Adding Sexual Orientation and Gender Identity Measures to the Medicare Current Beneficiary Survey (MCBS)

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Medicare Current Beneficiary Survey (CMS)

- Serves as the leading source of information on the Medicare program and its impact on beneficiaries.
- Conducted by the Centers for Medicare & Medicaid Services (CMS) through a contract with NORC at the University of Chicago.
- Nationally representative, continuous, longitudinal, multipurpose survey of the Medicare population.
- Primary topics include health care utilization and cost, access and barriers to care, and physical, emotional, and financial wellbeing.

MCBS Sociodemographic Items



- Prior to 2023, the MCBS did not capture beneficiary sexual orientation or gender identity (SOGI).
 - Prior to 2022, sex was preloaded from administrative data and confirmed by the interviewer.
 - In 2022, beneficiaries were asked if they are male or female in the Introductory Questionnaire section at the beginning of the interview.

Closing Data Gaps on the MCBS



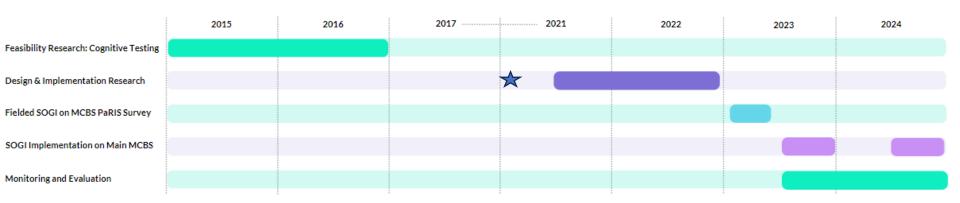
- CMS and NORC have conducted research spanning 2015-2023 to inform the implementation of SOGI items on the MCBS.
 - Early version of items was fielded in Winter 2023 to MCBS beneficiaries as part of an international research collaboration.
 - SOGI items will be added to the main MCBS starting in Fall 2023.
- This addition will improve measures of health equity on the MCBS:
 - Will provide nationally representative data on topics such as the accessibility and utilization of services by LGBTQ+ populations and resulting health disparities that impact this community.
 - Will help inform CMS' strategy to address Executive Order 13988 on Preventing and Combating Discrimination on the Basis of Gender Identity and Sexual Orientation.





Timeline of SOGI Research on the MCBS







Adopting SOGI on the MCBS



- Careful consideration has been given for implementing SOGI items from existing surveys in the context of the MCBS questionnaire.
- During this presentation, we will discuss:
 - Results from initial feasibility research/cognitive testing efforts.
 - Current item selection and design.
 - Operationalization of SOGI items in the context of a longitudinal health survey.
 - Interviewer training and preliminary results from fielding.

Initial Feasibility Research and Cognitive Testing

2015-2016





- Timing: 2015-2016
- Interview languages: English and Spanish
- Interview mode: In-person
- Tested abbreviated questionnaire with SOGI items at end in demographic section.

Focus of probing	Examples of probes
Comprehension of questions and terms; identification of sources of confusion or ambiguity	 Were there any words that you were uncertain about? Which ones? What does [bisexual/transgender] mean to you?
Uncover decision-making processes and assumptions that respondents make when answering identity questions	 How did you decide on that answer? What did you think about when I asked that question?
Ease in answering questions about one's sexual orientation and gender identity	 Did you have any trouble deciding on that answer?

SOGI Items Initially Tested



Sexual Orientation Question

Which of the following best represents how you think about yourself?

- Lesbian or gay
- Straight, that is, not lesbian or gay
- Bisexual
- Something else
- I don't know how to answer

Gender Identity Questions

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

- Male
- Female

How do you describe yourself?

- Male
- Female
- Transgender
- Do not identify as female, male, or transgender

Major Findings from Testing



- English-speaking respondents:
 - Answered SOGI questions without issue.
 - Provided responses consistent with screener responses.
- Spanish-speaking respondents:
 - Able to answer the two-step sex and gender questions even though they were often uncertain about the meaning of transgender.
 - Had problems answering the sexual orientation question:
 - Women and those with high school or less education did not understand meaning of response categories and were uncertain about the term "heterosexual".
 - Heterosexual participants identified their sexual orientation as "normal."

