

# *Uniform Data System (UDS) Management*

Columbia ADRC

Data Management and Statistics  
Core

Howard Andrews, PhD

Nicole Schupf, PhD

Ming Tang, PhD

David Merle

Greg Neils

Bianca Williams

100101101010010**DATA**10000011**COORDINATING**01110101**CENTER**10100010001010

# Overview

## ▶ Data Collection

- Collect UDS data for baseline, follow-up and phone interviews on standard NACC/UDS paper forms
- Collect Columbia-specific, non-UDS data on supplemental paper forms at each baseline and follow-up evaluation

## ▶ Data Entry

- Enter UDS data into a dedicated local database
- Enter Columbia-specific data into a separate local database

## ▶ Coordination: master interface synchronizes data entry into the two databases

## ▶ NACC Submission: programmed extraction/submission

## ▶ Reports/SPSS files: nightly updates for clinical core and investigators

100101101010010**DATA**10000011**COORDINATING**01110101**CENTER**10100010001010

# Data Flow

- ▶ Ongoing data collection by Clinical Core
- ▶ Ongoing submission of paper packets to Data Core
  - Data are entered and submitted to NACC as received
  - NACC error report generated after each submission
  - Errors are resolved, resubmitted as needed
- ▶ To avoid end-of-month and 'eve-of-freeze' pileup: no new packets are accepted at Data Center within 5 working days of a NACC deadline

# Database History

- ▶ Columbia ADRC and database established 1989
- ▶ Data collected continuously for 19 years, to present
- ▶ Total Columbia ADRC cases: 5,675 (including UDS cases)
- ▶ NACC/UDS database established at Columbia 9/1/2005
- ▶ Total Columbia NACC/UDS cases: 842
  - 814 in Current NACC/UDS database as of 9/01/2008



Find a Subject

11512

(or Create a New Subject)

Packet

11512

Form Version

1.1

PTID	Visit Number	NACC Forms	Completed
11470	0	Z1 Form Checklist	REQUIRED Z1
11471	1 10/03/2005	A1 Subject Demographics	REQUIRED A1
11472	2	A2 Informant Demographics	A2
11473	3	A3 Subject Family History	A3
11474	4	A4 Subject Medications	A4
11475	5	A5 Subject Health History	REQUIRED A5
11476	6	B1 Evaluation Form-Physical	B1
11477	7	B2 Eval. Form-Hachinski Ischemic	B2
11478	8	B3 Evaluation Form-UPDRS	B3
11479	9	B4 Global Staging-CDR	REQUIRED B4
11482	10	B5 Behavioral Assessment: NPI-Q	
11483	11	B6 Behavioral Assessment: GDS	
11484	12	B7 Functional Assessment: FAQ	B7
11485	13	B8 Evaluation: Physical/Neuro.	B8
11486	14	B9 Clinic. Judgment of Synptom	REQUIRED B9
11487	15	C1 Neuropsychological Battery	REQUIRED C1
11488	16	D1 Clinic. Diag.-Cognitive Status	REQUIRED D1
11490	17	E1 Imaging/Labs	REQUIRED E1
11491	18	K1 Milestones	
11492	19		
11493	20		
11494		ADRC Forms	
11495		PTRACK	
11496		BFORM	
11497		BFORM2	
11498		BRAIN	
11499		CCD	
11500		CCDALT	
11501		CPFORM	
11502		CONTACT	
11503		CTMRI	
11504		DFORM	
11505		FOLLOWUP	
11506		FOLSTEIN	
11508		GPFORM	
11509		HPFORM	
11510		IFORM	
11511		KFORM	
11512		LFORM	
		VFORM	
		NPICBYCSTM	

# ADRC Neuropsych Form (old)

SirForms

ADRC: Alzheimers Disease Research Center

Neuropsychological Testing Summary Sheet - WAIS R

Study Number **B000000035** Follow-up Period **0** Intake  
Form Date **08/10/2000** Examiner **mt**  
Corrective Lenses **1** Yes Available **1** Yes  
Auditory **0** Adequate Hearing Aid  
Handedness **0** Right Test Administered **0** English

