

## **MEDICARE CURRENT BENEFICIARY SURVEY (MCBS)**

# Task 1.32.a: Develop and Test Sexual and Gender Minority Status (LGBT) Items Final Summary Report

HHSM-500-2014-00035I, Task Order # HHSM-500-T0002

March 9, 2016

**PRESENTED TO:**

William Long, Contracting Officer's Representative  
Centers for Medicare and Medicaid Services  
7111 Security Boulevard  
Baltimore, MD 21244

**PRESENTED BY:**

Michael J. Stern, Stuart Michaels, Carolina Milesi, Melissa Heim Viox, and Heather Morrison  
NORC at the University of Chicago  
55 East Monroe Street  
30<sup>th</sup> Floor  
Chicago, IL 60603



*at the* UNIVERSITY of CHICAGO

# Task 1.32.a: Develop and Test Sexual and Gender Minority Status (LGBT) Items

## Final Summary Report

Michael J. Stern  
Stuart Michaels  
Carolina Milesi  
Melissa Heim Viox  
Heather Morrison

NORC at the University of Chicago

March 9, 2016

### **Prepared for**

The Centers for Medicare & Medicaid Services (CMS)  
Office of Minority Health and  
Office of Enterprise Data and Analytics  
US Department of Health and Human Services

**HHSM-500-2014-00035I, Task Order # HHSM-500-T0002**

This work was sponsored by the Centers for Medicare & Medicaid Services (CMS) Office of Minority Health (OMH) and the Office of Enterprise Data and Analytics (OEDA), but the opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of the US Department of Health and Human Services, the contractor or any other funding organization.

## Table of Contents

<b>Executive Summary .....</b>	<b>1</b>
<b>Introduction and Background .....</b>	<b>2</b>
Why Test Measures on LGBT Status for the MCBS? .....	3
<b>Methods.....</b>	<b>5</b>
Eligible Population .....	5
Recruitment .....	5
Interview Technique .....	7
Data Collection Instrument.....	8
<b>Results .....</b>	<b>11</b>
Quantitative Counts .....	11
Cognitive Testing Results.....	13
Sexual Identity: English Protocol .....	13
Sexual Identity: Spanish Protocol .....	18
Gender Identity: English Protocol .....	28
Gender Identity: Spanish Protocol.....	31
<b>Conclusions and Recommendations.....</b>	<b>40</b>
Summary of Findings .....	40
Final Recommendations .....	41
<b>Works Cited.....</b>	<b>43</b>
<b>Appendices.....</b>	<b>44</b>
Appendix A: Recruitment Message (English).....	44
Appendix B: Recruitment Script (English) .....	45
Appendix C: Medicare Beneficiary Study Frequently Asked Questions (English) .....	46
Appendix D: Recruitment Message (Spanish) .....	48
Appendix E: Recruitment Script (Spanish) .....	49
Appendix F: Medicare Beneficiary Study Frequently Asked Questions (Spanish) .....	50
Appendix G: Eligibility Screener Questionnaire (English).....	52

Appendix H: Eligibility Screener Questionnaire (Spanish) .....	54
Appendix I: Participant Consent Form (English).....	56
Appendix J: Cognitive Interview Protocol (English).....	57
Appendix K: Worksheet and Showcards for Questionnaire Testing (English).....	77
Appendix L: Participant Receipt Form (English).....	96
Appendix M: Participant Consent Form (Spanish) .....	97
Appendix N: Cognitive Interview Protocol (Spanish) .....	98
Appendix O: Worksheet and Showcards for Questionnaire Testing (Spanish) .....	120
Appendix P: Participant Receipt Form (Spanish) .....	138

## Executive Summary

At the request of the Office of Enterprise Data and Analytics (OEDA) and the Office of Minority Health (OMH), both at the Centers for Medicare & Medicaid Services (CMS), NORC engaged in research to explore including lesbian, gay, bisexual, and transgender (LGBT) measures in the Medicare Current Beneficiary Survey (MCBS). Importantly, the research explored extant measures that cover the two dimensions of LGBT reporting: sexual identity and gender identity. To date, there has been little work on sexual identity and gender identity on older segments of the population, especially those over 64, which make up the majority (85%) of Medicare beneficiaries. NORC conducted a series of cognitive interviews in both English and Spanish using existing sexual identity measures from the National Health Interview Survey (NHIS) as well as new gender identity measures to understand the level of comprehension and answerability of these questions among Medicare-eligible individuals. The methodology and results of this work are the basis for this report.

The cognitive interviews focused on comprehension (e.g., definition of transgender), decision-making (e.g., choosing the appropriate response from those listed), and ease in answering sensitive questions about one's sexual identity and gender identity. The 57 individuals with whom NORC completed interviews were of diverse backgrounds and included LGBT and non-transgender heterosexual respondents (hereinafter referred to as "R" or "Rs"); men, women, and one transgender individual; individuals who identified as Hispanic, African American, or White; English and Spanish speakers from a variety of national origins (e.g., Mexico, Cuba, and Puerto Rico); and different educational levels.

The major findings of this cognitive testing effort suggest that, in general, English speakers were able to comprehend questions about sexual identity and gender identity; however, a small number expressed discomfort with the questions and a few Rs did not understand the concept of "transgender". Still, these issues did not prevent the English speakers from answering the questions without difficulty. Conversely, Spanish speakers exhibited comprehension problems with questions about sexual identity; of particular concern was the term "heterosexual." Among Spanish speaking heterosexual Rs who struggled to comprehend this term, almost half stated "I don't know how to answer," while a majority stated they were "Something else." Both of these responses suggest that potentially among this group there could be increased levels of item nonresponse or non-substantive responses. Even though Spanish speakers expressed discomfort with the gender identity questions,

most often understanding non-transgender identity as a “normal” and “self-evident” gender expression, they were able to answer these questions.

We make several recommendations in this report. First, if CMS decides to add sexual identity measures to the MCBS, we suggest using the English version of the NHIS questions. For the Spanish version of the NHIS question, we suggest a minor revision. We recommend revising the response option for “heterosexual” with “not gay, that is, heterosexual”. We further recommend a brief introduction to these questions that lets Rs know the general topic of the subsequent three questions and also instructions for interviewers with responses they could provide to Rs if they are asked about the purpose of these questions, as it occurred frequently during cognitive testing. Finally, we recommend adding interviewer instructions with key terms and definitions used in these questions. The terms that should be defined include: Gay, Lesbian, Heterosexual, Bisexual, and Transgender. Consistent with other studies (e.g. Jans, 2016), our results suggest it is best to ask gender identity as a series of two questions, with an identical wording to what this study used in cognitive interviews: (1) gender assigned at birth, and (2) current gender identity.

## Introduction and Background

Eliminating health disparities in the U.S. has been a long-standing goal of the U.S. government and in particular the Department of Health and Human Services (DHHS). There is an increasing recognition that the lesbian, gay, bisexual, and transgender (LGBT) population, while diverse, experiences health disparities that are unique and related to its sexual and/or gender identities. The 2011 Institute of Medicine (IOM) report, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, was a major review of the state of knowledge of known and potential causes of health disparities as well as a call for more and better research emphasizing the need to include measures of sexual identity and gender identity in large representative population surveys. Healthy People 2020 (HP2020) set as an objective to “increase the number of population-based data systems used to monitor HP2020 objectives that include in their core a standardized set of questions that identify lesbian, gay, bisexual, and transgender populations.” Both HP2020 and the IOM report urge researchers to incorporate into their surveys questions that address the constructs of sexual identity and gender identity; further progress in this area should create useful data to assess health disparities within this population.

The Williams Institute at the UCLA School of Law has convened multi-disciplinary groups of experts to advance the development of sex and gender-related measures and increase population-based data about gay, lesbian, bisexual, transgender and other sexual and gender minorities. These research groups developed best practices for asking questions about sexual orientation and gender identity, which are consistent with the items tested in this study and with the recommendation made in this report (SMART, 2009; The GenIUSS Group 2014). Importantly, these reports concluded there is sufficient evidence to include measures of sexual orientation and gender identity in population-based surveys, and that it is possible to do so without sacrificing data integrity or respondent retention. The reports also highlight the importance of careful placement, mode adaptations, and interviewer training in order to improve quality of the data collected and provide sufficient privacy to encourage accurate responses.

A recent study tested alternative measures of gender identity with a subset of respondents in the California Health Interview Survey (CHIS), specifically 2,828 individuals ages 18-70 in cell-phone only households (Jans, 2016). Findings suggest it is best to ask gender identity as a series of two questions, with an identical wording to what this study used in cognitive interviews: (1) gender assigned at birth, and (2) current gender identity. Results also showed there were no break-offs or concerns noted after gender identity items were asked, suggesting that adding these questions to population-based surveys is not risky to surveys or offensive to respondents. There were no clear, systematic indicators of respondent difficulty such as asking clarification questions, long pauses, or expressing delay in response (e.g. *um*ing). There were no differences in length of response by respondents' age, but Spanish respondents took 2-6 seconds longer on average to answer these questions.

## Why Test Measures on LGBT Status for the MCBS?

---

The lack of representative population-based surveys that include measurement of the LGBT population has been one of the major hurdles to assessing the nature and extent of health disparities. As an increasing number of higher quality population surveys begin to collect at least some measures that allow the identification of sexual and gender minority individuals, the base of knowledge about the prevalence of health issues and other social disparities will continue to grow and develop, allowing more detailed analyses and informed policy decision-making.

The number of surveys that include measures that allow one to identify lesbian, gay, and bisexual older adults is still relatively low. However, in one of the rare instances where data exist on sexual identity on a large sample of older adults, there is strong evidence of health disparities in these populations. Karen Fredriksen-Goldsen and her colleagues (2013) used the cumulative data from the 2003 to 2010 Washington State Behavioral Risk Factor Surveillance System (BRFSS) surveys on adults 50 and above (N=96,992) to look at health outcomes, chronic conditions, access to care, behaviors and screening to compare men and women who self-identified as heterosexual to those who identified as gay, lesbian, or bisexual (LGB). They found that LGB older adults had higher risk of disability, poor mental health, smoking, and excessive drinking. Lesbian and bisexual women had higher rates of cardiovascular disease and obesity, and gay and bisexual men had higher rates of poor physical health and living alone than did heterosexuals. While limited to data on older adults from a single state, these findings point to the importance of surveys such as the MCBS to include at least a basic measure to identify members of the LGBT population who are likely to have differing health outcomes and needs.<sup>1</sup>

There has been relatively little work on sexual identity and gender identity on older segments of the population which make up the majority of Medicare beneficiaries; nearly 85 percent of all Medicare beneficiaries are 65 years or older. Given the lack of question testing on older adults, there is a significant benefit to cognitive testing of the question with Medicare beneficiaries, especially those over 64. Cognitive interviewing represents one important tool for pretesting survey instruments before they are fielded. This qualitative methodology is designed to address the cognitive processes Rs use when they answer survey questions, so that we can understand how Rs interpret the question and arrive at a final response. Through cognitive interviews, we can gather data on specific concerns such as the wording, concepts, and phrases used in draft questions and response categories. The following section presents details on the cognitive interview protocol designed to evaluate these questions and recruitment and interview methods. Following that we present a brief discussion of each theme identified in the cognitive interviews and present our recommendations for inclusion in the MCBS instruments.

---

<sup>1</sup> The central goals of MCBS are to determine expenditures and sources of payment for all services used by Medicare beneficiaries, including co-payments, deductibles, and non-covered services; to ascertain all types of health insurance coverage and relate coverage to sources of payment; and to trace processes over time, such as changes in health status and spending down to Medicaid eligibility and the impacts of program changes, satisfaction with care, and usual source of care.



## Methods

### Eligible Population

---

Medicare beneficiaries were eligible to participate in the cognitive testing. Interested participants were assigned a unique numeric identifier and were administered the Eligibility Screener Questionnaire (Appendices G and H) to determine their eligibility to participate in the cognitive interviews. The study aimed to conduct cognitive testing interviews with up to 60 individuals: 40 individuals self-identifying as Spanish speakers and 20 individuals whose primary spoken language is English. The team completed 37 interviews with Spanish speakers and 20 interviews with English speakers, for a total of 57 completed interviews.

### Recruitment

---

Based on the eligibility criteria mentioned above, NORC recruited participants between late August 2015 and January 2016. The recruitment relied on multiple methods and aimed to reach particular individuals or organizations that could, in turn, assist in the recruitment of individuals. NORC recruited participants through a variety of locations across Chicago, IL, Atlanta, GA, and Washington D.C. Locations for recruitment were diverse, including senior centers, health clinics, community centers, agencies with an LGBT focus and members, Craigslist, and through NORC researchers' personal networks. Flyers were created using existing language from the recruitment script approved by OMB. (See Appendices B and E). The recruitment was accomplished in two phases.

### Phase I

Participants were targeted based on four broad categories in order to produce a diverse study sample: English speaking non-transgender heterosexual identified participants (n=15), English speaking LGBT identified participants (n=5), Spanish speaking non-transgender heterosexual identified participants (n=25), and Spanish speaking LGBT identified participants (n=15). NORC oversampled Spanish speaking participants in order to account for understandings of sexual identity and gender identity based on cultural and demographic differences (Aday et al., 1980; D'Alonzo, 2011; Erens, 2014). In addition to these requirements, participant characteristics ranged in regard to age, gender, racial and ethnic identity, and education level.

NORC placed Craigslist ads online to recruit study participants in Chicago, Atlanta, and Washington D.C. Online advertising generated a pool of potential candidates. Interested individuals would call a toll-free number and leave a message on the voicemail for the number designated for this study or e-mail an inbox specific to the project. A NORC employee who spoke the same language as the potential R would then call them back and administer the screening questionnaire.

NORC carried out a systematic scan of senior living communities in Chicago, IL, and Washington, DC. Five of these centers partnered with NORC to recruit their members to join the study. Managers from these independent organizations agreed to inform and recruit residents. The building managers and community center personnel who recruited participants administered an abbreviated eligibility screening process with interested individuals. It is important to note that these centers were located in different neighborhoods. This allowed us to reach different racial and ethnic populations, as well as Rs who spoke English and Spanish.

NORC also reached out to a variety of community, research, and non-for-profit organizations that assisted in specifically locating Spanish speaking LGBT participants. These organizations contacted providers and community networks within their networks. These outreach efforts yielded some, but not sufficient study participants.

NORC researchers also scanned their networks to determine eligible participants. Project staff contacted personal and professional contacts who would likely be eligible for the project or had connections to those who would, and requested that they assist with recruitment. Informal snowball or referral sampling was also used, wherein participants were provided with flyers at the end of the interview and encouraged to share information about the project with their friends who might be interested in participating.

At the end of Phase I, 33 interviews had been completed including: 12 English, Heterosexuals; 5 English, LGBT; 15 Spanish, Heterosexual; and 1 Spanish, LGBT.

## Phase II

During the third month of recruitment, CMS and NORC met to discuss the challenges of continuing recruitment of LGBT Spanish speaking participants. To determine if further interviews were needed, NORC paused to review the findings from the initial completed interviews. In general, the findings showed that, similar to other available research and evidence, the sexual and gender identity items

were salient for sexual and gender minority individuals and that these Rs were therefore familiar with the language and wording of the questions tested. Also as expected, we did find that heterosexual, non-LGBT participants indicated some problems with the questions. Sexual and gender identity were not as salient for this group and some Rs were not as familiar with terms such as “heterosexual” and “bisexual”. This was particularly true among individuals with lower education levels, and especially non-English speakers. NORC therefore recommended that the remaining interviews focus on the Hispanic non-LGBT Rs, as this was the group identified as having the most issues with the items.

Based on this discussion, NORC received CMS guidance to shift the allocation of the remaining cognitive interviews. The target number of Spanish LGBT interviews was decreased from 15 to 5, and the Spanish non-transgender heterosexual category was increased from 25 to 35. In addition, the revised targets included one Spanish speaking transgender beneficiary of any age and at least one Spanish speaking LGBT beneficiary under age 65.

Taking both Phase I and Phase II into account, NORC recruited a total sample of 57 diverse Rs, including 9 LGBT individuals and 48 non-LGBT, non-transgender (referred sometimes as straight in subsequent discussions for ease of reference) individuals from three large metropolitan areas. Rs were identified from urban cities and suburban towns. The English speaking R pool included a range of racial backgrounds – White, Black, Asian, and American Indian. The Spanish speaking R pool included a variety of nationalities – Mexican, Puerto Rican, Honduran, Salvadorian, Nicaraguan, Panamanian, Cuban, and Peruvian. Additional demographic details on the Rs included in this research can be found in Table 1.

## Interview Technique

---

Cognitive interviewing is an important innovation in the development and testing of survey questionnaires that has emerged over the last 25 years. Its chief strength is in providing a structured methodology for ascertaining whether the R has understood the questions in the way the researchers intend them to be understood, and to assess the ability of the Rs to provide meaningful, accurate, and honest information. Cognitive interviewing techniques range from loosely organized “think aloud” interviews to structured “verbal probing” to elicit particular conceptual domains. Interview protocols can specify probing during an interview and/or at the end of the interview.

NORC implemented retrospective probing for MCBS cognitive interviews, in which Rs answer questions as normal and then interviewers probe with additional questions aimed at confirming

comprehension of questions and terms, identifying sources of confusion or ambiguity in survey questions and learning how Rs arrive at answers. This strategy was also intended to uncover the decision making processes and embedded assumptions that Rs harbor when answering questions of identity. Probing was also designed to reveal other differences; questions are also interpreted differently based on age (Austin et al., 2013; Haseldon & Joloza 2009), race and ethnicity, as well as minority status (Paterson 2000; Rith & Diamond 2013; Warner et al. 2013), among subgroups in the United States. In this research project, another reason cognitive interviewing is an effective method is due to the stigma facing sexual minorities to acknowledge homosexual or bisexual behavior (Centers for Disease Control and Prevention 2000) as well as the problematic attitudes heterosexuals hold toward non-heterosexual behavior (Michaels & Lhomond 2006; Rule et al. 2011).

In light of these cultural variations and concerns, cognitive interviewing exposed how each R interpreted questions on sexual identity and gender identity and how they arrived at their final response. Through this technique, NORC gathered data on specific concerns such as the wording, concepts, and phrases used in draft questions and response categories.

Some general probes used during the cognitive interviews on the sexual identity and gender identity questions were as follows:

- How did you decide on that answer?
- Can you tell me more about that?
- Can you give me an example of that?
- Tell me what you are thinking.
- What did you think about when I asked that question?
- What did you think about in deciding on your answer?
- What doctors did you include when you answered this question?
- What does [Bisexual / Transgender] mean to you?

## Data Collection Instrument

---

The LGBT cognitive testing protocol and materials, including the recruitment script, eligibility screener questionnaire, Frequently Asked Questions (FAQs), participant consent form, cognitive interview protocol, and participant receipt form, were submitted by CMS to OMB for review on June 22, 2015 under the Generic Clearance for Questionnaire Testing and Methodological Research for

the MCBS (No. 0938-1275, expiration 05/31/2018); OMB approved the test on July 14, 2015. NORC's Institutional Review Board (IRB) approved the testing protocol on June 21, 2015.

The cognitive interviews were conducted in-person by NORC staff with training and experience in cognitive interviewing and qualitative research. The cognitive interviews were conducted using abbreviated sections of the current MCBS questionnaire including the demographic items, which included the LGBT items to be tested. The interviewer first administered the survey items using a paper-and-pencil instrument and then led the R through a series of retrospective probes to explore how the R understood the questions and arrived at their response. The English and Spanish protocols are included in Appendices J and N. Each interview lasted between 20 and 60 minutes.

Cognitive testing focused on three specific items, displayed below in English and Spanish. These items correspond to questions 52, 53, and 54. While question 52 is related to individuals' sexual identity, questions 53 and 54 are related to individuals' gender identity.

### Sexual Identity Question: English protocol

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

[Response options for male Rs]:	[Response options for female Rs]:
<ul style="list-style-type: none"> <li>• Gay</li> <li>• Straight, that is, not gay</li> <li>• Bisexual</li> <li>• Something else</li> <li>• I don't know how to answer</li> </ul>	<ul style="list-style-type: none"> <li>• Lesbian or gay</li> <li>• Straight, that is, not lesbian or gay</li> <li>• Bisexual</li> <li>• Something else</li> <li>• I don't know how to answer</li> </ul>

### Gender Identity Questions: English protocol

<b>What sex were you assigned at birth, on your original birth certificate?</b>
<ul style="list-style-type: none"> <li>• Male</li> <li>• Female</li> </ul>
<b>How do you describe yourself?</b>
<ul style="list-style-type: none"> <li>• Male</li> <li>• Female</li> <li>• Transgender</li> <li>• Do not identify as female, male, or transgender</li> </ul>

### Sexual Identity Question: Spanish protocol

*¿Cuál de las siguientes mejor representa su manera de pensar en sí mismo?*

[Response options for male Rs]:	[Response options for female Rs]:
<ul style="list-style-type: none"> <li>• Gay</li> <li>• Heterosexual, o sea, no gay</li> <li>• Bisexual</li> <li>• Otra cosa</li> <li>• No sé la respuesta</li> </ul>	<ul style="list-style-type: none"> <li>• Lesbiana o gay</li> <li>• Heterosexual, o sea, no lesbiana o gay</li> <li>• Bisexual</li> <li>• Otra cosa</li> <li>• No sé la respuesta</li> </ul>

### Gender Identity Questions: Spanish protocol

<b>¿Qué sexo le asignaron al nacer, en su acta de nacimiento original?</b>
<ul style="list-style-type: none"> <li>• Hombre</li> <li>• Mujer</li> </ul>
<b>¿Se describe a sí mismo(a) como hombre, mujer o transgénero?</b>
<ul style="list-style-type: none"> <li>• Hombre</li> <li>• Mujer</li> <li>• Transgénero</li> <li>• No me identifico como mujer, hombre ni transgénero</li> </ul>

## Participant Incentives

Rs were provided with \$40 as an incentive for participating in the study. They also signed and received a copy of the Participant Receipt Form (Appendices L and P).

