

MEDICARE CURRENT BENEFICIARY SURVEY (MCBS)

2023 Content Management Cycle Cognitive Testing Report

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Executive Summary

The Medicare Current Beneficiary Survey (MCBS) is a continuously fielded survey of a nationally representative sample of the Medicare population conducted by the Centers for Medicare & Medicaid Services (CMS) through a contract with NORC at the University of Chicago (NORC). The Medicare population includes all Medicare eligible persons aged 65 and over, and persons under age 65 with certain disabilities or with end-stage renal disease (ESRD). The MCBS uses a rotating panel design and collects data from Medicare beneficiaries up to eleven times over a span of four years. Incoming panels are sampled and recruited in the fall of each year to replace the panel that rotates out in the winter. The survey covers topics including health care utilization and expenditures, sources of health insurance coverage, and health status and functioning. Data are collected for sampled beneficiaries living in noninstitutionalized (e.g., households) and institutionalized (e.g., nursing homes) settings.

Each year, CMS solicits content changes to the MCBS questionnaires from partners and stakeholders. As a result of this call in 2021, CMS obtained requests to consider a number of new items to be added to the MCBS Community questionnaire in 2023. These requests span a series of health-related topics and stem from a variety of sources (Exhibit 1). Based on draft wording of the items (either directly from other surveys or from other resources), a small-scale cognitive testing round was designed to assess comprehension, sensitivity, and overall flow of administration. Six interviews in English were conducted by phone in the Fall of 2021; two interviews in Spanish were conducted by phone in Winter of 2022.

Based on the results of this small-scale testing effort, items measuring the use of cannabidiol (CBD) for pain management, health equity items (related to perceived discrimination by health care providers and socio-demographic items about religious affiliation intended to improve analysis of health equity), use of the Medicare Savings Program (MSP), knowledge of the right to file a complaint or appeal under the Medicare program, and the prevalence of bowel incontinence are recommended for implementation. The testing found that a few questions needed minor revisions to improve clarity but all performed well and administration was straightforward in both English and Spanish. Adding these new items beginning with the 2023 MCBS will close important data gaps and improve analytic capability.

Introduction

The Medicare Current Beneficiary Survey (MCBS) is a continuously fielded survey of a nationally representative sample of the Medicare population conducted by the Centers for Medicare & Medicaid Services (CMS) through a contract with NORC at the University of Chicago (NORC). The Medicare population includes all Medicare eligible persons aged 65 and over, and persons under age 65 with certain disabilities or with end-stage renal disease (ESRD). The MCBS uses a rotating panel design and collects data from Medicare beneficiaries up to eleven times over a span of four years. Incoming panels are sampled and recruited in the fall of each year to replace the panel that rotates out in the winter. The survey covers topics including health care utilization and expenditures, sources of health insurance coverage, and health status and functioning. Data are collected for sampled beneficiaries living in noninstitutionalized (e.g., households) and institutionalized (e.g., nursing homes) settings.

Each year, CMS solicits content changes to the MCBS questionnaires from partners and stakeholders. As a result of this call in 2021, CMS obtained requests for a number of new items to be added to the MBCS Community questionnaire in 2023. These requests span a series of health-related topics and stem from a variety of sources (Exhibit 1); some items required development and others were derived from other surveys. One round of cognitive testing involving eight interviews (six in English, two in Spanish) were conducted to assess comprehension, sensitivity, and overall flow of administration.

Exhibit 1. 2023 Content Cycle Requests and Reasons for Cognitive Testing

Content Request	Item Source	Primary Reason for Cognitive Testing
Use of the Medicare Savings Program	Original Items	Assess comprehension
Beneficiary Knowledge of their Right to File a Complaint or Appeal	Original Items	Assess comprehension

Content Request	Item Source	Primary Reason for Cognitive Testing
Use of CBD for Pain Management	Original Item	Assess comprehension
Bowel Incontinence	Adapted from 2004 Mayo Clinic Study	Assess comprehension
Health Equity—Perceived Discrimination from Health Providers	Medicare Advantage (MA) and Prescription Drug Plan (PDP) Consumer Assessment of Healthcare Providers and Systems (CAHPS) Web Mode Field Test	Assess sensitivity
Health Equity—Expand Socio-Demographic Items to Include Religious Affiliation	General Social Survey (GSS)	Assess sensitivity

Original Items

Several of the requests for new content are original items that require testing to assess comprehension and clarity among Medicare beneficiaries. These include:

- Items about use of the Medicare Savings Program (MSP) to capture information about beneficiaries who are eligible but not enrolled in the MSP program. These items are formatted in a way similar to existing items in the MCBS Drug Coverage Questionnaire

(RXQ) about the Low-Income Subsidy (LIS) program which asks for a similar measure (awareness of a program that provides financial assistance to those in need).

- Items about the beneficiary's knowledge of their rights to file complaints or appeals under the Medicare program).
- An item on the use of cannabidiol (CBD) for pain management for inclusion to an existing pain management grid item in the MCBS Chronic Pain Questionnaire (CPQ) that asks about non-medication management methods used to manage pain. This item asks beneficiaries to identify whether they use specific methods, such as physical therapy, chiropractic care, or massage, to manage their chronic pain.

Adapted Items

Several of the requests for new content have been taken or adapted from other surveys. These include:

- An item on bowel incontinence, sourced from a 2004 Mayo Clinic Study¹ and adapted to model the urinary incontinence items in the MCBS Health Status and Functioning Questionnaire (HFQ) to capture prevalence and management of stool leakage.
- Eight items about health equity, including perceived discrimination by health care providers based on aspects of the beneficiary's identity. This series of items was developed and will be undergoing testing for implementation on the Medicare Advantage (MA) and Prescription Drug Plan (PDP) Consumer Assessment of Healthcare Providers and Systems (CAHPS) Web Mode Field Test (pending OMB approval).
- Two socio-demographic items about religious affiliation sourced from the General Social Survey (GSS)². These items are intended to improve measures of health equity as they will allow analysts to broaden socio-demographic analysis and assess whether key health outcomes differ by factors such as religious affiliation. These items will also help to evaluate whether perceived discrimination from health care providers varies based on religious affiliation.

