NACC Data Update

2020 Fall ADRC Meeting

October 1, 2020

Kari Stephens, Sean Mooney, Merilee Teylan, Brian Stahly, Ashleigh Lewis, Nic Dobbins, Bud Kukull

University of Washington

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

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
National Alzheimer's Coordinating Center
www.alz.washington.edu

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

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

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
National Alzheimer's Coordinating Center
www.alz.washington.edu

NACC data and informatics milestones accomplished

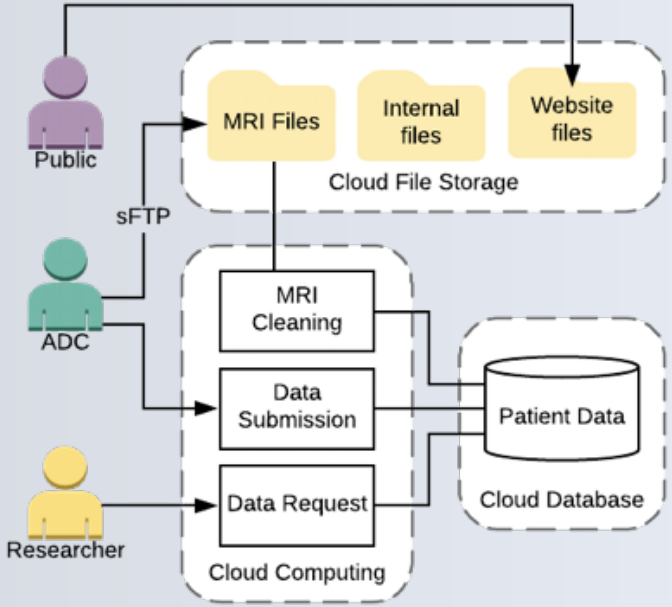
- COVID adaptation: Remote UDS packet (TFP/TIP) and neuropsych data
- Data distribution: 310+ data requests completed
- New collaboration with SCAN — image data
- New website Live! http://naccdata.org
- Cloud enabled
- New modules and revisions

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

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



NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

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

OHDSI
OBSERVATIONAL HEALTH DATA SCIENCES AND INFORMATICS

National COVID Cohort Collaborative

ACT
The ACT Network
Powered by NCATS CTSA Program

i2b2

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

NACC
National Alzheimer's Coordinating Center
www.alz.washington.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

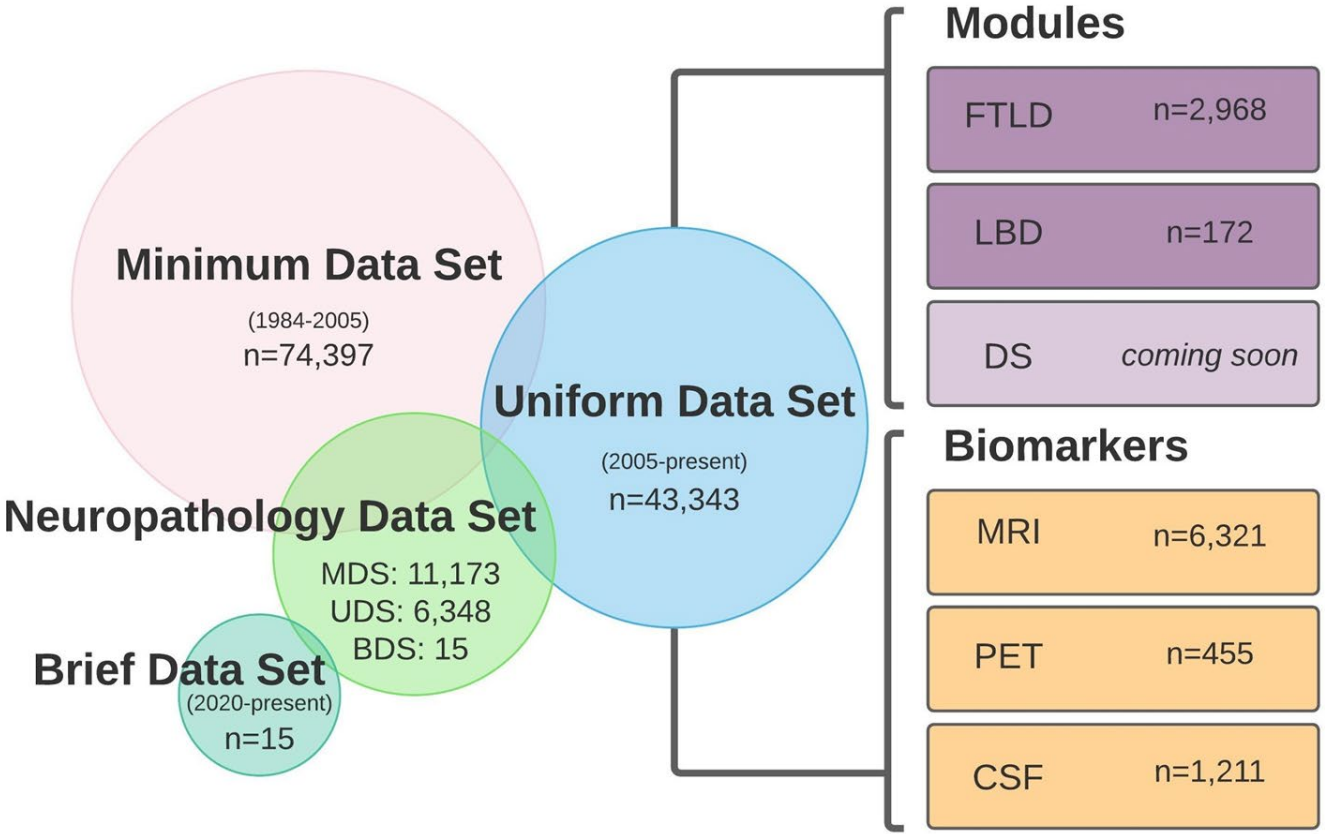
NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

