



Update on SDOH Module for UDS4

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Excitement for SDOH during the Fall 2022 Meeting in Chicago



Why are we including SDOH in the UDSv4?

Conditions in the environment where people live, learn, work, & age

- Impact health, including brain health
- Help us understand heterogeneity of cognitive aging
- Shape health behaviors
- Interact with each other to produce health
- Too important to ignore!



UDSv4 - SDOH Development

Process for creating the SDOH Form

Committee of 13 content experts representing 10 ADRCs developed SDOH form over 6 months

NACC disseminated two REDCap surveys to collect feedback on content from all ADRCs

The primary survey reviewing the form content garnered:

- **46** respondents from **31 ADRCs**, **120 comments**

NACC provided a customized report of the comments to the SDOH committee to incorporate ADRC feedback and respond to input

UDSv4 - SDOH Update

Removed SDOH questions from Form A1 to eliminate redundancy and improve efficiency

Incorporated most of those questions on the SDOH Form A1a

New and improved form:

- **~35** questions: Income and financial security, experiences with healthcare, discrimination exposure, transportation access, social connections & environment

Mandatory at first UDSv4 visit (1 time only!)

-Self-administered by persons with CDR = 0, 0.5, 1

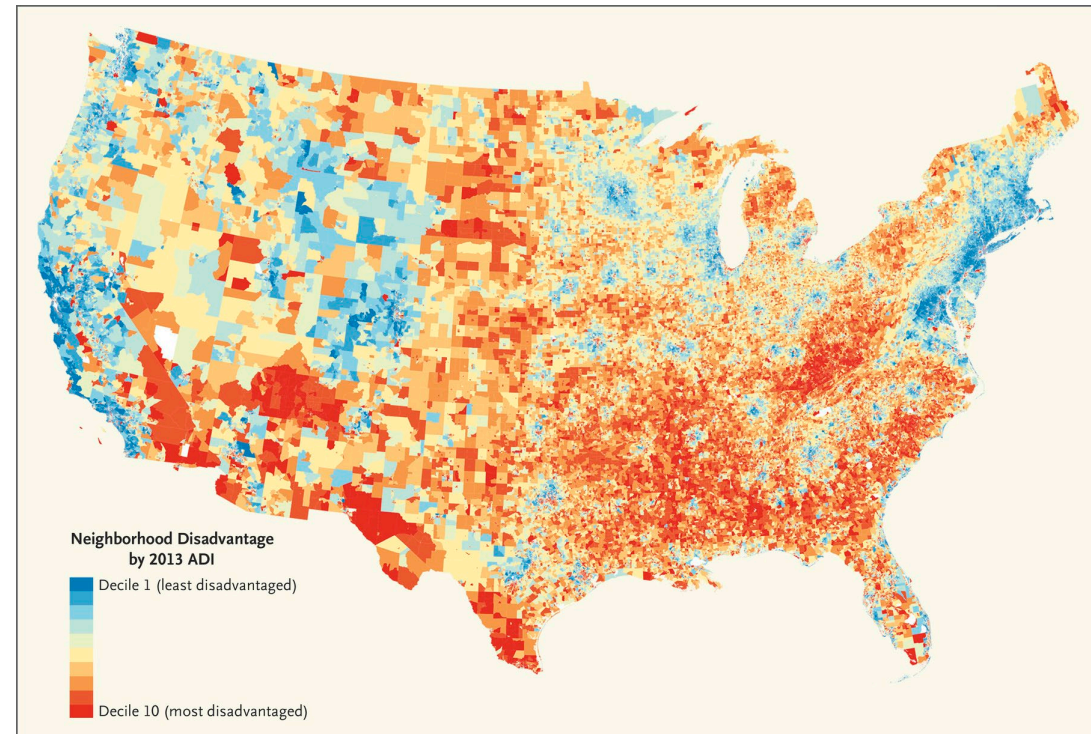
-Preliminary pilot testing demonstrated takes <10 minutes

New UDSv4 Tools to Support Health Equity Research

Other data collection for social determinants of health: Form A1

- **Area Deprivation Index (ADI, Any Kind)** to measure neighborhood disadvantage
- **Occupation** (participant's primary occupation throughout working life)

Mandatory at every UDSv4 visit



<https://www-nejm-org.offcampus.lib.washington.edu/doi/full/10.1056/NEJMp1802313>

UDSv4 - Capturing Gender and Race

New UDSv4 Tools to Support Health Equity Research

Questions focused on gender and race:

- **More inclusive gender and sexual orientation questions (Form A1)**
 - Expanded the gender identity, sex at birth, intersex, and sexual orientation
 - NACC aligned with the NASEM SOGI recommendations to ensure the best representation
- **More flexibility in listing multi-racial identity**
 - Select all that apply instead of limited to three races