¹ Bharucha AE, Locke GR 3rd, Seide BM, Zinsmeister AR. A new questionnaire for constipation and faecal incontinence. *Aliment Pharmacol Ther.* 2004 Aug 1;20(3):355-64. doi: 10.1111/j.1365-2036.2004.02028.x. PMID: 15274673

² The 2020 General Social Survey Questionnaire is available from:
http://gss.norc.org/Documents/quex/GSS2020panel_Ballot1_English_CAPI.pdf

Methods

The purpose of this cognitive testing study is to understand the processes people use to answer questions about several health-related topics and to identify potential problems in the questions and response categories. A qualitative analysis of the interviews was conducted.

Sampling, Recruitment, and Screener

As is typical of cognitive interviewing, convenience sampling was used by reaching out to a pool of potential participants or asking project staff to forward study information to their personal networks. Respondents were screened prior to interview administration via telephone. The screener consisted of items to measure eligibility, such as age, Medicare status, and basic demographics (see English-language screening instrument in Appendix A). To be eligible to participate, respondents had to self-report eligibility for Medicare and have at least one chronic health condition.

A total of eight interviews were completed. A total of six interviews were conducted in English in October 2021. Two additional interviews were conducted in Spanish in February 2022. Respondents were provided a \$40 incentive for participating. They ranged in age from 69 to 90 (mean age = 77.3). Exhibit 2 shows distributions for sex, ethnicity, race, and educational attainment as reported during screening.

Exhibit 2. Distribution of Sex, Ethnicity, Race, and Educational Attainment among Cognitive Interview Respondents

Characteristic	Count
Sex	
<i>Female</i>	6
<i>Male</i>	2
Ethnicity	
<i>Non-Hispanic</i>	5
<i>Hispanic</i>	3
Race	
<i>American Indian/Alaska Native and Black/African American</i>	1
<i>Black or African American alone</i>	2
<i>White</i>	4
<i>Don't Know/Refused</i>	1

Characteristic	Count
Education	
<i>No schooling completed</i>	1
<i>Some college, but no degree</i>	3
<i>Bachelor’s degree</i>	3
<i>Master’s, Professional, or Doctorate degree</i>	1

Data Collection

Interviewers administered the questionnaire as a paper-and-pencil interview (PAPI) remotely via telephone or the Zoom video conferencing platform. Once potential respondents were screened and determined to be eligible, interviewers reviewed and obtained informed consent and administered the test questionnaire in full. Interviews were audio or video recorded, with respondents’ permission, so that analysts could reference the recording during analysis as needed. After each series of items was administered, interviewers debriefed respondents, reviewing the questions and their answers and probing for information about how they interpreted the questions and arrived at their answers. The English version of the test questionnaire instrument is shown in Appendix B.

Data Analysis Methods

This cognitive testing effort primarily used ‘think aloud’ and retrospective probing techniques. Participants were asked to think aloud as they offered answers. Additionally, respondents were retrospectively asked additional questions about the items being tested. During and after each interview, interviewers wrote notes summarizing the themes and responses they heard. Analysts then reviewed the notes; listened to the interview recordings for additional clarity when needed; identified themes in the responses; and created typologies of key themes observed. This analysis provided insights into any confusion respondents may have had in responding to the draft items and identified items that respondents did not answer as intended. It also identified possible opportunities for improvement of some measures.

Results and Recommendations

The discussion below is structured around each set of items: (1) beneficiary use of the MSP program, (2) beneficiary knowledge about their right to file a complaint or appeal under the Medicare program, (3) use of CBD for pain management, (4) prevalence of bowel incontinence, (5) health equity—perceived discrimination from health providers, and (6) health equity—expanding socio-demographic items to include religious affiliation. For each group, this section

first describes the testing results and then, when appropriate, includes recommendations to improve or revise the questions. For each group of test questions, the report includes descriptive statistics and a discussion of item performance.

Use of the Medicare Savings Program (MSP)

Item Q1 (shown in Exhibit 3) asks respondents if they receive help in paying for their health care costs through the MSP program. If the respondent reported they do not, items Q2-4 were included in the cognitive testing questionnaire to further assess comprehension about the MSP program. The intent of these follow-up items was to gather additional information about how respondents are interacting with the MSP program by asking whether they have applied for help to their state Medicare office, whether their application was accepted or denied, and their awareness of the MSP program.

Exhibit 3. Medicare Savings Program, Item Q1-Q4 Question Text

Variable Name	Question Text	Code List
Q1	<p>We’re interested in learning more about how people covered under Medicare navigate certain programs available to beneficiaries—particularly those meant to help people pay for their healthcare costs. As you may know, the government has programs that help beneficiaries pay for the costs associated Medicare such as Part A or Part B premiums, deductibles, coinsurance, and copayments. We’re going to ask you a few questions about these programs, and what your experience, if any, has been with them.</p> <p>[Are you/Is (SP)] receiving this type of help to pay for [your/his/her] (CURRENT YEAR) health care costs?</p> <p>[EXPLAIN IF NECESSARY: These programs are called Medicare Savings Programs. There are four different Medicare Savings Programs: Qualified Medicare Beneficiary Program, Specified Low-Income Medicare Beneficiary Program, Qualifying Individual Program, and Qualified Disabled and Working Individuals Program.]</p>	<p>(A) YES→ Skip rest of series (B) NO (C) DON’T KNOW (D) REFUSED</p>
Q2	<p>Did [you/(SP)] apply to the [STATE] Medicare office for help with (CURRENT YEAR) expenses?</p>	<p>(A) YES (B) NO (C) DON’T KNOW (D) REFUSED</p>

Variable Name	Question Text	Code List
Q3	Was [your/(SP's)] application for a Medicare Savings Program accepted or denied?	(01) ACCEPTED (02) DENIED (03) STILL PENDING/NO DECISION YET (-8) Don't Know (-9) Refused
Q4	Before today, were you aware of these programs?	(A) YES (B) NO (C) DON'T KNOW (D) REFUSED

Half of respondents (n=4) initially stated that they had help through the MSP program to pay for health care costs. After probing, however, and further explanation of the MSP program, it became evident that several participants thought the item was referring to secondary insurance policies (Exhibit 4). For the remaining items (Q2-4), none of the respondents reported having applied to their state Medicare office for help with expenses and none were aware of the MSP program before today.

