

REDCap Collaborative UDS 3.0

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Outline

- What is available
- Who built it
- How was it built

Available Resources

- REDCap data dictionary for UDS 3.0
A1-A5, B1-B9, C2, D1, D2, M1
- Documentation of standards used
- Implementation notes
- Neuropathology forms – built by KU ADC
- Data Quality logic – built by Emory

Available Resources (more)

- FTLD Module – built by Arizona ADC
- LBD Module – built by Columbia ADCC

Possible Resources

- UDS 3.0 Spanish REDCap forms are being built by KU and UFl ADCs. It will take some work to make these shareable. Stay tuned ...
- New forms, Z1X and CLS, have not been created yet.

Sample of data dictionary (csv)

	A	B	C	D	E	F	
1	Variable / Field	Form Name	Section Header	Field Type	Field Label	Choices, C Field	
2	ptid	header		text	ADC Subject ID		
3	formver	header		dropdown	Form Version Num	3, 3 3.1, B5 v:	
4	adcid	header		dropdown	Center ID	2, Boston Univ	
5	visitmo	header		dropdown	Form date - month	1, 1 2, 2 3, 3	
6	visitday	header		dropdown	Form date - day	1, 1 2, 2 3, 3	
7	visityr	header		text	Form date - year		
8	visitnum	header		text	ADC Visit #		
9	initials	header		text	Examiner's initials (xxx)		
10	instructions_a1	ivp_a1	<center>NACC	descriptive	INSTRUCTIONS:		

or point & click Online Designer

Bells & Whistles

Links to important URLs
-online drug lookup
-coding guidebook

If a medication is not listed above, specify the drug or brand name and determine its NACC website at [NACC online Drug Lookup](#).

Type a drug ID as given in the look up table.



d,r,s,or n and 5 numbers

Type the name of the drug -



name of drug

Piping to help with accurate data entry



must provide value

Display from previous visits:
Age when fluctuating cognition began
Initial Visit: 81
Follow-Up: 777 = Age of onset provided at previous UDS visit, _____
Telephone: _____, _____

4g1. If yes, at what age did the fluctuating cognition begin?

(The clinician must use his/her best judgment to estimate an age of onset.)

* must provide value


 (15-110; 777 = provided at previous visit)

Alerts to help with accurate data entry

1f. TOTAL RAW SCORE - UNCORRECTED (Not corrected for education or visual/hearing impairment) *(Enter 88 if any of the following MoCA items were not administered: 1g-1l, 1n-1t, 1w-1bb)*



(0-30, 88)

Warning - 88 should be entered above.

At least one of the following was not administered: 1g-1l, 1n-1t, 1w-1bb.

1g. Visuospatial/executive -- Trails



(0-1, 95-98)

1h. Visuospatial/executive -- Cube



(0-1, 95-98)

A4 Medications - dropdown

This list includes commonly reported medications that may be purchased over the counter (but that may also be prescription).

Is the subject currently taking any medications? 0 No (END FORM HERE) 1 Yes
* must provide value

reset

Select a medication	<input type="text"/>
Select a 2nd medication	<input type="text"/>
Select a 3rd medication	<input type="text"/>
Select a 4th medication	<input type="text"/>
Select a 5th medication	<input type="text"/>
If a medication is not listed above, specify the drug or brand name NACC website at NACC online Drug Lookup	<input type="text"/>
Type a drug ID as given in the look up table.	<input type="text"/>
Type the name of the drug -	<input type="text"/>
Type a 2nd drug ID	<input type="text"/>
Type the name of the drug -	<input type="text"/>
Type a 3rd drug ID	<input type="text"/>

- acetaminophen (Anacin, Tempra, Tylenol)
- acetaminophen - HYDROcodone (Vicodin)
- Adalat
- Advair
- Advil
- Alavert
- albuterol (Proventil, Ventolin, Volmax)
- alendronate (Fosamax)
- Aleve
- Allegra
- allopurinol (Aloprim, Lopurin, Zyloprim)
- Aloprim

A4 explanation

	A
1	Numeric Order
2	100004, atenolol (Senormin, Tenormin)
3	200004, Senormin
4	300004, Tenormin
5	100013, enalapril (Vasotec)
6	200013, Vasotec
7	100015, ibuprofen (Advil, Motrin, Nuprin)
8	200015, Advil
9	300015, Motrin
10	400015, Nuprin

Who

I wish to acknowledge all those that gave their time to design, build and test the Collaborative UDS 3.0 REDCap forms:

University of Wisconsin – Madison
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Tom Mish M.S., Peggy Gulan-Parker B.A., Karen Lazar, Norca Dowling

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Who - continued

Emory University

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University of Kansas Medical Center

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M. Scot Fague, Sade Agboola M.P.H.