WAIS-R FSIQ \_\_\_\_\_  
WAIS-R VIQ \_\_\_\_\_  
WAIS-R PIQ \_\_\_\_\_

	Verbal	raw	sc	ag-sc
Information	_____	_____	_____	_____
Digit Span	_____	_____	_____	_____
Vocabulary	_____	_____	_____	_____
Arithmetic	_____	_____	_____	_____
Comprehension	_____	_____	_____	_____
Similarities	_____	_____	_____	_____
Letter Num Seq	_____	_____	_____	_____

09182000

Command:  
Mode: **FE** Screen: **NEURONEW (1/5)** Cir/Rec: **Old(PW:EX)/Old(PW:EX)**  
Status:

# NACC/UDS Neuropsych C1 Form

C1NEURO Page 1/2 11512 1

Patient ID: 11512    Month: 10 / Day: 3 / Year: 2005    Interviewer's Initials: RXC

Visit Number: 1    Packet: 1    Form ID: C1    Form Version: 1    Center ID: 4

### C1 MMSE and NEUROPSYCHOLOGY BATTERY

1a. The administration of the MMSE: 1 In ADC/Clinic    Specify

1a1. Language of MMSE administration: 1 English

1b1. Time: 5 (0 - 5)

1b2. Place: 4 (0 - 5)

1c. Total MMse score: 26 (0 - 30)

2. Remainder of the battery: 1 In ADC Clinic    Specify

2a. Language of test administration: 1 English

3a. If given in last 3 months: date    Month Day Year

3b. Total score from the previous: 88 N/A (0 - 25)

3c. Total number of story units recalled: 12 (0 - 25)

4a. Total number of correct trial: 7 (0 - 12)

4b. Digit span forward length: 6 (0 - 8)

Navigation icons: [Print] [Quit] [Save] [Print] [Home] [Back] [Forward] [Pg 1] [Home]

# Scientific Information Retrieval (SIR) relational database management

- ▶ Used for both the original Columbia ADRC database and the Columbia NACC/UDS database
- ▶ Case-structured design with visit # as key field prevents duplicate cases, evaluations
- ▶ Structured data entry screens enforce ranges, skip patterns
- ▶ Expanded set of variable attributes includes variable labels, value labels and missing values
- ▶ Generates self-documenting SAS, SPSS files



# Scientific Information Retrieval (SIR) relational database management

- ▶ Used for both the original Columbia ADRC database and the Columbia NACC/UDS database
- ▶ Case-structured design with visit # as key field
  - prevents duplicate cases, evaluations
- ▶ Structured data entry screens enforce ranges, skip patterns
- ▶ Expanded set of variable attributes includes variable labels, value labels and missing values
- ▶ Generates self-documenting SAS, SPSS files

# C1 output from SIR as SPSS file

1 : ptid 76 Visible: 48 of 48 Variables

	ptid	update	interval	pac ket	formid	formver	adcid	visitmo	visitday	visityr	initials	mmseloc	mmselan
1	76	11-Jul-2008	11 I	C1	1	4	11	27	2006	EXC	1	2	
2	76	11-Jul-2008	13 F	C1	2	4	6	2	2008	AMR	1	2	
3	83	18-Aug-2008	11 I	C1	1	4	10	6	2005	RC	1	2	
4	83	18-Aug-2008	13 F	C1	1	4	3	16	2007	PAA	1	2	
5	88	20-Aug-2008	16 I	C1	1	4	2	8	2006	KEH	1	1	
6	88	20-Aug-2008	17 F	C1	1	4	8	22	2007	KSM	1	1	
7	88	20-Aug-2008	18 F	C1	2	4	8	13	2008	LEB	1	1	
8	90	02-May-2008	8 I	C1	1	4	12	19	2005	LXG	1	2	
9	90	02-May-2008	10 F	C1	1	4	8	27	2007	PAA	1	1	
10	117	09-Jul-2008	9 I	C1	1	4	10	2	2006	LSH	1	2	
11	159	27-Sep-2007	11 I	C1	1	4	2	21	2007	KSM	1	1	
12	186	04-Apr-2008	8 I	C1	2	4	3	20	2008	PAA	1	1	
13	260	30-Nov-2007	6 I	C1	1	4	9	26	2005	SXR	1	1	
14	260	30-Nov-2007	9 F	C1	1	4	10	22	2007	PAA	1	1	
15	319	24-Aug-2007	13 I	C1	1	4	9	26	2005	LXG	1	1	
16	330	30-Jun-2008	8 I	C1	1	4	11	22	2005	KXS	1	1	
17	330	30-Jun-2008	9 F	C1	1	4	4	19	2007	KLB	1	1	
18	379	18-Sep-2008	13 I	C1	2	4	8	24	2008	LEB	1	1	