Exhibit 4. Responses to Q1 Before and After Probing

[Are you/Is (SP)] receiving this type of help to pay for [your/his/her] (CURRENT YEAR) health care costs?	Initial Response	Response After Probing and Explanation of MSP Program
Yes	4	0
No	4	8

Analysis and Recommendations

The largest comprehension issue arising from this set of questions was that respondents thought the questions asked about private insurance policies in addition to Medicare policies. Each respondent had another insurance plan, largely through their employer-sponsored retirement benefit plans, which helped them with costs and expenses not covered by Medicare. This resulted in overreporting of MSP as respondents interpreted any coverage they have beyond Medicare to fit the conceptual definition.

Additional questions and probing revealed that even those who reported living on small, fixed incomes and needing help paying for their prescriptions and other medical needs had not heard of support programs through Medicare and did not know there was an option to reach out to a state-based Medicare office. Two of the participants were aware that they had materials (e.g., Medicare cards, beneficiary literature) where they might find information on such a program.

However, two other respondents said they viewed Medicare as a large government effort so were more likely to reach out to a family member or online source to try to find information on alternate support options.

The terms “Qualified” used in the MSP program names in the help text at Q1 also caused confusion. Respondents were unsure how to interpret this term in the program name and thought they meant someone from Medicare might reach out to notify them they were qualified. Similar results were observed during testing of the items in Spanish.

A clearer and more direct definition of MSP at Q1 (proposed in Exhibit 5) would alleviate some of the confusion in this series as would introductory text helping respondents to differentiate MSP from other privately held insurances. As there was no variation in responses to Q2-4, it is recommended to not implement all three items in the MCBS survey. Instead, Q1 followed by Q2 would be sufficient to obtain the initial measure of whether respondents are receiving MSP assistance and whether they have applied for assistance.

Exhibit 5. Proposed Revisions to Medicare Savings Program Items

Variable Name	Question Text	Code List
Q1	<p>We’re interested in learning about how Medicare beneficiaries navigate certain programs available to help them pay for their-health care costs. As you may know, the government has a set of programs, called Medicare Savings Programs (MSP), that help beneficiaries pay for the costs associated with Medicare, such as Part A (Hospital Insurance) or Part B (Medical Insurance) premiums, deductibles, coinsurance, and copayments. Unlike additional insurance plans that require a monthly premium, Medicare Savings Programs provide financial help at no cost to eligible beneficiaries who have limited income and resources. We’re going to ask you a few questions about these programs, and what [your/(SP)’s] experience, if any, has been with them.</p> <p>[Are you/Is (SP)] receiving any assistance from a Medicare Savings Program (MSP) to help pay for [your/his/her] (CURRENT YEAR) health care costs?</p> <p>[EXPLAIN IF NECESSARY: Medicare Savings Programs pay for remaining costs (premiums, deductibles, coinsurance, and copayments) not covered by Medicare. These programs are different from additional insurance plans, such as Medicare Supplement Insurance (Medigap) or private insurance plans, in that beneficiaries will not pay for this extra financial help. Instead, beneficiaries must be eligible (i.e., have limited resources or income) and apply to receive this financial assistance from an MSP.</p>	<p>(A) YES→Next Series (B) NO→Q2 (C) DON’T KNOW→Q2 (D) REFUSED→Q2</p>
Q2	<p>Did [you/(SP)] apply to the [STATE] Medicare office for help with (CURRENT YEAR) expenses?</p>	<p>(A) YES (B) NO (C) DON’T KNOW (D) REFUSED</p>

Beneficiary Knowledge—Right to File a Complaint or Appeal

Testing items that measure knowledge of the right to file a complaint or appeal were focused on whether respondents would know about these rights and be able to answer the questions. For the cognitive test, introductory items not intended for survey implementation were used in the series to help better understand challenges individuals may face in using their Medicare coverage; these can be found in Exhibit 6, Q1—6. These introductory items provided context for the main items

being tested (Q7-9), to help determine whether the terms or approaches covered in items Q7-9 would be understood without additional explanations or needs for interviewer probing.

When asked what they would do if they had difficulty with obtaining medical services, all respondents said they would take action. Contacting Medicare was not reported as a possible outcome to addresses issues with access to quality healthcare. Instead, respondents said they would speak to members of management at a doctors’ office or medical facility, contact age-based advocacy groups, use resources from private insurance plans/retirement plans, or consult friends/family.

Exhibit 6. Right to Appeal Series—Introductory Items

Variable Name	Question Text	Code List
Q1	Think about all of the times you’ve sought healthcare under Medicare coverage. Have you ever had a difficult time getting <u>an appointment</u> with a healthcare provider you needed to see?	(A) YES (B) NO (C) DON’T KNOW (D) REFUSED
Q2	Think about all of the times you’ve sought healthcare under Medicare coverage. Have you ever had a difficult time getting <u>the care you needed during your appointment(s)</u> with a healthcare provider you saw?	(A) YES (B) NO (C) DON’T KNOW (D) REFUSED
Q3	If you had concerns about the <i>quality</i> of care you were receiving from a healthcare provider or facility, would you know how to file a complaint <u>with Medicare</u> ?	(A) YES (B) NO (C) DON’T KNOW (D) REFUSED
Q4	In your own words, can you tell me a bit about what you would do if you had difficulty with getting an appointment, getting the care you need, or getting the care you received paid for properly?	(01) CONTINUOUS ANSWER
Q5	Have you ever heard the term ‘right to appeal’? What do you think it means?	(01) CONTINUOUS ANSWER
Q6	What do you know about filing a complaint, or your right to file a complaint, based on concerns you have around the healthcare you’ve received?	(01) CONTINUOUS ANSWER

Following the introductory series, a statement (using Medicare text) on the definitions of the right to appeal was read verbatim to the respondents. Respondents were then asked items Q7-9 (shown in Exhibit 7). Even with the information provided in the introductory series, none knew how they would go about contacting Medicare to invoke their rights to appeal or file a complaint and reported that they would either use the information sources reported earlier including reaching out to advocacy groups or looking it up online or in the Medicare book.