## Confidentiality

Cognitive interview Rs were informed that their participation was voluntary. They were also informed that the information they provide was confidential, consistent with the Privacy Act of 1974. They were informed that the interview would be audio-recorded and that the recording would only be used for analysis and report writing. They were advised that any quotes used in research papers and professional presentations would not include any names or any information that could identify a participant. To protect R confidentiality, Rs were assigned a unique identifier. The signed consent forms were kept separately from the interview files in a locked cabinet for the duration of the study and will be destroyed after the final report is completed. (Appendices I and M)

# Results

## Quantitative Counts

---

Tables 1 and 2 show the distribution of English- and Spanish speaking Rs by demographic characteristics. Table 1 shows NORC conducted 20 cognitive interviews in English, including 15 heterosexual and non-transgender Rs, and 5 LGBT Rs. We interviewed 9 males and 11 females, with a diverse representation of race. All but one R reported having an education level of high school or more. Table 2 shows we conducted 37 cognitive interviews in Spanish, 33 of them with heterosexual and non-transgender Rs and 4 of them with LGBT Rs. We interviewed 13 males and 24 females, with a diverse representation of national origins, specifically 18 Rs who identified as Mexican/Mexican American/Chicano; 6 as Puerto Rican; 1 as Cuban; and 12 as Other Hispanic origin. Spanish speaking Rs had lower levels of education than English speaking Rs: Seventy percent of Spanish speaking Rs had not completed high school (n=26) and thirty percent had an education level of high school or more (n=11).

**Table 1:** Demographic characteristics of English speaking Rs

	Gender		Education		Race/Ethnicity				Age	
	Male	Female	Below HS	HS and above	White non-Hispanic	Black non-Hispanic	Asian non-Hispanic	Multiple (White/American Indian)	Mean	Median
<b>Non-transgender heterosexual</b>	5	10	1	14	4	8	2	1	67	70
<b>LGBT</b>	4	1	0	5	3	2	0	0	59	77

**Table 2:** Demographic characteristics of Spanish speaking Rs

	Gender		Education		Race/Ethnicity				Age	
	Male	Female	Below HS	HS and above	Hispanic (Mexican)	Hispanic (Puerto Rican)	Hispanic (Cuban)	Hispanic (Other)	Mean	Median
<b>Non-transgender heterosexual</b>	11	22	26	7	17	5	0	11	69	69
<b>LGBT</b>	2	2	0	4	1	1	1	1	56	58



## Cognitive Testing Results

---

This section provides a description of results from cognitive testing. Because the screener asked about sexual identity, we have an opportunity to compare screener results with results from answering the questionnaire items. We first present results from testing of the sexual identity item among English speaking Rs, followed by results from testing of the same item among Spanish speaking Rs. We then present results from testing the gender identity items, first for English speaking Rs and then for Spanish speaking Rs. The team identified the main themes that came up during cognitive testing of sexual identity and gender identity items for each language group. For each theme, results presents quotes from Rs and interviewer observations that exemplify and support that theme.

### Sexual Identity: English Protocol

---

#### Conflation of sexual identity and gender identity

A couple of English speaking participants seemed to confound sexual identity with their gender identity. As a result, these Rs explained their answers to the question about sexual identity by referring to their gender or gender identity.

- [R121, 81 years old] Male, Straight/Male, Straight<sup>2</sup>: He laughed before answering this question. He said he was “100% male or man” he knows what he is, he’s “110% male.”

#### Discomfort with question

Some participants expressed discomfort with this question and with the follow-up discussion about this question. Discomfort was related to (1) public disclosure of sexual identity; (2) difficulty discussing any sex-related issues; (3) moral concerns about non-heteronormative sexual identity.

- [R104, 44 years old] Male, Straight/Male, Don't know how to answer: When asked this question, R paused and thought for a while, then asked why they were asking this question. The interviewer responded by saying that it was to gather additional information. R chose the last response, “I don’t know how to answer.”

---

<sup>2</sup> The first two terms indicate R’s classification of their gender identity and sexual identity during the screener in questions 1 and 8, respectively. The last two terms indicate R’s classification of their gender identity and sexual identity during the cognitive interview in questions 54 and 52, respectively.

- [R107, 34 years old] Female, LGBT/Female, Lesbian: On the question of sexual identity, R107 expressed her discomfort with answering this question through another question asked to the interviewer. R107, upon being asked Q52, asked if her name would be linked to any information shared during the interview. R107 identifies as a lesbian, yet was cautious to publicly advertise this information when asked during the interview.
- [R118, 78 years old] Female, Straight/Female, Straight: R found the sexual identity ‘questionable’ – indicated that by us asking the question we were likely to convert people to being gay/lesbian/bi.
- [R132, 68 years old] Female, Straight/Female, Straight: The immediate reaction to this question was a drawn out “oh my goodness,” to suggest “why are you even asking me this.” R132 claimed that she would never ask this kind of question because it’s embarrassing. Asked what is embarrassing about this question, R132 claimed she “had never been asked, so it’s a little strange to ask,” suggesting that the shock value of this question relied on the fact that it is not something usually discussed. “Nobody has asked me that kind of question,” R132 stated. R132 also thought that the shock might be a “cultural difference.” R132 also thought that if a lady asked her this question she would react differently than having to explain her sexual identity to a male, a male who is her son’s age. “It’s just cultural, I have nothing against it (e.g., gay, bisexual), it’s just an open society here and I’m still old fashion” R132 finished off saying with a laugh.
- [R150, 78 years old] Female, Straight/Female, Don't know how to answer: When the interviewer asked “What did you think about when I asked that question?” participant said “Very unusual, but...very unusual but it’s...not really unusual in this day and age, but still to me, it’s unusual to be answering questions like this. I’m 78 years old. I’ve been married for 39 years to the same man. So, that’s why it’s so unusual to me.

### “Normal” sexual identity

Heterosexual participants identified their sexual identity as “normal.” This applied mostly to Spanish speakers (as we will discuss below), but some English speakers also equated being straight with being “normal” and “regular.”

- [R118, 78 years old] Female, Straight/Female, Straight: She reiterated that she was ‘normal’ and that straight was normal, others were not.

- [R121, 81 years old] Male, Straight/Male, Straight: When asked if there were any other terms he might use to describe straight he said “normal.”
- [R131, 75 years old] Female, Straight/Female, Straight: R131 said she understood these terms but did not want to explain them further, although when R131 did explain her understanding of these terms further she equated bisexual, lesbian and gay as terms that meant the same thing: that they are identities that stray away from the normative understanding of sexuality, as between a man and a women.
- [R150, 78 years old] Female, Straight/Female, Don't know how to answer: When the interviewer first asked this question, R started laughing and said “I don’t know how to answer this question. I’m a female and I’m not bisexual. I’m just a regular woman.”

### **Time frame of sexual identity**

Two participants expressed concern about the time frame of the question. They referred to (1) the fluid nature of sexual identity; and (2) the fact that past behavior may not determine one’s current sexual identity.

- [R104, 44 years old] Male, Straight/Male, Don't know how to answer: When probed on what R was thinking about for this question after the survey was completed R responded that it was about “which way someone goes” and added that it is something that could change day by day and minute by minute, that there was no “set thing with this type of thing.” R said it was “not constant” and could “change as you meet new people.”
- [R110, 24 years old] Male, LGBT/Male, Gay: The sexual identity question related to a concept of how you live your life right now and how you aspire to live your life. The question was not answered by R110 through past actions, which R110 claimed he did engage in a period of having sex with both men and women. Sexual identity, to R110, relies on the behavior someone is involved with currently or plans to be involved with in the future rather than behavior that has occurred in the past. The term “gay” related to having sex with a man but also aspiring to only have sexual relations with a man.

### **Ability to answer question about sexual identity**

Despite the issues discussed in this section, English speakers were able to consistently answer the question about sexual identity. We compared Rs’ self-reported sexual identity provided during the screener (Q. 8: “Do you, personally, identify as lesbian, gay, bisexual, or transgender?” Yes/No) to

Rs' self-reported sexual identity provided during the cognitive interview (Q. 52: 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). All but two English speaking Rs provided identical responses about their sexual identity during the screener and the cognitive interview, when the actual wording of question 52 was tested. The exception were two participants who, during the screener indicated they did not "personally, identify as lesbian, gay, bisexual, or transgender" while indicating "I don't know the answer" as their response to question 52 during the interview. Both participants, one male and one female, conveyed several challenges with question 52. This male participant (1) expressed some discomfort about this question (i.e., he asked why we were asking these questions); (2) indicated the time reference was not clear, as sexual identity is a fluid concept; and (3) suggested having an "all the above" response category. The female participant (1) thought it was "really unusual" for her to be answering these questions given her age and the fact she had been "married for 39 years to the same man"; and (2) indicated she was "just a regular woman." All other English speaking participants were able to provide an answer to the question about sexual identity and to do so in a consistent fashion across two different instruments and two different wordings of the question and its response categories.

**Table 3:** Consistency of sexual identity report in screener versus cognitive interview among English speaking Rs

Reported at screener: Do you, personally, identify as lesbian, gay, bisexual, or transgender?	Reported at cognitive interview: Which of the following best represents how you think about yourself?				
	Gay or lesbian	Straight/heterosexual	Bisexual	Something else	Don't know how to answer
Yes	5	0	0	0	0
No	0	13	0	0	2

**Table 4:** Demographic characteristics of English speaking Rs with consistent self-identification

Gender	Education		Race/Ethnicity					Age	
	Below HS	HS and above	White, non-Hispanic	Black, non-Hispanic	Asian, non-Hispanic	Hispanic	Multiple (White/American Indian)	Below 65	65 and above
Male	0	8	4	4	0	0	0	3	5
Female	1	9	2	5	2	0	1	2	8

**Table 5:** Demographic characteristics of English speaking Rs with inconsistent self-identification

Gender	Education		Race/Ethnicity				Age	
	Below HS	HS and above	White, non-Hispanic	Black, non-Hispanic	Asian, non-Hispanic	Hispanic	Below 65	65 and above
Male	0	1	1	0	0	0	1	0
Female	0	1	0	1	0	0	0	1

## Sexual Identity: Spanish Protocol

---

### Understanding sexual identity as gender

The majority of Spanish speaking participants did not distinguish sexual identity from gender identity. Therefore, they explained their answer to the question about their sexual identity by stating their gender, indicating they were “male” or “female”, a “real man or real woman”, and “100 percent male or female.”

- [R125, 71 years old] Female, Straight/Female, Don't know: “I decided on that answer [“I don't know how to answer”] because I am 100 percent woman.”
- [R128, 69 years old] Male, Straight/Male, Don't know: When asking question 52, participant defined himself as ‘a real man’.
- [R129, 73 years old] Female, Straight/Female, Don't know: “I have not been this, I have not been that, that question I wouldn't know how to answer. I identify as a woman... who hasn't been any of this.” When asked “What else would best represent how you think about yourself?” she replied “I consider myself a woman... 100 percent a woman.”
- [R135, 68 years old] Male, Straight/Male, Something else: When asked “What did you think about when I asked that question?” he said “well, I thought that I am not gay, not heterosexual, not bisexual, so I was confused. ‘Something else’ means that I am not none of these, that I am still a man.”
- [R136, 73 years old] Female, Straight/Female, Heterosexual: She used the word normal and “hembra” (female) to describe herself.
- [R139, 76 years old] Male, Straight/Male, Heterosexual: Hesitated with the answer choices. Said “I consider myself normal, a normal man. I have a marriage.”
- [R144, 66 years old] Female, Straight/Female, Heterosexual: When the interviewer asked “What did you think about when you decided what to answer?” R said “That yes, I am a woman.”
- [R145, 82 years old] Female, Straight/Female, Something else: “I am completely a woman...I am none of the things that are written there. But neither am I an enemy of any of those.”

- [R147, 71 years old] Female, Straight/Female, Something else: When the interviewer asked “What did you think about when I asked you this question?” R said “Well, I don’t know the response, because this is not for me. Because I’m not a lesbian, nor gay, nor any of these things. I was born a woman and will always be a woman. I will never change.”
- [R153, 73 years old] Female, Straight/Female, Something else: When the interviewer first asked this question, R indicated “none of those. I am a woman, but I don’t have any of those other things.”

### Discomfort with question

Several Spanish speaking participants expressed discomfort with the sexual identity question and with the follow-up discussion about this question. Discomfort is related to (1) lack of understanding of response categories accompanied by desire to answer the question correctly; (2) difficulty discussing any sex-related issues; and (3) understanding of question as a threat to one’s femininity or masculinity. Some Rs also questioned why we needed to gather this information and asked what the purpose of the study was.

- [R114, 62 years old] Male, Straight/Male, Heterosexual: Participant mentioned he did not have a problem answering these questions. Nonetheless, he seemed a little uncomfortable when he was probed about his thinking in answering. He expressed feeling a little nervous of the interviewer thinking he was not sure about his answer. He emphasized how sure he is of his manhood.
- [R116, 67 years old] Female, Straight/Female, Don’t know: When asking R116 about Q52 she laughed nervously. She read the show card several times and could not decide the term that described her best. She chose “I don’t know the answer” but asked several times for a definition of each word (which was not provided during the interview) so that she could “answer correctly.” She described these questions as something new for someone her age. She emphasized that her generation never had an open conversation regarding sexuality.
- [R124, 68 years old] Female, Straight/Female, Don’t know: Although participant #124 didn’t express any discomfort with the LGBT questions, she seemed ashamed about not knowing the terminology in questions 52 and 54.

- [R125, 71 years old] Female, Straight/Female, Don't know: "I thought you were asking me if I was a lesbian or if I was a man. I felt a bit uncomfortable, since I am a woman [...] the only question I have is why you are asking me all these questions if I am telling you I am 100 percent woman."
- [R128, 69 years old] Male, Straight/Male, Don't know: He seemed nervous about not having a proper answer or saying something that could question his masculinity.
- [R136, 73 years old] Female, Straight/Female, Heterosexual R said she thought the interviewer was "crazy" for asking those types of questions.
- [R144, 66 years old] Female, Straight/Female, Heterosexual: R was uncomfortable when asked to discuss specific terms. When the interviewer asked "What does bisexual mean to you?" R said "To be honest, I don't understand it. I don't understand it. I only know that I'm a woman, and that men exist. Those words to me – I don't know, I don't really understand them. I really respect – that they are very respectful, both men and women. But I don't understand anything."
- [R145, 82 years old] Female, Straight/Female, Something else: When the interviewer asked "What did you think about when I asked that question?" R said "Now, I didn't do anything, because in the beginning, when they would ask me this, [I would say], 'have you seen me carrying on with another woman? Have you seen me one time? That I have had [something] with someone?' 'Well, no, look, it's since one never sees you with a man...'"
- [R152, 65 years old] Male, Straight/Male, Heterosexual: When the interviewer asked "What did you think about when I asked you this question?" the participant provided a long answer, specifically indicating this was a very personal question. "They are very personal questions, no? The person who is answering has to be sincere, frank, in that respect. If some asks you, you have to say what you are. Because if not, you lead a double life, which often happens. If you're being interviewed, you have to be sincere in that case. One will not lie or hide what one is. Man, woman, whatever type of human being that they may be, if they are not sincere, what can they be? That's the first motive of a human being. No matter what kind of person, how they label themselves, what their personal life is like. If they're not sincere, then they're not even sincere with God. Because God pardons everyone, how they are, how they live. If one is not sincere with themselves and with others, [it is even less likely that] they will be sincere with God."



- [R153, 73 years old] Female, Straight/Female, Something else: R recognized the question was difficult to answer “because I wasn’t sure about what I was saying. What I could say.” When asked how would she described herself she said “I don’t have many words. I am a woman who helps others when she can, an amiable woman, I think before I speak...Look, lesbians live in their world, and I don’t have – every person has to live their own life. And if they’re bisexual, I don’t have to put myself – because sometimes they’re things that come from birth. I say, could they be things from God? Because I can’t say anything. So I don’t have a bad opinion about them.”
- [R154, 66 years old] Female, Straight/Female, Don’t know: During the prompts, when the interviewer asked “What did you think about when I asked that question?” R indicated “I thought you were asking me if I like women... but no! I am a woman but I don’t like women.” When the interviewer asked “How did you decide on that answer?” R said “The question caught me by surprise. I didn’t know what to reply. My problem was not knowing what to answer.” She recognized she had some trouble deciding what to answer because “sometimes I am doubtful about the question and the categories you are asking me about.”
- [R155, 35 years old] Female, Straight/Female, Don’t know: When the interviewer asked the R “What did you think about in deciding on your answer?” she said “I thought why you were asking me this question. Why are you interested in this?” When the interviewer asked “why do you think we are interested in this?” she said “I don’t know, maybe you want to know how many gay and lesbian people are there and this is what the survey is about.”
- [R157, 47 years old] Male, LGBT/Male, Gay: When the interviewer asked him “What did you think about when I asked that question?” he said “nothing. I am gay. I thought you were asking me how I consider myself and I didn’t get offended. I’m certain in who I am.” He later elaborated and said “I thought it was a bit odd you were asking this, but, well, this is a study and nowadays people are more open to whether people are gay, transgender, bisexual, or something else. I felt a bit uncomfortable. It was odd, but not too odd because the world is changing and being more accepting of different people.” When the interviewer asked “Why did you think we were asking this question? he said “maybe, it’s similar to the question you asked me about whether I was Hispanic or Latino, sometimes people are proud to be Puerto Rican or Mexican or whatever. It’s an odd question, but we are all the same in this world.”

## “Normal” sexual identity

During the probes, when asked “What else would best represent how you think about yourself?” it was very common for Spanish speaking heterosexual participants to identify their sexual identity as “normal.” Some Rs also referred to themselves as “regular”, “correct”, “complete”, a “very good person” or indicated they do not have a mental illness.

- [R120, 65 years old] Female, Straight/Female, Heterosexual: She defined herself as a normal person so she felt Q52 did not apply to her.
- [R126, 69 years old] Female, Straight/Female, Heterosexual: When explaining answer to question #52, she used the word “normal” to define herself rather than heterosexual.
- [R127, 71 years old] Female, Straight/Female, Don’t know: “I am not lesbian, not gay, I feel I am a normal woman.”
- [R128, 69 years old] Male, Straight/Male, Don’t know: Participant said he consider himself “normal.” When asking for a deeper exploration of his answer, he said he is a “normal man but normal behaviors who believe in having sex with a woman but never in excess.”
- [R133, 51 years old] Male, Straight/Male, Heterosexual: His initial response was “I’m regular.” While the interviewer waited for him to select a response, he said “the second one... how do you pronounce that? Hmmm, not gay.”
- [R134, 70 years old] Male, Straight/Male, Don’t know: When the interviewer asked him “What else would best represent how you think about yourself?” he said “I am a person, a man... I am a normal person... I am what I am.”
- [R137, 74 years old] Female, Straight/Female, Bisexual: She used the word “normal” more than once.
- [R138, 86 years old] Male, Straight/Male, Heterosexual: When the interviewer asked “What did you think about when I asked you that?” R said “I don’t have any mental illnesses [*trastorno mental*] to change my sex. I am heterosexual.”

- [R140, 67 years old] Female, Straight/Female, Heterosexual: R did not indicate she was “normal” but could not find a term other than “normal” to refer to heterosexual individuals. When the interviewer asked “What did you think about when I asked you this question?” she said “I have acquaintances and friends – and I have realized that the world is ugly. For the people who aren’t, and I don’t want to say ‘normal’ because that’s not a word, who is to say what is normal? That aren’t the most common things, their lives are difficult. And there are people who think, ‘why do they want to be like that?’ That they have decided to be like that, but that isn’t something that a person chooses, because it isn’t an easy life. There are people who say they were born like that, or they were made like that. I think that people are born like that.”
- [R143, 69 years old] Female, Straight/Female, Something else: When the interviewer asked “What did you think about when I asked you that question” she said “I didn’t think about anything. As I am...of no...I’m a “correct” woman, I got married...” When the interviewer asked “Is there another word that better represented how you consider yourself?” she said “I consider myself to be a ‘correct’ woman.”
- [R146, 80 years old] Female, Straight/Female, Something else and Don’t know: R hesitated over the responses and said “I separated from the father of my children when they were young, 57 years ago. Since then, I never got remarried. I stayed single. I don’t know the response...because I am a complete woman, I had my husband, my kids, it didn’t go well for me, I stayed single.” When the interviewer asked “What did you think about when I asked that question?” she said “That I’m not any of those...I’m a complete woman.”
- [R147, 71 years old] Female, Straight/Female, Something else: When the interviewer asked “what else would best represent how you think about yourself?” R said “A very good person.”
- [R151, 75 years old] Female, Straight/Female, Something else: When the interviewer asked “what else would best represent how you think about yourself?” R said “A normal woman....I am married, I have my family, my children.”

### Limited response options

Two LGBT Spanish speaking Rs questioned the lack of exhaustive response options. The transgender R identified as a “transsexual woman attracted to men”. She thought none of the response categories applied to her and as result selected “something else”. A gay R also

recommending adding the response “questioning” for individual who are uncertain of his or her sexual identity.

- [R156, 38 years old] Transgender, LGBT/Female, Something else: The R selected “something else” because she did not feel the choices were inclusive of diverse lives. The R had a very clear understanding of the definition for the terms gay/lesbian, bisexual, and heterosexual. She is a transsexual woman who is attracted to men, and none of the response choices apply to her. Since she is a woman attracted to men, she is not gay. She recommended that we add more inclusive response choices like “transsexual man” and “transsexual woman.”
- [R157, 47 years old] Male, LGBT/Male, Gay: When the interviewer asked “do you think there is any other information we could provide in this question to facilitate others’ responses to this question?” he said “I would recommend adding LGBTQ, with Q for questioning, they are still wondering and they are part of the community.”

### **Inability to answer question about sexual identity due to lack of comprehension of term “heterosexual”**

A lack of comprehension of the term “heterosexual” was found among most of the Spanish-speakers with low levels of education, especially women. For most of the non-LGBT Spanish speaking Rs’ lack of familiarity and misunderstanding of the term “heterosexual” prevents them from selecting the appropriate response category, namely “heterosexual, that is, not gay” (the literal English translation of the Spanish) Most Rs described a process in which they decided what to answer based on the elimination of categories they did not know or did not apply to them. Therefore, when the presumably heterosexual Spanish-speakers (based on their saying that they were not LGBT on the screener) reviewed response categories for question 52, they tended to select a category that was ‘not gay’, ‘not heterosexual’, and ‘not bisexual’ – since they thought none of these categories described them. We compared self-reported sexual identity provided during the screener (Q. 8: “Do you, personally, identify as lesbian, gay, bisexual, or transgender?” Yes/No) to self-report sexual identity provided during the cognitive interview (Q. 52: Which of the following best represents how you think about yourself? Lesbian or Gay; Heterosexual, that is, not lesbian or gay; Bisexual; Something else; I don’t know how to answer). We found that 20 out of 37 Spanish speakers provided inconsistent responses across these two instruments (54 percent of Spanish speakers). Out of 33 Rs who said they did not personally identify as LGBT during the screener, only 14 selected

“heterosexual” as their responses to question 52 during the interview – a consistent response across the screener and cognitive interview. Among the rest of Spanish speakers who said they did not personally identify as LGBT on the screener, 10 selected “I don’t know how to answer”; 6 selected “Something else”; 2 selected both “I don’t know” and “Something else”; and one selected “Bisexual”.

