NACC Data Update

2020 Fall ADRC Meeting October 1, 2020

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University of Washington



Who we are

Kari A. Stephens, PhD

Associate Professor Director of Clinical Research Informatics Department of Family Medicine University of Washington

Sean D. Mooney, PhD

Professor Chief Research Information Officer UW Medicine



NACC vision

- Facilitation of a more collaborative consortium
- Harmonization of data through use of shareable forms, common data models, standard nomenclature, etc.
- Self service access to data using internet technology
- Better prepared to enable machine learning/data science using integrated data through consultation and cloud enclaves
- Integration of new data types *e.g., claims or EHR data*
- Improved access to consortium biospecimens



Today presenting work we are doing to improve NACC informatics





- **Infrastructure** Leveraging the Cloud for NACC's Data Infrastructure
- **Data collection** Developing shareable forms utilizing REDCap for data capture





Self-service access — Providing a self service NACC
Data query tool using Leaf
Clinical data — Increasing use of administrative

datasets and EHR datasets within the ADRC Consortium



NACC data and informatics milestones accomplished

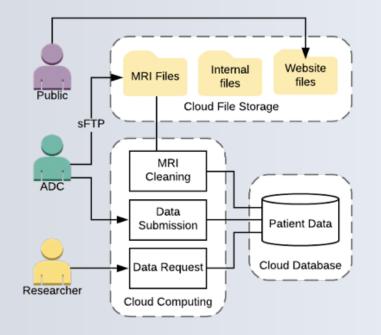
- COVID adaptation: Remote UDS packet (TFP/TIP) and neuropsych data
- Data distribution: 310+ data requests completed
- New collaboration with SCAN image data
- New website Live! <u>http://naccdata.org</u>
- Cloud enabled
- New modules and revisions



NACC's data infrastructure is Cloud native

Advantages of the Cloud:

- More FAIR (findable, accessible, interoperable, reusable)
- More collaborative
- Use of open APIs
- Better modularization
- Custom apps possible
- Integration with national cloud infrastructure at NIH possible





Opportunity to leverage EHR data with ADRCs

Recently, collection of EHR data has become very useful for research with many multisite networks forming

Data models have emerged that can support useful and easy collection of electronic health record data or administrative claims data





Potential of EHR and other data linkages to propel AD/ADRD research

NACC's goal is to support ADRCs to leverage existing local institutional infrastructure to collect and harmonize electronic health record data and claims data to enhance other existing data offerings within the ADRC network

EHR and Claims data can augment existing and planned clinical research data sets

Standardize consent for linkages

Next steps: If your ADRC is interested in EHR linkages, please reach out to nacchelp@uw.edu



Roadmap for today

Following presentations:

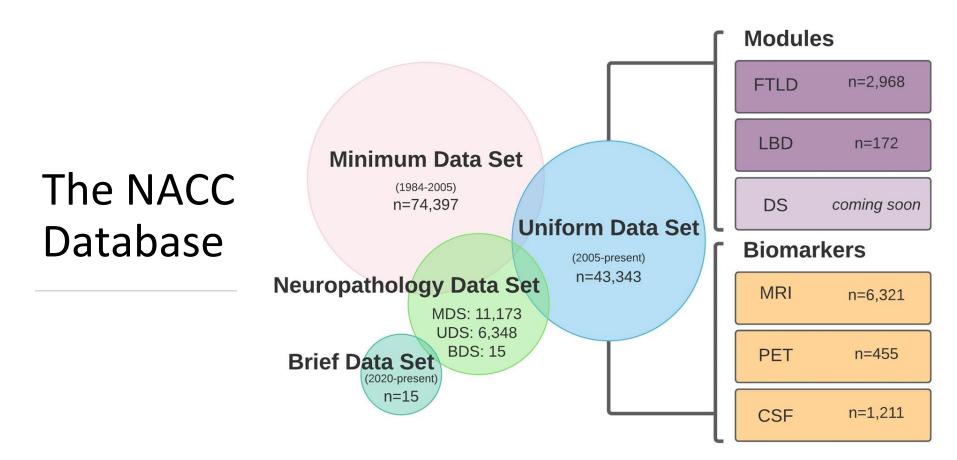
- NACC's data inventory: Update on the NACC database and collection forms
- Data capture: Data collection and new support for REDCap
- Data access: Self-service access to data sets: Leaf
- Q&A