Exhibit 7. Right to Appeal Series—Main Items

Variable Name	Question Text	Code List
Q7	If you felt that <u>a healthcare provider was ending your healthcare services too soon</u> , would you know who to contact <u>in Medicare</u> to protect your rights and appeal?	(A) YES (B) NO (C) DON'T KNOW (D) REFUSED
Q8	If you had concerns about the <i>safety</i> of care you were receiving from a healthcare provider or facility, would you know how to file a complaint <u>with Medicare</u> ?	(A) YES (B) NO (C) DON'T KNOW (D) REFUSED
Q9	If you had concerns about the <i>quality</i> of care you were receiving from a healthcare provider or facility, would you know how to file a complaint <u>with Medicare</u> ?	(A) YES (B) NO (C) DON'T KNOW (D) REFUSED

Analysis and Recommendations

While items Q7-9 were clearly understood, and participants all reported they would take action if needed, they do not measure a priori knowledge about rights to file a complaint or appeal. Also, it was unclear whether respondents would distinguish carefully between the three questions, each of which seeks to measure a slightly different issue that would lead to filing a complaint or appeal. Therefore, it is recommended that one question among this series is selected to add to the 2023 MCBS Questionnaire. It is also recommended to adapt Q3 to ask about knowledge of both the right to appeal and file a complaint by modifying it to ask: “If you had concerns about the *quality* of care you were receiving from a healthcare provider or facility, would you know how to file a complaint or an appeal with Medicare?” Similar results were observed during Spanish-language testing.

Use of CBD for Pain Management

An item on the use of CBD to manage pain was tested as part of an existing series about the use of non-medication management methods from the MCBS Chronic Pain Questionnaire (CPQ), as shown in Exhibit 8. This item asks beneficiaries to identify whether they use specific methods, such as physical therapy, chiropractic care, or massage, to manage their chronic pain. All but two respondents reported pain on some or more days in the past three months and therefore qualified for this series. Of the six respondents who were administered Q2, none reported use of CBD to manage pain.

Exhibit 8. Use of CBD for Pain Management

Variable Name	Question Text	Code List	
Q1	Now I would like to ask about your experiences with pain. In the past three months, how often did you have pain? Would you say:	(A) Never→ Skip rest of series (B) some days→Q2 (C) most days→Q2 (D) every day→Q2 (E) Don't Know→ Skip rest of series (F) Refused→Skip rest of series	
Q2	Since (TODAY'S MONTH AND YEAR - 3 MONTH), did you use any of the following to manage your pain? Please indicate yes or no to each one:	Yes	No
	Physical therapy, rehabilitative therapy, or occupational therapy	Yes	No
	Spinal manipulation or other forms of chiropractic care	Yes	No
	Massage	Yes	No
	Meditation, guided imagery, or other relaxation techniques	Yes	No
	CBD (cannabidiol) [IF NEEDED: CBD is different from Marijuana or THC. CBD is one of the many compounds that can be present in the cannabis plant and does not cause a “high” by itself. CBD is available in different forms, such as oils and tinctures (extracts), capsules (pills/softgels), edibles (gummies/candies), and topicals (creams/lotions/ointments).	Yes	No

Analysis and Recommendations

Questions on pain management were not challenging and were easily understood in both English and Spanish. Respondents knew what CBD was and had no challenge reporting on it.

Bowel Incontinence

The next series of items assessed prevalence and frequency of bowel incontinence (Exhibit 9). The follow-up items in this series were asked more for the interviewers to obtain additional information on the degree to which this series might eventually be expanded to mirror the

urinary incontinence series currently on the MCBS. As only one participant reported yes to Q1, only one person received follow-up items Q2-Q7.

Exhibit 9. Bowel Incontinence Items

Variable Name	Question Text	Code List
Q1	<p>We are now going to ask you some questions about your ability to control your bowel movements.</p> <p>In the last 12 months, have you had any problems with leakage of stool, for example leaking gas, accidents, or soiling?</p> <p>[IF NEEDED: Was that because you were sick?] SELECT 'NO' IF THE RESPONDENT HAD ANY PROBLEMS DUE TO A SHORT-TERM DIARRHEAL ILLNESSES SUCH AS THE FLU OR A VIRUS.</p>	<p>(A) YES→Q2 (B) NO →SKIP REST OF SERIES (C) DON'T KNOW→SKIP REST OF SERIES (D) REFUSED→SKIP REST OF SERIES</p>
Q2	<p>Did you have a problem with leaking gas only; a small amount of stool; a moderate amount of stool, often requiring a change of underwear; or a large amount of liquid stool, often requiring a complete change of clothes?</p> <p>SELECT ALL THAT APPLY</p>	<p>(A) LEAKING GAS ONLY (B) A SMALL AMOUNT OF STOOL (C) A MODERATE AMOUNT OF STOOL, OFTEN REQUIRING A CHANGE OF UNDERWEAR; OR (D) A LARGE AMOUNT OF LIQUID STOOL, OFTEN REQUIRING A COMPLETE CHANGE OF CLOTHES? (E) DON'T KNOW (F) REFUSED</p>
Q3	<p>In the last 12 months, did you have this problem more than once a week, about once a week, 2-3 times a month, about once a month, every 2-3 months, or once or twice a year?</p> <p>[IF NEEDED: Include all types of stool leakage, including: gas only; a small amount of stool; a moderate amount of stool, and/or a large amount of liquid stool.]</p>	<p>(A) MORE THAN ONCE A WEEK (B) ABOUT ONCE A WEEK (C) 2-3 TIMES A MONTH (D) ABOUT ONCE A MONTH (E) EVERY 2-3 MONTHS (F) ONCE OR TWICE A YEAR? (G) DON'T KNOW (H) REFUSED</p>

Variable Name	Question Text	Code List
Q4	Have you talked about your problem with stool leakage with [your/his/her] doctor or other health professional? [IF NECESSARY: This is also referred to as bowel or fecal incontinence.]	(A) YES (B) NO (C) DON'T KNOW (D) REFUSED
Q5	Has your doctor or other health professional asked you about how you feel about this problem?	(A) YES (B) NO (C) DON'T KNOW (D) REFUSED
Q6	Has your doctor or other health professional examined you to figure out why you have a problem with stool leakage? [IF NECESSARY: This is also referred to as bowel or fecal incontinence.]	(A) YES (B) NO (C) DON'T KNOW (D) REFUSED
Q7	Has your doctor or other health professional talked with you about taking medicine or having surgery for this problem? [IF NECESSARY: Please answer based on your usual use of medication.]	(A) YES (B) NO (C) DON'T KNOW (D) REFUSED

Analysis and Recommendations

Despite limited testing on follow-up items in this series, use of open-ended probes at Q1 revealed the possibility of underreporting of bowel-related issues in this series using the current question structure. When asked more generally about health-related issues, several respondents reported severe constipation and stomach issues from medication. To avoid being too restrictive in this series, it is recommended to combine Q1 and Q2 into a series where respondents are asked whether or not they have experienced each type of bowel incontinence issues (Exhibit 10).

