NCHS and Gender Identity Data Collection

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NCHS

The importance of gender identity

"Only when questions about sexual orientation and gender identity are included in national surveys, such as those conducted by the Department of Health and Human Services, can researchers identify health disparities within or across groups who identify as lesbian, gay, bisexual, or transgender"[1]

[1]Collect Data on Sexual Orientation and Gender Identity in Health Surveys | RAND

Figure 1. Federal Surveys that Collect SOGI Information (2016)

Survey	Sexual Identity	Sexual Attraction	Sexual Behavior	Gender Identity
National Adult Tobacco Survey (NATS)	YES			YES
National Health and Nutrition Examination Survey (NHANES)	YES		YES	
National Health Interview Survey (NHIS)	YES			
National Inmate Survey (NIS)	YES		YES	YES
National Crime Victimization Survey (NCVS)	YES			YES
National Survey of Family Growth (NSFG)	YES	YES	YES	
Youth Risk Behavior Surveillance System (YRBSS)	YES		YES	
National Survey on Drug Use and Health (NSDUH)	YES	YES		
National Survey of Older Americans Act Participants (NSOAAP)	YES			
Behavior Risk Factor Surveillance System (BRFSS)	YES			YES
Population Assessment of Tobacco and Health (PATH)	YES	YES		YES
Health Center Patient Survey (HCPS)	YES			YES

Source: Centers for Disease Control and Prevention's (CDC) Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. (2019, August 15). *Improving Measurement of Sexual Orientation and Gender Identity in the Federal Statistical System* [Video]. YouTube. https://www.youtube.com/embed/WPeqKrAhGO4?cc_load_policy=1

HHS Updates Interoperability Standards to Support the Electronic Exchange of Sexual Orientation, Gender Identity and Social Determinants of Health

The U.S. Department of Health and Human Services' Office of the National Coordinator for Health Information Technology (ONC) today released the United States Core Data for Interoperability version 2 (USCDI v2), a standardized set of health data classes and constituent data elements for nationwide, interoperable health information exchange.

With this new update, health IT stakeholders nationwide will have clearer direction toward the standardized, electronic exchange of social determinants of health (SDOH), sexual orientation, and gender identity (SO/GI) among several other updated data elements. This lays the foundation for the provider community to start systemizing the capture and use of SDOH and SO/GI data in the clinical setting. While encouraged, this update does not require health professionals, such as doctors and nurses, to record this data or individuals to share such data. It does however set a path forward for health IT to build in support for exchanging these data as they become applicable to an individual's care.

NCHS gender identity activities

NCHS Health Equity CORE Goal: By July 2023, using a range of methodologies, NCHS will identify and evaluate various question sets related to health equity, including approaches that most accurately assess gender identity.

> Beginning on January 1, 2022, NCHS will collect information on gender identity among sample adults in the NHIS

> In 2023, NHANES will also add gender identity questions

> First year in NHIS will be experimental, testing various question approaches

SOGI Interoperability Standards: NCHS involved in discussions with others within CDC around approaches to USCDI standards

Cognitive interviewing and question testing

Gender Identity Measure Development

Kristen Miller

Collaborating Center for Question Design and Evaluation Research (CCQDER)

Organization of Discussion

1. **Overview of CCQDER Program**

2. **Gender Identity Question Design**
   - **Features**
   - **Data quality issues**

3. **CCQDER Gender Identity-Related Projects**

Activities

1. Methodological Research Program
   – Study of meaning and question response in relation to data quality
   – Development of design and evaluation methods

2. Questionnaire Design Research Lab
   – Question Development and Testing Projects
   – For NCHS, CDC, HHS, and others

3. Question Evaluation Applications
   – Q-Notes: Data entry and analysis tool for cognitive interviewing studies
   – Q-Video: Cognitive Interview/Data Storage
   – Q-Bank: Online library of question evaluation findings

NCHS Evaluation Methods

- Cognitive Interviewing

- Experimental Design and Embedded Probing with the Research and Development Survey (RANDS)