Major Findings from Testing, Ctd



- Based on these findings, the CMS Office of Minority Health, National Center for Health Statistics (NCHS) Questionnaire Design Research Laboratory, and NORC drafted alternative versions of Spanish language sexual orientation question response categories and completed further cognitive testing with 39 Spanish speakers.
- The revised question showed marked improvement in comprehension and consistency.
- Other Federal agencies, including NCHS, tested and implemented a revised Spanish version of the item.

Current Design and Implementation Research

2021-2023

SOGI Implementation on MCBS



- CMS and NORC leveraged SOGI research efforts and advancements from across the federal statistical community:
 - Previous cognitive testing conducted by CMS/NORC in 2015-2016.
 - Review of current SOGI items on other large, federal surveys.
 - Alignment with recommendations from the National Academies of Sciences, Engineering, and Medicine's (NASEM) 2022 report, "Measuring Sex, Gender Identity, and Sexual Orientation".
 - Discussions with survey and SOGI experts at NORC and other organizations.

SOGI Items from Other Surveys



- Items selected for 2023 MCBS were drawn from the most current national surveys fielding SOGI:
 - Two items about sexual orientation from the National Health Interview Survey (NHIS).
 - Two items about gender identity from the U.S. Census Household Pulse Survey.

Sexual Orientation Items



Variable	Question Text	Code List
SEXORINT	Do you think of yourself as lesbian or gay; straight, that is, not lesbian or gay; bisexual; something else; or you don't know the answer?	(01) LESBIAN OR GAY (02) STRAIGHT, THAT IS, NOT LESBIAN OR GAY (03) BISEXUAL (04) SOMETHING ELSE (05) I DON'T KNOW THE ANSWER (-8) Don't Know (-9) Refused
SEXORIOS	What do you mean by something else?	(01) continuous answer

Gender Identity Items



Variable	Question Text	Code List
GENIDENT	[(Do you)/(Does (SP))] currently describe [yourself/themselves] as male, female or transgender?	(01) MALE(02) FEMALE(03) TRANSGENDER(04) NONE OF THESE(-8) Don't Know(-9) Refused
SEXASGN	What sex [(were you)/(was (SP))] assigned at birth on [your/(SP)'s] original birth certificate?	(01) MALE (02) FEMALE (-8) Don't Know (-9) Refused

Issues of Operationalization



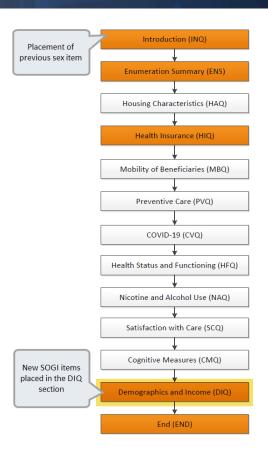
- Even though CMS and NORC used existing, tested SOGI items, there were still challenges in operationalizing these items within the complex structure of a longitudinal, general health survey with a rotating panel design:
 - Where to place these items in the survey vis-à-vis other questionnaire sections related to health care experiences, cost, and utilization?
 - How often to administer these items to beneficiaries during their tenure in the study?
 - How to navigate text fills for interviews conducted with proxy respondents?
 - How to navigate routing for sex-specific health status and prevention items?

SOGI Item Administration



Placement

- Replaced previous sex item in Introduction with NHIS and Census Pulse SOGI items.
- Placed new items in Demographics and Income (DIQ) Section (per recommendations outlined in the NASEM report).
- Frequency of Administration
 - Administered to all beneficiaries in Fall 2023 and then in subsequent years, only to Incoming panel beneficiaries.



Proxy Interview Administration



Proxy Interview Administration - English

Refer to survey respondents by their first name, rather than pronouns

[Has SP] ever had an exam for oral cancer in which the doctor or dentist pulls on [his/her] tongue, sometimes with gauze wrapped around it, and feels under the tongue and inside the cheeks?



[Has SP] ever had an exam for oral cancer in which the doctor or dentist pulls on [(SP)'s] tongue, sometimes with gauze wrapped around it, and feels under the tongue and inside the cheeks?