- [R125, 71 years old] Female, Straight/Female, Don’t know: “I don’t identify with any of those categories... I hear now on TV what it means to be a lesbian, heterosexual, all those things.”
- [R134, 70 years old] Male, Straight/Male, Don’t know: Participant selected “I don’t know how to answer.” When asked “What did you think about when I asked that question?” he said “I thought I was something else. I am neither gay, nor heterosexual, nor bisexual... I am none of these [categories].” He reported there are no words he is uncertain about. He defined *heterosexual* as “don’t know... somebody who likes other... bad habits! [“mala maña”].” When I asked him what bisexual means to him, he said “I don’t know how to explain it to you.” When I asked him what gay means to him, he said “people who are not what they are.”
- [R135, 68 years old] Male, Straight/Male, Something else: When I ask “Did you have any trouble deciding on that answer?” he said “no, but the question was a bit confusing... I don’t know what I could answer, since I am neither gay, heterosexual, nor bisexual. So, I started thinking. I know what the question is about, so I decided to answer ‘something else’.” He reported there are no words he is uncertain about. When I asked him what heterosexual means to him, he said “heterosexual is a person who... I don’t know... in my opinion... bisexual is a person who likes both sexes... gay is a person who... I don’t what word to use... gay... heterosexual is somebody who doesn’t have sex... that’s what I understand... In Puerto Rico when you say the word ‘gay’ it means that it is an effeminate person.”
- [R137, 74 years old] Female, Straight/Female, Bisexual: When asking participant #137 question 52, she struggled with terminology and with the idea of identifying herself. Participant also lacked understanding of terminology like heterosexual, bisexual, and transgender.
- [R139, 76 years old] Male, Straight/Male, Heterosexual: Did not recognize the word “heterosexual.”

- [R146, 80 years old] Female, Straight/Female, Something else and Don't know: When the interviewer asked "what does heterosexual mean to you" she said "Heterosexual? No... I'm not [sure]."
- [R151, 75 years old] Female, Straight/Female, Something else: When the interviewer asked "do you know the word heterosexual?" R said "honestly, no." The interviewer defined the term and R said "Oh, it means that you aren't? Ok then." The interviewer asked if R would identify as heterosexual and R said "yes."
- [R154, 66 years old] Female, Straight/Female, Don't know: When the interviewer first asked this question, R carefully read all response categories and asked "what does 'something else' mean?" She said "heterosexual... no, I am not gay, not lesbian... what does bisexual mean? Hmm. I don't know how to answer. I'd select that."
- [R155, 35 years old] Female, Straight/Female, Don't know: R looked at the showcard, read all the response categories, and pointing to the bisexual category, asked if "this is about people who only like men." She continued saying "I'm not a lesbian. I like men only. Which one should I choose? Hmm. I don't know how to answer." During the probing, the R read the categories in the showcard once again and realized that the definition of heterosexual was given in the second response category ("heterosexual, that is, not gay or lesbian"). Only at that point she realized she could have chosen heterosexual. When the interviewer asked her "Did you have any trouble deciding on that answer?" she said "yes. I was confused. I didn't know what the name is of the category I am in." She commented it would be "simpler to ask whether people like women or men. That would be clearer." When the interviewer asked "Were there any words that you were uncertain about?" she mentioned heterosexual and bisexual. She recognized that the term heterosexual was defined in the response category but was still unsure about the meaning of bisexual. She defined bisexual as "somebody who was a man and changed to a woman." She also indicated that the response "something else" was not clear to her. She asked what was included in that category.

**Table 6:** Consistency of sexual identity report in screener versus cognitive interview among Spanish speaking Rs

Reported at screener: Do you, personally, identify as lesbian, gay, bisexual, or transgender?	Reported at cognitive interview: Which of the following best represents how you think about yourself?					
	Gay or lesbian	Straight/het erosexual	Bisexual	Something else	Don't know how to answer	Something else and Don't know how to answer
Yes	2	0	1	1	0	0
No	0	14	1	6	10	2

**Table 7:** Demographic characteristics of Spanish speaking Rs with consistent self-identification

Gender	Education		Ethnicity				Age	
	Below HS	HS and above	Hispanic (Mexican)	Hispanic (Puerto Rican)	Hispanic (Cuban)	Hispanic (Other)	Below 65	65 and above
Male	4	5	4	1	1	3	4	5
Female	6	2	4	2	0	2	1	7

**Table 8:** Demographic characteristics of Spanish speaking Rs with inconsistent self-identification

Gender	Education		Ethnicity				Age	
	Below HS	HS and above	Hispanic (Mexican)	Hispanic (Puerto Rican)	Hispanic (Cuban)	Hispanic (Other)	Below 65	65 and above
Male	2	2	2	2	0	0	0	4
Female	14	2	8	1	0	7	2	14

## Gender Identity: English Protocol

---

### Effective comprehension of question 53 regarding sex assigned at birth

English speaking participants understood question 53 regarding the sex they had been assigned at birth. They did not express any concerns or issues about this question.

### Transgender as a physical transformation

The majority of English speaking participants defined transgender as a temporary or permanent change and emphasized the physical component of this transformation.

- [R101, 77 years old] Male, LGBT/Male, Gay: Transgender could be a term someone could identify with momentarily—while transitioning between sexes—but appears not to be a term someone who has fully transitioned would accept as part of their identity.
- [R102, 83 years old] Male, LGBT/Male, Gay: When asked how R102 understands “transgender,” R102 classified it as an “umbrella term” that covers a wide range of activities, from cross-dressing to performing as a drag queen, to going as far as going through hormone treatment and surgery. R102 thinks most people have a specific idea on what this term means: a concentration on one aspect such as cross-dressing. When asked if a cross dresser would be the same as someone who has undergone surgery, R102 claimed these two are different. Someone who has undergone sex change surgery is considered a “transsexual” to R102, someone who is in the process of transitioning their sex through surgery. This process begins with hormone treatment, claimed R102, and cited personal examples of friends who have undergone this process. Transsexual is a period of time when someone transitions their sex through surgery. When asked about when this transition period ends, R102 claimed that a fully transitioned person then identifies either male or female.
- [R104, 44 years old] Male, Straight/Male, Don't know how to answer: Probed on what R was thinking about for this question. R was thinking about “body functions” “genital area” and “what type of organs you have.”



- [R105, 63 years old] Male, Straight/Male, Straight: When prompted what “transgender” meant to R, R said it was a male who had “taken on physical characteristics of a female...dresses like a female...has done certain things or certain operations to their body to make themselves...more feminine in physical characteristics.” The interviewer asked if R thought this applied to females changing to become more male as well (since R did not mention this). R paused and then said “yes.” R thought the term was straightforward.
- [R108, 78 years old] Male, LGBT/Male, Gay: When probed on what “transgender” meant to R, R said it was somebody “who has transferred from male to female or female to male...usually through some physical adjustment...hormonal treatment, maybe surgery.”
- [R118, 78 years old] Female, Straight/Female, Straight: R defined procedure of changing anatomy from female to male or male to female.
- [R119, 70 years old] Female, Straight/Female, Straight: R gave the example of Caitlyn Jenner on the Kardashians. R clarified that Caitlyn is ‘on her way’ to being totally transgender, but to be transgender you had to have sex reassignment surgery. R stated that Jenner ‘dresses that way now’ but isn’t trans yet. R considers Jenner to be in transition, and might self-identify as transgender but is just dressing up like that now.
- [R121, 81 years old] Male, Straight/Male, Straight: R described trans as someone who changed “sexuality” – different than what one is born with. R then asked me what transgender was, said he thought it was a sex change. After probing, he stated that a crossdresser is still ‘a male’, not transgender.
- [R122, 80 years old] Female, Straight/Female, Straight: R defined transgender as anatomical reassignment, but then had a lot of questions about how that would actually work. She wasn’t sure if it was possible to have anatomical surgery to transition from female to male. When probed, R clarified that cross-dressers do not qualify as transgender, one has to have the surgery from male to female or vice versa.
- [R123, 68 years old] Male, Straight/Male, Straight: When asked about “transgender,” R123 used an anecdote to describe how he’s been told transgender is: a person undergoes a sex change in order to align with the sex/gender they feel they should be. To sum up R123’s understanding, the psychological does not align with the physical and this individual changes the physical to align with the psychological.

- [R150, 78 years old] Female, Straight/Female, Don't know how to answer: R defined transgender as “change from man to woman and woman to man.” She added “If I haven't changed in all these years, I don't think I'm going to change now. I'm 78 [laughs]. Oh boy, that would be something else.”

### Transgender as a gender identity

Other English speaking participants understood transgender as being mostly about one’s identity and emphasized issues of one’s feelings and “true self” rather than physical transformation, surgery, or medical procedures

- [R106, 45 years old] Female, Straight/Female, Straight: Asked R what transgender meant. R responded it was someone who was born a certain sex but feels differently...and you actually make that switch.” Followed up by asking if it had to be someone who’s made a physical change? R said that it didn’t necessarily have to be, just that they can “convert themselves” later on in life “taking on a male role.” Asked if it had to do with how someone feels about themselves and R agreed.
- [R107, 34 years old] Female, LGBT/Female, Lesbian: “Transgender” meant someone who changed, or is in the process of changing, their gender identity. Caitlyn Jenner was invoked as an example of someone who publically changed their gender identity. Laverne Cox’s, actress from “Orange is the New Black,” was also referenced as a cultural icon.
- [R110, 24 years old] Male, LGBT/Male, Gay: “Transgender,” refers to someone who is enacting their “true self,” despite how they present throughout their life. Bruce/Caitlyn Jenner was invoked as an example of a cultural icon that represents this transition from someone not living a “true self,” someone masking their sexual identity until just recently.
- [R148, 73 years old] Female, Straight/Female, Straight: R defined trans as being born with anatomy that differs from the gender one feels they are.
- [R149, 80 years old] Female, Straight/Female, Straight: When probed on what “transgender” meant to her, R said it meant being a female and wanting to be a male or dress up like one, or vice versa. Followed up by confirming whether it could apply to men and women and R agreed it could be either one.

### Inability to define term “transgender”

A couple of English speaking participants could not provide a definition of transgender or conflated transgender with gay/lesbian or bisexual.

- [R131, 75 years old] Female, Straight/Female, Straight: R131 was able to answer the question with “female,” but when asked about the other options, R131 was confused by the term “transgender.” R131 asked what “transgender” means and the interviewer used the example of Hijra, the accepted term for transgender individuals in South Asia, which then made the term immediately intelligible to R131.
- [R132, 68 years old] Female, Straight/Female, Straight: When asked what she thought transgender meant, R132 compared being bisexual to being transgender. Going further into this explanation, R132 began to doubt her comparison, claiming “I don’t know, but it could be that a male or female dresses up as something they are not, that a male dresses up as a female and a female dresses up as a male” yet is attracted to the opposite sex. At the conclusion of this explanation, R132 let out a defeated “but I don’t know (with a laugh),” suggesting her uncertainty in the explanation she just produced.

### Ability to answer questions regarding gender identity

Despite the issues discussed in this section, English speaking participants were able to consistently respond to the gender identity questions. All English speakers replied to questions 53 and 54 and no English speakers selected response option “do not identify as female, male, or transgender” in question 54. Furthermore, we compared self-reported responses provided during the screener (Q.1: “Are you male or female?” Male/Female; and Q.8: “Do you, personally, identify as lesbian, gay, bisexual, or transgender?” Yes/No) to self-report responses provided during the cognitive interview (questions 53 and 54). All English speakers reported the same gender across these two instruments.

## Gender Identity: Spanish Protocol

---

### Comprehension of question regarding sex assigned at birth

All Spanish speaking participants were able to answer question 53. Some replied to the question indicating “feminine” and “masculine” rather than “female” and “male.” The interviewed transgender R was easily able to answer this question. She is a transgender woman who was assigned male in her original birth certificate. As such, she selected “male” in question 53 and “female” in

question 54, which refer to current gender identity and sex assigned at birth, respectively. Her rationale for answering question 54 is discussed below in section “Limited response options”.

- [R134, 70 years old] Male, Straight/Male, Don’t know: Participant didn’t understand the question. I had to repeat a couple of times and finally I read the response categories. He then selected “male.”
- [R139, 76 years old] Male, Straight/Male, Heterosexual: R answered “male” without hesitation.
- [R144, 66 years old] Female, Straight/Female, Heterosexual: R answered “female” without hesitation.
- [R147, 71 years old] Female, Straight/Female, Something else: R answered woman without hesitation.
- [R156, 38 years old] Transgender, LGBT/Female, Something else: R looked the show card and selected “male”.

### Inability to define term “transgender”

The majority of Spanish speaking participants could not provide a definition of transgender or conflated transgender with gay/lesbian or bisexual.

- [R116, 67 years old] Female, Straight/Female, Don’t know: R116 said she did not have questions about Q54 but she could not define the word transgender.
- [R112, 88 years old] Female, Straight/Female, Heterosexual: Upon probing about the definition of “transgender” R answered “I have not had much schooling.” R did not know of the term.
- [R125, 71 years old] Female, Straight/Female, Don’t know: When asked “what does transgender mean to you”, she said “I wouldn’t know how to answer that question.”
- [R126, 69 years old] Female, Straight/Female, Heterosexual: She wasn’t sure about the word transgender but defined it as people who dresses as men or women, or individuals who feel attracted to both genders. She also thought that someone called transgender could be a person who feels attracted to other women (for instance) if they feel lonely. She said: perhaps out of loneliness some people they develop interest for people of the same sex. She repeated the word ‘loneliness’ as the reason to seek that type of companionship.

- [R127, 71 years old] Female, Straight/Female, Don't know: She acknowledged she didn't know what transgender means. She said "Transgender, hmmm, I don't know what that word means but it doesn't sound good."
- [R128, 69 years old] Male, Straight/Male, Don't know: Participant had no idea of the meaning of transgender.
- [R129, 73 years old] Female, Straight/Female, Don't know: She acknowledged she did not know what transgender means.
- [R130, 67 years old] Female, Straight/Female, Something else and Don't know: Participant does not know the definition of transgender but she tried to define it with her own words as 'someone could be man and woman at the same time'.
- [R137, 74 years old] Female, Straight/Female, Bisexual: Participant #137 believes transgender individuals do not know what they want, that's why they must try other alternatives.
- [R143, 69 years old] Female, Straight/Female, Something else: When the interviewer asked "What does transgender mean to you" R said "I don't understand that word."
- [R144, 66 years old] Female, Straight/Female, Heterosexual: When the interviewer asked "What does transgender mean to you?" R said "we come back to the same [issue] – that I don't understand any of that. Transgender, what does that mean? I have to go study."
- [R145, 82 years old] Female, Straight/Female, Something else: When the interviewer asked "What does transgender mean to you?" R said "That I don't know. What does it mean? Tell me. I would like for you to tell me." The interviewer gave definition included in the screener and R said "I have heard that there are people who are born with both [sex organs]. They're born with the female one and the male one. They are half of one and half of the other. I've heard about it. But I haven't seen it."
- [R153, 73 years old] Female, Straight/Female, Something else: R did not know how to define transgender. She said "I don't know how that is...I've heard [the word] on television. I have heard it, but haven't had the curiosity to say, 'what is that?' I don't like to go around asking...I can't answer because I don't know."

## Transgender as a physical transformation

A few of the Spanish-speaker participants defined transgender as a temporary or permanent change and emphasized the physical component of this transformation.

- [R114, 62 years old] Male, Straight/Male, Heterosexual: R described the term transgender as someone who dresses as a woman without been necessarily gay.
- [R115, 63 years old] Female, Straight/Female, Heterosexual: She defined transgender as someone who gets surgery.
- [R142, 52 years old] Male, Straight/Male, Heterosexual: He defined transgender as “men who dress like women even if they are not homosexual.”
- [R146, 80 years old] Female, Straight/Female, Something else and Don’t know: R defined transgender as “those who dress – men who dress like women and women who dress like men.”
- [R147, 71 years old] Female, Straight/Female, Something else: When asked “what does transgender mean to you” R said “Transgender is to transform into something else.” The interviewer asked “like what?” R said “like a woman to man, man to woman. I don’t know [laughs].
- [R151, 75 years old] Female, Straight/Female, Something else: R defined transgender saying “when one changes from one sex to another.”
- [R152, 65 years old] Male, Straight/Male, Heterosexual: R defined transgender as “people who dress like men, and women, and all those things.”
- [R154, 66 years old] Female, Straight/Female, Don’t know: When asked “what does transgender mean to you” she said “I imagine that it’s somebody who wants to transform into another character.”
- [R155, 35 years old] Female, Straight/Female, Don’t know: R defined transgender as “a man who changes to a woman.”

## Transgender as a gender identity

Many Rs understood transgender as being mostly about one’s identity and emphasized issues of one’s feelings and “true self” rather than physical transformation, surgery, or medical procedures

- [R109, 68 years old] Female, LGBT/Female, Bisexual: P defined transgender as children who are born as women and later on realize they do not feel as either as woman or man.
- [R120, 65 years old] Female, Straight/Female, Heterosexual: R120 defined transgender as people who cannot define themselves as men or women; people who struggle with their identity.
- [R141, 71 years old] Male, LGBT/Male, Gay: Participant described transgender as the person who does not feel right in the body that he or she was born.
- [R140, 67 years old] Female, Straight/Female, Heterosexual: When the interviewer asked “What does transgender mean to you?” she said “that they were born one way, but – I don’t know if the word is emotional, or what – but there are people who, what appears to be when the doctor looks at them, they are one sex, but internally, they feel like another sex. What appears to be on the outside, isn’t always what is on the inside, in the chemistry of the blood and in the mind of the person.”
- [R157, 47 years old] Male, LGBT/Male, Gay: R defined transgender as “somebody who feels...since I have educated myself in this... if you are a man as a kid you want to do things as a woman and he feel trapped in that body. Also, a woman sometimes dresses like a man because she feels she is trapped in that body and she doesn’t want to be a woman, she wants to be a man.”

### Discomfort with questions

Some Spanish speaking participants were uncomfortable answering and discussing questions about gender identity. Other Rs wondered why we needed to gather this information. We did not find discomfort expressed by any English speaking participants.

- [R116, 67 years old] Female, Straight/Female, Don’t know: R116 said she did not feel uncomfortable with these topics but she was caught by surprise since anything related to sexuality was a taboo when she was younger. R116 thought I needed to ask question 54 because nowadays is hard to know who is who.
- [R125, 71 years old] Female, Straight/Female, Don’t know: “The question makes me uncomfortable.”

- [R126, 69 years old] Female, Straight/Female, Heterosexual: Participant seemed uncomfortable with question #54. She laughed nervously when asked if she was woman, man or transgender.
- [R129, 73 years old] Female, Straight/Female, Don't know: When asked "What did you think about when I asked that question?" she said "why would you be asking me all these questions, since I am a woman." She raised the same concern when asked "What did you think about in deciding on your answer?" She said "I don't know what the reason is for these questions."
- [R134, 70 years old] Male, Straight/Male, Don't know: Participant didn't understand the concept of gender identity, had trouble answering previous question on gender assigned at birth, and didn't comprehend the term transgender. Yet, he was able to easily answer the question because he looked at the response options and "male." He confused the term "transgender" with "transgenic." When asked "were there any words that you were uncertain about", he indicated "no, I am certain I am a man." When asked what transgender means to him, he said "I don't know what to say to you."
- [R137, 74 years old] Female, Straight/Female, Bisexual: She added how strict parents were when she was growing up, that's why those topics are so challenging for her and people of her generation.
- [R142, 52 years old] Male, Straight/Male, Heterosexual: "... Why is Medicare interested in this? Are they interested in sexually transmitted diseases?"
- [R152, 65 years old] Male, Straight/Male, Heterosexual: When the interviewer first asked the question R laughed and said "this is a very bold question. I'm blushing. Man!" When the interviewer asked "What did you think about when I asked you that question?" R replied "perhaps the question is to learn about how one is. How they speak, how they express themselves, how they answer the question. If one hesitates when they respond, or gets nervous. Normally, people aren't prepared to respond to those kinds of questions, because they've never been asked them. We're not accustomed to being asked those questions, no? So one may not have the word, the correct response in the moment. So one has to think a bit and give their opinion, what they can answer, also, according to their education. There are people who don't know how to respond to things because sometimes they don't have the adequate education to respond to the question."



- [R153, 73 years old] Female, Straight/Female, Something else: When the interviewer asked “What did you think about when I asked you this question?” R said “As there are so many things now...there are people who, we don’t know the other person. So I can’t, I said, I don’t know what I’m going to respond, something that isn’t. That’s why I didn’t answer. Because I haven’t had a lot of knowledge about that. One can’t say anything because until they see something that they see, because sometimes there are things that one says and they are not.”
- [R157, 47 years old] Male, LGBT/Male, Gay: The R commented “the question was odd. Maybe, since this is a medical survey, you want to know more about the gender of men, woman, and gay, if they have more health problems or not.”

### “Normal” and “non-deviant” gender identity

Non-transgender participants associated their identity with “normal” and transgender as a sexual deviation. This understanding of sexual identity was observed exclusively among Spanish-speakers. Rs defined non-transgender identity using terms such as “correct” and “complete,” parallel to the terms they had used when describing heterosexual sexual identity.

- [R117, 67 years old] Male, Straight/Male, Don’t know: R117 said he was not sure how to define transgender but defined it as a man who acts normal during the day and transforms at night.
- [R135, 68 years old] Male, Straight/Male, Something else: When the interviewer asked “What did you think about when I asked that question?” he said “Well, since I was small my family told me I was a man and as time has gone by I haven’t felt any other deviation... I am only attracted by women. I don’t have any other desire such as bisexual or something like that.”
- [R138, 86 years old] Male, Straight/Male, Heterosexual: R confused terms bisexual and transgender and wondered whether these terms were associated with a mental illness. When the interviewer asked “What does bisexual mean to you?” he replied “Two sexes...There are people who are born as males, but as they develop, they appear to be female. Is that a genetic mental illness? I was born a male, and in me, in my body, none of that has happened.”
- [R139, 76 years old] Male, Straight/Male, Heterosexual: What were you thinking when I asked you that question? “If I had any deviation – sexual [deviation].”

- [R143, 69 years old] Female, Straight/Female, Something else: When the interviewer asked “How did you decide how to answer?” R said “Since I got married, I’m a ‘correct’ woman, a normal [woman].”
- [R146, 80 years old] Female, Straight/Female, Something else and Don’t know: When the interviewer asked “what did you think when I asked that question” she said “It didn’t bother me. I know that I’m a complete woman.” The interviewer followed up and asked “What does it mean to be a complete woman?” R said “I haven’t thought – I’ve had my husband, my children.”