NACC’s data inventory

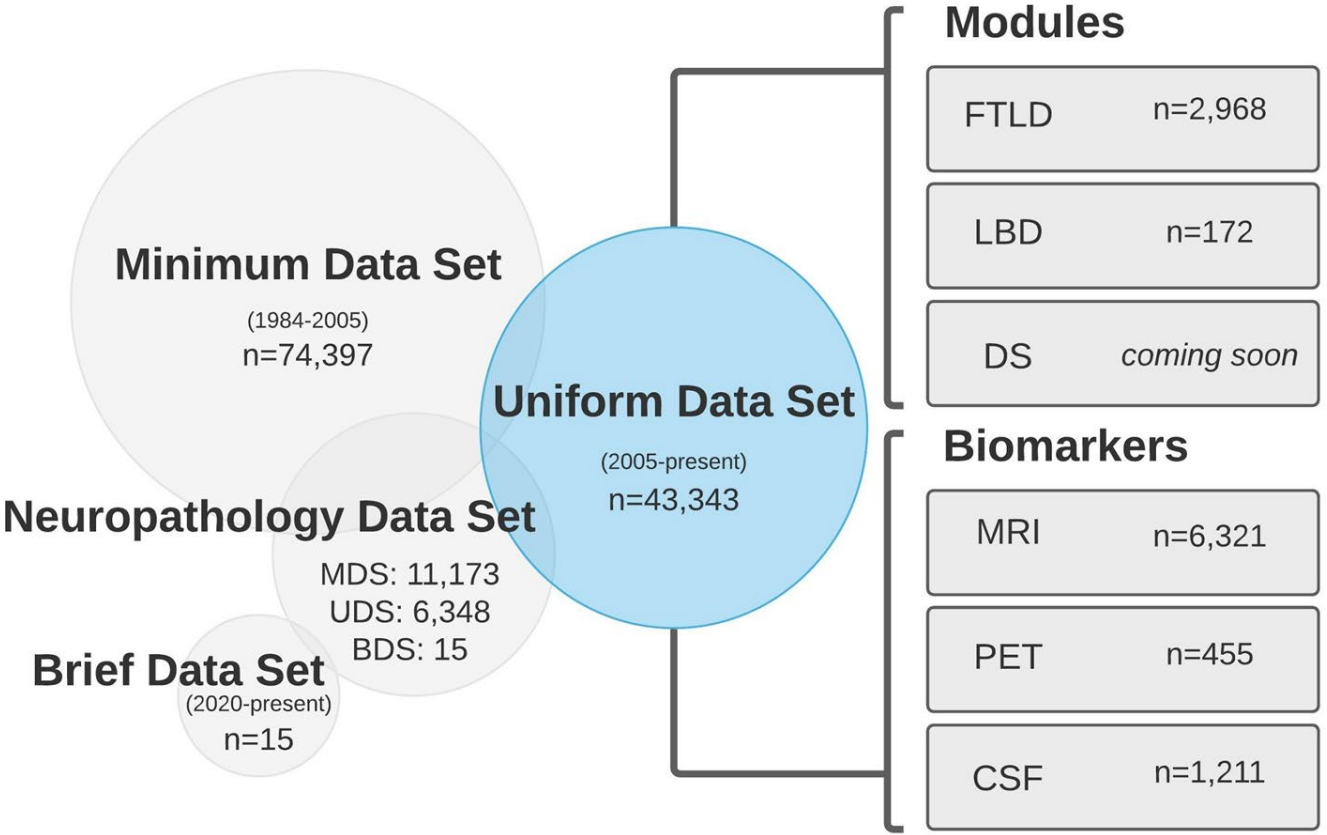
NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

September 2020 data freeze

The NACC Database



Uniform Data Set



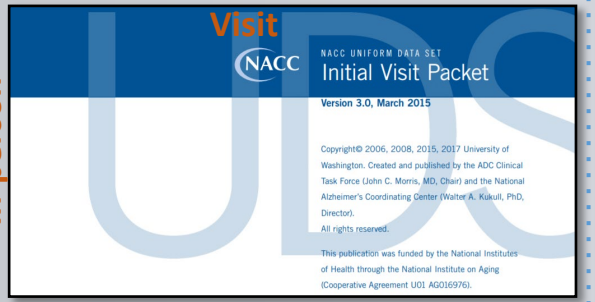
What's new with UDS data collection?

