



# NACC Session

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**Thursday, October 17, 2024**

**2024 Fall ADRC Meeting**

# Welcome to the NACC Session!

Topic	Speaker Names
Welcome	Walter Kukull, PhD (NACC)
UDSv4 Launch	Sarah Biber, PhD (NACC) Jess Welsch, MBA (NACC) Cindy Carlsson, PhD (Wisconsin ADRC) Sudeshna Das, PhD (Massachusetts ADRC)
NACC Data Platform	Sarah Biber, PhD (NACC)
Becoming More Multimodal and Expanding Interoperability	Kristen Russ, PhD (NCRAD) Gil Rabinovici, PhD (UCSF ADRC) Rhoda Au, PhD (Boston University ADRC) Bill Jagust, PhD (UC Berkeley ADRC)



# Welcome!

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**Bud Kukull, PhD – NACC Director**  
**Thursday, October 17, 2024**  
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# One of the largest and most comprehensive longitudinal, standardized, clinical phenotypic and neuropathological datasets in the world!



HAPPY ANNIVERSARY  
**25**

## UDS Impact



**52,500+**

Participants with data at NACC  
(19,000+ active participants)



**195,000+**

Clinical assessments  
(1-20 visits per participant)



**8,150+**

Neuropathology datasets  
(From 58% of deceased participants)



**1,350+**

Published studies using  
NACC data



**35**

35 ADRCs contributing data  
(Across 26 states)

## MDS Impact



**71,000+**

Participants with MDS data

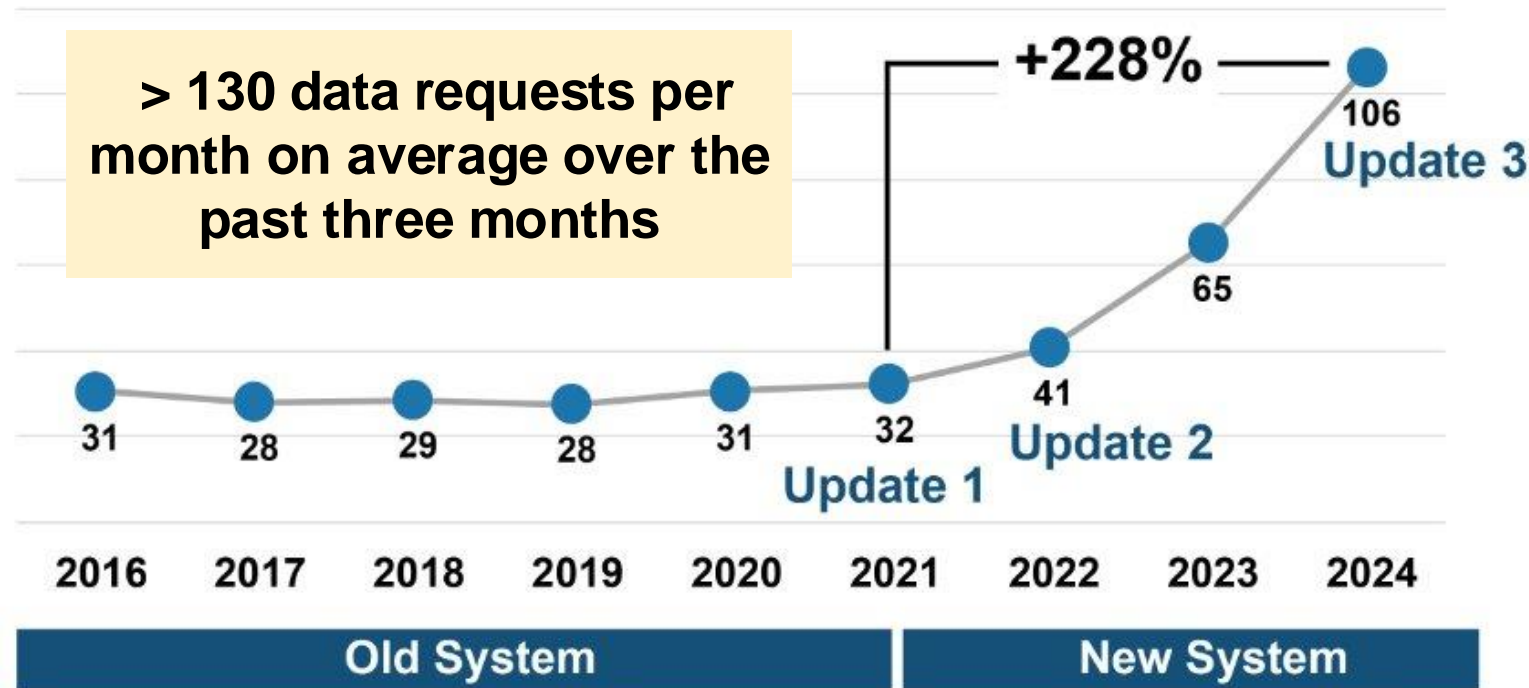


**11,000+**

Neuropathology datasets

# Increased NACC Data Utilization - More FAIR!

 **228% Increase in Average Data Requests per Month**



**955 data requests in 2024!**

*74% of new requests include imaging data*

**Update 1** (Nov 3, 2021): Expanded Quick-Access file types (FTLD, LBD, CSF, MRI, PET, scans)

**Update 2** (Jun 4, 2023): Data request survey through REDCap

**Update 3** (Apr 30, 2024): SCAN analysis data available