### Gender identity as self-evident gender expression

Non-transgender participants reported their gender identity was “self-evident”, meaning that they did not need to report it, there was nothing to discuss, and it was obvious – by looking at them—that they were either male or female. These Rs also did not understand their gender identity could change, since they thought of it as something permanent, intended to remain unchanged. In their minds, this self-evidence made the question irrelevant and unnecessary. This issue was observed exclusively among Spanish-speakers.

- [R125, 71 years old] Female, Straight/Female, Don’t know: During the probes she said “I wonder what you are looking at to ask me if it’s correct for me to say what I am saying [that I am a woman].”
- [R130, 67 years old] Female, Straight/Female, Something else and Don’t know: When asking question 54 she thought of it as ‘weird’; especially because she knows she is a woman and was expecting that to be obvious.
- [R137, 74 years old] Female, Straight/Female, Bisexual: She described herself as a woman but thought I should have known the answer to that question because of her appearance.
- [R138, 86 years old] Male, Straight/Male, Heterosexual: When the interviewer asked “What did you think about when I asked you that?” R said “I thought I can’t change, I am a man, and I will continue being one.”
- [R142, 52 years old] Male, Straight/Male, Heterosexual: When I asked him “What did you think about when I asked that question?” he said “Nothing. I am a man. There is nothing else for me to think about.”

- [R144, 66 years old] Female, Straight/Female, Heterosexual: When the interviewer first asked Q54, R said “Woman, woman, woman. 100%.” When the interviewer asked “What did you think about when I asked you this question?” she said “I am simply a woman.” When the interviewer asked “What did you think about when you decided what to answer?” she said “I didn’t think about anything.”
- [R155, 35 years old] Female, Straight/Female, Don’t know: When the interviewer asked R “What did you think about when I asked that question?” she said “the question was confusing to me. Why are you asking me this if I am here? I know that there are a lot of women who look like men and that there are a lot of changes like that out there, but I wondered why you were asking me this if you are looking at me and seeing that I am a woman. I am here and I am woman, but maybe you don’t really know I am a woman.” She indicated she decided on that answer “because it’s obvious.”

### Limited response options

The Spanish speaking transgender R provided a rationale for selecting “woman” rather than “transgender”. She reported having been assigned “male” at birth in question 53, but selected “female” in question 54.

- [R156, 38 years old] Transgender, LGBT/Female, Something else: The R answered the question very quickly with the response “woman.” When prompted to explain what she was thinking of when answering the question, she noted “I feel like a woman, a transsexual woman.” She noted that the term “transgender” alone was just that, a term. She is a woman. That’s why she recommended adding “transgender man” and “transgender woman.” That way you are adding the gender to the term, instead of making them feel like a third “other” gender. She recommended adding other terms for inclusiveness, including “transsexual woman” and “transsexual man.”

### Ability to properly answer question regarding gender identity

Despite the discomfort and comprehension challenges discussed in this section, Spanish speaking participants were able to consistently identify their sex and gender identity in questions 53 and 54. Similarly to English speakers, all Spanish speaking participants replied to questions 53 and 54 and none selected the response option “do not identify as female, male, or transgender” in question 54. All Spanish-speakers reported the same gender identity during the screener (Q.1: “Are you male or

female?” Male/Female; and Q.8: “Do you, personally, identify as lesbian, gay, bisexual, or transgender?” Yes/No) as during the cognitive interview (questions 53 and 54).

## Conclusions and Recommendations

### Summary of Findings

---

The English versions of the sexual and gender identity items tested well enough for NORC to recommend adding these measures to the MCBS if CMS wishes to add them to the survey.

Regarding the Spanish translations, the gender identity question was well understood and can be added to the survey if CMS sees fit to do so; however, NORC recommends a slight revision of the Spanish version of the sexual identity question. Below, we summarize these recommendations.

English speaking participants were able to comprehend questions about sexual identity and gender identity. They understood the wording of questions 52, 53, and 54 and also the response categories provided in show cards for questions 52 and 54. All but two English speaking Rs provided identical responses about their sexual identity during the screener and the cognitive interview, when the actual wording of question 52 was tested. In response to probes, some English speakers confused sexual identity with gender identify and did not quite understand the concept of transgender identity as independent from medical procedures involving a sex change. Yet, in the vast majority of cases, these issues did not prevent English speakers from answering questions 52, 53, and 54 and from answering consistently across the screener and cognitive interview.

Spanish speakers exhibited comprehension problems with questions about sexual identity and gender identity. Comprehension problems were most problematic for question 52 regarding sexual identity, since participants, particularly those with low levels of education, especially women, did not understand the meaning of the response categories provided and were particularly uncertain about or unfamiliar with the term “heterosexual.” More than half of all Spanish-speakers participants were unable to select a sexual identity as heterosexual during the cognitive interview even though they had stated that they were not lesbian, gay, bisexual, or transgender in the screener. The majority of these participants had less than a high school education and almost all of them were 65 or over. Among these “straight” (and in one case, bisexual) participants who did not understand the term “heterosexual” applied to them, about half answered “I don’t know how to answer” and the other half selected “Something else.” Questions about gender identify presented some challenges for Spanish-

speakers due to their discomfort, their lack of comprehension of transgender gender identity, and the understanding of non-transgender identity as a “normal” and “self-evident” gender expression.

## Final Recommendations

---

1. We recommend keeping as is the wording of the English version of questions 52, 53, and 54. Despite some comprehension and discomfort problems, all English speakers were able to properly answer these three questions.
2. We recommend changing the wording of the second response category of the Spanish-version of question 52. This recommendation is based on the observed widespread lack of comprehension of the term “heterosexual” and Rs’ process of elimination as a way of selecting their response, which resulted in biased responses among straight Rs. We specifically recommend reversing the order of the term “heterosexual” and its explanation “that is, not gay” so that instead the response first presents the explanation “not gay” and then includes the term “heterosexual.” We believe this will improve Spanish speaking Rs’ ability to properly report their sexual identity.

Question 52	Current version	Recommended version
Male R	(02) Heterosexual, o sea, no gay	(02) No gay, o sea, heterosexual
Female R	(02) Heterosexual, o sea, no gay o lesbiana	(02) No gay o lesbiana, o sea, heterosexual

3. We recommend keeping as is the wording of the Spanish-version of questions 53 and 54. Despite Rs’ discomfort and lack of understanding of gender identity as a separate concept from sexual identity and gender expression, Spanish-speakers were able to properly answer these two questions.
4. We recommend adding interviewer instructions with key terms and definitions used in these questions. Interviewers may refer to these instructions in cases in which (1) Rs ask for further clarification or (2) Rs cannot answer the questions given only the information provided in the question and its response categories. We recommend adding brief interviewer instructions regarding definitions of the following terms. While we have provided best-available definitions of these constructs, we recognize the challenge in translating these definitions into terms that a lay person can understand. We suggest that – prior to any planned

implementation – additional input be sought from stakeholder communities regarding these definitions:<sup>3</sup>

- a. Gay: In this case we are referring to a man whose physical, romantic and/or emotional attraction is to other men.
- b. Lesbian: A woman whose physical, romantic and/or emotional attraction is to other women.
- c. Heterosexual: People whose physical, romantic and/or emotional attraction is to people of the opposite sex.
- d. Bisexual: A person who has the capacity to form physical, romantic and/or emotional attractions to both men and women.
- e. Transgender: A man or woman whose gender identity does not match their sex assigned at birth. That is, a man who identifies as a woman or a woman who identifies as a man. Some transgender individuals dress like the opposite sex, some may have surgery to change sexes, while others do neither.

We believe that simple and standard definitions of these terms may improve Rs' ability to properly answer these questions, particularly among Spanish-speaker Rs.

5. Regarding placement and periodicity, we found evidence that Rs viewed these questions as demographic information. As a result, we would suggest placing these items with other demographic questions in the MCBS. Because of the potential fluidity of gender identity, CMS could consider asking the questions in the initial interview and then one additional time before the R cycles out of the survey.
6. Finally, the two measures – sexual identity and gender identity - should be viewed independently when CMS contemplates adding these to the MCBS. In other words, the sexual identity question can be added regardless of whether the gender identity questions are added.

---

<sup>3</sup> Gay, Lesbian, Heterosexual, and Bisexual definitions are adaptations from those used by GLAAD (<http://www.glaad.org/>). The Transgender definition was created for the purposes of this report and draws on our experience defining the terms for comprehension by the general public. It conforms to the various GLAAD definitions provided at <http://www.glaad.org/reference/transgender>.

## Works Cited

- Aday, L. A., Chiu, G. Y., & Anderson, R. (1980). Methodological issues in health care surveys of the Spanish heritage population. *American Journal of Public Health* 70: 367-374.
- D'Alonzo, K. T. (2011). Evaluation and revision of questionnaires for use among low-literacy immigrant Latinos. *Revista Latino-Americana de Enfermagem* 19 (5): 1255-64.
- Erens, B. (2014). Designing high-quality surveys of ethnic minority groups in the United Kingdom. *Surveying Ethnic Minorities and Immigrant Populations*, 45.
- Fredriksen-Goldsen, K. I., Kim, H-J., Barkan, S. E., Muraco, A., & Hoy-Ellis, C. P. (2013). Health Disparities Among Lesbian, Gay, and Bisexual Older Adults: Results from a Population-Based Study. *American Journal of Public Health* 103 (10): 1802-1809.
- IOM (Institute of Medicine). (2011). *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Washington, DC: The National Academies Press.
- <http://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health/objectives> accessed on March 24, 2015.
- Medicare Beneficiary Survey website: <https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/MCBS/index.html?redirect=/MCBS>
- SMART (Sexual Minority Assessment Research Team). (2009). *Best Practices for Asking Sexual Orientation on Surveys*. Los Angeles: Williams Institute, UCLA School of Law.
- The GenIUSS Group. (2014). *Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys*. J.L. Herman (Ed.). Los Angeles, CA: The Williams Institute.
- Zea, M. C., Reisen, C. A., & Diaz, R. M. (2003). Methodological issues in research with Latino gay and bisexual men. *American Journal of Community Psychology* 31: 281-291.

## Appendices

### Appendix A: Recruitment Message (English)

---

On behalf of the Centers for Medicare and Medicaid Services (CMS), NORC at the University of Chicago is conducting research to improve the Medicare Current Beneficiary Survey (MCBS). CMS sponsors the MCBS, a nationally representative survey of Medicare beneficiaries. The MCBS collects information on health status, sources of health care, satisfaction with care, and health care expenditures of Medicare beneficiaries. NORC is working on improving the survey by testing new questions that may add important information about health disparities among small population groups. The question topics range from access to health care and usual sources of care, to basic demographic questions such as race, and education. We are inviting Medicare beneficiaries to participate in an interview; the interview involves first completing the survey and talking with the interviewer about some of the survey items. Hearing what Medicare beneficiaries have to say about the survey will help us to improve the questions. If you are eligible and choose to participate, you will receive \$40 as an incentive for participating in this study. If you are interested in learning more, please contact the Study Coordinator, NAME at NAME@norc.org.



## Appendix B: Recruitment Script (English)

---

Hello. My name is [NAME] and I work for NORC at the University of Chicago. I'm calling about your interest in the Medicare Current Beneficiary Study. Is this a good time?

[IF YES] Let me tell you a little bit about what we are going to do and then you can let me know if you are still interested. First, are you 18 years or older? [IF NO, let individual know we are only interviewing people aged 18 or older and thank them for interest]

[IF YES] We are conducting this study to improve the way information is collected for the Medicare Current Beneficiary Survey (MCBS), which is a survey sponsored by the Centers for Medicare and Medicaid Services. The MCBS is a national survey of Medicare beneficiaries in the United States. It collects information on health status, sources of health care, satisfaction with care, and health care expenditures.

If you agree to participate in this interview, we will ask you to answer survey questions asked by a NORC staff member. After you complete the questionnaire, the interviewer will ask you some questions about the survey as well as your understanding of survey concepts that will help us improve the questionnaire. Some people may view some questions as sensitive – the questions you will be asked range from access to health care and usual source of care to demographic questions such as race, and education. The interview will take no more than 60 minutes. You will receive \$40 as an incentive for participating in this survey.

Would you like to participate?

- ▶ [IF YES] Great. I am going to ask you a few background questions to confirm your eligibility. Then we can schedule an appointment time for you. → GO TO ELIGIBILITY SCREENER QUESTIONNAIRE
- ▶ [IF NO] That's okay. We appreciate your interest. But for research purposes, we would like to know why you choose not to participate. NOTE TO RECRUITER: IF POTENTIAL RESPONDENT DECIDES AFTER HEARING ABOUT THE STUDY THAT HE/SHE DOES NOT WANT TO PARTICIPATE, ASK WHY NOT AND OFFER TO ANSWER QUESTIONS. RECORD THE RESPONDENT'S REASONS FOR NOT PARTICIPATING BELOW:

Thank you. Have a nice day.

Notes:

**PRA Disclosure Statement**

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-1275. The time required to complete this information collection is estimated to average 60 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850. **Please do not send applications, claims, payments, medical records or any documents containing sensitive information to the PRA Reports Clearance Office. Please note that any correspondence not pertaining to the information collection burden approved under the associated OMB control number listed on this form will not be reviewed, forwarded, or retained. If you have questions or concerns regarding where to submit your documents, please contact 1-800-MEDICARE or William Long at 410-786-7927.**

## Appendix C: Medicare Beneficiary Study Frequently Asked Questions (English)

---

### ***What is the MCBS?***

The **Medicare Current Beneficiary Survey (MCBS)** is a national survey of Medicare beneficiaries in the United States and Puerto Rico. It collects information on health status, sources of health care, satisfaction with care, and health care expenditures.

### ***What is the study about?***

This study is being conducted on behalf of the Centers for Medicare and Medicaid Services (CMS) to try to improve the way information is collected for the MCBS.

### ***What is the Centers for Medicare and Medicaid Services (CMS)?***

CMS is a federal agency that is part of the United States Department of Health and Human Services. CMS administers the Medicare, Medicaid, and Child Health Insurance programs as well as the Health Insurance Marketplace. For more information about CMS, please visit the website [www.cms.gov](http://www.cms.gov).

### ***Why are you testing new questions?***

Studying the ways people use the healthcare system in the U.S. population has been a long-standing goal of the U.S. government and in particular the Department of Health and Human Services (DHHS). Your participation in this study will help to improve how these data are collected and analyzed for the MCBS.

### ***Who is NORC?***

NORC is a not-for-profit social science research organization affiliated with the University of Chicago. NORC is conducting this study on behalf of the Centers for Medicare and Medicaid Services. You can learn more about NORC at its website, [www.norc.org](http://www.norc.org), or by contacting the Study Director, Susan Schechter at [schechter-susan@norc.org](mailto:schechter-susan@norc.org).

### ***Do I have to participate?***

Participation by respondents is voluntary. You may choose whether or not you want to be in this study. If you decide to be in the study, you may choose to skip any question you do not want to answer or stop participating at any time. Your Medicare benefits will not be affected in any way by your decision whether to participate.

### ***Will I receive an incentive for participating?***

An incentive of \$40 will be provided to the Medicare beneficiary for participating in the study.

### ***How long will the study take?***

The interview will take about one hour.

***Why should I participate?***

We are testing a new version of the MCBS questionnaire. Input from beneficiaries on how the new questionnaire is working will help improve the data we collect. By participating in this study you can help make sure that CMS collects the most complete and accurate data possible on the experiences of Medicare beneficiaries.

***Who do I contact if I have questions about my rights as a study participant?***

If you have any questions regarding your rights as a study participant, you may call the NORC IRB Manager, toll-free, at 866-309-0542.

***How is my privacy protected?***

Your answers will always be kept private, and none of the information that you provide will be used for any purpose other than research. Your name or any information that could identify you will never be used.

***What information will be shared with the government/with CMS?***

Your name will not be associated with any of the responses you give to the survey questions, and we will not provide the names of any participants to CMS. CMS will receive information about this study in a form that will not lead to the identification of any participants.

## Appendix D: Recruitment Message (Spanish)

---

NORC en la Universidad de Chicago está llevando a cabo un estudio de parte de los Centros para Servicios de Medicare y Medicaid (CMS por sus siglas en inglés), para mejorar la Encuesta de Beneficiarios Actuales de Medicare (MCBS por sus siglas en inglés). CMS es el patrocinador de MCBS, la encuesta representativa a nivel nacional de los beneficiarios de Medicare. El MCBS obtiene información sobre el estado de salud, las fuentes de atención médica, la satisfacción con los servicios, y los gastos en la atención de la salud de los beneficiarios de Medicare. NORC está tratando de mejorar la encuesta agregando nuevas preguntas que pueden ayudar a generar más información acerca de desigualdades sociales entre grupos sociales reducidos. Los temas de las preguntas van desde el acceso a la atención médica y las fuentes habituales de la misma, hasta preguntas personales básicas como su raza y su educación. Estamos invitando a los beneficiarios de Medicare a participar en una entrevista; la entrevista consiste en completar primero la encuesta y hablar luego con el entrevistador sobre algunas de las preguntas de la encuesta. Escuchar lo que los beneficiarios de Medicare tienen que decir sobre la encuesta nos ayudará a mejorar las preguntas. Si usted califica y decide participar, recibirá \$40 como incentivo por participar en este estudio. Si usted está interesado(a) en saber más al respecto, por favor contacte al Coordinador del Estudio, NAME al [NAME@norc.org](mailto:NAME@norc.org).

## Appendix E: Recruitment Script (Spanish)

Buenos días/Buenas tardes/Buenas noches. Mi nombre es [NAME] y trabajo para NORC en la Universidad de Chicago. Le estoy llamando porque usted dijo estar interesado(a) en participar en el Encuesta de los Actuales Beneficiarios de Medicare. ¿Ahora es un buen momento para hablar?

[IF YES] Permítame explicarle un poco más de qué se trata y después me dice si aún está interesado(a) en participar. Antes de empezar, ¿tiene usted 18 años o más? [IF NO, let individual know we are only interviewing people aged 18 or older and thank them for interest]

[IF YES] Estamos llevando a cabo este estudio para mejorar cómo se obtiene la información en la Encuesta de los Actuales Beneficiarios de Medicare (MCBS por sus siglas en inglés). La encuesta MCBS está patrocinada por los Centros de Servicios de Medicare y Medicaid (CMS, por sus siglas en inglés). MCBS es una encuesta nacional de los beneficiarios de Medicare en los Estados Unidos que recolecta información sobre el estado de salud, las fuentes de atención médica, la satisfacción con los servicios y los gastos en la atención de la salud de los beneficiarios de Medicare.

Si usted está de acuerdo en participar en esta entrevista, le vamos a pedir que complete un cuestionario con un miembro del personal de NORC. Después de que complete el cuestionario, el entrevistador le hará algunas preguntas sobre la encuesta que nos ayudarán a mejorar el cuestionario. A algunas personas puede parecerles que algunas de las preguntas son demasiado personales – las preguntas que se le harán van desde temas como su acceso a la atención médica y sus fuentes habituales de la misma, hasta preguntas personales tales como raza y educación. La entrevista le tomará aproximadamente 60 minutos. Usted recibirá \$40 dólares por su participación en este estudio.

¿Está interesado(a) en participar?

- ▶ [IF YES] Muy bien. Voy hacerle algunas preguntas generales para confirmar si es elegible. De ser así, podremos programar una cita para su entrevista. → GO TO ELIGIBILITY SCREENER QUESTIONNAIRE
- ▶ [IF NO] Está bien, no hay problema. Apreciamos mucho su interés. Pero para los propósitos de este estudio, nos gustaría saber por qué decidió no participar. NOTE TO RECRUITER: IF POTENTIAL RESPONDENT DECIDES AFTER HEARING ABOUT THE STUDY THAT HE/SHE DOES NOT WANT TO PARTICIPATE, ASK WHY NOT AND OFFER TO ANSWER QUESTIONS. RECORD THE RESPONDENT’S REASONS FOR NOT PARTICIPATING BELOW:

Muchas gracias. Que tenga un buen día.

NOTES:

### PRA Disclosure Statement

Según lo establece la Ley de Reducción del Papeleo de 1995, ninguna persona tiene obligación de responder a un pedido de información si el mismo no tiene un número de control de OMB que esté vigente. El número de control de OMB vigente para este pedido de información es 0938-1275. Se calcula que el tiempo necesario para completar este pedido de información es de 60 minutos por respuesta, incluyendo el tiempo para revisar las instrucciones, buscar fuentes existentes de datos, juntar los datos necesarios, y completar y revisar el pedido de información. Si tiene comentarios con respecto al cálculo de tiempo o sugerencias para mejorar este formulario, por favor escriba a: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850. **Por favor no envíe solicitudes, reclamos, pagos, expedientes médicos ni ningún otro documento que contenga información privilegiada a la Oficina 'PRA Reports Clearance'. Por favor note que cualquier correspondencia que no tenga que ver con el tiempo de obtención de información aprobado bajo el número de control de OMB que aparece en este formulario no será revisada, reenviada, ni retenida. Si tiene alguna pregunta o inquietud sobre dónde enviar sus documentos, por favor contacte a 1-800-MEDICARE o a William Long llamando al 410-786-7927.**

## Appendix F: Medicare Beneficiary Study Frequently Asked Questions (Spanish)

---

### ***¿Qué es MCBS?***

La Encuesta sobre los Actuales Beneficiarios de Medicare (MCBS por sus siglas en inglés) es una encuesta nacional de beneficiarios de Medicare en los Estados Unidos y Puerto Rico. Esta encuesta recolecta información sobre el estado de salud, las fuentes de atención médica, la satisfacción con los servicios y los gastos de atención de la salud de los beneficiarios de Medicare.

### ***¿De qué se trata el estudio?***

Este estudio se está llevando a cabo en nombre de los Centros de Servicios de Medicare y Medicaid (CMS, por sus siglas en inglés) para tratar de mejorar cómo se recolecta información para el MCBS.

### ***¿Qué son los Centros de Servicios de Medicare y Medicaid (CMS por sus siglas en inglés)?***

CMS es una agencia federal que forma parte del Departamento de Salud y Servicios Humanos de los Estados Unidos. CMS administra los programas de Medicare, Medicaid, y del Seguro de Salud para Niños, así como también el Mercado de Seguros de Salud. Para más información sobre CMS, por favor visite el sitio de internet [www.cms.gov](http://www.cms.gov).

### ***¿Por qué están probando preguntas nuevas?***

El gobierno de los Estados Unidos y en particular del Departamento de Salud y Servicios Humanos (DHHS por sus siglas en inglés) tiene como meta desde hace muchos años estudiar las maneras en que las personas usan el sistema de atención médica en los Estados Unidos. Su participación en este estudio ayudará a mejorar cómo esta información se recolecta y analiza para la encuesta MCBS.