Visit the UDSv4 Forms Booth

- Learn more about the SDOH Form A1a
- Review the SOGI and race questions on A1

INITIAL VISIT PACKET UNIFORM DATA SET (UDS) VERSION 4.0



Form A1a: Social Determinants of Health

In-person Remote

ADRC name: _____ Participant ID: _____ Form date: ____ / ____ / ____

Visit #: _____ Examiner's initials: _____ Language: English Spanish

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="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Prefer not to answer
2. Do you have consistent access to transportation?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Prefer not to answer
3. In the past 30 days, how often were you not able to leave the house when you wanted to	<input type="checkbox"/> 1 Often



INITIAL VISIT PACKET UNIFORM DATA SET (UDS) VERSION 4.0

Form A1: Participant Demographics

In-person Remote

ADRC name: _____ Participant ID: _____ Form date: ____ / ____ / ____

Visit #: _____ Examiner's initials: _____ Language: English Spanish

INSTRUCTIONS: This form may be completed by intake interviewer based on ADRC scheduling records, participant interview, medical records, and proxy co-participant report (as needed). This information can be collected by mail-in survey, electronic capture (web-based), phone or video interview, or during the in-person visit to accommodate and lessen participant visit burden. For additional clarification and examples, see the **UDS Coding Guidebook, Form A1**. Check only one box per question unless otherwise specified.

Section 1 — Demographics

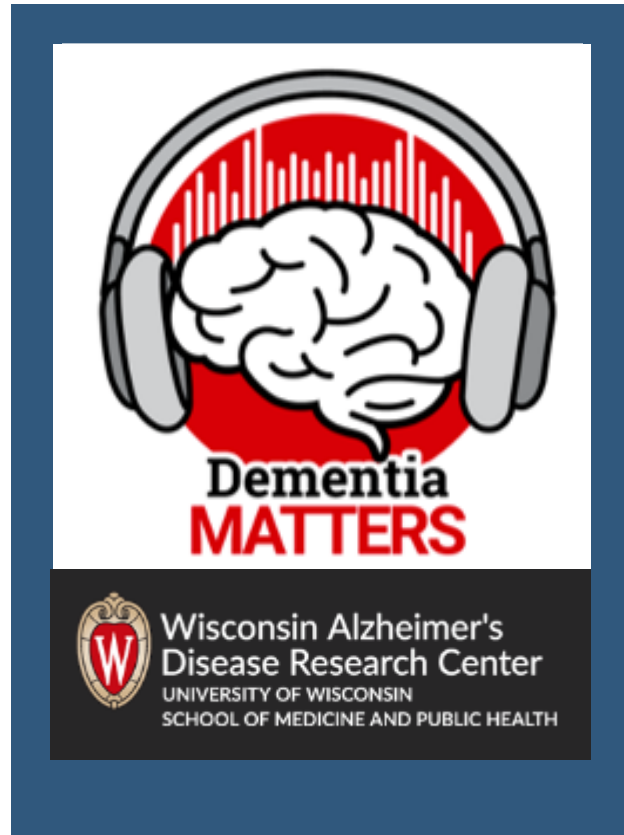
1. What is your month and year of birth (MM / YYYY)?	____ / ____
2. What is your ethnicity and race? (Check all that apply)	2a. <input type="checkbox"/> 1 White 2b. <input type="checkbox"/> 1 Black or African American 2c. <input type="checkbox"/> 1 American Indian or Alaska Native (AIAN) 2d. <input type="checkbox"/> 1 Native Hawaiian or other Pacific Islander 2e. <input type="checkbox"/> 1 Asian 2f. <input type="checkbox"/> 1 Hispanic 2g. <input type="checkbox"/> 1 Other (SPECIFY): _____ 2h. <input type="checkbox"/> 1 Don't know

The next four questions ask about your gender identity, sex assigned at birth, sexual orientation, and intersex status. This information will be used to help us improve health, well-being, and quality of care. By gender identity, we mean the inner sense that you have of yourself as being a man, woman, or a different gender. Gender identity can be different from your sex assigned at birth or your sexual orientation, and it can change over time.

3. Which term(s) best describes your current gender identity? (Check all that apply)	3a. <input type="checkbox"/> 1 Man 3b. <input type="checkbox"/> 1 Woman 3c. <input type="checkbox"/> 1 Transgender man 3d. <input type="checkbox"/> 1 Transgender woman 3e. <input type="checkbox"/> 1 Non-binary/genderqueer 3f. <input type="checkbox"/> 1 Two-Spirit (if you are AIAN) 3g. <input type="checkbox"/> 1 I use a different term (SPECIFY): _____ 3h. <input type="checkbox"/> 1 Don't know 3i. <input type="checkbox"/> 1 Prefer not to answer
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DROPPING TODAY: DEI-Focused Dementia Matters Special Series



Interviewee	Tentative Release Date
Sarah Biber, PhD National Alzheimer's Coordinating Center	May 2nd (Today!)
Lisa Barnes, PhD Rush ADRC	May 30th, 2023
Gina Green-Harris, MBA Wisconsin ADRC	June 13th, 2023
Crystal Glover, PhD Rush ADRC	June 27th, 2023

<https://naccddata.org/nacc-collaborations/dm-pod-info>

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Thank you!