While combining Q1 and Q2 will more accurately measure prevalence of bowel incontinence issues, the format recommended is a yes/no to each of the bowel-related problems. Beneficiaries would first be asked if they have experienced several types of bowel incontinence including leaking gas, leaking a small amount of stool, leaking a moderate amount of stool, and leaking a large amount of liquid stool. Beneficiaries who respond affirmatively to any type of bowel incontinence would next be asked if they have talked with their health care provider about this issue. It is recommended to limit follow-up questions to one item (Q4) to reduce respondent burden. This revised format will allow CMS to understand the prevalence of bowel incontinence among beneficiaries and develop better awareness and outreach regarding this medical issue. This revised format was tested with two Spanish-speaking respondents and performed well.

Exhibit 10. Proposed Revisions to Initial Bowel Incontinence Items

Variable Name	Question Text	Code List		
Combined Q1/Q2	We are now going to ask you some questions about your ability to control your bowel movements. In the last 12 months, have you had any of the following problems? [IF NEEDED: Was that because [you/(SP)] [were/was] sick?] SELECT 'NO' IF THE RESPONDENT HAD ANY PROBLEMS DUE TO SHORT-TERM DIARRHEAL ILLNESSES SUCH AS THE FLU OR A VIRUS. Leaking gas?	Yes	No	Don't Know
	Leaking a small amount of stool?	Yes	No	Don't Know
	Leaking a moderate amount of stool, requiring a change of underwear?	Yes	No	Don't Know
	Leaking a large amount of liquid stool, requiring a complete change of clothes?	Yes	No	Don't Know
Q4	Have you talked about your problem with stool leakage with [your/his/her] doctor or other health professional? [IF NECESSARY: This is also referred to as bowel or fecal incontinence.]	(A) YES (B) NO (C) DON'T KNOW (D) REFUSED		

Health Equity—Perceived Discrimination from Health Providers

The first health equity series (shown in Exhibit 11) asked if respondents perceived that they were treated in an unfair or sensitive way by health providers due to certain personal attributes. All eight respondents reported “no” to each item in this series.

Exhibit 11. Health Equity Items—Perceived Discrimination from Health Providers

Variable Name	Question Text	Code List		
Q1	In the last 12 months, did anyone from a clinic, emergency room, or doctor’s office where you got care treat you in an unfair or insensitive way because of any of the following things about you?	Yes	No	Don't Know
	Race or ethnicity	Yes	No	Don't Know
	Language or accent	Yes	No	Don't Know
	Gender or gender identity	Yes	No	Don't Know
	Sexual orientation	Yes	No	Don't Know

Variable Name	Question Text	Code List		
	Age	Yes	No	Don't Know
	Culture or religion	Yes	No	Don't Know
	Disability	Yes	No	Don't Know
	Medical history	Yes	No	Don't Know

Analysis and Recommendations

The items on health equity performed well as tested in both English and Spanish. Respondents did not find these items to be sensitive nor did they require definitions to clarify terms. Including standard definitions and help text for interviewers will be important for uniform interpretation of terms.

Health Equity—Socio-Demographic Items about Religious Affiliation

The final item asked about the respondent’s religious preference (Exhibit 12). Three respondents reported that they identified as Jehovah’s witness, two reported being affiliated with the Church of Latter-Day Saints, one respondent reported identifying as Catholic, and two respondents reported identifying as Christian.

Exhibit 12. Health Equity Items—Socio-Demographic Items about Religious Affiliation

Variable Name	Question Text	Code List
Q1	<p>What is your religious preference?</p> <p>IF NEEDED: Please select the religion with which you most closely identify.</p>	<p>(A) PROTESTANT</p> <p>(B) CATHOLIC</p> <p>(C) EASTERN ORTHODOX, SUCH AS GREEK OR RUSSIAN ORTHODOX</p> <p>(D) JEWISH</p> <p>(E) BUDDHIST</p> <p>(F) HINDU</p> <p>(G) MUSLIM, ISLAM, SUFI, SUNNI, OR SHIA</p> <p>(H) SOME OTHER RELIGION</p> <p>(I) NO RELIGION</p> <p>(J) DON'T KNOW</p> <p>(K) REFUSED</p> <p>(L) NA</p>
Q2	What is your religious preference?	(A) Continuous Answer

Analysis and Recommendations

The item on religious preference performed well as tested in both English and Spanish. The item was easily understood, every participant was able to report on it, and all stated no hesitation in doing so.

Discussion

This section includes recommendations for whether the draft items require additional revisions before implementation.

- **Recommended for Implementation Without Revision.** Items measuring the use of CBD for pain management, health equity, and religious affiliation were easily understood in both English and Spanish and were not considered sensitive by respondents (Exhibit 13). Based on the results of this small testing effort, it is recommended that these three sets of items be included in a full clearance revision to the main MCBS (0938-0568) for implementation in 2023.

Exhibit 13. Items Recommended for Implementation without Revision

Content Request	# of Items	Questionnaire Section	Administration Schedule
Use of CBD	1	Chronic Pain Questionnaire (CPQ)	Annually, Summer Round
Health Equity	8	Satisfaction with Care (SCQ)	Annually, Fall Round
Religious Affiliation	2	Demographics and Income Questionnaire (DIQ)	Baseline Interview Only, Fall Round

- **Recommended for Implementation with Minor Revisions.** Three additional new measures are recommended for implementation as part of the 2023 MCBS questionnaires with minor revisions.
 - ▶ Items measuring use of the MSP program were somewhat confusing to respondents, who interpreted them as asking about secondary sources of insurance. Clarifying the text and terms in the initial question, and limiting the number of follow-up items, is likely to reduce overreporting of MSP participation.
 - ▶ Items measuring knowledge of the right to file a complaint or appeal under the Medicare program were somewhat challenging as it is difficult to measure knowledge about something that is very program specific and usually requires education or broad promotional materials. However, the question could be implemented if it were revised to measure whether a respondent would know how to submit a complaint or an appeal.

- ▶ Similarly, items measuring the prevalence and frequency of bowel incontinence would benefit from minor question restructuring to avoid underreporting. Using a yes/no format to ask beneficiaries about the prevalence of each bowel-related problem will improve comprehension and allow respondents to answer each item separately. Limiting follow-up questions to one item will provide necessary information for analysts while minimizing respondent burden. This revised format tested well with two Spanish-speaking respondents.