### ***¿Qué es NORC?***

NORC es una organización sin fines de lucro afiliada a la Universidad de Chicago que se dedica a hacer estudios a través de encuestas. NORC está llevando a cabo este estudio en nombre de los Centros de Servicios de Medicare y Medicaid. Usted puede informarse más sobre NORC en su sitio de internet, [www.norc.org](http://www.norc.org), o contactando a la directora del estudio, Susan Schechter at [schechter-susan@norc.org](mailto:schechter-susan@norc.org).

### ***¿Tengo que participar?***

La participación de los participantes es voluntaria. Usted decide si quiere o no participar en el estudio. Si decide participar, podrá saltarse cualquier pregunta que no desee contestar y podrá dejar de participar en cualquier momento. Sus beneficios de Medicare no se verán afectados de ninguna forma ya sea que decida participar o no.

### ***¿Voy a recibir un incentivo por participar?***

Un incentivo de \$40 dólares será provisto para el/la beneficiario(a) de Medicare [y el intérprete] por participar en el estudio.

***¿Cuánto tiempo durará el estudio?***

La entrevista durará aproximadamente una hora.

***¿Por qué debería participar?***

Estamos probando una nueva versión de los cuestionarios de MCBS. La ayuda de beneficiarios para saber cómo los cuestionarios nuevos están funcionando, nos permitirá mejorar la información que recolectamos. Al participar en este estudio usted puede ayudar a asegurar que CMS recolecta la información más completa y precisa posible de las experiencias de los beneficiarios de Medicare.

***¿A quién puedo contactar si tengo preguntas sobre mis derechos como participante del estudio?***

Si usted tiene alguna pregunta con respecto a sus derechos como participante del estudio, puede llamar al director de IRB en NORC, al número gratuito, 866-309-0542.

***¿Cómo se protegerá mi privacidad?***

Sus respuestas se mantendrán siempre en privado, y nada de la información que usted nos proporcione se usará para ningún otro propósito fuera del estudio. Nunca se usará su nombre ni cualquier otra información que pudiera identificarlo(a).

***¿Qué información será compartida con el gobierno /con CMS?***

Su nombre no será vinculado con ninguna de sus respuestas a las preguntas de la encuesta y nosotros no daremos a CMS los nombres de ninguno de los participantes. La manera en que CMS recibirá la información de este estudio no permitirá identificar a los participantes.

## Appendix G: Eligibility Screener Questionnaire (English)

---

PARTICIPANT NUMERIC IDENTIFIER: \_\_\_\_\_

1. Are you male or female?
  1. MALE
  2. FEMALE
  
2. I need to confirm, do you receive health insurance through Medicare?
  1. YES
  2. NO→I am sorry, but only people who receive insurance through Medicare are eligible for this study.

READ IF NECESSARY: Do you have a Medicare card? 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. Medicare Part A includes coverage for hospital stays and Part B includes coverage for doctor's services. Part C, Medicare Advantage Plans, is offered through private insurance companies under contract with Medicare. Some people opt to add on Part D, which is prescription drug coverage.

3. Would you be able to come in person to one of our offices in Chicago, either downtown or in Hyde Park, to complete an interview?
  1. YES, DOWNTOWN OFFICE
  2. YES, HYDE PARK
  3. NO→FIND OUT WHERE RESPONDENT WOULD LIKE TO BE INTERVIEWED; WE WILL DETERMINE IF TRAVEL ARRANGEMENTS CAN BE MADE; CONTINUE SCREENING.
  
4. How old are you?  
\_\_\_\_\_ years
  
5. What is the highest degree or level of school you have completed?
  1. NO SCHOOLING COMPLETED
  2. NURSERY SCHOOL TO 8TH GRADE
  3. 9TH-12TH GRADE, NO DIPLOMA
  4. HIGH SCHOOL GRADUATE (HIGH SCHOOL DIPLOMA OR THE EQUIVALENT)
  5. VOCATIONAL/TECHNICAL/BUSINESS/TRADE SCHOOL CERTIFICATE OR DIPLOMA (BEYOND THE HIGH SCHOOL LEVEL)
  6. SOME COLLEGE, BUT NO DEGREE
  7. ASSOCIATE DEGREE
  8. BACHELOR'S DEGREE
  9. MASTER'S, PROFESSIONAL OR DOCTORATE DEGREE
  10. DON'T KNOW
  11. REFUSED



6. Are you of Hispanic, Latino, or Spanish origin?
  1. YES
  2. NO
  
7. What is your race? Please choose one or more.
  1. American Indian or Alaska Native
  2. Asian
  3. Black or African American
  4. Native Hawaiian or other Pacific Islander
  5. White
  6. DON'T KNOW
  7. REFUSED
  
8. Do you, personally, identify as lesbian, gay, bisexual, or transgender?
  1. Yes
  2. No

[IF RESPONDENT ASKS WHAT TRANSGENDER MEANS:  
SOME PEOPLE DESCRIBE THEMSELVES AS TRANSGENDER WHEN THEY EXPERIENCE A DIFFERENT GENDER IDENTITY FROM THEIR SEX AT BIRTH. FOR EXAMPLE, A PERSON BORN INTO A MALE BODY, BUT WHO FEELS FEMALE OR LIVES AS A WOMAN WOULD BE TRANSGENDER. SOME TRANSGENDER PEOPLE CHANGE THEIR PHYSICAL APPEARANCE SO THAT IT MATCHES THEIR INTERNAL GENDER IDENTITY. SOME TRANSGENDER PEOPLE TAKE HORMONES AND SOME HAVE SURGERY. ]

We would like to audio-record the interview so that we may review our conversation as we prepare a summary of our findings. Is this OK with you? [NOTE TO RECRUITER: THIS QUESTION IS NOT MEANT TO ASK FOR CONSENT. RESPONDENTS WILL BE ASKED AGAIN ABOUT RECORDING DURING THE CONSENT PROCESS. THEY WILL HAVE THE OPPORTUNITY TO DECIDE NOT BE RECORDED AND STILL PARTICIPATE IN THE INTERVIEW. WE PREFER TO RECRUIT RESPONDENTS WHO ARE LIKELY TO CONSENT TO RECORDING.]

1. YES
2. NO

- ▶ Ok, let's schedule an appointment for you to come in for the interview.
- ▶ CONFIRM CONTACT INFORMATION AND SCHEDULE APPOINTMENT

**PRA Disclosure Statement**

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-1275. The time required to complete this information collection is estimated to average 60 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850. **Please do not send applications, claims, payments, medical records or any documents containing sensitive information to the PRA Reports Clearance Office. Please note that any correspondence not pertaining to the information collection burden approved under the associated OMB control number listed on this form will not be reviewed, forwarded, or retained. If you have questions or concerns regarding where to submit your documents, please contact 1-800-MEDICARE or William Long at 410-786-7927.**

## Appendix H: Eligibility Screener Questionnaire (Spanish)

PARTICIPANT NUMERIC IDENTIFIER: \_\_\_\_\_

[NOTE: THIS QUESTIONNAIRE IS DIRECTED TOWARD THE MEDICARE BENEFICIARY AS THE RESPONDENT. IF SPEAKING WITH A LANGUAGE ASSISTANT, MODIFY THE LANGUAGE ACCORDINGLY.]

1. ¿Es usted hombre o mujer?
  1. HOMBRE
  2. MUJER
  
2. Necesito confirmar, ¿tiene usted seguro de salud a través de Medicare?
  1. YES
  2. NO→Lo siento, pero sólo las personas que tienen seguro de salud a través de Medicare califican para este estudio.

READ IF NECESSARY: ¿Tiene usted tarjeta de Medicare? Medicare es un programa federal de seguro de salud para personas de 65 años o más, para ciertas personas jóvenes con algún tipo de discapacidad y para personas con enfermedad renal en etapa terminal. La Parte A de Medicare incluye cobertura por estar internado(a) en el hospital y la Parte B incluye cobertura por los servicios de los doctores. La Parte C, que se refiere a los Planes de Beneficio de Medicare, son ofrecidos a través de compañías de seguros privadas bajo contrato con Medicare. Algunas personas deciden agregar la Parte D, la cual cubre recetas médicas.

3. ¿Podría venir a una de nuestras oficinas en Chicago, ya sea en el centro de la ciudad o en Hyde Park, para completar una entrevista?
  1. YES, DOWNTOWN OFFICE
  2. YES, HYDE PARK
  3. NO→FIND OUT WHERE RESPONDENT WOULD LIKE TO BE INTERVIEWED; WE WILL DETERMINE IF TRAVEL ARRANGEMENTS CAN BE MADE; CONTINUE SCREENING.
  
4. ¿Cuántos años tiene?  
 \_\_\_\_\_ years
  
5. ¿Cuál es el grado o nivel de estudios más alto que usted ha completado?
  1. NO TIENE ESTUDIOS
  2. PREESCOLAR A 8°. GRADO
  3. 9° -12° GRADO, SIN DIPLOMA
  4. GRADUADO(A) DE *HIGH SCHOOL* (CON DIPLOMA DE *HIGH SCHOOL* O SU EQUIVALENTE)
  5. VOCACIONAL/TÉCNICO/DE NEGOCIOS/CERTIFICADO O DIPLOMA DE ESCUELA DE OFICIOS (MÁS ALLÁ DEL NIVEL DE *HIGH SCHOOL*)
  6. ALGO DE *COLLEGE* O UNIVERSIDAD, PERO SIN DIPLOMA
  7. GRADUADO DE UNIVERSIDAD DE 2 AÑOS CON GRADO DE ASOCIADO
  8. GRADUADO DE UNIVERSIDAD DE 4 AÑOS CON GRADO DE BACHILLERATO
  9. MAESTRÍA, TÍTULO PROFESIONAL O DOCTORAL
  10. DON'T KNOW
  11. REFUSED

6. ¿Es usted de origen hispano, latino o español?
  1. YES
  2. NO
  
7. ¿De qué raza es? Por favor elija una o más respuestas.
  1. Indígena de las Américas o nativa de Alaska
  2. Asiática
  3. Negra o afroamericana
  4. Nativa de Hawái u otras Islas del Pacífico
  5. Blanca
  6. DON'T KNOW
  7. REFUSED
  
8. ¿Se identifica usted como lesbiana, gay, bisexual o transgénero?
  1. Sí
  2. No

[IF RESPONDENT ASKS WHAT TRANSGENDER MEANS:

ALGUNAS PERSONAS SE DESCRIBEN A SÍ MISMAS COMO TRANSGÉNERO CUANDO SIENTEN QUE SU IDENTIDAD DE GÉNERO ES DIFERENTE A LA DE SU SEXO AL NACER. POR EJEMPLO, UNA PERSONA QUE NACIÓ CON EL CUERPO DE UN HOMBRE, PERO QUE SE SIENTE MUJER O VIVE COMO MUJER, SERÍA TRANSGÉNERO. ALGUNAS PERSONAS TRANSGÉNERO CAMBIAN SU APARIENCIA FÍSICA PARA QUE CORESPONDA CON SU IDENTIDAD DE GÉNERO INTERNA. ALGUNAS PERSONAS TRANSGÉNERO TOMAN HORMONAS Y ALGUNAS SE SOMETEN A CIRUGÍAS. ]

Nos gustaría poder grabar nuestra entrevista para revisar nuestra conversación después y preparar un resumen de lo que conversamos. ¿Está de acuerdo? [NOTE TO RECRUITER: THIS QUESTION IS NOT MEANT TO ASK FOR CONSENT. RESPONDENTS WILL BE ASKED AGAIN ABOUT RECORDING DURING THE CONSENT PROCESS. THEY WILL HAVE THE OPPORTUNITY TO DECIDE NOT BE RECORDED AND STILL PARTICIPATE IN THE INTERVIEW. WE PREFER TO RECRUIT RESPONDENTS WHO ARE LIKELY TO CONSENT TO RECORDING.]

3. YES
  4. NO
- ▶ Muy bien, vamos a programar una cita para que usted haga la entrevista.
  - ▶ CONFIRM CONTACT INFORMATION AND SCHEDULE APPOINTMENT

**PRA Disclosure Statement**

Según lo establece la Ley de Reducción del Papeleo de 1995, ninguna persona tiene obligación de responder a un pedido de información si el mismo no tiene un número de control de OMB que esté vigente. El número de control de OMB vigente para este pedido de información es 0938-1275. Se calcula que el tiempo necesario para completar este pedido de información es de 60 minutos por respuesta, incluyendo el tiempo para revisar las instrucciones, buscar fuentes existentes de datos, juntar los datos necesarios, y completar y revisar el pedido de información. Si tiene comentarios con respecto al cálculo de tiempo o sugerencias para mejorar este formulario, por favor escriba a: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850. **Por favor no envíe solicitudes, reclamos, pagos, expedientes médicos ni ningún otro documento que contenga información privilegiada a la Oficina 'PRA Reports Clearance'. Por favor note que cualquier correspondencia que no tenga que ver con el tiempo de obtención de información aprobado bajo el número de control de OMB que aparece en este formulario no será revisada, reenviada, ni retenida. Si tiene alguna pregunta o inquietud sobre dónde enviar sus documentos, por favor contacte a 1-800-MEDICARE o a William Long llamando al 410-786-7927.**

## Appendix I: Participant Consent Form (English)

PARTICIPANT NUMERIC IDENTIFIER: \_\_\_\_\_

The Centers for Medicare and Medicaid Services (CMS) is a federal agency that is part of the United States Department of Health and Human Services. CMS administers the Medicare program and conducts the Medicare Current Beneficiary Survey (MCBS), a national survey of Medicare beneficiaries in the United States. To assure that the MCBS obtains the best information possible, CMS sometimes conducts evaluations of the MCBS questionnaire.

You have volunteered to take part in a study to improve the MCBS. 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 and destroyed at the conclusion of the study. We plan to use the recording to verify our notes to improve the survey. Only staff 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.

Your participation in this interview is voluntary. Some questions include sensitive topics. You may skip questions or end the interview at any time. You will receive \$40 as an incentive for participating in this study. The information you provide is confidential, consistent with the Privacy Act of 1974. Your Medicare benefits will not be affected in any way by your decision whether to participate. The OMB control number for this study is OMB No. 0938-1275, expiration 05/31/2018.

For questions regarding research subjects' rights, please contact the NORC IRB Administrator, toll-free at 866-309-0542.

I have volunteered to participate in this study, and I give permission for my tapes to be used for the purposes stated above.

\_\_\_\_\_  
Researcher's Signature

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

**PRA Disclosure Statement**

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-1275. The time required to complete this information collection is estimated to average 60 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850. **Please do not send applications, claims, payments, medical records or any documents containing sensitive information to the PRA Reports Clearance Office. Please note that any correspondence not pertaining to the information collection burden approved under the associated OMB control number listed on this form will not be reviewed, forwarded, or retained. If you have questions or concerns regarding where to submit your documents, please contact 1-800-MEDICARE or William Long at 410-786-7927.**

## Appendix J: Cognitive Interview Protocol (English)

PARTICIPANT NUMERIC IDENTIFIER: \_\_\_\_\_

### **PRA Disclosure Statement**

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-1275. The time required to complete this information collection is estimated to average 60 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850. **Please do not send applications, claims, payments, medical records or any documents containing sensitive information to the PRA Reports Clearance Office. Please note that any correspondence not pertaining to the information collection burden approved under the associated OMB control number listed on this form will not be reviewed, forwarded, or retained. If you have questions or concerns regarding where to submit your documents, please contact 1-800-MEDICARE or William Long at 410-786-7927.**

### **MATERIALS NEEDED FOR INTERVIEW**

- INTERVIEWER PROTOCOL BOOKLET (THIS BOOKLET), WORKSHEET AND SHOWCARDS
- CONSENT FORM (TWO COPIES)
- ENVELOPE WITH \$40 CASH
- RECEIPT FORM
- DIGITAL RECORDER AND EXTRA BATTERIES
- PENS AND PENCILS

### **STEP 1: INFORMED CONSENT**

PROVIDE RESPONDENT WITH A COPY OF THE INFORMED CONSENT FORM. ANSWER ANY QUESTIONS THE BENEFICIARY MAY HAVE, AND HAVE THE BENEFICIARY SIGN A SEPARATE FORM.

- SIGNED CONSENT FORM COLLECTED

- IF THE BENEFICIARY HAS CONSENTED TO RECORDING, START THE RECORDER.

### **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. I will complete the survey by asking you questions. 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 will show me how to make the questions better.

### **STEP 3: DEBRIEFING**

Now I would like to talk with you about some of the survey questions you just answered.

**GENERAL PROBES:** Suggested general neutral probing for issues that arise.

- How did you decide on that answer?
- Can you tell me more about that?
- Can you give me an example of that?
- Tell me what you are thinking.
- What did you think about when I asked that question?
- What did you think about in deciding on your answer?
- What doctors did you include when you answered this question?
- What does [QUESTION/TERM] mean to you?

**COGNITIVE INTERVIEW SURVEY ITEMS AND PROBES**

#	Question Text
1.	The first questions are about health care services you may have used in the past year. In the past year, did you go to a hospital emergency room? (01) YES (02) NO (-8) Don't Know (-9) Refused
<b>Observations:</b>	
2.	In the past year, did you go to a hospital clinic or outpatient department? DO NOT INCLUDE HOSPITAL INPATIENT STAYS. (01) YES (02) NO (-8) Don't Know (-9) Refused
<b>Observations:</b>	
3.	Next, I want to ask about your visits to doctors in the past year. Have you seen a medical doctor in the past year? Please do not include a doctor seen at home, at an emergency room or outpatient department, or while an inpatient at a hospital. [IF NECESSARY, SAY, 'Please look at show card AC1 for examples of types of medical doctors.']  (01) YES (02) NO (-8) Don't Know (-9) Refused

<b>Observations:</b>	
4.	<p>SHOW CARD AC1</p> <p>[I have a few more questions about visits that you had in the past.]</p> <p>Think about the most recent time you saw a medical doctor somewhere other than at home or at a hospital. What was the doctor’s specialty?</p> <p>[PROBE FOR RESPONDENT TO SELECT A CHOICE FROM THE CARD IF THEY MENTION A 'GENERIC' SPECIALTY LIKE 'HEART DOCTOR.' IF RESPONDENT ONLY GIVES A 'GENERIC' SPECIALTY AND THE GENERIC WORD IS SHOWN IN PARENTHESES FOLLOWING ONE OF THE RESPONSES, SELECT THE RESPONSE CATEGORY FOR THAT SPECIALTY (E.G., 'CARDIOLOGY'). OTHERWISE SELECT 'OTHER DR SPECIALTY'.]</p> <p>(01) ALLERGY/IMMUNOLOGY                      (02) ANESTHESIOLOGY                      (03) CARDIOLOGY (HEART)                      (05) DERMATOLOGY (SKIN)                      (07) ENDOCRINOLOGY/METABOLISM (DIABETES, THYROID)                      (08) FAMILY PRACTICE                      (09) GASTROENTEROLOGY                      (10) GENERAL PRACTICE                      (11) GENERAL SURGERY                      (12) GERIATRICS (ELDERLY)                      (13) GYNECOLOGY - OBSTETRICS                      (14) HEMATOLOGY (BLOOD)                      (15) HOSPITAL RESIDENCE                      (16) INTERNAL MEDICINE (INTERNIST)                      (17) NEPHROLOGY (KIDNEYS)                      (18) NEUROLOGY                      (19) NUCLEAR MEDICINE                      (20) ONCOLOGY (TUMORS, CANCER)                      (21) OPHTHALMOLOGY (EYES)                      (22) ORTHOPEDICS                      (24) OSTEOPATHY (DO)                      (25) OTORHINOLARYNGOLOGY (EAR, NOSE, THROAT)                      (26) PATHOLOGY                      (27) PHYS MED/REHAB                      (28) PLASTIC SURGERY                      (29) PROCTOLOGY                      (30) PSYCHIATRY/PSYCHIATRIST                      (31) PULMONARY (LUNGS)                      (32) RADIOLOGY                      (33) RHEUMATOLOGY (ARTHRITIS)                      (34) THORACIC SURGERY (CHEST)                      (35) UROLOGY                      (91) OTHER DR SPECIALTY (SPECIFY _____)                      (-8) Don't Know                      (-9) Refused</p>



<b>Observations:</b>	
5.	<p>SHOW CARD SC1</p> <p>We're interested in how you feel about the health care you have received over the past year from doctors and hospitals. Please tell me how satisfied you have been with the following:</p> <p>The overall quality of the health care you have received over the past year.</p> <p>(01) VERY SATISFIED  (02) SATISFIED  (03) DISSATISFIED  (04) VERY DISSATISFIED  (05) NOT APPLICABLE  (-8) Don't Know  (-9) Refused</p>
<b>Observations:</b>	
6.	<p>SHOW CARD SC1</p> <p>[Please tell me how satisfied you have been with . . .]</p> <p>The availability of health care at night and on weekends.</p> <p>(01) VERY SATISFIED  (02) SATISFIED  (03) DISSATISFIED  (04) VERY DISSATISFIED  (05) NOT APPLICABLE  (-8) Don't Know  (-9) Refused</p>
<b>Observations:</b>	
7.	<p>SHOW CARD SC1</p> <p>[Please tell me how satisfied you have been with . . .]</p> <p>The ease and convenience of getting to a doctor from where you live.</p> <p>(01) VERY SATISFIED  (02) SATISFIED  (03) DISSATISFIED  (04) VERY DISSATISFIED  (05) NOT APPLICABLE  (-8) Don't Know  (-9) Refused</p>
<b>Observations:</b>	
8.	<p>SHOW CARD SC1</p> <p>[Please tell me how satisfied you have been with . . .]</p> <p>The out-of-pocket costs you paid for health care.</p> <p>(01) VERY SATISFIED  (02) SATISFIED  (03) DISSATISFIED  (04) VERY DISSATISFIED  (05) NOT APPLICABLE  (-8) Don't Know  (-9) Refused</p>

<b>Observations:</b>	
9.	<p>SHOW CARD SC1 [Please tell me how satisfied you have been with . . .]</p> <p>The information given to you about what was wrong with you.</p> <p>(01) VERY SATISFIED (02) SATISFIED (03) DISSATISFIED (04) VERY DISSATISFIED (05) NOT APPLICABLE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
10.	<p>SHOW CARD SC1 [Please tell me how satisfied you have been with . . .]</p> <p>The follow-up care you received after an initial treatment or operation.</p> <p>(01) VERY SATISFIED (02) SATISFIED (03) DISSATISFIED (04) VERY DISSATISFIED (05) NOT APPLICABLE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
11.	<p>SHOW CARD SC1 [Please tell me how satisfied you have been with . . .]</p> <p>The concern of doctors for your overall health rather than just for an isolated symptom or disease.</p> <p>(01) VERY SATISFIED (02) SATISFIED (03) DISSATISFIED (04) VERY DISSATISFIED (05) NOT APPLICABLE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
12.	<p>SHOW CARD SC1 [Please tell me how satisfied you have been with . . .]</p> <p>Getting all your health care needs taken care of at the same location.</p> <p>(01) VERY SATISFIED (02) SATISFIED (03) DISSATISFIED (04) VERY DISSATISFIED (05) NOT APPLICABLE (-8) Don't Know (-9) Refused</p>