How

- Followed NACC protocol
- Standardized naming conventions
forms: ivp_d1, fvp_d1, tvp_d1
field names: sex, fu_sex, tele_sex
- Proofreading
- Testing on different REDCap versions

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


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Sample Event Grid











Event Grid

The grid below displays the form-by-form progress of data entered into the project for one particular ADC Subject ID for all defined events. You may click on the colored buttons to access that form for that event. If you wish, you may modify the events below by navigating to the [Define My Events](#) page.

Legend for status icons:

-  Incomplete  Incomplete (no data saved) 
-  Unverified
-  Complete

ADC Subject ID sHunt1









Data Collection Instrument	initial_visit (1)	follow_up_1 (2)	follow_up_2 (3)	telephone_1 (4)	telephone_2 (5)	milestone_1 (6)	milestone_2 (7)
Header							
Ivp A1							
Ivp A2							
Ivp A3							
Ivp A4							
Ivp A5							
Ivp B1							
Ivp B4							
Ivp B5							
Ivp B6							

ADC Subject ID sHunt1

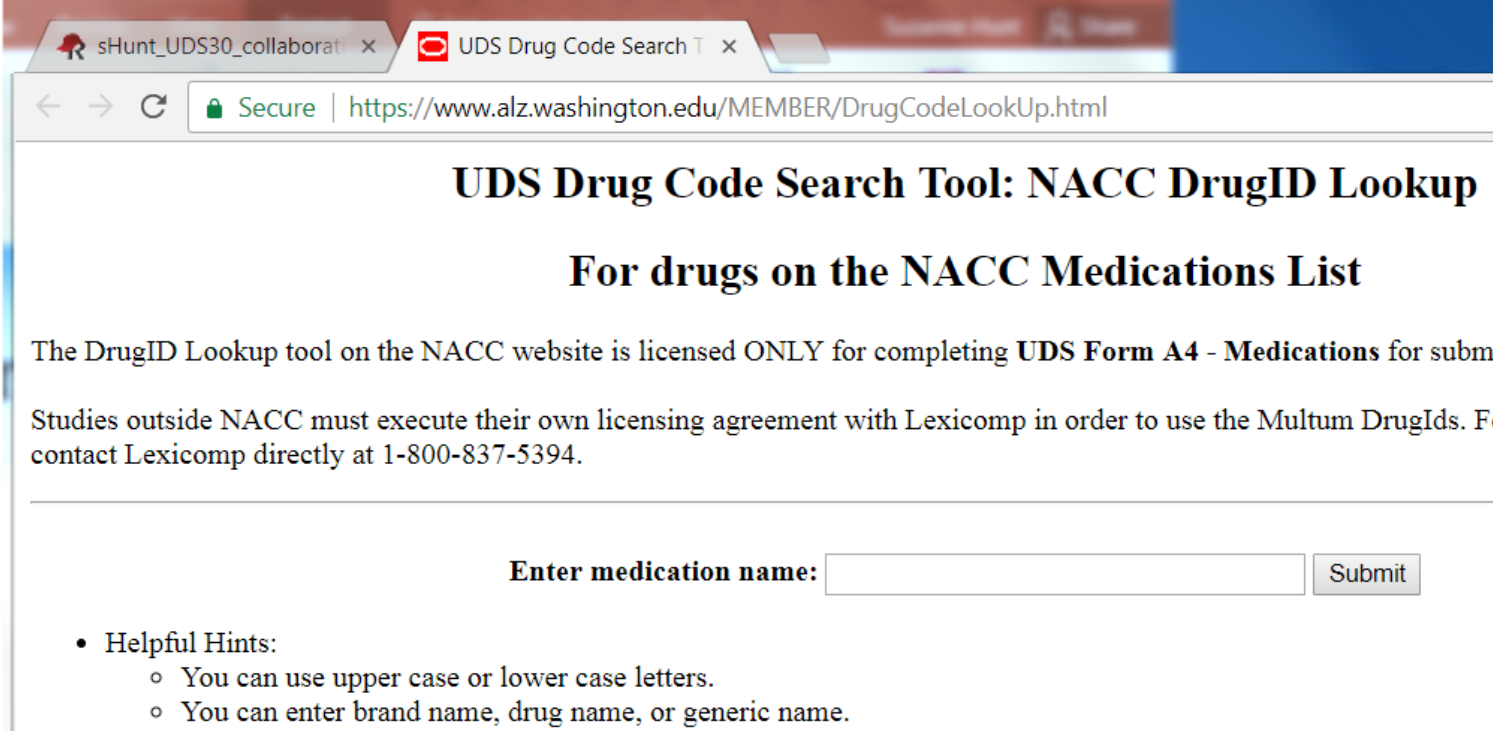
Data Collection Instrument	initial_visit (1)	follow_up_1 (2)	follow_up_2 (2)	telephone_1 (4)	telephone_2 (5)	milestone_1 (6)	milestone_2 (7)
Header	●						
Ivp A1	●						
Ivp A2	●						
Ivp A3	●						
Ivp A4	●						
Ivp A5	●						
Ivp B1	●						
Ivp B4	●						
Ivp B5	●						
Ivp B6	●						
Ivp B7	●						
Ivp B8	●						
Ivp B9	●						
Ivp C2	●						
Ivp D1	●						
Ivp D2	●						
Ivp Z1	●						
Fvp A1		●	●				
Fvp A2		●	●				
Fvp A3		●	●				
Fvp A4		●	●				
Fvp B1		●	●				
Fvp B4		●	●				
Fvp B5		●	●				
Fvp B6		●	●				
Fvp B7		●	●				
Fvp B8		●	●				
Fvp B9		●	●				
Fvp C1		●	●				
Fvp C2		●	●				
Fvp D1		●	●				
Fvp D2		●	●				
Fvp Z1		●	●				
Tvp T1				●	●		
Tvp A1				●	●		
Tvp A2				●	●		
Tvp A3				●	●		
Tvp A4				●	●		
Tvp B4				●	●		
Tvp B5				●	●		
Tvp B7				●	●		
Tvp B9				●	●		
Tvp D1				●	●		
Tvp D2				●	●		
Tvp Z1				●	●		
M1				●	●	●	●

