



Electronic Data Capture and UDS V4

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EDC Workgroup Update – Data Core Workshop – October 18, 2023

2023 Fall ADRC Meeting

Support and Resources to Reduce ADRC Staff Burden

REDCap Specific

- A complete UDS V4 Project – XML and CSV
- Individual instruments – Zip files
- REDCap logic and QA/QC metadata rolled in
- Implemented as surveys

For all Electronic Data Capture

- Tabular data and metadata dictionaries– CSV
- Coding element guide– CSV
- QA/QC validation rules – CSV and JSON
- UDS V3 to UDS V4 Variable Crosswalk

A1a – A Working Example



A1a Overview – History of Social Determinants

INITIAL VISIT PACKET UNIFORM DATA SET (UDS) VERSION 4.0



Form A1a: Social Determinants of Health

ADDR: _____ PTID: _____ Form date: ___/___/___ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> English <input type="checkbox"/> Spanish	Mode: <input type="checkbox"/> In-person <input type="checkbox"/> Remote (reason): <input type="checkbox"/> Telephone <input type="checkbox"/> Video	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound or nursing home 4=Refused in-person visit 5=Other
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INSTRUCTIONS: The following questions are designed to assess your current and past life experiences. These questions will help us understand how certain experiences affect your health. You do not have to answer any question that makes you feel uncomfortable.

Section 1 – Transportation

1. Do you or someone in your household currently own a car?	<input type="radio"/> No <input type="radio"/> Yes <input type="radio"/> Prefer not to answer
2. Do you have consistent access to transportation?	<input type="radio"/> No <input type="radio"/> Yes <input type="radio"/> Prefer not to answer
3. In the past 30 days, how often were you not able to leave the house when you wanted to because of a problem with transportation?	<input type="radio"/> 1 Often <input type="radio"/> 2 Sometimes <input type="radio"/> 3 Never <input type="radio"/> 8 Prefer not to answer
4. In the past 30 days, how often did you worry about whether or not you would be able to get somewhere because of a problem with transportation?	<input type="radio"/> 1 Often <input type="radio"/> 2 Sometimes <input type="radio"/> 3 Never <input type="radio"/> 8 Prefer not to answer
5. In the past 30 days, how often did it take you longer to get somewhere than it would have taken you if you had different transportation?	<input type="radio"/> 1 Often <input type="radio"/> 2 Sometimes <input type="radio"/> 3 Never <input type="radio"/> 8 Prefer not to answer
6. In the past 30 days, how often has a lack of transportation kept you from medical appointments or from doing things needed for daily living?	<input type="radio"/> 1 Often <input type="radio"/> 2 Sometimes <input type="radio"/> 3 Never <input type="radio"/> 8 Prefer not to answer

Section 2 – Financial security

7. Which of these income groups represents your household income for the past year? Include income from all sources such as wages, salaries, social security or retirement benefits, help from relatives, rent from property, and so forth. <i>This information will be kept confidential and will not be shared in a way that identifies you with any other person, organization or government entity.</i>	<input type="radio"/> 1 \$0 - \$14,999 <input type="radio"/> 2 \$15,000 - \$29,999 <input type="radio"/> 3 \$30,000 - \$74,999 <input type="radio"/> 4 \$75,000 and over <input type="radio"/> 8 Prefer not to answer <input type="radio"/> 9 Don't know
8. How satisfied are you with your current personal financial condition?	<input type="radio"/> 1 Completely satisfied <input type="radio"/> 2 Satisfied <input type="radio"/> 3 Somewhat satisfied <input type="radio"/> 4 Not very satisfied <input type="radio"/> 5 Not at all satisfied <input type="radio"/> 8 Prefer not to answer
9. How difficult is it for you to meet monthly payments on your bills?	<input type="radio"/> 1 Not at all <input type="radio"/> 2 Slightly <input type="radio"/> 3 Moderately <input type="radio"/> 4 Very <input type="radio"/> 5 Extremely <input type="radio"/> 8 Prefer not to answer

NACC Uniform Data Set (UDS) Version 4.0 - INITIAL VISIT PACKET

FORM A1a: SOCIAL DETERMINANTS OF HEALTH

INSTRUCTIONS: The following questions are designed to assess your current and past life experiences. These questions will help us understand how certain experiences affect your health. You do not have to answer any question that makes you feel uncomfortable.

Section 1 – Transportation

1. Do you or someone in your household currently own a car?	<input type="radio"/> No <input type="radio"/> Yes <input type="radio"/> Prefer not to answer	reset
2. Do you have consistent access to transportation?	<input type="radio"/> No <input type="radio"/> Yes <input type="radio"/> Prefer not to answer	reset
3. In the past 30 days, how often were you not able to leave the house when you wanted to because of a problem with transportation?	<input type="radio"/> Often <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> Prefer not to answer	reset
4. In the past 30 days, how often did you worry about whether or not you would be able to get somewhere because of a problem with transportation?	<input type="radio"/> Often <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> Prefer not to answer	reset
5. In the past 30 days, how often did it take you longer to get somewhere than it would have taken you if you had different transportation?	<input type="radio"/> Often <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> Prefer not to answer	reset
6. In the past 30 days, how often has a lack of transportation kept you from medical appointments or from doing things needed for daily living?	<input type="radio"/> Often <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> Prefer not to answer	reset