<b>Observations:</b>	
13.	<p>SHOW CARD SC1 [Please tell me how satisfied you have been with . . .]</p> <p>The availability of care by specialists when you feel you need it.</p> <p>(01) VERY SATISFIED (02) SATISFIED (03) DISSATISFIED (04) VERY DISSATISFIED (05) NOT APPLICABLE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
14.	<p>SHOW CARD SC1 [Please tell me how satisfied you have been with . . .]</p> <p>The ease of obtaining answers to questions over the telephone about your treatment or prescriptions.</p> <p>(01) VERY SATISFIED (02) SATISFIED (03) DISSATISFIED (04) VERY DISSATISFIED (05) NOT APPLICABLE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
15.	<p>SHOW CARD SC1 [Please tell me how satisfied you have been with . . .]</p> <p>The amount you have to pay for your prescribed medicines.</p> <p>(01) VERY SATISFIED (02) SATISFIED (03) DISSATISFIED (04) VERY DISSATISFIED (05) NOT APPLICABLE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
16.	<p>Please think about all of the health care services you receive, including services provided by doctors, hospitals and pharmacies.</p> <p>What things, if anything, about the health care services you receive are you dissatisfied with?</p> <p>(01) RESPONDENT IS NOT DISSATISFIED WITH ANYTHING (91) RESPONDENT IS DISSATISFIED (RECORD VERBATIM BELOW) (-8) Don't Know (-9) Refused RESPONDENT VERBATIM:</p>
<b>Observations:</b>	

17.	<p>Is there a particular medical person or a clinic you usually go to when you are sick or for advice about your health?</p> <p>(01) YES</p> <p>(02) NO → GO TO Q40</p>
<b>Observations:</b>	
18.	<p>What kind of place do you usually go to when you are sick or for advice about your health -- is that a managed care plan or HMO center, a clinic, a doctor's office, a hospital, or some other place?</p> <p>IF CLINIC, ASK: Is it a hospital outpatient clinic, or some other kind of clinic?</p> <p>IF SOME OTHER PLACE, ASK: Where is this?</p> <p>(01) DOCTOR'S OFFICE OR GROUP PRACTICE</p> <p>(02) MEDICAL CLINIC</p> <p>(03) MANAGED CARE PLAN CENTER/HMO</p> <p>(04) NEIGHBORHOOD/FAMILY HEALTH CENTER</p> <p>(05) FREESTANDING SURGICAL CENTER</p> <p>(06) RURAL HEALTH CLINIC</p> <p>(07) COMPANY CLINIC</p> <p>(08) OTHER CLINIC</p> <p>(09) WALK-IN URGENT CENTER</p> <p>(10) DOCTOR COMES TO SP'S HOME</p> <p>(11) HOSPITAL EMERGENCY ROOM</p> <p>(12) HOSPITAL OUTPATIENT DEPARTMENT/CLINIC</p> <p>(13) VA FACILITY</p> <p>(14) MENTAL HEALTH CENTER</p> <p>(91) OTHER (SPECIFY _____)</p> <p>(-8) DON'T KNOW</p> <p>(-9) REFUSED</p>
<b>Observations:</b>	
19.	What is the complete name of the place that you go to? WRITE NAME ON WORKSHEET
<b>Observations:</b>	
20.	<p>Is there a particular doctor you usually see at this place?</p> <p>(01) YES</p> <p>(02) NO → GO TO Q24</p> <p>(-8) DON'T KNOW</p> <p>(-9) REFUSED</p>
<b>Observations:</b>	
21.	What is the complete name of that doctor? WRITE NAME ON WORKSHEET

<b>Observations:</b>	
22.	<p>SHOW CARD AC1</p> <p>What is (PROVIDER NAME FROM Q21)'s specialty?</p> <p>[PROBE FOR RESPONDENT TO SELECT A CHOICE FROM THE CARD IF THEY MENTION A 'GENERIC' SPECIALITY LIKE 'HEART DOCTOR.' IF RESPONDENT ONLY GIVES A 'GENERIC' SPECIALTY AND THE GENERIC WORD IS SHOWN IN PARENTHESES FOLLOWING ONE OF THE RESPONSES, SELECT THE RESPONSE CATEGORY FOR THAT SPECIALTY (E.G., 'CARDIOLOGY'). OTHERWISE SELECT 'OTHER DR SPECIALTY'.]</p> <p>(01) ALLERGY/IMMUNOLOGY                      (02) ANESTHESIOLOGY                      (03) CARDIOLOGY (HEART)                      (05) DERMATOLOGY (SKIN)                      (06) EMERGENCY ROOM PHYSICIAN                      (07) ENDOCRINOLOGY/ METABOLISM (DIABETES, THYROID)                      (08) FAMILY PRACTICE                      (09) GASTROENTEROLOGY                      (10) GENERAL PRACTICE                      (11) GENERAL SURGERY                      (12) GERIATRICS (ELDERLY)                      (13) GYNECOLOGY - OBSTETRICS                      (14) HEMATOLOGY (BLOOD)                      (15) HOSPITAL RESIDENCE                      (16) INTERNAL MEDICINE (INTERNIST)                      (17) NEPHROLOGY (KIDNEYS)                      (18) NEUROLOGY                      (19) NUCLEAR MEDICINE                      (20) ONCOLOGY (TUMORS, CANCER)                      (21) OPHTHALMOLOGY (EYES)                      (22) ORTHOPEDICS                      (24) OSTEOPATHY (DO)                      (25) OTORHINOLARYNGOLOGY (EAR, NOSE, THROAT)                      (26) PATHOLOGY                      (27) PHYS MED/REHAB                      (28) PLASTIC SURGERY                      (29) PROCTOLOGY                      (30) PSYCHIATRY/PSYCHIATRIST                      (31) PULMONARY (LUNGS)                      (32) RADIOLOGY                      (33) RHEUMATOLOGY (ARTHRITIS)                      (34) THORACIC SURGERY (CHEST)                      (35) UROLOGY                      (91) OTHER DR SPECIALTY                      (-8) DON'T KNOW                      (-9) REFUSED</p>

<b>Observations</b>	
23.	OTHER DR SPECIALTY (SPECIFY) _____
24.	Do you usually have someone accompany you there? (01) YES (02) NO→GO TO Q28 (-8) DON'T KNOW (-9) REFUSED
<b>Observations:</b>	
25.	Who usually goes with you?  (SPECIFY) _____
<b>Observations</b>	
26.	How often is [RESPONSE FROM Q25] with you while you see the doctor or other medical person? Would you say always, sometimes, or never? (01) ALWAYS (02) SOMETIMES (03) NEVER (-8) DON'T KNOW (-9) REFUSED
<b>Observations:</b>	
27.	What are the reasons this person accompanies you there? What does this person do?  [PROBE: Any other reason?] CHECK ALL THAT APPLY. (01) WRITES DOWN WHAT DOCTOR SAYS/RECORDS INSTRUCTIONS/TAKES NOTES/REMEMBERS (02) GIVES INFORMATION/EXPLAINS SP'S MEDICAL CONDITION OR NEEDS TO THE DOCTOR (03) EXPLAINS DOCTOR'S INSTRUCTIONS TO SP (04) ASKS QUESTIONS (05) TRANSLATES LANGUAGE (06) SCHEDULES APPOINTMENTS (07) NOTHING/KEEPS SP COMPANY/SITS WITH SP/MORAL SUPPORT (08) TRANSPORTATION (09) SP NEEDS PHYSICAL ASSISTANCE (91) OTHER (SPECIFY _____) (-8) DON'T KNOW (-9) REFUSED

<b>Observations:</b>	
28.	<p>SHOW CARD US1</p> <p>How long have you been seeing (PROVIDER NAME FROM Q21)/going to (PLACE NAME FROM Q19)?</p> <p>(01) LESS THAN 1 YEAR                      (02) 1 YEAR TO LESS THAN 3 YEARS                      (03) 3 YEARS TO LESS THAN 5 YEARS                      (04) 5 YEARS TO LESS THAN 10 YEARS                      (05) 10 YEARS OR MORE                      (-8) DON'T KNOW                      (-9) REFUSED</p>
<b>Observations:</b>	
29.	<p>SHOW CARD US3</p> <p>Now I am going to read some statements people have made about their health care. Think about the care you receive from (PROVIDER NAME FROM Q21/ PLACE NAME FROM Q19). For each statement, please tell me whether you strongly agree, agree, disagree, or strongly disagree.</p> <p>[(PROVIDER NAME FROM Q21) is/The doctors at (PLACE NAME FROM Q19) are] very careful to check everything when examining you.</p> <p>(01) STRONGLY AGREE                      (02) AGREE                      (03) DISAGREE                      (04) STRONGLY DISAGREE                      (05) NOT APPLICABLE                      (-8) Don't Know                      (-9) Refused</p>
<b>Observations</b>	
30.	<p>SHOW CARD US3</p> <p>[(PROVIDER NAME FROM Q21) is/The doctors at (PLACE NAME FROM Q19) are] competent and well-trained.</p> <p>(01) STRONGLY AGREE                      (02) AGREE                      (03) DISAGREE                      (04) STRONGLY DISAGREE                      (05) NOT APPLICABLE                      (-8) Don't Know                      (-9) Refused</p>

<b>Observations:</b>	
31.	<p>SHOW CARD US3                      [(PROVIDER NAME FROM Q21) has/The doctors at (PLACE NAME FROM Q19) have] a complete understanding of the things that are wrong with you.</p> <p>(01) STRONGLY AGREE                      (02) AGREE                      (03) DISAGREE                      (04) STRONGLY DISAGREE                      (05) NOT APPLICABLE                      (-8) Don't Know                      (-9) Refused</p>
<b>Observations:</b>	
32.	<p>SHOW CARD US3                      [(PROVIDER NAME FROM Q21) often seems/The doctors at (PLACEFROM Q19) often seem] to be in a hurry.</p> <p>(01) STRONGLY AGREE                      (02) AGREE                      (03) DISAGREE                      (04) STRONGLY DISAGREE                      (05) NOT APPLICABLE                      (-8) Don't Know                      (-9) Refused</p>
<b>Observations:</b>	
33.	<p>SHOW CARD US3                      [Think about the care you receive from [(PROVIDER NAME FROM Q21)/(PLACE NAME FROM Q19)].]</p> <p>[(PROVIDER NAME FROM Q21) often does/The doctors at (PLACE NAME FROM Q19) often do] not explain your medical problems to you.</p> <p>(01) STRONGLY AGREE                      (02) AGREE                      (03) DISAGREE                      (04) STRONGLY DISAGREE                      (05) NOT APPLICABLE                      (-8) Don't Know                      (-9) Refused</p>
<b>Observations:</b>	
34.	<p>SHOW CARD US3                      You often have health problems that should be discussed but are not.</p> <p>(01) STRONGLY AGREE                      (02) AGREE                      (03) DISAGREE                      (04) STRONGLY DISAGREE                      (05) NOT APPLICABLE                      (-8) Don't Know                      (-9) Refused</p>



<b>Observations:</b>	
35.	<p>SHOW CARD US3</p> <p>[(PROVIDER NAME FROM Q21) often acts/The doctors at (PLACE NAME FROM Q19) often act] as though [(he/she) was/they were] doing you a favor by talking to you.</p> <p>(01) STRONGLY AGREE  (02) AGREE  (03) DISAGREE  (04) STRONGLY DISAGREE  (05) NOT APPLICABLE  (-8) Don't Know  (-9) Refused</p>
<b>Observations:</b>	
36.	<p>SHOW CARD US3</p> <p>[(PROVIDER NAME FROM Q21) tells/The doctors at (PLACE NAME FROM Q19) tell] you all you want to know about your condition and treatment.</p> <p>(01) STRONGLY AGREE  (02) AGREE  (03) DISAGREE  (04) STRONGLY DISAGREE  (05) NOT APPLICABLE  (-8) Don't Know  (-9) Refused</p>
<b>Observations:</b>	
37.	<p>SHOW CARD US3</p> <p>[(PROVIDER NAME FROM Q21) answers/The doctors at (PLACE NAME FROM Q19) answer] all your questions.</p> <p>(01) STRONGLY AGREE  (02) AGREE  (03) DISAGREE  (04) STRONGLY DISAGREE  (05) NOT APPLICABLE  (-8) Don't Know  (-9) Refused</p>
<b>Observations:</b>	
38.	<p>SHOW CARD US3</p> <p>[Think about the care you receive from (PROVIDER NAME FROM Q21/PROVIDER NAME FROM PLACE).]</p> <p>You have great confidence in [(PROVIDER NAME FROM Q21)/the doctors at (PLACE NAME FROM Q19)].</p> <p>(01) STRONGLY AGREE  (02) AGREE  (03) DISAGREE  (04) STRONGLY DISAGREE  (05) NOT APPLICABLE  (-8) Don't Know  (-9) Refused</p>

<b>Observations:</b>	
39.	<p>SHOW CARD US3</p> <p>You depend on [(PROVIDER NAME FROM Q21)/the doctors at (PLACE NAME FROM Q19)] in order to feel better both physically and emotionally.</p> <p>(01) STRONGLY AGREE  (02) AGREE  (03) DISAGREE  (04) STRONGLY DISAGREE  (05) NOT APPLICABLE  (-8) Don't Know  (-9) Refused</p> <p>ALL RESPONSES→GO TO Q47</p>
<b>Observations:</b>	
40.	<p>[IF NO USUAL SOURCE OF CARE]</p> <p>I am going to read some reasons that people have given for not having a usual source of health care. For each one, please tell me whether or not it is a reason you do not have a usual place for health care.</p> <p>There is no reason to have a usual source of health care because you seldom or never get sick. [Is that a reason you do not have a usual source of health care?]</p> <p>(01) YES  (02) NO  (-8) DON'T KNOW  (-9) REFUSED</p>
<b>Observations:</b>	
41.	<p>You recently moved into the area. [Is that a reason you do not have a usual source of health care?]</p> <p>(01) YES  (02) NO  (-8) DON'T KNOW  (-9) REFUSED</p>
<b>Observations:</b>	
42.	<p>Your usual source of health care in this area is no longer available. [Is that a reason you do not have a usual source of health care?]</p> <p>(01) YES  (02) NO→GO TO Q44  (-8) DON'T KNOW→GO TO Q44  (-9) REFUSED→GO TO Q44</p>

<b>Observations:</b>	
43.	<p>Why is your usual source of health care no longer available?</p> <p>(01) PREVIOUS DOCTOR RETIRED  (02) PREVIOUS DOCTOR DIED  (03) PREVIOUS DOCTOR MOVED  (04) RESPONDENT MOVED  (05) PREVIOUS DR/PLACE TOO FAR AWAY  (91) OTHER (SPECIFY _____)  (-8) DON'T KNOW  (-9) REFUSED</p>
<b>Observations:</b>	
44.	<p>Thinking about other possible reasons that people have for not having a usual source of health, please tell me if this statement applies to you:</p> <p>You like to go to different places for different health care needs. [Is that a reason you do not have a usual source of health care?]</p> <p>(01) YES  (02) NO  (-8) DON'T KNOW  (-9) REFUSED</p>
<b>Observations:</b>	
45.	<p>The places where you can receive health care are too far away. [Is that a reason you do not have a usual source of health care?]</p> <p>(01) YES  (02) NO  (-8) DON'T KNOW  (-9) REFUSED</p>
<b>Observations:</b>	
46.	<p>The cost of health care is too expensive. [Is that a reason you do not have a usual source of health care?]</p> <p>(01) YES  (02) NO  (-8) DON'T KNOW  (-9) REFUSED</p>
47.	<p>I would like to get a little information about your background.  Are you of Hispanic, Latino, or Spanish origin?</p> <p>(01) YES  (02) NO→GO TO Q49  (-8) Don't Know→GO TO Q49  (-9) Refused→GO TO Q49</p>

<b>Observations:</b>	
48.	<p>SHOW CARD DI1 Looking at this card, are you Mexican, Mexican American, or Chicano/Chicana, Puerto Rican, Cuban, or of another Hispanic, Latino/Latina or Spanish origin? CHECK ALL THAT APPLY.</p> <p>(01) MEXICAN/MEXICAN AMERICAN/CHICANO(A) (02) PUERTO RICAN (03) CUBAN (91) OTHER HISPANIC, LATINO(A), OR SPANISH ORIGIN (SPECIFY _____) (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
49.	<p>SHOW CARD DI2 Looking at this card, what is your race?</p> <p>[ASK IF NECESSARY: Are there any options from this card that you would like me to record?]</p> <p>(01) AMERICAN INDIAN OR ALASKA NATIVE (02) ASIAN (03) BLACK OR AFRICAN AMERICAN (04) NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER (05) WHITE (-8) Don't Know (-9) Refused</p> <p>IF RACE INCLUDES ASIAN, GO TO Q50. ELSE IF RACE INCLUDES NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER, GO TO Q51. ELSE GO TO Q52.</p>

<b>Observations:</b>	
50.	<p><b>SHOW CARD DI3</b> Looking at this card, are you Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese or some other Asian group?</p> <p>You can choose more than one group. CHECK ALL THAT APPLY. (01) ASIAN INDIAN (02) CHINESE (03) FILIPINO (04) JAPANESE (05) KOREAN (06) VIETNAMESE (91) OTHER ASIAN GROUP (SPECIFY _____) (-8) Don't Know (-9) Refused IF RACE AT Q49 INCLUDES NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER, GO TO Q51. ELSE GO TO Q52.</p>
<b>Observations:</b>	
51.	<p><b>SHOW CARD DI4</b> Looking at this card, are you Native Hawaiian, Guamanian or Chamorro, Samoan, or some other Pacific Islander group?</p> <p>You can choose more than one group. CHECK ALL THAT APPLY. (01) NATIVE HAWAIIAN (02) GUAMANIAN OR CHAMORO (03) SAMOAN (91) OTHER PACIFIC ISLANDER GROUP (SPECIFY _____) (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
52.	<p><b>SHOW CARD DI5</b> [FOR MALE RESPONDENTS] Which of the following best represents how you think about yourself? (01) Gay (02) Straight, that is, not gay (03) Bisexual (04) Something else (05) I don't know how to answer [FOR FEMALE RESPONDENTS] Which of the following best represents how you think about yourself? (01) Lesbian or Gay (02) Straight, that is, not lesbian or gay (03) Bisexual (04) Something else (05) I don't know how to answer</p>

**Probes**

- What did you think about when I asked that question?
- What did you think about in deciding on your answer?
- How did you decide on that answer?
  - Can you tell me more about that?
- Did you have any trouble deciding on that answer?
  - If YES, What were you concerned about?
- Were there any words that you were uncertain about?
  - Which ones?
  - How did this affect your answer?
- What does [Bisexual] mean to you?
- [IF R ANSWERED: SOMETHING ELSE: ]
  - What else would best represent how you think about yourself?
- [IF R ANSWERED: I don't know how to answer: ]
  - What makes it difficult for you to answer this question?

**Note to Interviewers**

How does the R interpret these questions and decide on their answer? Are there terms or words that cause any confusion? Even if there are words that they were uncertain about how did they decide which answer to give? For example, some respondents may not be sure about “straight” or “bisexual” or “transgender”. What process did they use to decide which response to give? If they said that “don’t know,” what would they want to know to be able to choose a response?

**Observations:**

53.	What sex were you assigned at birth, on your original birth certificate? (01) FEMALE (02) MALE
-----	--

**Observations:**

54.	SHOW CARD DI6 How do you describe yourself? (select one) (01) Female (02) Male (03) Transgender (04) Do not identify as female, male, or transgender
-----	---

**Probes**

- What did you think about when I asked that question?
- What did you think about in deciding on your answer?
- How did you decide on that answer?
  - Can you tell me more about that?
- Did you have any trouble deciding on that answer?
  - If YES, What were you concerned about?
- Were there any words that you were uncertain about?
  - Which ones?
  - How did this affect your answer?

- IF R ANSWERED “Do not identify as female, male, or transgender”:
  - How do you describe yourself?
  - Is there some other term that you would use?
- What does [Transgender] mean to you?

**Note to Interviewers**

How does the R interpret these questions and decide on their answer? Are there terms or words that cause any confusion? Even if there are words that they were uncertain about how did they decide which answer to give? For example, some respondents may not be sure about “straight” or “bisexual” or “transgender”. What process did they use to decide which response to give? If they said that “don’t know,” what would they want to know to be able to choose a response?