Exhibit 14. Items Recommended for Implementation with Minor Revision

Content Request	# of Items	Questionnaire Section	Administration Schedule
Use of MSP Program	2	Beneficiary Knowledge and Decision-Making Questionnaire (KNQ)	Annually, Winter Round
Right to File a Complaint or Appeal	1	Beneficiary Knowledge and Decision-Making Questionnaire (KNQ)	Annually, Winter Round
Bowel Incontinence	5	Health Status and Functioning Questionnaire (HFQ)	Annually, Fall Round

Following OMB approval and CMS implementation, all questions will be closely monitored in 2023 to determine if any residual comprehension issues need to be addressed via interviewer training or on-screen help text within the questionnaire.

Appendix A: Cognitive Interview Screening Instrument

PARTICIPANT NUMERIC IDENTIFIER: _____

1. What is your sex? Are you male, female, or do you identify yourself another way?
 - a) MALE
 - b) FEMALE
 - c) I IDENTIFY AS _____
 - d) I don't know
 - e) Refused

2. How old are you?

_____ years

3. Medicare is the federal health insurance program for people who are 65 or older, certain younger people with disabilities, and people with End-Stage Renal Disease. Do you receive health insurance through Medicare?
 - a) YES
 - b) NO → I am sorry, but only people who receive insurance through Medicare are eligible for this study.

4. What is the highest degree or level of school you have completed?
 - a) NO SCHOOLING COMPLETED
 - b) NURSERY SCHOOL TO 8TH GRADE
 - c) 9TH-12TH GRADE, NO DIPLOMA
 - d) HIGH SCHOOL GRADUATE (HIGH SCHOOL DIPLOMA OR THE EQUIVALENT)
 - e) VOCATIONAL/TECHNICAL/BUSINESS/TRADE SCHOOL CERTIFICATE OR DIPLOMA (BEYOND THE HIGH SCHOOL LEVEL)
 - f) SOME COLLEGE, BUT NO DEGREE
 - g) ASSOCIATE DEGREE
 - h) BACHELOR'S DEGREE
 - i) MASTER'S, PROFESSIONAL OR DOCTORATE DEGREE

5. Are you of Hispanic, Latino, or Spanish origin?
 - a) YES
 - b) NO

7. What is your race? [SELECT ONE OR MORE. READ RESPONSE OPTIONS IF NEEDED.]
 - a) American Indian or Alaska Native
 - b) Asian
 - c) Black or African American
 - d) Native Hawaiian or Other Pacific Islander
 - e) White
 - f) Something else: _____

8. Would you prefer to conduct the interview over the phone or over video, using Zoom?
 - a) PHONE
 - b) ZOOM

9. CONFIRM CONTACT INFORMATION AND SCHEDULE APPOINTMENT:

Ok, let's schedule an appointment to do the interview.

[TAKE INFORMATION]

IF PHONE:

10. Can you confirm that [PHONE NUMBER] is the best number to contact you on [DATE] for the interview?

[TAKE INFORMATION]

IF ZOOM:

11. Could you please provide an email address to send you the Zoom link information to for the interview?

[TAKE INFORMATION]

Thank you for volunteering to participate. We will speak with you on [REPEAT DATE AND TIME OF APPOINTMENT] by [REPEAT MODE]. I will reach out the day before the interview to remind you of the appointment and to confirm the name [and phone number] of the interviewer who will be contacting you.

With your permission, your interview session will be recorded to allow us to ensure we capture all of the feedback you provide us. Only staff directly involved in the project will have access to the recording. If you do not want to be recorded, we can do the interview without recording. Your answers will always be kept private, and none of the information that you provide will be used for any purpose other than research.

AFTER HANGING UP, ENTER THE INFORMATION FROM THIS SCREENER INTO THE RECRUITMENT SPREADSHEET ALONG WITH THE DATE, TIME, AND MODE OF THE APPOINTMENT.

Appendix B: Cognitive Interview Instrument

MATERIALS NEEDED FOR INTERVIEW

- INTERVIEWER PROTOCOL BOOKLET (THIS BOOKLET)
- INFORMED CONSENT
- RECORDING DEVICE/VOICE RECORDING APP
- PENS AND PENCILS; SOFTWARE FOR DIGITAL NOTETAKING

STEP 1: INFORMED CONSENT

INT1. The Medicare Current Beneficiary Survey (MCBS) asks Medicare beneficiaries about their health status, sources of health care, satisfaction with care, and health care expenditures. In today's interview I will be asking you about your health conditions and experiences health care providers.

Periodically during the interview, I will ask you some questions about how you decided to answer some of the survey questions. Getting your feedback on the questions can help make the questions better.

[CONTINUE]

INT2. All survey information will be kept private to the extent permitted by law, as prescribed by the Privacy Act of 1974. Medicare benefits will not be affected in any way by survey responses or participation.

Do you agree to participate in this interview?

- a. YES -> GO TO NEXT QUESTION
- b. NO -> STOP INTERVIEW AND THANK THEM FOR THEIR TIME.

INT3. In order to have a complete record of your comments, with your permission, your interview session will be audio taped. The recording will be stored electronically on NORC's secure servers. We plan to use the recording to ensure that we capture all of the feedback you provide us. Only staff at directly involved in this research project will have access to the recording. Any quotes used in presentations and publications will not include any names or any information that could identify any participant.

Is it okay for me to proceed with the recording on?

- a. YES -> TURN RECORDING ON
- b. NO -> PROCEED WITHOUT RECORDING

STEP 2: COMPLETION OF THE QUESTIONNAIRE

The Medicare Current Beneficiary Survey (MCBS) asks Medicare beneficiaries about their health status, sources of health care, satisfaction with care, and health care expenditures. In today's interview I will be asking you about your recent health care and some of your medical conditions.

After we have finished the survey, I would like to talk with you about some of the questions in the survey. Getting your feedback on the questions can help make the questions better.