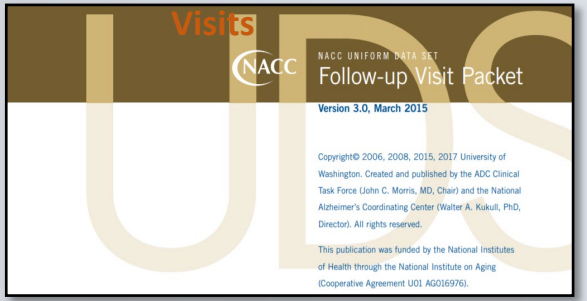
Initial Visit

Follow-up Visits

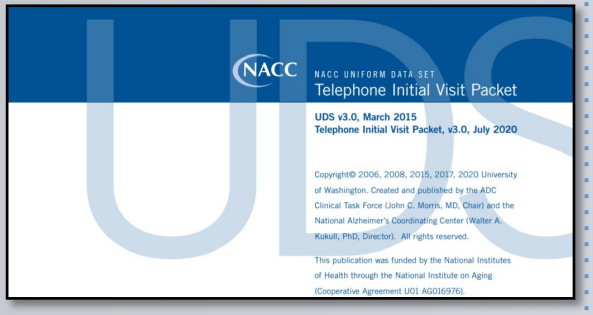
Remote Neuropsychological Test Battery

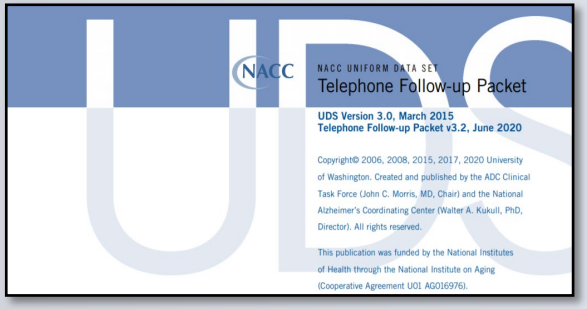
In-person

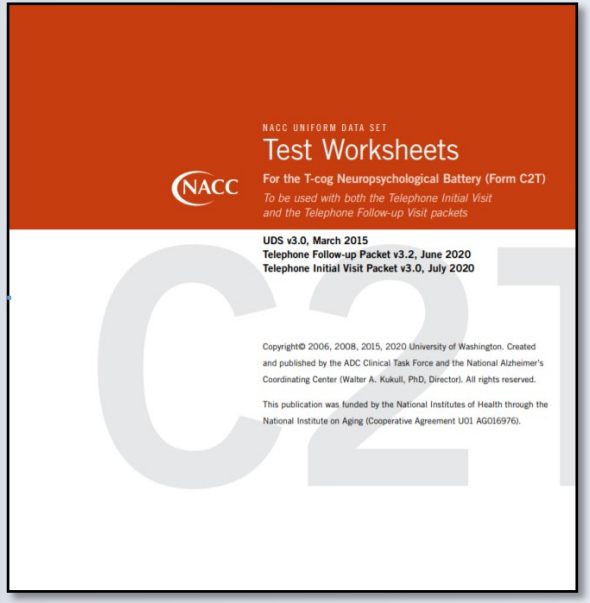




Remote







NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

UDS remote assessments

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

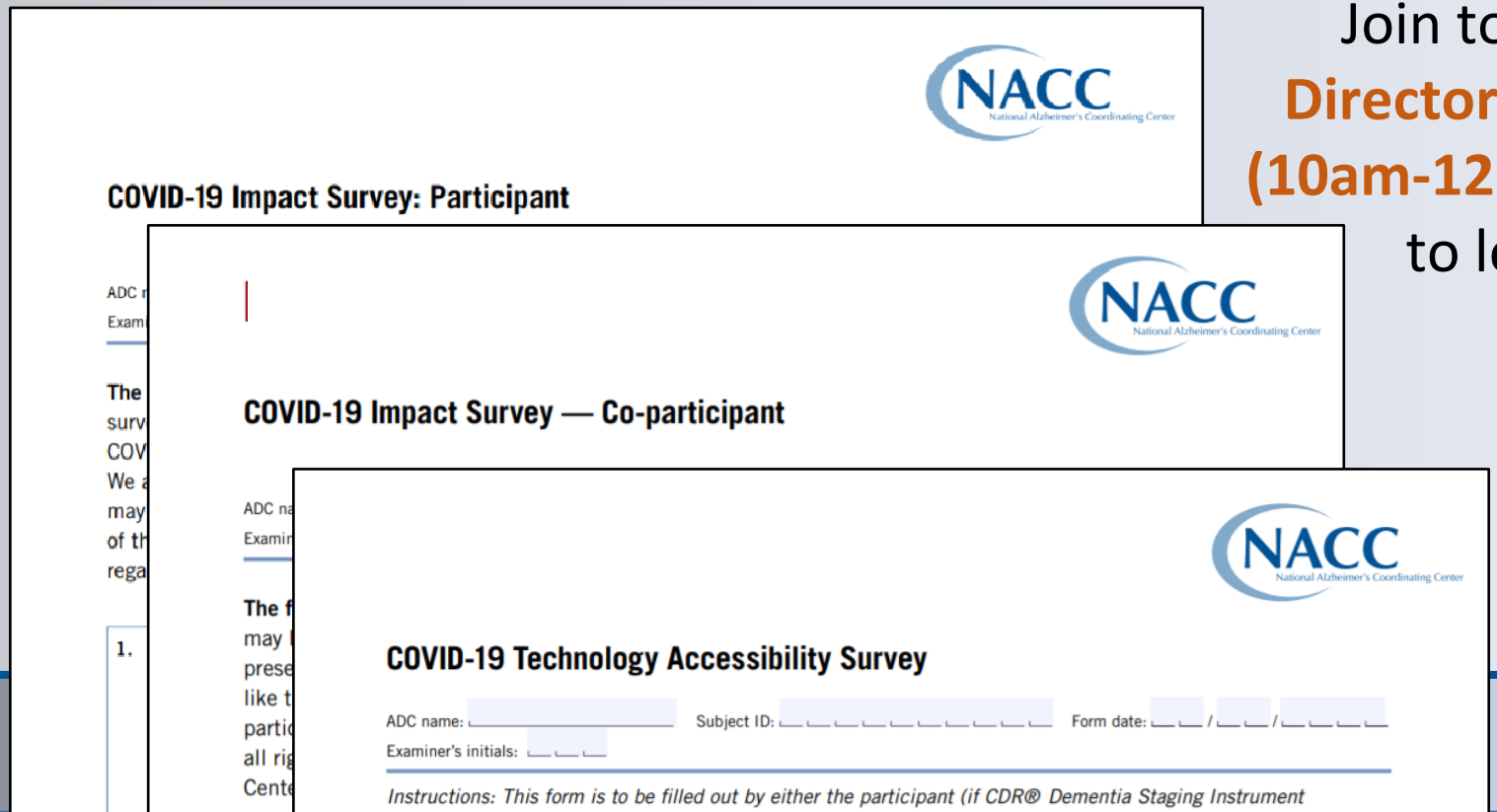
UDSv3 Packet information

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

Form	IVP	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	○	○	•	•	Made a required form (i.e., not required for IVP or FVP)	—

NACC National Alzheimer's Coordinating Center www.alz.washington.edu

COVID-19 Impact & Technology Surveys



Join tomorrow's **Directors Meeting (10am-12:30pm ET)** to learn more

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

NACC implementation of remote assessments

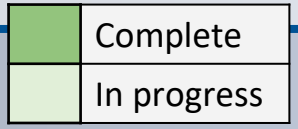
	CTF/Work Group ratified	Clinical documents released	Database documents released	Database submission live
Telephone Follow-up visit Packet (TFP) v3.2				
Telehealth Cognitive Battery (T-Cog)				
Telephone Initial visit Packet (TIP) v3.0				
COVID Impact Survey				
COVID Tech Accessibility Survey				

