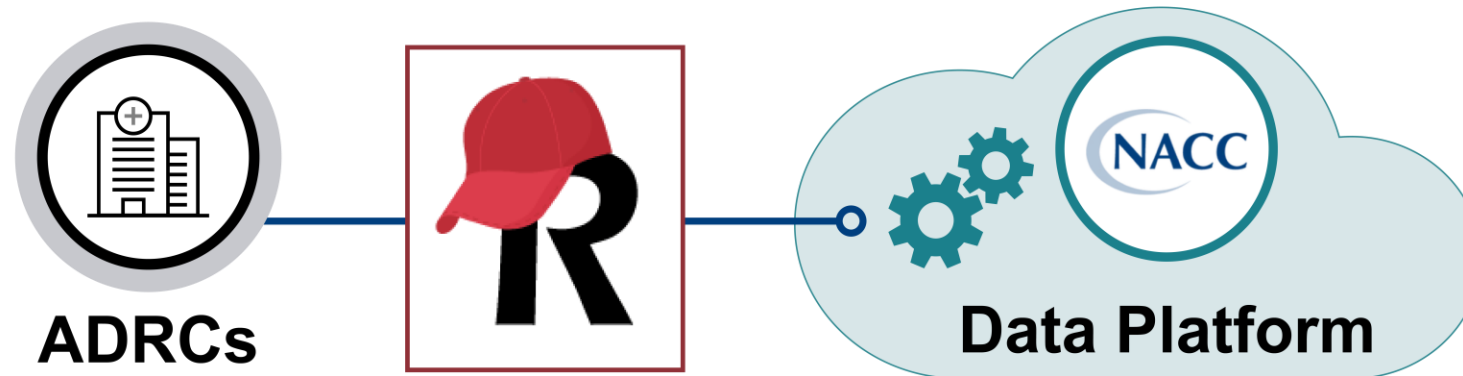
Cognitive Workgroup

Co-leads: Andy Saykin, PsyD and Lisa Barnes, PhD

Social Determinants of Health Workgroup

Co-lead: Lisa Barnes, PhD and Megan Zuelsdorff, PhD

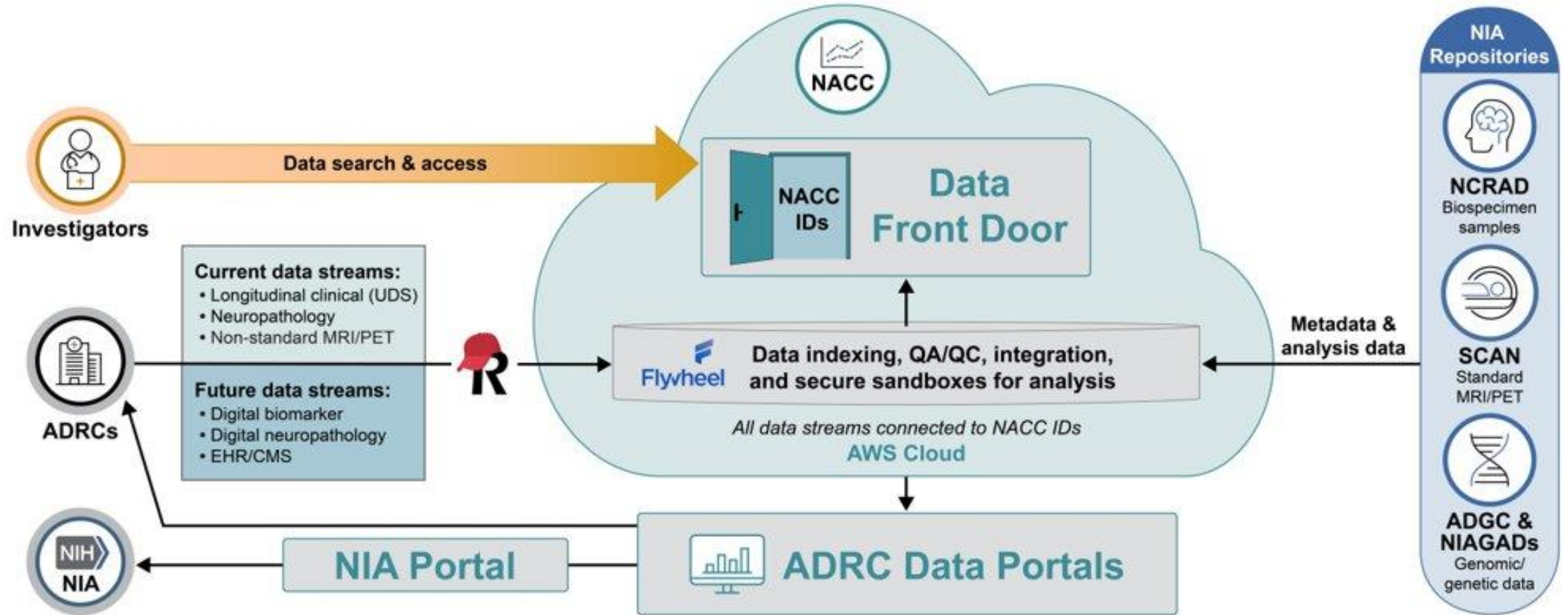
Electronic Data Capture System for UDSv4



EDC Benefits

- **Save time**
- **Enhance sharing**
- **Improve data quality**

Expanded Multimodal Data Integration and Sharing



Go to the NACC Sessions to Learn More!

Tuesday, May 2nd, 8 a.m. to 9:30 a.m. (Eastern), In Constitution B-E

Topic	Speaker Name
*NACC Modernization and the New NACC Data Platform	Sarah Biber, PhD
*Update on Social Determinants Module for UDS4	Lisa Barnes, PhD
NACC and ADRC Collaborative Neuroimaging Efforts	Elizabeth Mormino, PhD - Stanford ADRC
The Electronic Data Capture Working Group: A NACC-ADRC Collaborative Effort	Sudeshna Das, PhD - Massachusetts ADRC
ALZ-NET and NACC: Opportunities for Collaboration and Synergy	Gil Rabinovici, MD - UCSF ADRC
Multimodal Deep Learning for Dementia Assessment	Vijaya Kolachalama, PhD - Boston University ADRC
Generalizable Deep Learning Model for Early Alzheimer's Disease Detection from Structural MRIs	Narges Razavian, PhD - NYU ADRC
Genetic Drivers of Risk and Resilience	Tim Hohman, PHD - Vanderbilt Exploratory ADRC
Shared Q&A	All presenter

UDSv4 Status of Form Content

Find out from the Clinical Task Force (CTF)

CTF Lunch Breakout Tomorrow!

Ask the CTF about UDSv4!

12:00 p.m. - 1:00 p.m. (Eastern)

Constitution A

Go to the NACC UDSv4 / EDC Booth

Review draft forms and ask questions

Thank you!



Connect with NACC

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