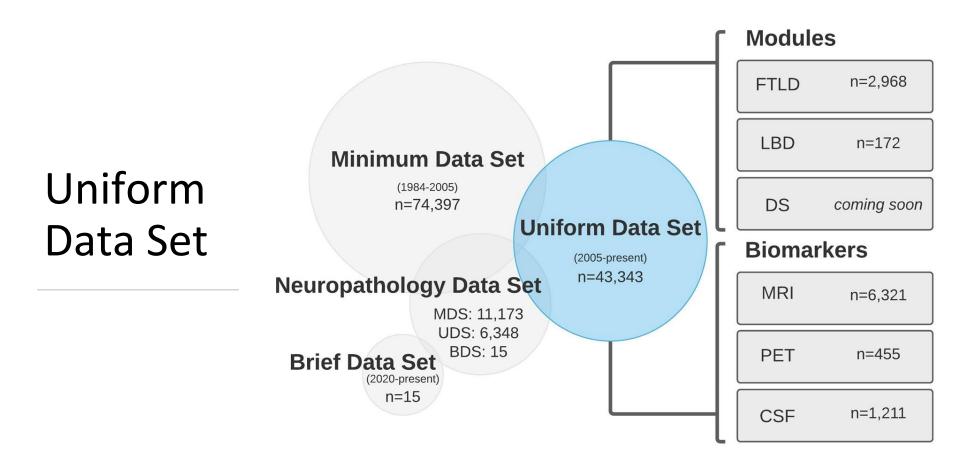
NACC's data inventory



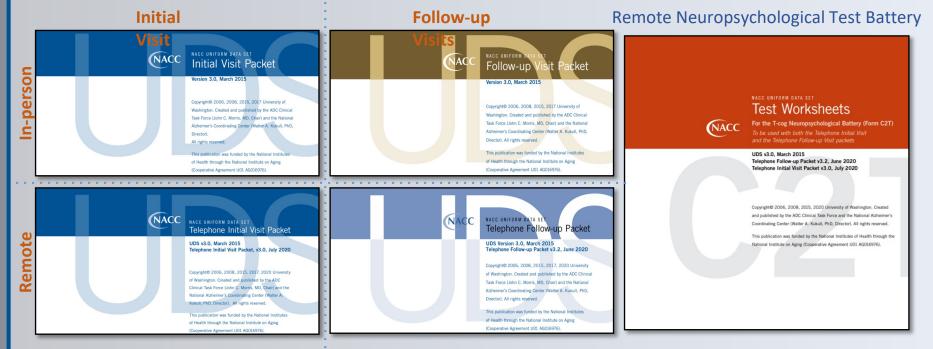
September 2020 data freeze



September 2020 data freeze



What's new with UDS data collection?





UDS remote assessments

Find out more: <u>https://naccdata.org/data -</u> collection/forms-documentation/uds-3-packet-info/