	Complete
	In progress

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

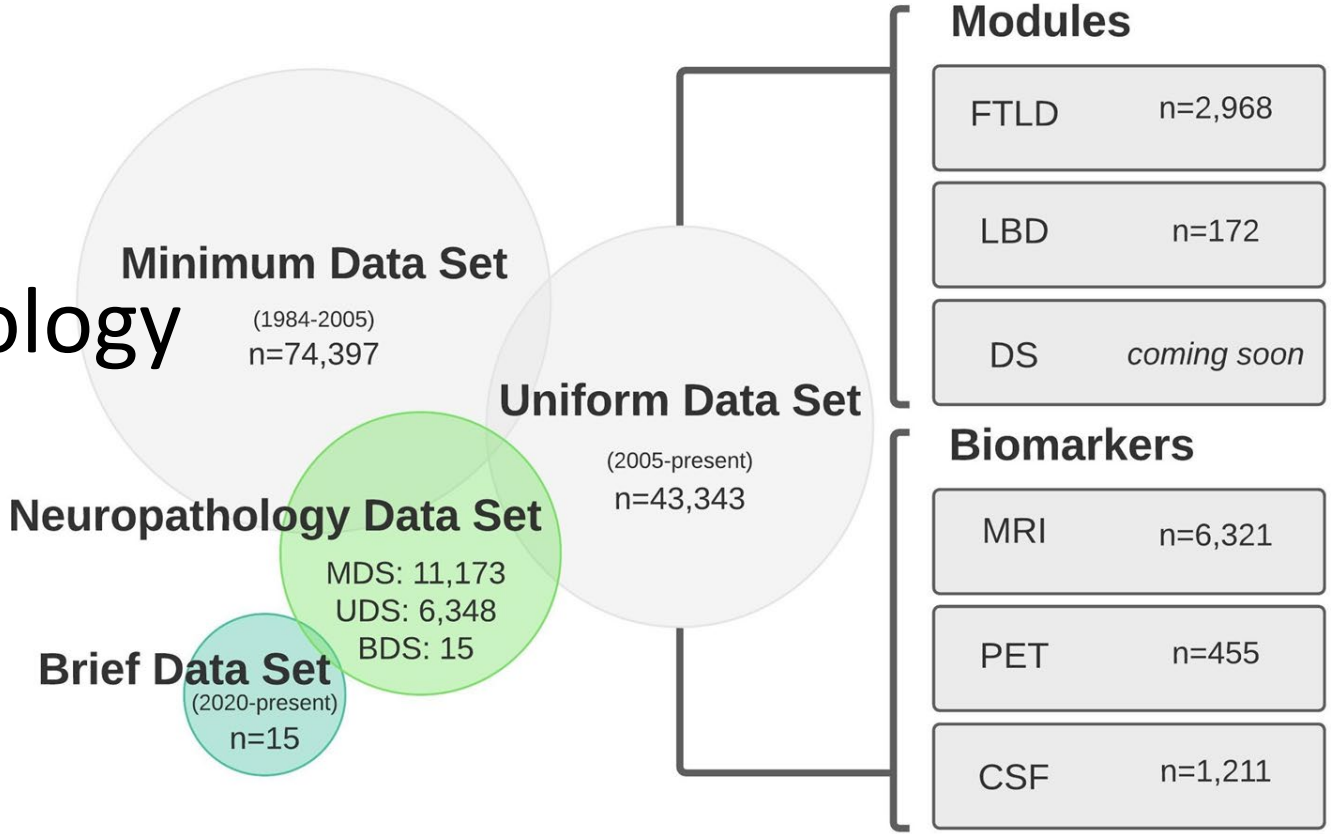
Spanish-translated remote assessments

	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				



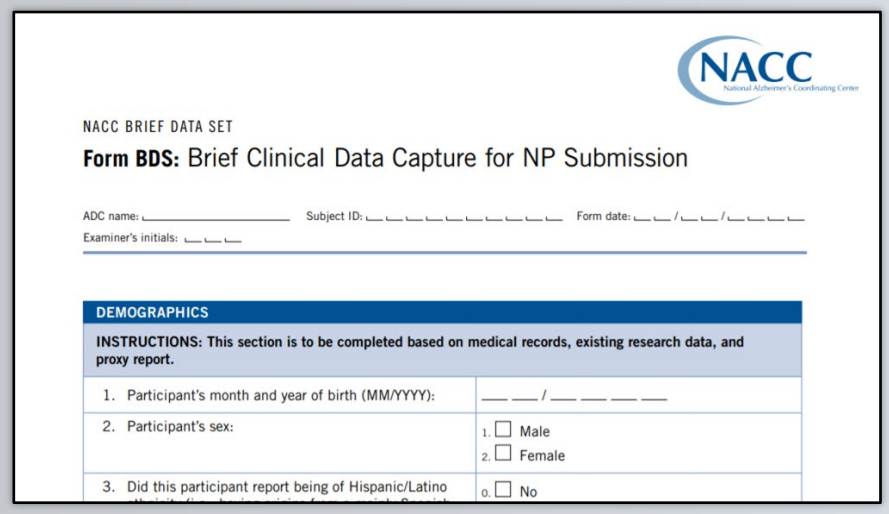
NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

Neuropathology Data Set



NP data collection — without MDS or UDS

NACC Brief Data Set (BDS) + NP Form



NACC BRIEF DATA SET

Form BDS: Brief Clinical Data Capture for NP Submission

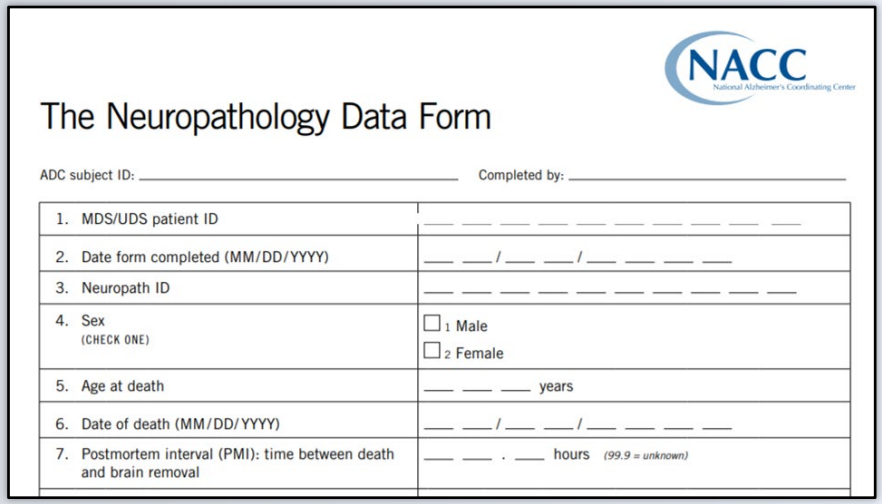
ADC name: _____ Subject ID: _ _ _ _ _ _ _ _ _ _ Form date: _ _ / _ _ / _ _ _ _

Examiner's initials: _ _ _

DEMOGRAPHICS

INSTRUCTIONS: This section is to be completed based on medical records, existing research data, and proxy report.

1. Participant's month and year of birth (MM/YYYY):	_ _ / _ _ _ _
2. Participant's sex:	1. ☐ Male 2. ☐ Female
3. Did this participant report being of Hispanic/Latino	0. ☐ No