[INTERVIEWER: EACH TEST QUESTION IN THE PROTOCOL IS IMMEDIATELY FOLLOWED BY A SET OF EXAMPLE PROBES AND INTERVIEWER NOTES DESIGNED TO AID THE DEBRIEFING PROCESS; WHILE SPECIFIC PROBES WILL VARY, THE EXAMPLES PROVIDED IN THE PROTOCOL ARE MEANT TO BE A STARTING POINT FOR DIALOG WITH THE RESPONDENT. ALTHOUGH THESE PROBES APPEAR ADJACENT TO THE QUESTIONS THEMSELVES, IT IS GENERAL PRACTICE TO ADMINISTER THE QUESTIONNAIRE IN FULL BEFORE USING THE EXAMPLE PROBES AND INTERVIEWER NOTES TO DEBRIEF THE RESPONDENT. REMIND THE RESPONDENT OF THE QUESTION AND HIS/HER RESPONSE IN ADVANCE OF USING PROBES.]

MEDICARE Savings Program

[INTERVIEWER READ Instructions]: We’re interested in learning more about how people covered under Medicare navigate certain programs available to beneficiaries—particularly those meant to help people pay for their healthcare costs. As you may know, the government has programs that help beneficiaries pay for the costs associated Medicare such as Part A or Part B premiums, deductibles, coinsurance, and copayments. We’re going to ask you a few questions about these programs, and what your experience, if any, has been with them.

NEWVAR1	<p>[Are you/Is (SP)] receiving this type of help to pay for [your/his/her] (CURRENT YEAR) health care costs?</p> <p>[EXPLAIN IF NECESSARY: These programs are called Medicare Savings Programs. There are four different Medicare Savings Programs: Qualified Medicare Beneficiary Program, Specified Low-Income Medicare Beneficiary Program, Qualifying Individual Program, and Qualified Disabled and Working Individuals Program.]</p>	<p>(01) YES→ (02) NO→ (-8) Don't Know→ (-9) Refused→</p>	<p>(01) skip rest of MSP series (02) NEWVAR2 (-8) NEWVAR2 (-9) NEWVAR2</p>
<p>Required probes:</p> <ul style="list-style-type: none"> • Please tell me in your own words what you think this question is asking. • If receiving: How did you first become aware of these programs? • If not receiving: Have you heard of these programs before? 			
NEWVAR2	<p>Did [you/(SP)] apply to the [STATE] Medicare office for help with (CURRENT YEAR) expenses?</p>	<p>(01) YES (02) NO (-8) Don't Know (-9) Refused</p>	
<p>Required probes:</p> <ul style="list-style-type: none"> • Please tell me in your own words what you think this question is asking. • What did you think about when answering this question? What factors did you consider? 			
NEWVAR3	<p>Was [your/(SP's)] application for a Medicare Savings Program accepted or denied?</p>	<p>(01) ACCEPTED (02) DENIED (03) STILL PENDING/NO DECISION YET (-8) Don't Know (-9) Refused</p>	

<p>Required probes:</p> <ul style="list-style-type: none"> • Please tell me in your own words what you think this question is asking. • What did you think about when answering this question? What factors did you consider? • IF DENIED: Do you know why it was denied? What else are you doing now that it's been denied? 		
NEWVAR4	Before today, were you aware of these programs?	(01) YES (02) NO (-8) Don't Know (-9) Refused
<p>Required probes:</p> <ul style="list-style-type: none"> • What did you know about these programs? Where did you get that information? • If you didn't know much, or wanted to know more after this conversation, where would you go to get information? 		

RIGHT TO APPEAL/COMPLAINTS

These next questions ask about your experiences getting access to quality healthcare, and what you might do if you have any challenges to getting access to quality healthcare.

1. Think about all of the times you've sought healthcare under Medicare coverage. Have you ever had a difficult time getting an appointment with a healthcare provider you needed to see?
 - a. Yes
 - b. No
 - c. I don't know

2. Think about all of the times you've sought healthcare under Medicare coverage. Have you ever had a difficult time getting the care you needed during your appointment(s) with a healthcare provider you saw?
 - a. Yes
 - b. No
 - c. I don't know

3. Think about all of the times you've sought healthcare under Medicare coverage. Have you ever had a difficult time getting your care paid for through your Medicare insurance with a healthcare provider you saw because they were not submitting the correct claim information?
 - a. Yes
 - b. No
 - c. I don't know

4. In your own words, can you tell me a bit about what you would do if you had difficulty with getting an appointment, getting the care you need, or getting the care you received paid for properly?

5. Have you ever heard the term 'right to appeal'? What do you think it means?

6. What do you know about filing a complaint, or your right to file a complaint, based on concerns you have around the healthcare you've received?

[INTERVIEWER READ-ALOUD]: Everyone covered by Medicare has certain rights and protections under their Medicare coverage.

These rights include the right to file a complaint or appeal any decision or action made by a medical provider if you think you are being unfairly denied coverage, or denied adequate and complete treatment of your condition.

An appeal is the action you can take if you disagree with a coverage or payment decision by Medicare or your Medicare plan. For example, you can appeal if Medicare or your plan denies:

- A request for a health care service, supply, item, or drug you think Medicare should cover.

- A request for payment of a health care service, supply, item, or drug you already got.
- A request to change the amount you must pay for a health care service, supply, item, or drug.

You can also appeal:

- If Medicare or your plan stops providing or paying for all or part of a health care service, supply, item, or drug you think you still need.
- An at-risk determination made under a drug management program that limits access to coverage for frequently abused drugs, like opioids and benzodiazepines.

A **complaint** is about the quality of care you got or are getting. For example, you can file a complaint if you have a problem calling the plan, or you're unhappy with how a staff person at the plan treated you.

You file an appeal if you have an issue with a plan's refusal to cover a service, supply, or prescription. Learn more about appeals.

Thinking about this definition of your rights to complaints and appeals, please think about the following questions.

1. If you felt that a healthcare provider was ending your healthcare services too soon, would you know who to contact in Medicare to protect your rights and appeal?
2. If you had concerns about the **safety** of care you were receiving from a healthcare provider or facility, would you know how to file a complaint with Medicare?
3. If you had concerns about the **quality** of care you were receiving from a healthcare provider or facility, would you know how to file a complaint with Medicare?

USE OF CBD FOR PAIN MANAGEMENT

Q1: Now I would like to ask about your experiences with pain. In the past three months, how often did you have pain? Would you say:

- a. Never
- b. some days
- c. most days
- d. every day
- e. Don't Know
- f. Refused

If response is “Never, Don’t Know, or Refused” then skip to next series of items (Bowel Incontinence).