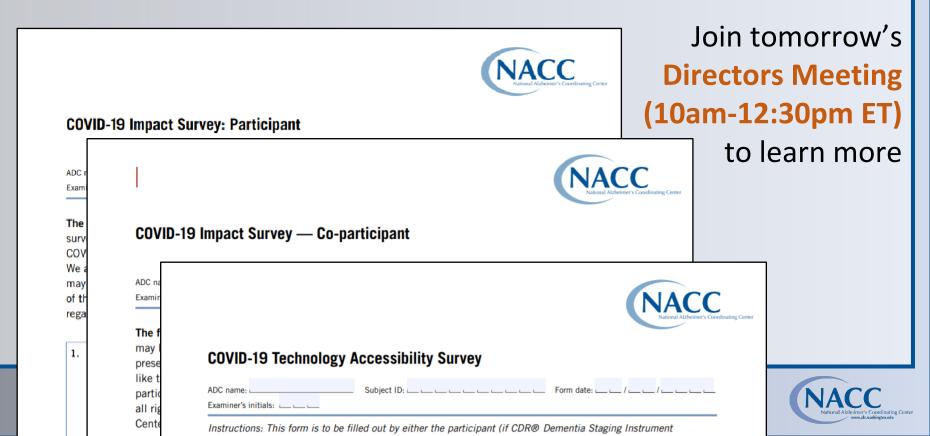
UDSv3 Packet information

Table 1. Required and optional forms included in UDSv3 packets *

Form	MP	FVP	TIP	TFP	Summary of changes made for TIP	Summary of changes made for TFP
T1: Inclusion Form			•	•	Adapted TFP version of the form for initial visit	Added response option to capture COVID-19 as a reason for telehealth visit; Added question about modality of administration (telephone, video conference, combination)
A1: Subject Demographics	•	•	•	•	-	-
A2: Co-participant Demographics	۰	۰	•	•	Made a required form (i.e., not required for IVP or FVP)	-



COVID-19 Impact & Technology Surveys



NACC implementation of remote assessments

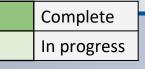
	CTF/Work Group ratified	Clinical documents released	Database documents released	Database submissio n live
Telephone Follow-up visit Packet (TFP) v3.2				
Telehealth Cognitive Battery (T-Cog)				
Telephone Initial visit Packet (TIP) v3.0				
COVID Impact Survey				
COVID Tech Accessibility Survey				

Complete
In progress



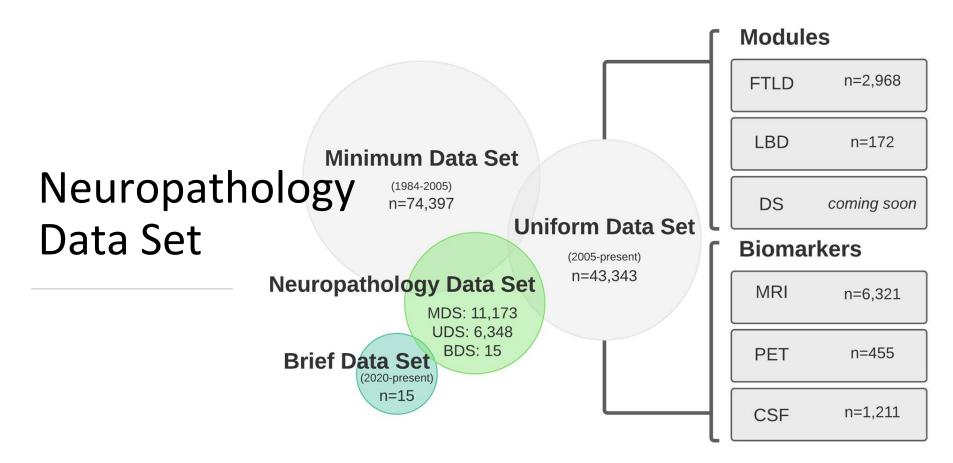
Spanish-translated remote assessments

	English Forms		Spanish Forms	
	CTF/Work Group ratified	Clinical documents released	Latino ADC Group ratified	Translated documents released
Telephone Follow-up visit Packet (TFP) v3.2				
Telehealth Cognitive Battery (T-Cog)				
Telephone Initial visit Packet (TIP) v3.0				
COVID Impact Survey				
COVID Tech Accessibility Survey				





September 2020 data freeze



NP data collection — without MDS or UDS

NACC Brief Data Set (BDS) + NP Form

NACC National Alaberter's Coordinating Center

NACC BRIEF DATA SET

Form BDS: Brief Clinical Data Capture for NP Submission

DC name:	Subject ID:	Form date: / /
xaminer's initials:		

DE	MOGRAPHICS	
	TRUCTIONS: This section is to be completed based on ky report.	medical records, existing research data, and
1.	Participant's month and year of birth (MM/YYYY):	/
2.	Participant's sex:	1. D Male 2. Female
3.	Did this participant report being of Hispanic/Latino	o. 🗖 No