Data View Variable View SPSS Processor is ready

# C1 SPSS file: var & value labels

\*c1 neuro.sav [DataSet1] - SPSS Data Editor

File Edit View Data Transform Analyze Graphs Utilities Add-ons Window Help

1 : ptid 76 Visible: 48 of 48 Variables

	ptid	update	interval	pac ket	formid	formver	addc	visitmo	visitday	visityr	initials	mmseloc	mmselan
1	76	11-Jul-2008	11	I	C1	1	4	11	27	2006	EXC	In ADC/Clinic	Spanish
2	76	11-Jul-2008	13	F	C1	2	4	6	2	2008	AMR	In ADC/Clinic	Spanish
3	83	18-Aug-2008	11	I	C1	1	4	10	6	2005	RC	In ADC/Clinic	Spanish
4	83	18-Aug-2008	13	F	C1	1	4	3	16	2007	PAA	In ADC/Clinic	Spanish
5	88	20-Aug-2008	16	I	C1	1	4	2	8	2006	KEH	In ADC/Clinic	English
6	88	20-Aug-2008	17	F	C1	1	4	8	22	2007	KSM	In ADC/Clinic	English
7	88	20-Aug-2008	18	F	C1	2	4	8	13	2008	LEB	In ADC/Clinic	English
8	90	02-May-2008	8	I	C1	1	4	12	19	2005	LXG	In ADC/Clinic	Spanish
9	90	02-May-2008	10	F	C1	1	4	8	27	2007	PAA	In ADC/Clinic	English
10	117	09-Jul-2008	9	I	C1	1	4	10	2	2006	LSH	In ADC/Clinic	Spanish
11	159	27-Sep-2007	11	I	C1	1	4	2	21	2007	KSM	In ADC/Clinic	English
12	186	04-Apr-2008	8	I	C1	2	4	3	20	2008	PAA	In ADC/Clinic	English
13	260	30-Nov-2007	6	I	C1	1	4	9	26	2005	SXR	In ADC/Clinic	English
14	260	30-Nov-2007	9	F	C1	1	4	10	22	2007	PAA	In ADC/Clinic	English
15	319	24-Aug-2007	13	I	C1	1	4	9	26	2005	LXG	In ADC/Clinic	English
16	330	30-Jun-2008	8	I	C1	1	4	11	22	2005	KXS	In ADC/Clinic	English
17	330	30-Jun-2008	9	F	C1	1	4	4	19	2007	KLB	In ADC/Clinic	English

Data View Variable View

SPSS Processor is ready

# SIR/SPSS variable attributes

The screenshot shows the 'Variables' dialog box in SPSS. The 'Variable Information' section is active, displaying details for the selected variable 'mmseloc'. The variable list on the left includes 'visitday', 'visityr', 'initials', 'mmseloc', 'mmselan', 'mmselanx', 'mmseorda', 'mmseorlo', 'pentagon', 'mmse', 'npsycloc', 'npsylan', 'npsylanx', 'logimo', 'logiday', 'logiyr', and 'logiprev'. The 'mmseloc' variable is highlighted in blue.

Variable Information:

mmseloc  
Label: 1a. The administration of the MMSE  
Type: F8  
Missing Values: none  
Measurement Level: Scale

Value Labels:  
1 In ADC/Clinic  
2 In home  
3 In person other

Buttons: Go To, Paste, Close, Help

# Suggestion for NACC:

Develop Enhanced Download Files to Facilitate Data Use and Minimize User Error

- ▶ Include variable labels in SAS file downloads of NACC/UDS files
- ▶ Make SAS FORMAT files available with value labels for each NACC/UDS form
- ▶ Offer SPSS file download option, with integrated variable *and* value labeling

# Thank You, Duane, Janene and Woody and the NACC team!

Duane Beekly

Janene Hubbard

Woody Dietrich

And a special thanks to

Larry Honig, MD, Columbia ADRC Clinical Core Director and  
honorary Data Core member