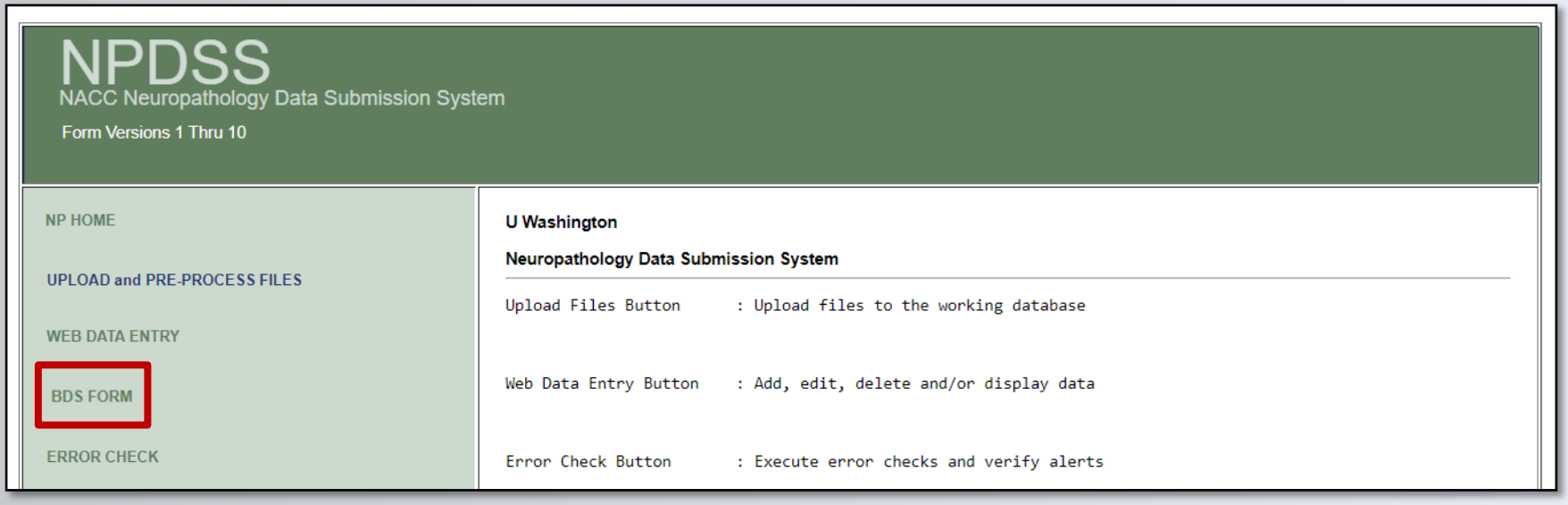
The Neuropathology Data Form

ADC subject 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)*

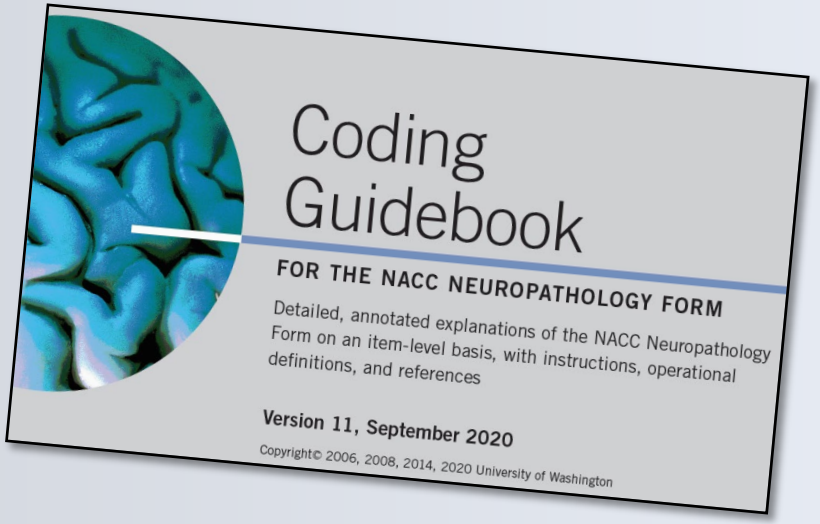
NACC National Alzheimer's Coordinating Center www.alz.washington.edu

How to submit BDS data?



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
National Alzheimer's Coordinating Center
www.alz.washington.edu