Th	The Neuropathology Data Form					
ADC s	ubject ID:	Completed by:				
1.	MDS/UDS patient ID					
2.	Date form completed (MM/DD/YYYY)	//				
3.	Neuropath ID					
4.	Sex (CHECK ONE)	□ 1 Male □ 2 Female				
5.	Age at death	years				
6.	Date of death (MM/DD/YYYY)	//				
7.	Postmortem interval (PMI): time between death and brain removal	hours (99.9 = unknown)				



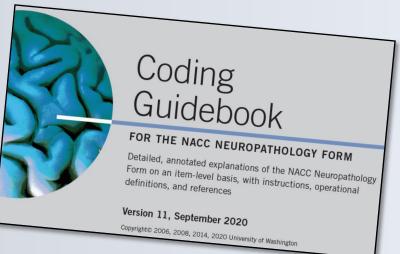
How to submit BDS data?

NPDSS NACC Neuropathology Data Submission System Form Versions 1 Thru 10				
NP HOME	U Washington			
UPLOAD and PRE-PROCESS FILES	Neuropathology Data Submission System			
	Upload Files Button : Upload files to the working database			
WEB DATA ENTRY				
BDS FORM	Web Data Entry Button : Add, edit, delete and/or display data			
ERROR CHECK	Error Check Button : Execute error checks and verify alerts			



What's new with NP data collection?

Join tomorrow's NP Core Leaders Session (12:45-2:45pm ET) to learn about Version 11 of the NACC NP Form and Guidebook





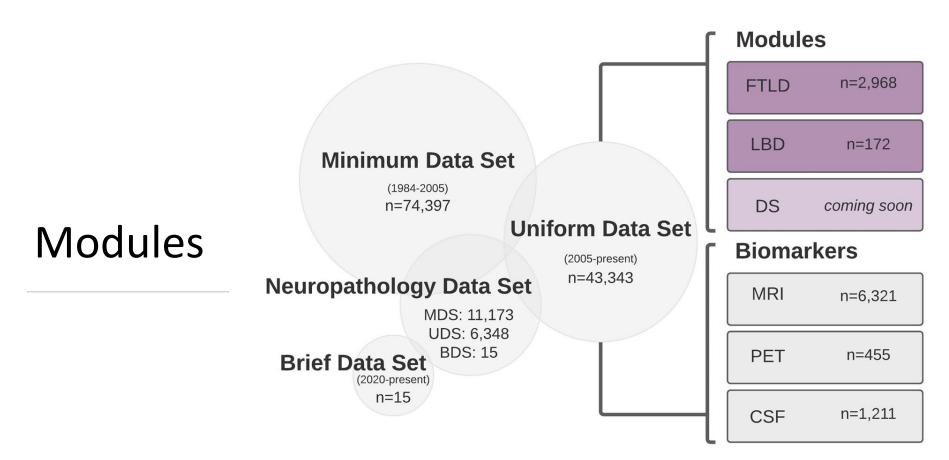
NACC implementation of BDS and NPv11

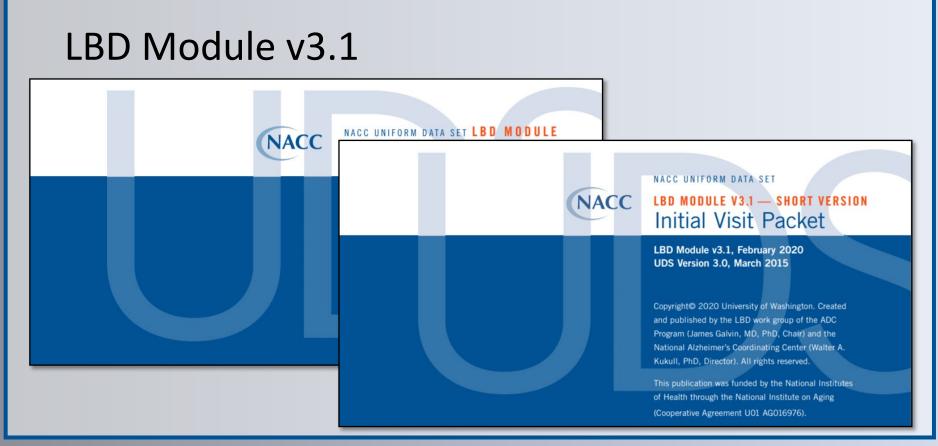
	CTF/Work Group ratified	Clinical documents released	Database documents released	Database submission live
Brief Data Set				
NPv11				