**Observations:**

55.	<p>The next two questions are about education and income.                  SHOW CARD DI7                  What is the highest degree or level of school you have completed?                  [IF THE SAMPLE PERSON ATTENDED SCHOOL IN A FOREIGN COUNTRY, IN AN UNGRADED SCHOOL, HOME SCHOOLING, OR UNDER OTHER UNIQUE CIRCUMSTANCES, REFER THE RESPONDENT TO THE SHOWCARD AND ASK FOR THE NEAREST EQUIVALENT.]</p> <p>(01) NO SCHOOLING COMPLETED                  (02) NURSERY SCHOOL TO 8TH GRADE                  (03) 9TH-12TH GRADE, NO DIPLOMA                  (04) HIGH SCHOOL GRADUATE (HIGH SCHOOL DIPLOMA OR THE EQUIVALENT)                  (05) VOCATIONAL/TECHNICAL/BUSINESS/TRADE SCHOOL CERTIFICATE OR DIPLOMA (BEYOND THE HIGH SCHOOL LEVEL)                  (06) SOME COLLEGE, BUT NO DEGREE                  (07) ASSOCIATE DEGREE                  (08) BACHELOR'S DEGREE                  (09) MASTER'S, PROFESSIONAL OR DOCTORATE DEGREE                  (-8) Don't Know                  (-9) Refused</p>
-----	---

<b>Observations:</b>	
56.	<p><b>SHOW CARD DI8</b>                      Looking at this card, which letter best represents your total income before taxes during the past 12 months? Include income from jobs, Social Security, Railroad Retirement, other retirement income, and the other sources of income we just talked about.</p> <p>[EXPLAIN IF NECESSARY: Income is important in analyzing the information we collect. For example, this information helps us learn whether persons in one income group use certain types of medical care services or have certain medical conditions more or less often than those in another group.]</p> <p>(01) A. Less than \$5,000                      (02) B. \$5,000 - 9,999                      (03) C. \$10,000 - 14,999                      (04) D. \$15,000 - 19,999                      (05) E. \$20,000 - 24,999                      (06) F. \$25,000 - 29,999                      (07) G. \$30,000 - 39,999                      (08) H. \$40,000 - 49,999                      (09) I. \$50,000 or more                      (-8) Don't Know                      (-9) Refused</p>
<b>Observations:</b>	



## Appendix K: Worksheet and Showcards for Questionnaire Testing (English)

---

Place name from Q19:

Provider name from Q21:

# AC1

- (01) Allergy/Immunology (Allergies, Asthma)
- (02) Anesthesiology
- (03) Cardiology (Heart)
- (05) Dermatology (Skin)
- (07) Endocrinology/Metabolism (Diabetes, Thyroid)
- (08) Family Practice
- (09) Gastroenterology (Digestive System)
- (10) General Practice
- (11) General Surgery
- (12) Geriatrics (Elderly)
- (13) Gynecology – Obstetrics
- (14) Hematology (Blood)
- (15) Hospital Residence
- (16) Internal Medicine (Internist)
- (17) Nephrology (Kidneys)
- (18) Neurology (Nervous System)
- (19) Nuclear Medicine
- (20) Oncology (Tumors, Cancer)
- (21) Ophthalmology (Eyes)
- (22) Orthopedics (Bones, Joints)
- (24) Osteopathy (DO)
- (25) Otorhinolaryngology (Ear, Nose, Throat)
- (26) Pathology
- (27) Physical Med/Rehab
- (28) Plastic Surgery
- (29) Proctology

- (30) Psychiatry/Psychiatrist (Mental Health)
- (31) Pulmonary (Lungs)
- (32) Radiology
- (33) Rheumatology (Arthritis)
- (34) Thoracic Surgery (Chest)
- (35) Urology (Urinary Tract)

# SC1

- Very Satisfied
- Satisfied
- Dissatisfied
- Very Dissatisfied

## SC2

- Didn't Think the Problem Was Serious
- Thought It Would Cost Too Much
- Trouble Finding or Getting to the Doctor
- Time, Schedule, or Personal Conflicts
- Thought Doctor Couldn't Do Much about the Problem
- Was Afraid of Finding out What Was Wrong
- Doctor Would Not Accept My Insurance

## SC3

- Thought It Would Cost Too Much
- Didn't Think Medicine Would Help the Condition
- Was Afraid of Medicine Reactions or Contraindications
- Don't Like to Take Medicine
- Didn't Think Medicine Was Necessary
- The Medicine Was Not Covered by Insurance or Not on the Plan's Formulary
- Trouble Obtaining Medicine
- Obtained or Used Samples
- Used Another Medicine as a Substitution

## SC4

- Often
- Sometimes
- Never

# US1

- Less Than 1 Year
- 1 Year to Less Than 3 Years
- 3 Years to Less Than 5 Years
- 5 Years to Less Than 10 Years
- 10 Years or More



US2

- Never
- Sometimes
- Usually
- Always

US3

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree

# DI1

- Mexican, Mexican American, Chicano(a)
- Puerto Rican
- Cuban

## DI2

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White

## DI3

- Asian Indian
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese

# DI4

- Native Hawaiian
- Guamanian or Chamorro
- Samoan

## DI5

### **Male Respondents**

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

## DI5

### **Female Respondents**

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



## DI6

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

## DI7

- No Schooling Completed
- Nursery School to 8TH Grade
- 9TH-12TH Grade, No Diploma
- High School Graduate (High School Diploma or the Equivalent)
- Vocational/Technical/Business/Trade School Certificate or Diploma (Beyond the High School Level)
- Some College, But No Degree
- Associate Degree
- Bachelor's Degree
- Master's, Professional, or Doctorate Degree

DI8

**Annual Income**

A. Less than \$5,000
B. \$5,000 - 9,999
C. \$10,000 - 14,999
D. \$15,000 - 19,999
E. \$20,000 - 24,999
F. \$25,000 - 29,999
G. \$30,000 – 39,999
H. \$40,000 - 49,999
I. \$50,000 +

## Appendix L: Participant Receipt Form (English)

---

### National Opinion Research Center (NORC) Participant Receipt Form

**Instructions:** Please check box below. Sign your name indicating you have read this Receipt and have received \$40 as an incentive for participating in this survey.

I have received \$40.00 (cash) from an NORC staff member as an incentive for participating in this survey.

---

Participant Signature

\_\_\_\_|\_\_\_\_|\_\_\_\_|\_\_\_\_|\_\_\_\_|\_\_\_\_|  
**Month                  Day                  Year**

## Appendix M: Participant Consent Form (Spanish)

PARTICIPANT NUMERIC IDENTIFIER: \_\_\_\_\_

Los Centros de Servicios de Medicare y Medicaid (CMS por sus siglas en inglés) es una agencia federal que forma parte del Departamento de Salud y Servicios Humanos de los Estados Unidos. CMS administra el programa de Medicare y dirige la Encuesta de Beneficiarios Actuales de Medicare (MCBS por sus siglas en inglés), que es la encuesta a nivel nacional de los beneficiarios de Medicare en los Estados Unidos. Para asegurar que MCBS obtiene la mejor información posible, algunas veces el CMS evalúa los cuestionarios de MCBS.

Usted ha decidido voluntariamente participar en un estudio para mejorar MCBS. Con el fin de tener un registro completo de sus comentarios, la entrevista será grabada en audio con su consentimiento. La grabación se guardará electrónicamente en un servidor seguro de NORC y será destruida al final del estudio. Nuestro propósito es usar la grabación para mejorar las encuestas. Únicamente el personal relacionado directamente en este estudio tendrá acceso a la grabación. Los comentarios que hagan los participantes y que se usen en presentaciones y publicaciones no incluirán ningún nombre ni otra información que pudiera identificar a los participantes.

Su participación en esta entrevista es voluntaria. Algunas preguntas incluyen temas sensibles.

Usted puede saltar cualquier pregunta o terminar la entrevista en cualquier momento. Usted recibirá un incentivo de \$40 dólares por su participación en el estudio. La información que proporcione es confidencial, de conformidad con la Ley de Privacidad de 1974. Su decisión de participar o no, no afectará de ninguna manera sus beneficios de Medicare. El número de control de OMB para este estudio es OMB No. 0938-1275, expiración 05/31/2018.

Si tiene preguntas sobre los derechos de los participantes, por favor contacte al administrador de IRB en NORC, al número gratuito 866-309-0542.

He decidido participar en este estudio por propia voluntad y doy mi permiso para que mi grabación sea usada para los fines arriba mencionados.

\_\_\_\_\_  
Firma del entrevistador

\_\_\_\_\_  
Firma del participante

\_\_\_\_\_  
Nombre en letra de imprenta

\_\_\_\_\_  
Nombre en letra de imprenta

\_\_\_\_\_  
Fecha

\_\_\_\_\_  
Fecha

### **PRA Disclosure Statement**

Según lo establece la Ley de Reducción del Papeleo de 1995, ninguna persona tiene obligación de responder a un pedido de información si el mismo no tiene un número de control de OMB que esté vigente. El número de control de OMB vigente para este pedido de información es 0938-1275. Se calcula que el tiempo necesario para completar este pedido de información es de 60 minutos por respuesta, incluyendo el tiempo para revisar las instrucciones, buscar fuentes existentes de datos, juntar los datos necesarios, y completar y revisar el pedido de información. Si tiene comentarios con respecto al cálculo de tiempo o sugerencias para mejorar este formulario, por favor escriba a: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850. **Por favor no envíe solicitudes, reclamos, pagos, expedientes médicos ni ningún otro documento que contenga información privilegiada a la Oficina 'PRA Reports Clearance'. Por favor note que cualquier correspondencia que no tenga que ver con el tiempo de obtención de información aprobado bajo el número de control de OMB que aparece en este formulario no será revisada, reenviada, ni retenida. Si tiene alguna pregunta o inquietud sobre dónde enviar sus documentos, por favor contacte a 1-800-MEDICARE o a William Long llamando al 410-786-7927.**

## Appendix N: Cognitive Interview Protocol (Spanish)

PARTICIPANT NUMERIC IDENTIFIER: \_\_\_\_\_

### **PRA Disclosure Statement**

Según lo establece la Ley de Reducción del Papeleo de 1995, ninguna persona tiene obligación de responder a un pedido de información si el mismo no tiene un número de control de OMB que esté vigente. El número de control de OMB vigente para este pedido de información es 0938-1275. Se calcula que el tiempo necesario para completar este pedido de información es de 60 minutos por respuesta, incluyendo el tiempo para revisar las instrucciones, buscar fuentes existentes de datos, juntar los datos necesarios, y completar y revisar el pedido de información. Si tiene comentarios con respecto al cálculo de tiempo o sugerencias para mejorar este formulario, por favor escriba a: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850. **Por favor no envíe solicitudes, reclamos, pagos, expedientes médicos ni ningún otro documento que contenga información privilegiada a la Oficina 'PRA Reports Clearance'. Por favor note que cualquier correspondencia que no tenga que ver con el tiempo de obtención de información aprobado bajo el número de control de OMB que aparece en este formulario no será revisada, reenviada, ni retenida. Si tiene alguna pregunta o inquietud sobre dónde enviar sus documentos, por favor contacte a 1-800-MEDICARE o a William Long llamando al 410-786-7927.**

### **MATERIALS NEEDED FOR INTERVIEW**

- INTERVIEWER PROTOCOL BOOKLET (THIS BOOKLET), WORKSHEET AND SHOWCARDS
- CONSENT FORM (TWO COPIES)
- ENVELOPE WITH \$40 CASH
- PAYMENT RECEIPT FORM
- DIGITAL RECORDER AND EXTRA BATTERIES
- PENS AND PENCILS

### **STEP 1: INFORMED CONSENT**

PROVIDE RESPONDENT WITH A COPY OF THE INFORMED CONSENT FORM. ANSWER ANY QUESTIONS THE BENEFICIARY MAY HAVE, AND HAVE THE BENEFICIARY SIGN A SEPARATE FORM.

SIGNED CONSENT FORM COLLECTED

IF THE BENEFICIARY HAS CONSENTED TO RECORDING, START THE RECORDER.

### **STEP 2: COMPLETION OF THE QUESTIONNAIRE**

La Encuesta de los Beneficiarios Actuales de Medicare (MCBS por sus siglas en inglés) hace preguntas a los beneficiarios de Medicare sobre el estado de salud, las fuentes de atención médica, la satisfacción con los servicios y los gastos en la atención de la salud. Después que hayamos terminado la encuesta, me gustaría conversar con usted sobre alguna de las preguntas de la encuesta. Saber sus comentarios nos ayudará a mejorar las preguntas.

### **STEP 3: DEBRIEFING**

Ahora me gustaría hablar con usted sobre algunas de las preguntas de la encuesta que acaba de responder.

**GENERAL PROBES:** Suggested general neutral probing for issues that arise.

- ¿Cómo decidió qué responder?
- ¿Puede contarme un poco más sobre eso?
- ¿Podría darme un ejemplo?
- Dígame qué está pensando.
- ¿En qué estaba pensando cuando le hice esa pregunta?
- ¿En qué estaba pensando cuando decidió dar esa respuesta?
- ¿A qué doctores incluyó cuando respondió esta pregunta?
- ¿Qué quiere decir para usted [QUESTION/TERM]?

**COGNITIVE INTERVIEW SURVEY ITEMS AND PROBES**

#	Question Text
1.	<p>Las siguientes preguntas son sobre servicios de cuidado de salud que usted puede haber usado durante el año pasado. Durante el año pasado, ¿fue usted a la sala de emergencias de un hospital?</p> <p>(01) YES (02) NO (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
2.	<p>Durante el año pasado, ¿fue usted a la clínica o departamento de pacientes externos o ambulatorios de un hospital?</p> <p>NO INCLUYA HOSPITALIZACIONES.</p> <p>(01) YES (02) NO (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
3.	<p>A continuación, quiero preguntarle sobre sus visitas a médicos en el último año.</p> <p>¿Ha visto usted un médico durante el año pasado? Por favor no incluya médicos que haya visto en el hogar, en una sala de emergencia, departamento de pacientes externos o ambulatorios, o mientras era un paciente interno en un hospital.</p> <p>(01) YES (02) NO (-8) Don't Know (-9) Refused</p>



#	Question Text
<b>Observations:</b>	
4.	<p>SHOW CARD AC1</p> <p>Tengo unas preguntas más sobre las visitas que usted ha tenido en el pasado.</p> <p>Piense acerca de la vez más reciente en que usted vio un médico en algún lugar distinto al hogar u hospital. ¿Cuál era la especialidad del médico?</p> <p>[PROBE FOR RESPONDENT TO SELECT A CHOICE FROM THE CARD IF THEY MENTION A 'GENERIC' SPECIALTY LIKE 'HEART DOCTOR.' IF RESPONDENT ONLY GIVES A 'GENERIC' SPECIALTY AND THE GENERIC WORD IS SHOWN IN PARENTHESES FOLLOWING ONE OF THE RESPONSES, SELECT THE RESPONSE CATEGORY FOR THAT SPECIALTY (E.G., 'CARDIOLOGY'). OTHERWISE SELECT 'OTHER DR SPECIALTY'.]</p> <ol style="list-style-type: none"> <li>1. ALERGIA/INMUNOLOGÍA</li> <li>2. ANESTESIOLOGÍA</li> <li>3. CARDIOLOGIA (CORAZÓN)</li> <li>5. DERMATOLOGÍA (PIEL)</li> <li>6. MÉDICO DE SALA DE EMERGENCIA</li> <li>7. ENDOCRINOLOGÍA/METABOLISMO (DIABETES, TIROIDE)</li> <li>8. PRÁCTICA FAMILIAR</li> <li>9. GASTROENTEROLOGÍA</li> <li>10. PRÁCTICA GENERAL</li> <li>11. CIRUGÍA GENERAL</li> <li>12. GERIATRÍA (ENVEJECIENTES)</li> <li>13. GINECOLOGÍA - OBSTETRICIA</li> <li>14. HEMATOLOGÍA (SANGRE)</li> <li>15. RESIDENCIA EN HOSPITAL</li> <li>16. MEDICINA INTERNA (INTERNISTA)</li> <li>17. NEFROLOGÍA (RIÑONES)</li> <li>18. NEUROLOGÍA</li> <li>19. MEDICINA NUCLEAR</li> <li>20. ONCOLOGÍA (TUMORES, CÁNCER)</li> <li>21. OFTALMOLOGÍA (OJOS)</li> <li>22. ORTOPEdia</li> <li>24. OSTEOPATÍA</li> <li>25. OTORINOLARINGOLOGÍA</li> <li>26. PATOLOGÍA</li> <li>27. FISILOGÍA/REHABILITACIÓN</li> <li>28. CIRUGÍA PLÁSTICA</li> <li>29. PROCTOLOGÍA</li> <li>30. PSIQUIATRÍA/PSIQUIATRA</li> <li>31. PULMONAR (PULMONES)</li> <li>32. RADIOLOGÍA</li> <li>33. REUMATOLOGÍA (ARTRITIS)</li> <li>34. CIRUGÍA DEL TÓRAX (PECHO)</li> <li>35. UROLOGÍA</li> <li>36. OTRA ESPECIALIDAD MÉDICA</li> <li>(91) OTHER DR SPECIALTY</li> <li>(-8) DON'T KNOW</li> <li>(-9) REFUSED</li> </ol>

#	Question Text
<b>Observations:</b>	
5.	<p>SHOW CARD SC1</p> <p>Estamos interesados en saber qué piensa acerca de los servicios de salud que usted ha recibido durante el año pasado de los médicos y hospitales. Por favor dígame qué tan satisfecho(a) se ha sentido con lo siguiente:</p> <p>La calidad general de los servicios de salud que usted ha recibido durante el año pasado.</p> <p>1. MUY SATISFECHO(A)                  2. SATISFECHO(A)                  3. INSATISFECHO(A)                  4. MUY INSATISFECHO(A)                  5. NO CORESPONDE                  (-8) Don't Know                  (-9) Refused</p>
<b>Observations:</b>	
6.	<p>SHOW CARD SC1</p> <p>[Por favor dígame qué tan satisfecho(a) se ha sentido con ...]</p> <p>La disponibilidad de los servicios de salud en la noche y los fines de semana.</p> <p>1. MUY SATISFECHO(A)                  2. SATISFECHO(A)                  3. INSATISFECHO(A)                  4. MUY INSATISFECHO(A)                  5. NO CORESPONDE                  (-8) Don't Know                  (-9) Refused</p>
<b>Observations:</b>	
7.	<p>SHOW CARD SC1</p> <p>[Por favor dígame qué tan satisfecho(a) se ha sentido con lo siguiente:]</p> <p>La facilidad y conveniencia de llegar donde un médico desde donde usted vive.</p> <p>1. MUY SATISFECHO(A)                  2. SATISFECHO(A)                  3. INSATISFECHO(A)                  4. MUY INSATISFECHO(A)                  5. NO CORESPONDE                  (-8) Don't Know                  (-9) Refused</p>

#	Question Text
<b>Observations:</b>	
8.	<p>SHOW CARD SC1 [Por favor dígame qué tan satisfecho(a) se ha sentido con ...]</p> <p>Los costos que usted paga de su propio dinero por los servicios de cuidado de salud.</p> <p>1. MUY SATISFECHO(A) 2. SATISFECHO(A) 3. INSATISFECHO(A) 4. MUY INSATISFECHO(A) 5. NO CORESPONDE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
9.	<p>SHOW CARD SC1 [Por favor dígame qué tan satisfecho(a) se ha sentido con ...]</p> <p>La información que le dan a usted sobre lo que está mal con usted.</p> <p>1. MUY SATISFECHO(A) 2. SATISFECHO(A) 3. INSATISFECHO(A) 4. MUY INSATISFECHO(A) 5. NO CORESPONDE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
10.	<p>SHOW CARD SC1 [Por favor dígame qué tan satisfecho(a) se ha sentido con ...]</p> <p>Los cuidados de seguimiento que usted recibe después de un tratamiento o cirugía inicial.</p> <p>1. MUY SATISFECHO(A) 2. SATISFECHO(A) 3. INSATISFECHO(A) 4. MUY INSATISFECHO(A) 5. NO CORESPONDE (-8) Don't Know (-9) Refused</p>

#	Question Text
<b>Observations:</b>	
11.	<p>SHOW CARD SC1 [Por favor dígame qué tan satisfecho(a) se ha sentido con ...]</p> <p>El interés de los médicos por su salud en general en lugar del interés sólo por un síntoma o enfermedad aislada.</p> <p>1. MUY SATISFECHO(A) 2. SATISFECHO(A) 3. INSATISFECHO(A) 4. MUY INSATISFECHO(A) 5. NO CORESPONDE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
12.	<p>SHOW CARD SC1 [Por favor dígame qué tan satisfecho(a) se ha sentido con ...]</p> <p>Recibir el cuidado para todas sus necesidades de salud en el mismo lugar.</p> <p>1. MUY SATISFECHO(A) 2. SATISFECHO(A) 3. INSATISFECHO(A) 4. MUY INSATISFECHO(A) 5. NO CORESPONDE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
13.	<p>SHOW CARD SC1 [Por favor dígame qué tan satisfecho(a) se ha sentido con ...]</p> <p>La disponibilidad de cuidado de salud de especialistas cuando usted piensa que los necesita.</p> <p>1. MUY SATISFECHO(A) 2. SATISFECHO(A) 3. INSATISFECHO(A) 4. MUY INSATISFECHO(A) 5. NO CORESPONDE (-8) Don't Know (-9) Refused</p>

#	Question Text
<b>Observations:</b>	
14.	<p>SHOW CARD SC1 [Por favor dígame qué tan satisfecho(a) se ha sentido con ...]</p> <p>La facilidad para obtener respuestas por teléfono a preguntas sobre su tratamiento o medicinas.</p> <p>1. MUY SATISFECHO(A) 2. SATISFECHO(A) 3. INSATISFECHO(A) 4. MUY INSATISFECHO(A) 5. NO CORESPONDE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
15.	<p>SHOW CARD SC1 [Por favor dígame qué tan satisfecho(a) se ha sentido con ...]</p> <p>La cantidad que usted ha tenido que pagar por sus medicinas recetadas.</p> <p>1. MUY SATISFECHO(A) 2. SATISFECHO(A) 3. INSATISFECHO(A) 4. MUY INSATISFECHO(A) 5. NO CORESPONDE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
16.	<p>Por favor piense acerca de todos los servicios de cuidado de salud que usted recibe, incluyendo los servicios proporcionados por los médicos, hospitales y farmacias.</p> <p>¿Con qué cosas, si hay algo, acerca de los servicios de salud que usted recibe, está insatisfecho(a)?</p> <p>(01) RESPONDENT IS NOT DISSATISFIED WITH ANYTHING (91) RESPONDENT IS DISSATISFIED (RECORD VERBATIM BELOW) (-8) Don't Know (-9) Refused</p> <p>RESPONDENT VERBATIM:</p>
<b>Observations:</b>	
17.	<p>¿Hay alguna persona de profesión médica o una clínica en particular a la cuál usted va habitualmente cuando está enfermo(a) o necesita consejo sobre su salud?</p> <p>(01) YES (02) NO → GO TO Q40</p>

#	Question Text
<b>Observations:</b>	
18.	<p>¿A qué tipo de lugar va habitualmente usted cuando está enfermo(a) o necesita consejo sobre su salud -- es ése un centro de un plan de cuidado administrado o HMO, una clínica, el consultorio de un médico, un hospital o algún otro lugar?</p> <p>IF CLINIC, ASK: ¿Es ésta una clínica de pacientes externos o ambulatorios, o algún otro tipo de clínica? IF SOME OTHER PLACE, ASK: ¿Dónde es esto?</p> <p>(1) CONSULTORIO DE UN MÉDICO O PRÁCTICA DE GRUPO (2) CLÍNICA MÉDICA (3) CENTRO DE UN PLAN DE SERVICIOS DE CUIDADO ADMINISTRADO/HMO (4) CENTRO DE SALUD DEL VECINDARIO/FAMILIAR (5) CENTRO DE CIRUGÍA INDEPENDIENTE (6) CLÍNICA RURAL DE SALUD (7) CLÍNICA DE UNA COMPAÑÍA (8) OTRA CLÍNICA (9) CENTRO DE EMERGENCIAS (10) MÉDICO VA A LA CASA DE SP (11) SALA DE EMERGENCIA DE UN HOSPITAL (12) DEPARTAMENTO DE PACIENTES EXTERNOS O AMBULATORIOS DE UN HOSPITAL/CLÍNICA (13) ESTABLECIMIENTO DE LA ADMINISTRACIÓN DE VETERANOS (V.A.). (14) CENTRO DE SALUD MENTAL (91) OTHER (SPECIFY _____) (-8) DON'T KNOW (-9) REFUSED</p>
<b>Observations:</b>	
19.	¿Cuál es el nombre completo del lugar al que usted va? WRITE NAME ON WORKSHEET
<b>Observations:</b>	
20.	<p>¿Hay un médico en particular que usted ve normalmente en este lugar?</p> <p>(01) YES (02) NO → GO TO Q24 (-8) DON'T KNOW (-9) REFUSED</p>
<b>Observations:</b>	
21.	¿Cuál es el nombre completo de ese médico? WRITE NAME ON WORKSHEET