- Ethnographic Methods: In-depth interviewing, Free Lists, Card Sorts

- Focus Groups

- Interviewer Debriefing

- Usability Testing

WILEY SERIES IN SURVEY METHODOLOGY

Question Evaluation Methods

Contributing to the Science of Data Quality

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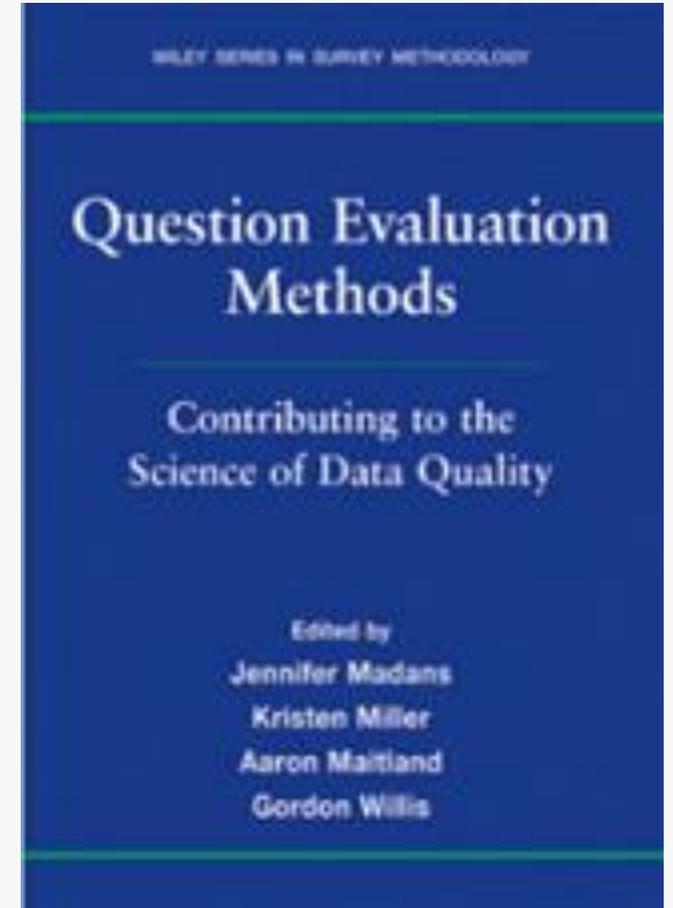
Cognitive Interviewing at NCHS

- First cognitive laboratory, 1980s
- Scientific study
  – Systematic analysis
  – Data quality
  – Maintenance of data
  – Transparency
  – Documentation
- Cognitive interviewing as validation
- Ensuring Comparability and Measurement Equity (AAPOR Webinar)
- Research and Development Survey (RANDS): Mixed Method
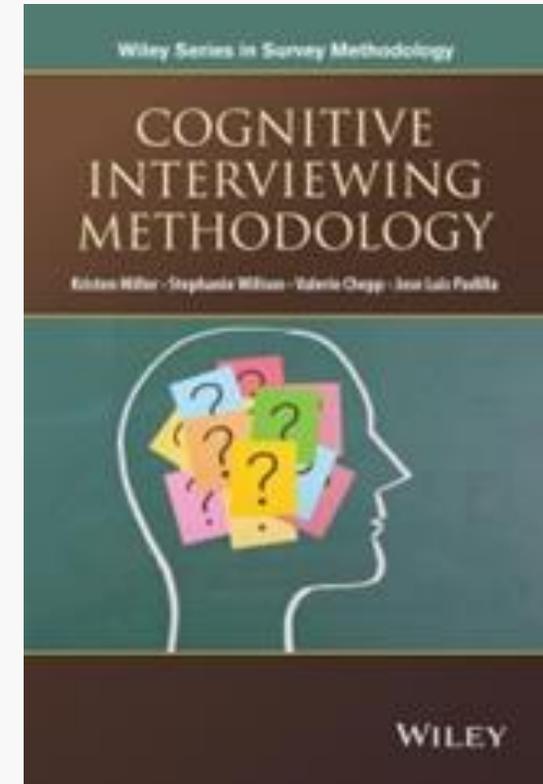
Analytic Goals of Cognitive Interviewing Studies

- Cognitive Testing: Conducting interviews to "look for problems."

- Construct Validity Study: Identifying the constructs captured by individual questions by identifying the specific phenomena that account for respondents' answers.