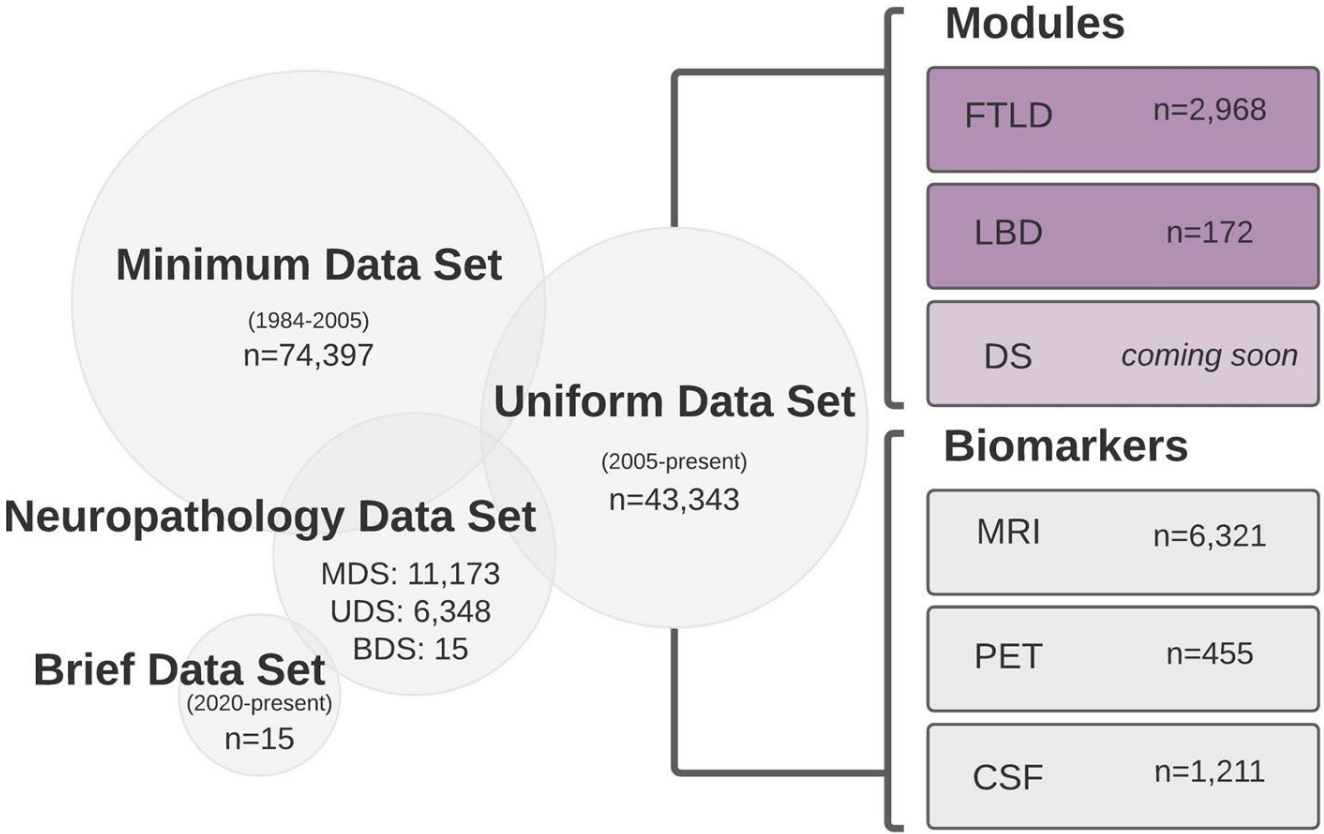
NACC implementation of BDS and NPv11

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

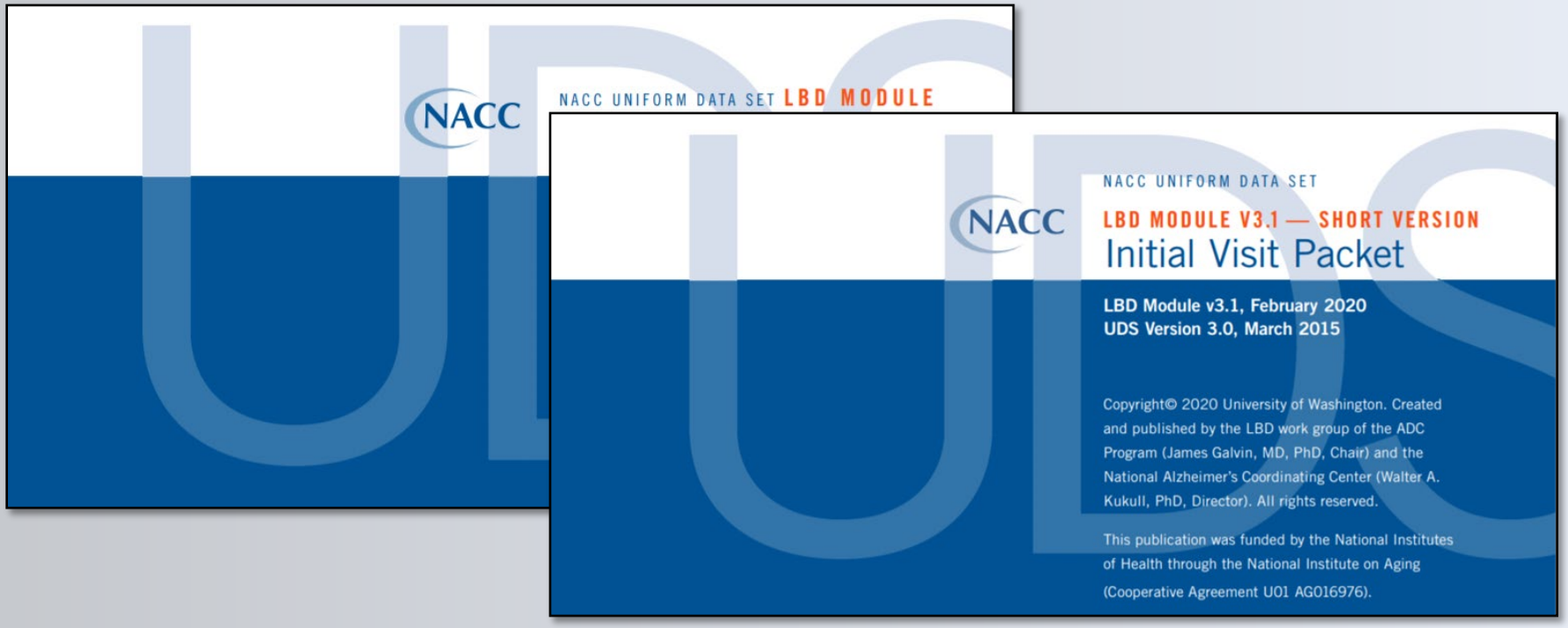
	Complete
	In progress

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

Modules


Minimum Data Set
(1984-2005)
n=74,397
Uniform Data Set
(2005-present)
n=43,343
Neuropathology Data Set
MDS: 11,173
UDS: 6,348
BDS: 15
Brief Data Set
(2020-present)
n=15
Modules
FTLD n=2,968
LBD n=172
DS coming soon
Biomarkers
MRI n=6,321
PET n=455
CSF n=1,211