Complete Event Grid

Example of a matrix layout

In the past four weeks, did the subject have difficulty or need help with:							
		8 Not applicable (e.g., never did)	0 Normal	1 Has difficulty, but does by self	2 Requires assistance	3 Dependent	9 Unknown
1. Writing checks, paying bills, or balancing a checkbook <small>* must provide value</small>	 	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Assembling tax records, business affairs, or other papers <small>* must provide value</small>	 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Shopping alone for clothes, household necessities, or groceries <small>* must provide value</small>	 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Playing a game of skill such as bridge or chess, working on a hobby <small>* must provide value</small>	 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

online drug lookup



The screenshot shows a web browser window with two tabs. The active tab is titled "UDS Drug Code Search T" and the address bar shows the URL "https://www.alz.washington.edu/MEMBER/DrugCodeLookUp.html". The page content includes a title "UDS Drug Code Search Tool: NACC DrugID Lookup" and a subtitle "For drugs on the NACC Medications List". Below this, there is a paragraph of text explaining the tool's licensing. At the bottom, there is a form with a text input field labeled "Enter medication name:" and a "Submit" button. A "Helpful Hints" section follows, listing two points: "You can use upper case or lower case letters." and "You can enter brand name, drug name, or generic name."

UDS Drug Code Search Tool: NACC DrugID Lookup

For drugs on the NACC Medications List

The DrugID Lookup tool on the NACC website is licensed **ONLY** for completing **UDS Form A4 - Medications** for submission.

Studies outside NACC must execute their own licensing agreement with Lexicomp in order to use the Multum DrugIDs. For more information, contact Lexicomp directly at 1-800-837-5394.

Enter medication name:

- Helpful Hints:
 - You can use upper case or lower case letters.
 - You can enter brand name, drug name, or generic name.

Family Hx - diagnoses

**APPENDIX 1: PRIMARY DIAGNOSIS CODES

040	Mild cognitive impairment (MCI), not otherwise specified
041	MCI — single domain amnesic
042	MCI — multiple domain with amnesia
043	MCI — single domain nonamnesic
044	MCI — multiple domain nonamnesic
045	Impaired, but not MCI
050	Alzheimer's disease dementia
070	Dementia with Lewy bodies
090	Major depressive disorder, moderate to severe

***APPENDIX 2: METHOD OF EVALUATION

1. Autopsy

If the autopsy was performed at an outside institution, **you must have the report** to code as diagnosis by autopsy.

2. Examination

The subject must have been examined in person at your ADC/ institution or by genetic studies staff associated with your ADC institution to code as diagnosis by examination. Medical records may or may not have been used when assigning diagnosis.