Section 2 – Financial security

7. Which of these income groups represents your household income for the past year? Include income from all sources such as wages, salaries, social security or retirement benefits, help from relatives, rent from property, and so forth. <i>This information will be kept confidential and will not be shared in a way that identifies you with any other person, organization or government entity.</i>	<input type="radio"/> \$0 - \$14,999 <input type="radio"/> \$15,000 - \$29,999 <input type="radio"/> \$30,000 - \$74,999 <input type="radio"/> \$75,000 and over <input type="radio"/> Prefer not to answer <input type="radio"/> Don't know	reset
8. How satisfied are you with your current personal financial condition?	<input type="radio"/> Completely satisfied <input type="radio"/> Satisfied <input type="radio"/> Somewhat satisfied <input type="radio"/> Not very satisfied <input type="radio"/> Not at all satisfied <input type="radio"/> Prefer not to answer	reset

Initial visit specific form;
40 questions across
5 sections

In REDCap

- IV event specific
- Commonly used ADRC layout and formatting
- Survey format with Tablet-friendly design
- Bundled with logic flow and error validation
- Deployment ready Zip file

A1a – Data Dictionary for all EDC Implementations

Form	Packet	Question	Variable	MISSINGNESS: Is this required to be present if this form is submitted?	CONFORMITY What values ranges or characters are allowed for this field	LABELS What are the associated labels for field conformity
A1a	I	1. Do you or someone in your household currently own a car?	OWNSCAR	Always	0-1, 8	0, No 1, Yes 8 Prefer not to answer
A1a	I	2. Do you have consistent access to transportation?	TRSPACCESS	Always	0-1, 8	0, No 1, Yes 8 Prefer not to answer
A1a	I	3. In the past 30 days, how often were you not able to leave the house when you wanted to because of a problem with transportation?	TRANSPROB	Always	1-3, 8	1, Often 2, Sometimes 3, Never 8, Prefer not to answer
A1a	I	4. In the past 30 days, how often did you worry about whether or not you would be able to get somewhere because of a problem with transportation?	TRANSWORRY	Always	1-3, 8	1, Often 2, Sometimes 3, Never 8, Prefer not to answer
A1a	I	5. In the past 30 days, how often did it take you longer to get somewhere than it would have taken you if you had different transportation?	TRSPLONGER	Always	1-3, 8	1, Often 2, Sometimes 3, Never 8, Prefer not to answer
A1a	I	6. In the past 30 days, how often has a lack of transportation kept you from medical appointments or from doing things needed for daily living?	TRSPMED	Always	1-3, 8	1, Often 2, Sometimes 3, Never 8, Prefer not to answer
A1a	I	7. Which of these income groups represents your household income for the past year? Include income from all sources such as wages, salaries, social security or retirement benefits, help from relatives, rent from property, and so forth.	INCOMEYR	Always	1-4, 8-9	1, \$0 - \$14,999 2, \$15,000 - \$29,999 3, \$30,000 - \$74,999 4, \$75,000 and over 8, Prefer not to answer 9, Don't know
A1a	I	8. How satisfied are you with your current personal financial condition?	FINSATIS	Always	1-5, 8	1, Completely satisfied 2, Satisfied 3, Somewhat satisfied 4, Not very satisfied 5, Not at all satisfied 8, Prefer not to answer

Tabular Data Dictionary in CSV format to promote easy and consistent deployment

A1a – QA/QC Used by NACC’s Upload System

Form	Packet	Variable	Error_alert test name	Short test Description (English)	Full test Description (English)	Test Description Logic	Form(s) compared in test	Variable(s) compared in test	Error or alert?	Can be done in REDCap?	Type of test
A1a	I	OWNSCAR	OWNSCAR must be present	OWNSCAR cannot be blank	Q1. OWNSCAR (Owns a car?) cannot be blank	If OWNSCAR = blank	n/a	n/a	Error	Yes	Missingness
A1a	I	OWNSCAR	OWNSCAR must conform	OWNSCAR must be an integer between 0 and 1	Q1. OWNSCAR (Owns a car?) must be an integer between 0 and 1	If OWNSCAR < 0 or OWNSCAR > 1	n/a	n/a	Error	Yes	Conformity
A1a	I	TRSPACCESS	TRSPACCESS must be present	TRSPACCESS cannot be blank	Q2. TRSPACCESS (Access to transportation?) cannot be blank	If TRSPACCESS = blank	n/a	n/a	Error	Yes	Missingness
A1a	I	TRSPACCESS	TRSPACCESS must conform	TRSPACCESS must be an integer between 1 and 3	Q2. TRSPACCESS (Access to transportation?) must be an integer between 1 and 3	If TRSPACCESS < 1 or TRSPACCESS > 3	n/a	n/a	Error	Yes	Conformity
A1a	I	BILLPAY	Consistency in income across forms	IF BILLPAY = 4 or 5 (very or extremely), and Form A1 INCOME 3 or 4 (have excess income)	IF Q7. BILLPAY (Difficulty with monthly payments?) = 4 or 5 (very or extremely), and Form A1 Q18. INCOME (household income) = 3 or 4 (have excess income)	If BILLPAY in (4,5) and INCOME in (3,4)	A1	BILLPAY, INCOME	Alert	No	Plausibility
A1a	I	BILLPAY	Consistency in income across forms	IF BILLPAY = 1 (not at all), and Form A1 INCOME = 1 (insufficient to meet needs)	IF Q7. BILLPAY (Difficulty with monthly payments?) = 1 (not at all), and Form A1 Q18. INCOME (household income) = 1 (insufficient to meet needs)	If BILLPAY=1 and INCOME=1	A1	BILLPAY, INCOME	Alert	No	Plausibility

Transparent QA/QC rule sets used by NACC during uploads for errors and alerts; available in both CSV and JSON formats