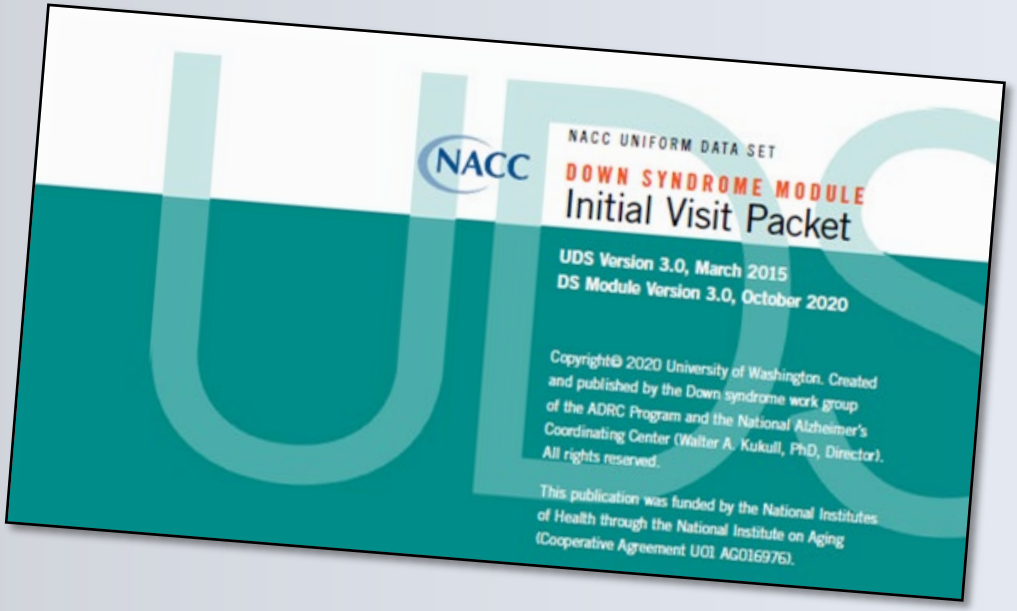
LBD Module v3.1



NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

Coming soon: Down Syndrome Module

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



NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

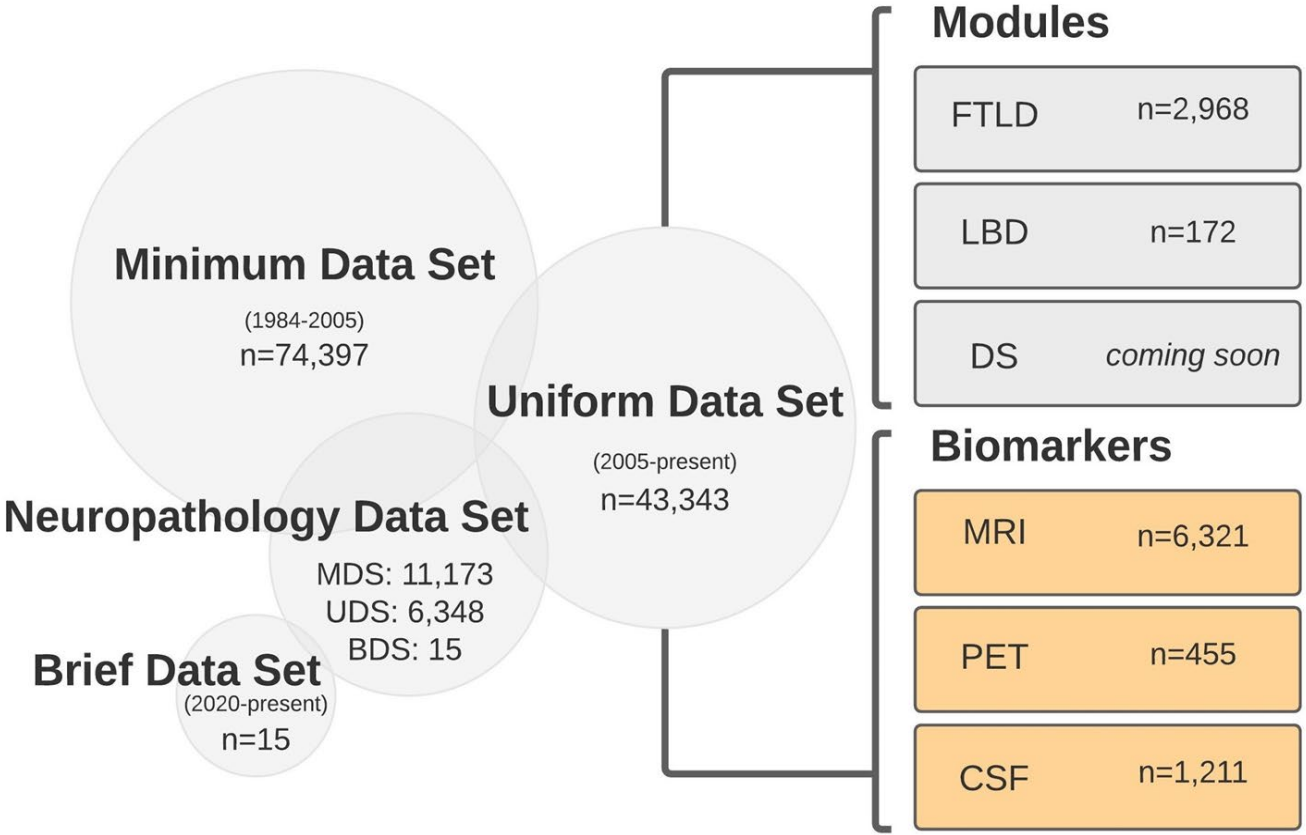
NACC module implementation

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

	Complete
	In progress

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

Biomarkers


Minimum Data Set
(1984-2005)
n=74,397
Uniform Data Set
(2005-present)
n=43,343
Neuropathology Data Set
MDS: 11,173
UDS: 6,348
BDS: 15
Brief Data Set
(2020-present)
n=15
Modules
FTLD n=2,968
LBD n=172
DS coming soon
Biomarkers
MRI n=6,321
PET n=455
CSF n=1,211

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**

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

Partners

NCRAD
NIAGADS

ADGC
Alzheimer's Disease
Genetics Consortium
adsp
Alzheimer's Disease
Sequencing Project
scan
NACC
National Alzheimer's Coordinating Center

Data capture

How we're streamlining data collection

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

REDCap
Research Electronic Data Capture

Research Electronic Data Capture

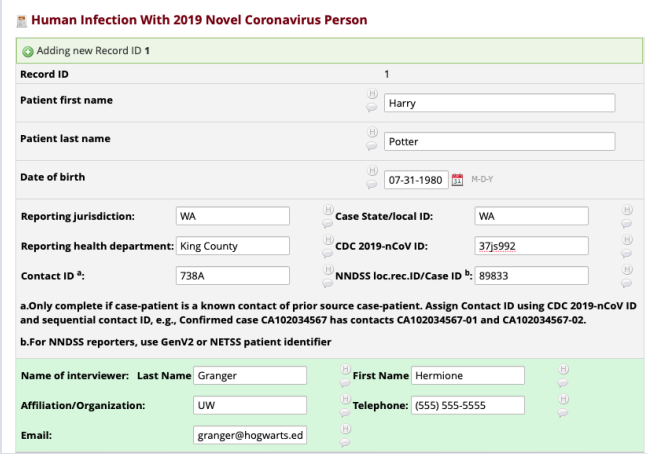
- Leading tool in clinical research with over 4500 institutions worldwide currently utilizing
- Web based
- Built for research by researchers
- HIPAA-compliant
- Highly customizable with external modules
- Seamlessly allows sharing projects/data collection instruments between sites

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

REDCap
Research Electronic Data Capture

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


Human Infection With 2019 Novel Coronavirus Person

Adding new Record ID 1

Record ID	1
Patient first name	Harry
Patient last name	Potter
Date of birth	07-31-1980 M-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

a.Only complete if case-patient is a known contact of prior source case-patient. Assign Contact ID using CDC 2019-nCoV ID and sequential contact ID, e.g., Confirmed case CA102034567 has contacts CA102034567-01 and CA102034567-02.

b.For NNDSS reporters, use GenV2 or NETSS patient identifier

Name of interviewer: Last Name	Granger	First Name	Hermione
Affiliation/Organization:	UW	Telephone:	(555) 555-5555
Email:	granger@hogwarts.ed		

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

Thanks to our ADRC REDCap community!

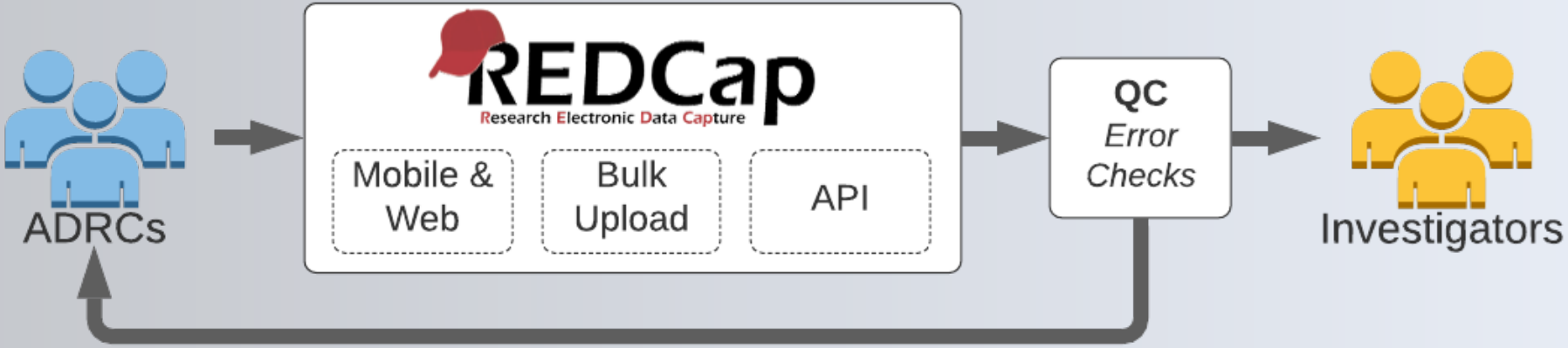
Sharing files, tools, and advice with the greater community has:

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

REDCap
Research Electronic Data Capture

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

Where does REDCap fit into data submission?



NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

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

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

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 nacchelp@uw.edu

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

We welcome your questions and feedback about REDCap!

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

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

Data access

How people get data

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

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.

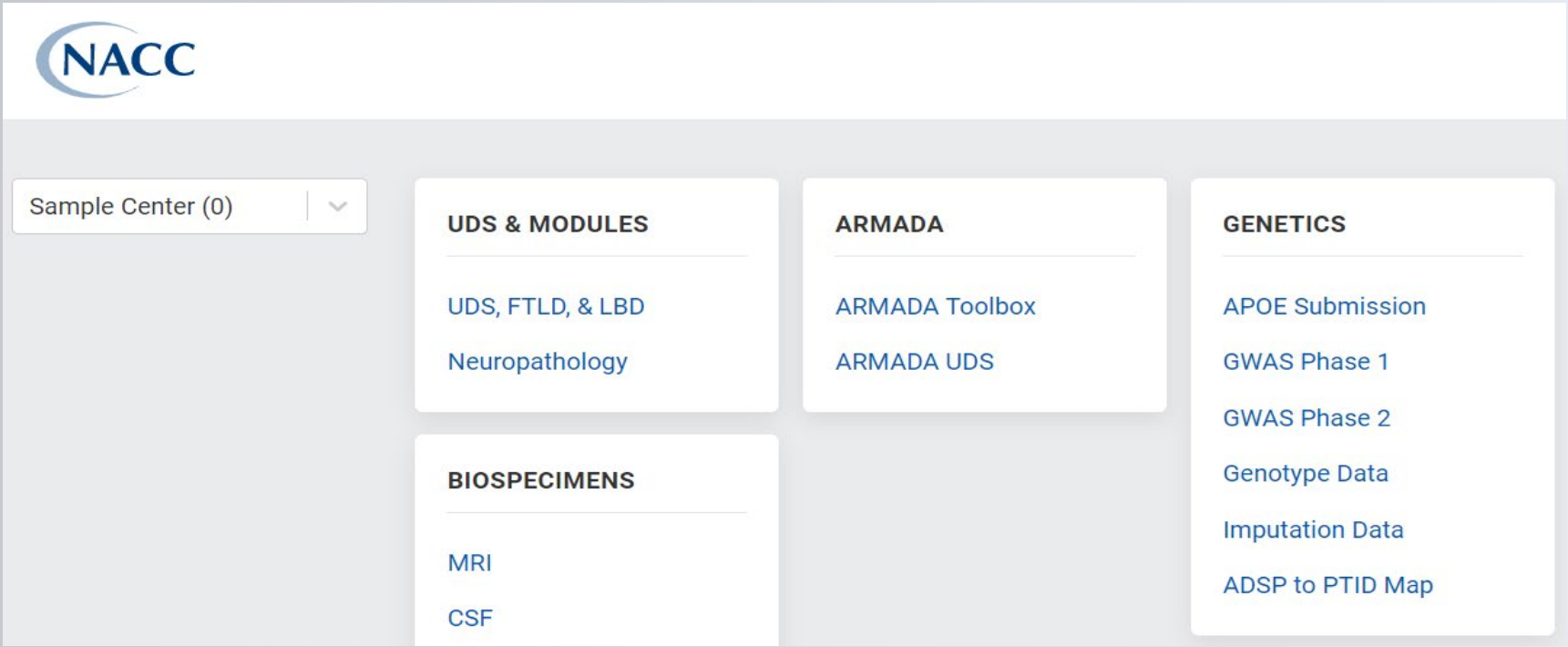
We'd love to hear your feedback during this time!
nacchelp@uw.edu

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

A simple, accessible interface

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

All of your tools in one place



NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

Improvements to data access: Leaf!

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

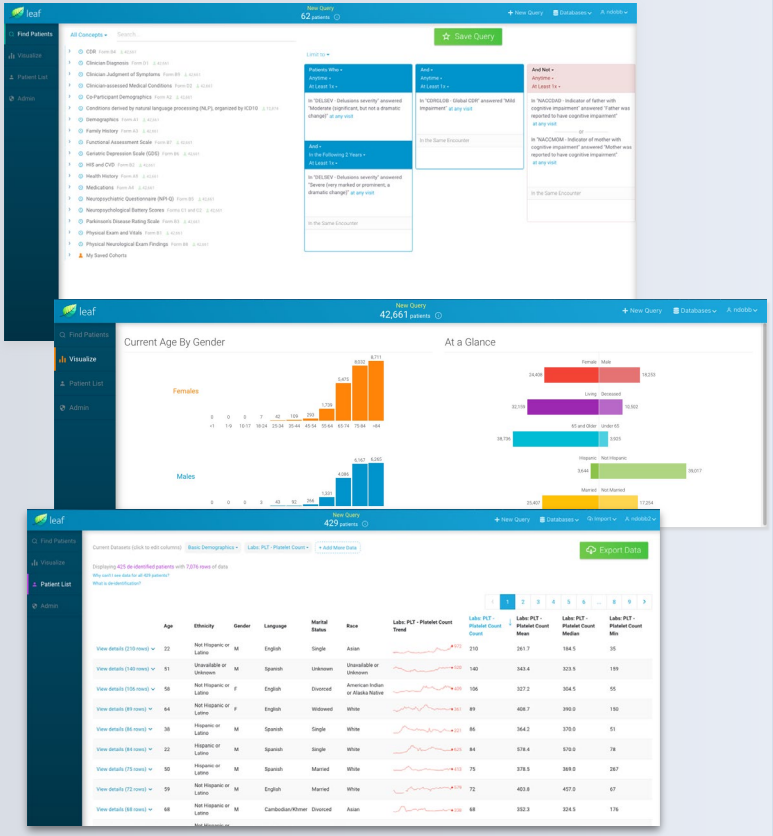
Connections with NCRAD, NIAGADS, and SCAN data will be possible with shared study IDs.

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

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

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



NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

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...

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu

Questions and answers

Please submit any questions or comments in the Q&A.

Thanks for coming!

NACC
National Alzheimer's Coordinating Center
www.alz.washington.edu