Otherwise, continue to Q2.

Q2: Since (TODAY'S MONTH AND YEAR - 3 MONTH), did you use any of the following to manage your pain? Please indicate yes or no to each one:

	Yes	No
Physical therapy, rehabilitative therapy, or occupational therapy		
Spinal manipulation or other forms of chiropractic care		
Massage		
Meditation, guided imagery, or other relaxation techniques		
CBD (cannabidiol) [IF NEEDED: CBD is different from Marijuana or THC. CBD is one of the many compounds that can be present in the cannabis plant and does not cause a “high” by itself. CBD is available in different forms, such as oils and tinctures (extracts), capsules (pills/softgels), edibles (gummies/candies), and topicals (creams/lotions/ointments).]		

BOWEL INCONTINENCE

Q1: We are now going to ask you some questions about your ability to control your bowel movements.

In the last 12 months, have you had any problems with leakage of stool, for example leaking gas, accidents, or soiling?

[IF NEEDED: Was that because you were sick?]

SELECT 'NO' IF THE RESPONDENT HAD ANY PROBLEMS DUE TO A SHORT-TERM DIARRHEAL ILLNESSES SUCH AS THE FLU OR A VIRUS.

- a. Yes
- b. No
- c. Don't Know
- d. Refused

**If response is “No, Don't Know, or Refused” then skip to next series of items (Health Equity).
Otherwise, continue to Q2.**

Q2: Did you have a problem with leaking gas only; a small amount of stool; a moderate amount of stool, often requiring a change of underwear; or a large amount of liquid stool, often requiring a complete change of clothes?

SELECT ALL THAT APPLY

- (A) leaking gas only
- (B) a small amount of stool
- (C) a moderate amount of stool, often requiring a change of underwear; or
- (D) a large amount of liquid stool, often requiring a complete change of clothes?
- (E) Don't Know
- (F) Refused

Q3: In the last 12 months, did you have this problem more than once a week, about once a week, 2-3 times a month, about once a month, every 2-3 months, or once or twice a year?

[IF NEEDED: Include all types of stool leakage, including: gas only; a small amount of stool; a moderate amount of stool, and/or a large amount of liquid stool.]

- a. more than once a week
- b. about once a week
- c. 2-3 times a month
- d. about once a month

- e. every 2-3 months
- e. once or twice a year?
- f. Don't Know
- g. Refused

Q4: Have you talked about your problem with stool leakage with [your/his/her] doctor or other health professional?

[IF NECESSARY: This is also referred to as bowel or fecal incontinence.]

- a. Yes
- b. No
- c. Don't Know
- d. Refused

Q5: Has your doctor or other health professional asked you about how you feel about this problem?

- a. Yes
- b. No
- c. Don't Know
- d. Refused

Q6: Has your doctor or other health professional examined you to figure out why you have a problem with stool leakage?

[IF NECESSARY: This is also referred to as bowel or fecal incontinence.]

- a. Yes
- b. No
- c. Don't Know
- d. Refused

Q7: Has your doctor or other health professional talked with you about taking medicine or having surgery for this problem?

[IF NECESSARY: Please answer based on your usual use of medication.]

- a. Yes
- b. No
- c. Don't Know
- d. Refused

HEALTH EQUITY—Perceived Discrimination

Q1: In the last 12 months, did anyone from a clinic, emergency room, or doctor’s office where you got care treat you in an unfair or insensitive way because of any of the following things about you?
(Response Options: Yes, No, Don’t know)

	Yes	No	Don’t know if this happened to me	Don’t know what this question is asking
Race or ethnicity				
Language or accent				
Gender or gender identity				
Sexual orientation				
Age				
Culture or religion				
Disability				
Medical history				

REQUIRED PROBES:

- What do you think these questions are asking?
- IF DON’T KNOW: Can you tell me more about what you’re thinking? If you were to answer these questions on your own (without me here) how do you think you’d guess at the meaning or answer? Do you not know if this happened to you or do you not know what this question is asking?
- When you were/if you were ever treated negatively, what would you do about it? Would you file a complaint or appeal with Medicare?
- Are there any reasons you think you’ve been treated negatively, that we didn’t list here?

DEFINITIONS:

[INTERVIEWER READ AS NECESSARY] Please think about the following terms and definitions when you answer these next questions. We are interested in how you personally identify, and whether you think that has influenced your care in the [REFERENCE PERIOD] regardless of whether you have told your care provider about these identities directly.

Race or ethnicity: This is how you think about or what you call your racial or ethnic background. For example, Black, Dominican, Hispanic, Mexican, Asian-American, Chinese.

Age: This is how old you are, in years. You might also think of it as being older, younger, or middle aged.

Sex: This is what is on your original birth certificate, such as male or female.

Gender: This is often what you call yourself, such as man or woman.

Gender Identity: This is often what you call yourself, and how you present yourself—such as man, woman, nonbinary, or genderqueer.

Sexual orientation: This is how you describe your sexual preferences and identities, such as straight, gay, lesbian, or bisexual.

Religion; This is the religion/religious preference with which you identify, such as Christian, Jewish, Muslim, or Agnostic.

Disability: This may mean a physical, mental, or other disability that you have currently or have experienced in the past year.

Health Equity—Religious Affiliation

<p>Q1. What is your religious preference?</p> <p>IF NEEDED: Please select the religion with which you most closely identify.</p>	<p>(01) PROTESTANT (02) CATHOLIC (03) EASTERN ORTHODOX, SUCH AS GREEK OR RUSSIAN ORTHODOX (04) JEWISH (05) BUDDHIST (06) HINDU (07) MUSLIM, ISLAM, SUFI, SUNNI, OR SHIA (08) SOME OTHER RELIGION (09) NO RELIGION (10) DON'T KNOW (11) REFUSED (12) NA</p>	<p>(01) End (02) End (03) End (04) End (05) End (06) End (07) End (08) Q2 (09) End (10) End (11) End (12) End</p>
<p>Q2. What is your religious preference?</p>	<p>(01) CONTINUOUS ANSWER</p>	<p>END</p>

REQUIRED PROBES:

STEP 3: THANK YOU AND INCENTIVE

[INTERVIEWER] Thank you for participating in the interview today. To thank you for your time, we'd like to send you a check for \$40. Could you please provide me with an address to mail the check to?

NAME: _____

STREET: _____

CITY: _____

STATE: _____ ZIP: _____