Proxy Interview Administration



Proxy Interview Administration - Spanish

• Spanish proxy interviews use respondent first name, but some gendered language structure had to be retained.

English question text HOSMED	Spanish question text HOSMED
After [your/(SP)'S] most recent hospital stay, [were you/was (SP)] prescribed any medicines?	Después de [su/la] estancia hospitalaria más reciente [de (SP)], ¿fue [usted/(SP)] recetado/a algunas medicinas?

Sex-Specific Health Questions



Some health status and prevention items are dependent on the anatomy of the beneficiary:

For example, items about hysterectomies and prostate surgery.

Sex assigned at birth (SAAB) is used to drive routing for questions related to a beneficiary's anatomy.

- When SAAB is not available, administrative data is used.
- Added response option for when beneficiaries feel a question does not apply.

Variable	Question Text	Code List
		(01) YES
		(02) NO
HYSTEREC	[Have you/Has (SP)] ever had a hysterectomy?	(03) QUESTION DOES NOT APPLY TO SP
		(-8) Don't Know
		(-9) Refused

Additional Considerations



- To reflect current best practice in SOGI administration and to promote data quality, additional adaptations were made in operationalizing SOGI items on the MCBS:
 - ✓ Proxy administration is permitted for gender identity but not sexual orientation items.
 - ✓A soft edit check is included for differing responses at gender identity items for interviewer reference to reduce the potential for data entry errors.
 - √"Don't Know" and "Refused" response options are included at SOGI items to allow respondents to opt out.

Early Implementation Findings

2023

SOGI on MCBS PaRIS Survey



- As a result of an international collaboration with the Organization for Economic Cooperation and Development (OECD), CMS and NORC fielded an earlier version of SOGI items via phone to MCBS beneficiaries in Winter 2023 via the Patient-Reported Indicator Survey (PaRIS).
- This effort informed our training and implementation plans and reinforced that administration of SOGI items to Medicare beneficiaries was feasible by telephone.

Interviewer Listening Sessions



- NORC held two listening sessions with interviewers following the MCBS PaRIS Survey
- Themes
 - Training was thorough for the SOGI questions.
 - Interviewers are experienced at neutral administration of other sensitive questions (e.g., income).
 - Some respondents prefer not to answer or give non-answers training on these scenarios is helpful.
- Application to Fall 2023 training
 - Interviewer attitude can project a sense of neutrality at these questions.
 - Reinforce the importance of reading verbatim without additional prelude.
 - Educate interviewers further on the importance and purpose of the items.

MCBS Interviewer Training



Interviewers were trained on SOGI administration for the main MCBS via a training module, which covered:

- Background and research importance of the SOGI questions.
- Introduction to the questions and response options.
- Skills for probing, gaining cooperation, and reading verbatim.
- Practice with potential scenarios.
 - Respondent is unfamiliar with response options.
 - Respondent feels the questions are too sensitive or doesn't want to answer.
 - Respondent provides alternative response options (e.g., "I'm normal").
 - Respondents wonder why these questions are being asked.

Monitoring and Evaluation



- Fall 2023 data collection round runs from July-December 2023.
- Item performance is being monitored and evaluated:

In-Round Monitoring

Preliminary Frequency Review

Interviewer Monitoring and Feedback

Round-End Review

Record Review

Respondent Characteristics

Open-Ended Responses

In-Round Monitoring



- NORC conducts weekly review of item-level frequencies to monitor item-level non-response and item performance.
- Preliminary findings from frequency review show item-level non-response of less then 3%, which is in line with results from other federal surveys.

Preliminary Frequency Review



- Differential analysis to look for patterns of skipped/don't know/refused among specific interviewers, regions, etc.
- Computer-assisted recorded interviewing (CARI) for all SOGI variables.
- Interviewer feedback on item administration also assessed via discussions with managers.

Interviewer Monitoring



Round-End Review



- Record review
 - Review agreement of self-and proxy-reported gender identity with administrative data and Fall 2022 reports.
- Respondent characteristics
 - Tabulate patterns in reporting by respondent language, use of an assistant, and self-report or proxy report.
- Open-ended responses
 - Review free text entries for training points and/or questionnaire improvements.

Thank you!

For any questions, please contact: Mayfield-Andrea@norc.org

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