- Comparability Study: Determining whether constructs are consistently captured across salient respondent groups.

Research and Development Survey (RANDS)

- Mixed Method:
  - Cognitive Interviewing + Web Panel Survey Data
  - How much error? In what demographic groups?

- Embedded Construct and Error Probes
  - 'When answering the last question, were you thinking about X, Y or Z?'

- Experimental Design:
  - To test different versions of questions

Gender Identity Measurement

External Collaborations

- CDC coordination of data collection systems

- NCVHS Workgroup on SOGI & SDOH Data (ASPE)

- NASEM Workgroup

- OMB, Domestic Policy Council, State Dept

- FCSM SOGI Workgroup

- Interagency Response Error Group

- Community Groups

Gender Identity, Census PULSE, July 2021

SEX: What sex were you assigned at birth, on your original birth certificate?
- ❑ Male
- ❑ Female
- ❑ Refused
- ❑ Don't know

GENDER: How do you describe yourself?
- ❑ Male
- ❑ Female
- ❑ Transgender
- ❑ None of these

CONFIRM: Just to confirm, you were assigned {FILL} at birth and now you describe yourself as {FILL}. Is that correct?
- ❑ Yes
- ❑ No
- ❑ Refused
- ❑ Don't know

Gender Identity, Census PULSE, Week 34, 2021

Total Sample (unweighted)	**64,562**
Cis-gender (M/M; F/F)	96.75%
Gender minority (M/F; F/M)	.2%
Selected "transgender"	.3%
Selected "none of these"	1.16%
Missing	1.57%

Percentages are weighted.

- Very small transgender population; no room for error

- Question design goal: Get everyone in the right bucket

- False positives = bad for understanding disparities

- False negatives = bad for population estimates

- For this data:
  - Confirmation question false positives = 22% (corrected)
  - Cases not corrected = ?
  - "None of these" false positive/negative = ?

Question Design Goals

- Capture complexity and range of sex and gender identities
  - Asking both SAB and Gender
  - Mark all that apply

- Reduce false positive and false negative error
  - Why is error occurring? What is the reason?
  - Privacy = false negative; Misunderstanding = false positive

- Research activities: To understand the various question design features,
  - Response categories
  - Order
  - Wording and phrase choices
  - …. and how they relate to performance (in allowing for complexity and generating error)

2021 NCHS Gender Identity Question Design and Evaluation Studies

Cognitive interviewing   NIOSH/YRBSS, ACES, NAMCS, NSVIS, NSFG

1. Constructs captured: Sex and Gender questions
2. Changing terms/understanding differences between gender minorities/non-minorities
3. Adults vs. Teens: Different interpretive processes
4. Proxy: What contexts are appropriate?

Usability testing

- Gender X marker passport application form (for US State Dept) – 100 in-depth interviews conducted

Split sample with embedded probes

- RANDS with NISVS Questionnaire
- RANDS with NSFG Questionnaire

RANDS Split Sample with Embedded Probes
(Experiment: Order and Gender/Sex Categories)

1. What sex were you assigned at birth, on your original birth certificate?

 Male

 Female

 [Don't know]

2a. How do you describe yourself? Select all that apply.
 Male
 Female
 Transgender
 Something else: _____

2b. Do you describe yourself as a man, a woman, or in some other way? Select all that apply.
 Man
 Woman
 In some other way: _____ [text box]

3. Just to confirm, you were assigned {FILL} at birth and describe yourself as {FILL}. Is that correct?
 Yes

 No

4. [PROBE]. You didn't answer "what sex were you assigned at birth, on your original birth certificate?" Can you tell us why? Select all that apply.

 I don't understand what the question is asking

 I've never seen my birth certificate

 I don't want to answer this question
 This was a mistake, I meant to say: _____ [text box]
 Other, specify: _____ [text box]

QBank: wwwn.cdc.gov/qbank

Miller, K., Willson, S., Ryan, V. (2021). *An Initial Cognitive Evaluation of a 2-Step Gender Identity Measure.* National Center for Health Statistics - CCQDER. Hyattsville, MD https://wwwn.cdc.gov/QBank/Report.

For questions, email Kristen Miller: ksmiller@cdc.gov
https://www.cdc.gov/nchs/ccqder
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