Complete		
In progress		



September 2020 data freeze







Coming soon: Down Syndrome Module

Collaborative effort with Alzheimer's Biomarkers Consortium — Down Syndrome (ABC-DS)





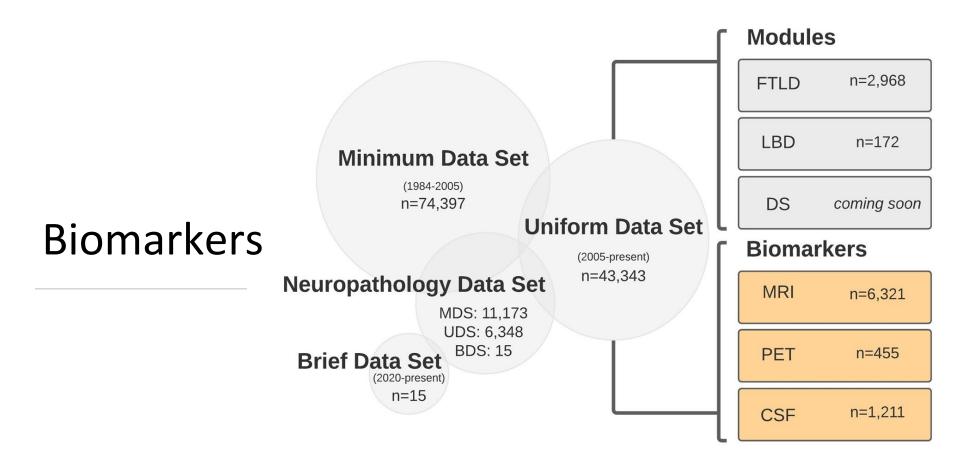
NACC module implementation

	CTF/Work Group ratified	Clinical documents released	Database documents released	Database submission live
LBD Module v3.1				
DS Module				





September 2020 data freeze



MRI cleaning processor — Progress update

- 13 ADRCs participated in our pilot
- Successfully processed over 70% of the legacy scans contributed to NACC through the old system
- Nearly 4,000 additional scans have been submitted to the new system
- Invitation to all ADRCs to the new system



Questions about data forms or submission? Email: nacchelp@uw.edu





Partners



Data capture How we're streamlining data collection





Research Electronic Data Capture

- Leading tool in clinical research with over 4500 institutions worldwide currently utilizing
- Web based
- Built for research by researchers
- HIPAA-compliant
- Highly customizable with external modules
- Seamlessly allows sharing projects/data collection instruments between sites





University of Washington ITHS REDCap instance

- One of the largest REDCap instances in the REDCap consortium
- Supporting over 12,000 active users with over 25,000 projects
- UW REDCap team administers and ensures security of REDCap for other National Studies
- Allows data upload from other REDCap supported sites
- Comprehensive support model

Adding new Record ID 1			
Record ID		1	
Patient first name		Harry	
Patient last name		Potter	
Date of birth		⊖ 07-31-1980 🛅	N-D-Y
Reporting jurisdiction:	WA	🕒 Case State/local ID:	WA
Reporting health department:	King County	CDC 2019-nCoV ID:	37js992
Contact ID ^a :	738A	NNDSS loc.rec.ID/Case ID ^b :	89833
	, Confirmed case CA102	prior source case-patient. Assign Co 034567 has contacts CA102034567-0 lentifier	
Name of interviewer: Last Na	me Granger	First Name Hermione	
Affiliation/Organization:	UW	Helephone: (555) 555-55	55
U			



Thanks to our ADRC REDCap community!

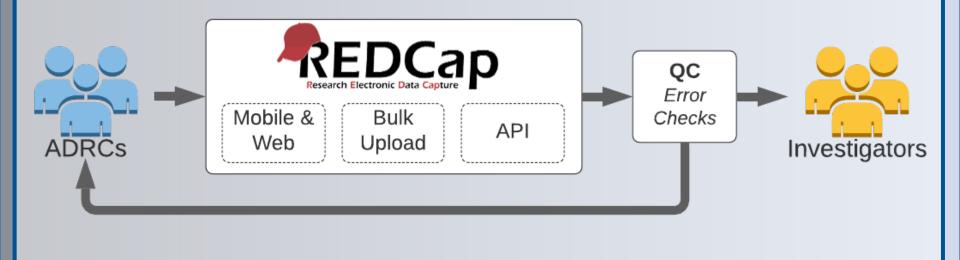
Sharing files, tools, and advice with the greater community has:

- Helped standardize tools across the ADRCs
- Helped new centers get set up quickly
- Greatly reduced duplicated work
- Given NACC a head start implementing REDCap





Where does REDCap fit into data submission?





How do we get there?

- 1. Set up COVID-19 Surveys
- 2. Configure user access
- 3. Invite users to try things out
- 4. Integrate QC and distribution systems
- 5. Set up additional forms



What does this mean for you?

- Faster release of forms and modules
- Improved upload options (web interface, API)
- An even more streamlined process for ADRCs using REDCap for their own data capture

Please enter any questions / comments into the Q&A, and you're welcome to email us at <u>nacchelp@uw.edu</u>



We welcome your questions and feedback about REDCap!

Post in the Q&A or email nacchelp@uw.edu



Data access How people get data



The prototype is live at naccdata.org, check it out!

- Simplified layout and navigation
- Accessible & mobile-friendly
- Streamlined access to submission systems

The existing website will be kept online through October as we wrap up this work.

We'd love to hear your feedback during this time! <u>nacchelp@uw.edu</u>



A simple, accessible interface

Requesting data

NACC

the NIA ALZHEIMER'S DISEASE RESEARCH CENTERS PROGRAM National Alzheimer's Coordinating Center

Publishing

Webinars



Social Determinants of Health

NACC collaborations

Presentations include "Social Determinants and Cognitive Aging" with Lisa Barnes, PhD, Rush University; and "The Power of Context: Considering Multi-Level Social Determinants in Brain Health" with Amy Kind, MD, PhD, University of

New at NACC

NACC productivity

New job opportunities page

Request a new QUICK-ACCESS Full Data File, with complete UDS and NP data

Data collection

ADRC resources

New guidelines for working with an EAC







PORTAL

Q

All of your tools in one place						
NACC						
Sample Center (0) 🖌 🗸	UDS & MODULES UDS, FTLD, & LBD Neuropathology	ARMADA Toolbox ARMADA UDS	GENETICS APOE Submission GWAS Phase 1 GWAS Phase 2			
	BIOSPECIMENS MRI CSF		Genotype Data Imputation Data ADSP to PTID Map			



Improvements to data access: Leaf!

Leaf is a tool that will allow authorized users to view and download NACC data in-browser.

Connections with NCRAD, NIAGADS, and SCAN data will be possible with shared study IDs.

Leaf will help NACC become a one-stop-shop for data access.



Leaf — Clinical Data Explorer

- Free, open-source web application for cohort discovery
- Adaptable to nearly any clinical database
- Developed at UW Medicine Research IT
- In use or being piloted at 10+ academic medical centers, including:
 - Johns Hopkins
 - University of Chicago
 - University of California at Irvine
 - University of Washington

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Leaf – Clinical Data Explorer

Leaf with NACC

- Current prototype includes NACC UDS data
- Leaf will be a self-service application
- Leaf will be available only to users who are authorized and have signed Data Use Agreements
- Allows for:
 - Simple or sophisticated self-service queries in seconds.
 - Basic demographic visualizations
 - Fast, direct NACC data exports to .csv files
 - And more...



Questions and answers

Please submit any questions or comments in the Q&A. Thanks for coming!