#	Question Text
<b>Observations:</b>	
22.	<p>SHOW CARD AC1            ¿Cuál es la especialidad de (PROVIDER NAME FROM Q21)?</p> <p>[PROBE FOR RESPONDENT TO SELECT A CHOICE FROM THE CARD IF THEY MENTION A 'GENERIC' SPECIALITY LIKE 'HEART DOCTOR.' IF RESPONDENT ONLY GIVES A 'GENERIC' SPECIALTY AND THE GENERIC WORD IS SHOWN IN PARENTHESES FOLLOWING ONE OF THE RESPONSES, SELECT THE RESPONSE CATEGORY FOR THAT SPECIALTY (E.G., 'CARDIOLOGY'). OTHERWISE SELECT 'OTHER DR SPECIALTY'.]</p> <ol style="list-style-type: none"> <li>1. ALERGIA/INMUNOLOGÍA</li> <li>2. ANESTESIOLOGÍA</li> <li>3. CARDIOLOGIA (CORAZÓN)</li> <li>5. DERMATOLOGÍA (PIEL)</li> <li>6. MÉDICO DE SALA DE EMERGENCIA</li> <li>7. ENDOCRINOLOGÍA/METABOLISMO (DIABETES, TIROIDE)</li> <li>8. PRÁCTICA FAMILIAR</li> <li>9. GASTROENTEROLOGÍA</li> <li>10. PRÁCTICA GENERAL</li> <li>11. CIRUGÍA GENERAL</li> <li>12. GERIATRÍA (ENVEJECIENTES)</li> <li>13. GINECOLOGÍA - OBSTETRICIA</li> <li>14. HEMATOLOGÍA (SANGRE)</li> <li>15. RESIDENCIA EN HOSPITAL</li> <li>16. MEDICINA INTERNA (INTERNISTA)</li> <li>17. NEFROLOGÍA (RIÑONES)</li> <li>18. NEUROLOGÍA</li> <li>19. MEDICINA NUCLEAR</li> <li>20. ONCOLOGÍA (TUMORES, CÁNCER)</li> <li>21. OFTALMOLOGÍA (OJOS)</li> <li>22. ORTOPEDIA</li> <li>24. OSTEOPATÍA</li> <li>25. OTORINOLARINGOLOGÍA</li> <li>26. PATOLOGÍA</li> <li>27. FISILOGÍA/REHABILITACIÓN</li> <li>28. CIRUGÍA PLÁSTICA</li> <li>29. PROCTOLOGÍA</li> <li>30. PSIQUIATRÍA/PSIQUIATRA</li> <li>31. PULMONAR (PULMONES)</li> <li>32. RADIOLOGÍA</li> <li>33. REUMATOLOGÍA (ARTRITIS)</li> <li>34. CIRUGÍA DEL TÓRAX (PECHO)</li> <li>35. UROLOGÍA</li> <li>36. OTRA ESPECIALIDAD MÉDICA</li> <li>(91) OTHER DR SPECIALTY</li> <li>(-8) DON'T KNOW</li> <li>(-9) REFUSED</li> </ol>
<b>Observations:</b>	
23.	OTHER DR SPECIALTY (SPECIFY) _____

#	Question Text
24.	<p>Normalmente, ¿tiene alguien que le acompañe a usted para ir ahí?</p> <p>(01) YES                      (02) NO→GO TO Q28                      (-8) DON'T KNOW                      (-9) REFUSED</p>
<b>Observations:</b>	
25.	<p>¿Quién va normalmente con usted?</p> <p>(SPECIFY) _____</p>
<b>Observations:</b>	
26.	<p>¿Con qué frecuencia está esa persona con usted mientras está con el médico u otro personal médico?                      ¿Diría que siempre, algunas veces o nunca?</p> <p>(01) SIEMPRE                      (02) ALGUNAS VECES                      (03) NUNCA                      (-8) DON'T KNOW                      (-9) REFUSED</p>
<b>Observations:</b>	
27.	<p>¿Cuáles son las razones por las que esta persona le acompaña cuando usted va ahí? ¿Qué hace esta persona?</p> <p>[PROBE: ¿Cualquier otra razón?                      CHECK ALL THAT APPLY.</p> <p>(1) ANOTA LO QUE EL MÉDICO DICE/ANOTA LAS INSTRUCCIONES/TOMA NOTAS/RECUERDA                      (2) DA INFORMACIÓN/EXPLICA LA CONDICIÓN MÉDICA O NECESIDADES SUYAS AL MÉDICO                      (3) LE EXPLICA A USTED LAS INSTRUCCIONES DEL MÉDICO                      (4) HACE PREGUNTAS                      (5) TRADUCE                      (6) HACE LAS CITAS                      (7) NADA/LE ACOMPAÑA A USTED/SE SIENTA CON USTED/LE DA APOYO MORAL                      (8) TRANSPORTACIÓN                      (9) USTED NECESITA AYUDA FÍSICA                      (91) OTHER (SPECIFY _____)                      (-8) DON'T KNOW                      (-9) REFUSED</p>



#	Question Text
<b>Observations:</b>	
28.	<p>SHOW CARD US1</p> <p>¿Cuánto tiempo hace que usted ha estado [(viendo a (PROVIDER NAME FROM Q21)/yendo a ((PLACE NAME FROM Q19)])?</p> <p>(1) MENOS DE 1 AÑO                      (2) DE 1 AÑO A MENOS DE 3 AÑOS                      (3) DE 3 AÑOS A MENOS DE 5 AÑOS                      (4) DE 5 AÑOS A MENOS DE 10 AÑOS                      (5) 10 AÑOS O MÁS                      (-8) DON'T KNOW                      (-9) REFUSED</p>
<b>Observations:</b>	
29.	<p>SHOW CARD US3</p> <p>Ahora le voy a leer algunas afirmaciones que algunas personas han hecho sobre el cuidado de salud de ellos. Piense sobre el cuidado de salud que usted recibe de (PROVIDER NAME FROM Q21/ PLACE NAME FROM Q19)]. Para cada afirmación, por favor dígame si usted está totalmente de acuerdo, de acuerdo, en desacuerdo, o totalmente en desacuerdo.</p> <p>[(PROVIDER NAME FROM Q21) es /Los médicos en (PLACE NAME FROM Q19) son] muy cuidadoso(s) de chequear todo cuando lo examinan a (usted/él/ella).</p> <p>(01) TOTALMENTE DE ACUERDO                      (02) DE ACUERDO                      (03) EN DESACUERDO                      (04) TOTALMENTE EN DESACUERDO                      (05) NO CORESPONDE                      (-8) Don't Know                      (-9) Refused</p>
<b>Observations:</b>	
30.	<p>SHOW CARD US3</p> <p>[(PROVIDER NAME FROM Q21) es /Los médicos en (PLACE NAME FROM Q19) son] competente(s) y bien capacitados.</p> <p>(01) TOTALMENTE DE ACUERDO                      (02) DE ACUERDO                      (03) EN DESACUERDO                      (04) TOTALMENTE EN DESACUERDO                      (05) NO CORESPONDE                      (-8) Don't Know                      (-9) Refused</p>

#	Question Text
<b>Observations:</b>	
31.	<p>SHOW CARD US3</p> <p>[(PROVIDER NAME FROM Q21) tiene /Los médicos en (PLACE NAME FROM Q19) tienen] una idea completa de los problemas de (usted/él/ella).</p> <p>(01) TOTALMENTE DE ACUERDO                      (02) DE ACUERDO                      (03) EN DESACUERDO                      (04) TOTALMENTE EN DESACUERDO                      (05) NO CORESPONDE                      (-8) Don't Know                      (-9) Refused</p>
<b>Observations:</b>	
32.	<p>SHOW CARD US3</p> <p>[(PROVIDER NAME FROM Q21) con frecuencia parece/Los médicos en (PLACE NAME FROM Q19) con frecuencia parecen] estar apurados.</p> <p>(01) TOTALMENTE DE ACUERDO                      (02) DE ACUERDO                      (03) EN DESACUERDO                      (04) TOTALMENTE EN DESACUERDO                      (05) NO CORESPONDE                      (-8) Don't Know                      (-9) Refused</p>
<b>Observations:</b>	
33.	<p>SHOW CARD US3</p> <p>Piense sobre el cuidado de salud que usted recibe de [(PROVIDER NAME FROM Q21)/(PLACE NAME FROM Q19)].</p> <p>[(PROVIDER NAME FROM Q21)/Los médicos en ((PLACE NAME FROM Q19)] no le explica(n) a (usted/él/ella) sus problemas médicos.</p> <p>(01) TOTALMENTE DE ACUERDO                      (02) DE ACUERDO                      (03) EN DESACUERDO                      (04) TOTALMENTE EN DESACUERDO                      (05) NO CORESPONDE                      (-8) Don't Know                      (-9) Refused</p>

#	Question Text
<b>Observations:</b>	
34.	<p>SHOW CARD US3 Frecuentemente usted tiene problemas de salud que deberían ser discutidos pero no se discuten.</p> <p>(01) TOTALMENTE DE ACUERDO (02) DE ACUERDO (03) EN DESACUERDO (04) TOTALMENTE EN DESACUERDO (05) NO CORESPONDE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
35.	<p>SHOW CARD US3</p> <p>[(PROVIDER NAME FROM Q21) /Los médicos en (PLACE NAME FROM Q19)] con frecuencia actúa(n) como si [(él/ella) le estuviera/le estuvieran] haciendo un favor a usted al hablar con (usted/él/ella).</p> <p>(01) TOTALMENTE DE ACUERDO (02) DE ACUERDO (03) EN DESACUERDO (04) TOTALMENTE EN DESACUERDO (05) NO CORESPONDE (-8) Don't Know (-9) Refused</p>
<b>Observations:</b>	
36.	<p>SHOW CARD US3</p> <p>[(PROVIDER NAME FROM Q21) le dice/Los médicos en (PLACE NAME FROM Q19) le dicen] a (usted/él/ella) todo lo que (usted/él/ella) desea saber acerca de su problema de salud y tratamiento.</p> <p>(01) TOTALMENTE DE ACUERDO (02) DE ACUERDO (03) EN DESACUERDO (04) TOTALMENTE EN DESACUERDO (05) NO CORESPONDE (-8) Don't Know (-9) Refused</p>

#	Question Text
<b>Observations:</b>	
37.	<p>SHOW CARD US3</p> <p>[(PROVIDER NAME FROM Q21) le contesta/Los médicos en (PLACE NAME FROM Q19) le contestan] a (usted/él/ella) todas sus preguntas.</p> <p>(01) TOTALMENTE DE ACUERDO                      (02) DE ACUERDO                      (03) EN DESACUERDO                      (04) TOTALMENTE EN DESACUERDO                      (05) NO CORESPONDE                      (-8) Don't Know                      (-9) Refused</p>
<b>Observations:</b>	
38.	<p>SHOW CARD US3</p> <p>Piense sobre el cuidado de salud que usted recibe de [(PROVIDER NAME FROM Q21)/PLACE NAME FROM Q19].</p> <p>Usted le tiene mucha confianza a [(PROVIDER NAME FROM Q21)/los médicos en (PLACE NAME FROM Q19)].</p> <p>(01) TOTALMENTE DE ACUERDO                      (02) DE ACUERDO                      (03) EN DESACUERDO                      (04) TOTALMENTE EN DESACUERDO                      (05) NO CORESPONDE                      (-8) Don't Know                      (-9) Refused</p>
<b>Observations:</b>	
39.	<p>SHOW CARD US3</p> <p>Usted depende de [(PROVIDER NAME FROM Q21)/los médicos en (PLACE NAME FROM Q19)] para sentirse bien tanto física como emocionalmente.</p> <p>(01) TOTALMENTE DE ACUERDO                      (02) DE ACUERDO                      (03) EN DESACUERDO                      (04) TOTALMENTE EN DESACUERDO                      (05) NO CORESPONDE                      (-8) Don't Know                      (-9) Refused</p> <p>ALL RESPONSES → GO TO Q47</p>

#	Question Text
<b>Observations:</b>	
40.	<p>[IF NO USUAL SOURCE OF CARE]</p> <p>Le voy a leer algunas razones que las personas han dado para no tener una fuente habitual para cuidado de salud. Para cada una, por favor dígame si esta es o no una razón por la cual usted no tiene un lugar habitual para cuidado de salud.</p> <p>No hay razón para tener una fuente habitual de cuidado de salud porque usted rara vez o nunca se enferma. [¿Es esa una razón por la cual usted no tiene una fuente habitual de cuidado de salud?]</p> <p>(01) YES                      (02) NO                      (-8) DON'T KNOW                      (-9) REFUSED</p>
<b>Observations:</b>	
41.	<p>Usted se mudó recientemente al área. [¿Es esa una razón por la cual usted no tiene una fuente habitual de cuidado de salud?]</p> <p>(01) YES                      (02) NO                      (-8) DON'T KNOW                      (-9) REFUSED</p>
<b>Observations:</b>	
42.	<p>Su fuente habitual de cuidado de salud ya no está disponible en esta área. [¿Es esa una razón por la cual usted no tiene una fuente habitual de cuidado de salud?]</p> <p>(01) YES                      (02) NO → GO TO Q44                      (-8) DON'T KNOW → GO TO Q44                      (-9) REFUSED → GO TO Q44</p>
<b>Observations:</b>	
43.	<p>¿Por qué su fuente habitual de cuidado de salud ya no está disponible?</p> <p>(01) MÉDICO ANTERIOR SE RETIRÓ                      (02) MÉDICO ANTERIOR FALLECIÓ                      (03) MÉDICO ANTERIOR SE MUDÓ                      (04) SP SE MUDÓ                      (05) MÉDICO/LUGAR ANTERIOR ES MUY LEJOS                      (91) OTHER (SPECIFY _____)                      (-8) DON'T KNOW                      (-9) REFUSED</p>

#	Question Text
<b>Observations:</b>	
44.	<p>Pensando sobre otras posibles razones que las personas tienen para no tener una fuente habitual de cuidado de salud, por favor dígame si esta afirmación es válida para usted:</p> <p>A usted le gusta ir a diferentes lugares para diferentes necesidades de salud. [¿Es esa una razón por la cual usted no tiene una fuente habitual de cuidado de salud?]</p> <p>(01) YES                      (02) NO                      (-8) DON'T KNOW                      (-9) REFUSED</p>
<b>Observations:</b>	
45.	<p>Los lugares en que usted puede recibir cuidados de salud están muy lejos. [¿Es esa una razón por la cual usted no tiene una fuente habitual de cuidado de salud?]</p> <p>(01) YES                      (02) NO                      (-8) DON'T KNOW                      (-9) REFUSED</p>
<b>Observations:</b>	
46.	<p>El costo del cuidado de salud es muy caro. [¿Es esa una razón por la cual usted no tiene una fuente habitual de cuidado de salud?]</p> <p>(01) YES                      (02) NO                      (-8) DON'T KNOW                      (-9) REFUSED</p>
<b>Observations:</b>	
47.	<p>Me gustaría obtener un poco de información general acerca de usted.</p> <p>¿Es usted de origen hispano, latino o español?</p> <p>(01) YES                      (02) NO→GO TO Q49                      (-8) Don't Know→GO TO Q49                      (-9) Refused→GO TO Q49</p>

#	Question Text
<b>Observations:</b>	
48.	<p>SHOW CARD DI1</p> <p>Mire esta tarjeta. ¿Es usted mexicano(a), mexicano(a) americano(a) o chicano(a), puertorriqueño(a), cubano(a) o de otro origen hispano, latino o español?</p> <p>CHECK ALL THAT APPLY.</p> <p>(01) MEXICAN/MEXICAN AMERICAN/CHICANO(A)            (02) PUERTO RICAN            (03) CUBAN            (91) OTHER HISPANIC, LATINO(A), OR SPANISH ORIGIN (SPECIFY _____)            (-8) Don't Know            (-9) Refused</p>
<b>Observations:</b>	
49.	<p>SHOW CARD DI2</p> <p>Mirando esta tarjeta, ¿cuál es su raza?</p> <p>[EXPLAIN IF NECESSARY: Para esta encuesta, los orígenes hispanos no son una raza.]</p> <p>(01) AMERICAN INDIAN OR ALASKA NATIVE            (02) ASIAN            (03) BLACK OR AFRICAN AMERICAN            (04) NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER            (05) WHITE            (-8) Don't Know            (-9) Refused</p> <p>IF RACE INCLUDES ASIAN, GO TO Q50.</p> <p>IF RACE INCLUDES NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER, GO TO Q51.            ELSE GO TO Q52.</p>

#	Question Text
<b>Observations:</b>	
50.	<p>SHOW CARD DI3</p> <p>Mire esta tarjeta. ¿Es usted hindú, chino(a), filipino(a), japonés, coreano(a), vietnamita o de otro origen asiático?</p> <p>Puede seleccionar más de un grupo. CHECK ALL THAT APPLY</p> <p>(01) ASIAN INDIAN (02) CHINESE (03) FILIPINO (04) JAPANESE (05) KOREAN (06) VIETNAMESE (91) OTHER ASIAN GROUP (SPECIFY _____) (-8) Don't Know (-9) Refused</p> <p>IF RACE INCLUDES NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER, GO TO Q51. ELSE GO TO Q52.</p>
<b>Observations:</b>	
51.	<p>SHOW CARD DI4</p> <p>Mire esta tarjeta. ¿Es usted nativo de Hawái, guameño(a) o chamorro(a), samoano(a) o de otro origen de las Islas del Pacífico?</p> <p>Puede seleccionar más de un grupo. CHECK ALL THAT APPLY.</p> <p>(01) NATIVE HAWAIIAN (02) GUAMANIAN OR CHAMORO (03) SAMOAN (91) OTHER PACIFIC ISLANDER GROUP (SPECIFY _____) (-8) Don't Know (-9) Refused</p>



#	Question Text
<b>Observations:</b>	
52.	<p>SHOW CARD DI5</p> <p>[PARA HOMBRES PARTICIPANTES] ¿Cuál de las siguientes mejor representa su manera de pensar en sí mismo?</p> <p>(01) <i>Gay</i> (02) Heterosexual, o sea, no <i>gay</i> (03) Bisexual (04) Otra cosa (05) No sé la respuesta</p> <p>[PARA MUJERES PARTICIPANTES] ¿Cuál de las siguientes mejor representa su manera de pensar en sí misma?</p> <p>(01) Lesbiana o <i>Gay</i> (02) Heterosexual, o sea, no <i>gay</i> o lesbiana (03) Bisexual (04) Otra cosa (05) No sé la respuesta</p>
<b>Probes</b>	
<ul style="list-style-type: none"> <li>■ ¿En qué pensó cuando le hice esta pregunta?</li> <li>■ ¿En qué pensó para decidir qué contestar?</li> <li>■ ¿Cómo decidió dar esa respuesta? <ul style="list-style-type: none"> <li>• ¿Podría contarme un poco más de eso?</li> </ul> </li> <li>■ ¿Tuvo algún problema para decidir qué contestar? <ul style="list-style-type: none"> <li>• If YES, ¿Qué le preocupaba?</li> </ul> </li> <li>■ ¿Hubo alguna palabra de la que no estuviera seguro(a)? <ul style="list-style-type: none"> <li>• ¿Cuál o cuáles?</li> <li>• ¿Cómo influyó eso en su respuesta?</li> </ul> </li> <li>■ ¿Qué quiere decir [bisexual] para usted?</li> <li>■ [IF R ANSWERED: SOMETHING ELSE: ] <ul style="list-style-type: none"> <li>• ¿Qué otra cosa representaría mejor cómo se considera usted?</li> </ul> </li> <li>■ [IF R ANSWERED: No sé cómo contestar: ] <ul style="list-style-type: none"> <li>• ¿Qué le dificulta contestar esta pregunta?</li> </ul> </li> </ul>	
<b>Note to Interviewer</b>	
<p>How does the R interpret these questions and decide on their answer? Are there terms or words that cause any confusion? Even if there are words that they were uncertain about how did they decide which answer to give? For example, some respondents may not be sure about “straight” (“Heterosexual, o sea, no <i>gay</i> o lesbiana”) or “bisexual”. What process did they use to decide which response to give? If they said that “don’t know,” what would they want to know to be able to choose a response?</p>	
<b>Observations:</b>	
53.	<p>¿Qué sexo le asignaron al nacer, en su acta de nacimiento original?</p> <p>(01) HOMBRE (02) MUJER</p>

#	Question Text
<b>Observations:</b>	
54.	<p>SHOW CARD DI6</p> <p>¿Se describe a sí mismo(a) como hombre, mujer o transgénero?</p> <p>(01) Hombre                      (02) Mujer                      (03) Transgénero                      (04) No me identifico como mujer, hombre ni transgénero</p>
<p><b>Probes</b></p> <ul style="list-style-type: none"> <li>■ ¿En qué pensó cuando le hice esta pregunta?</li> <li>■ ¿En qué pensó para decidir qué contestar?</li> <li>■ ¿Cómo decidió dar esa respuesta?                             <ul style="list-style-type: none"> <li>• ¿Podría contarme un poco más de eso?</li> </ul> </li> <li>■ ¿Tuvo algún problema para decidir qué contestar?                             <ul style="list-style-type: none"> <li>• If YES, ¿Qué le preocupaba?</li> </ul> </li> <li>■ ¿Hubo alguna palabra de la que no estuviera seguro(a)?                             <ul style="list-style-type: none"> <li>• ¿Cuál o cuáles?</li> <li>• ¿Cómo influyó eso en su respuesta?</li> </ul> </li> <li>■ IF R ANSWERED “No me identifico como mujer, hombre ni transgénero”:                             <ul style="list-style-type: none"> <li>• ¿Cómo se describe usted?</li> <li>• ¿Hay algún otro término que usted usaría?</li> </ul> </li> <li>■ ¿Qué quiere decir [transgénero] para usted?</li> </ul> <p><b>Note to Interviewers</b></p> <p>How does the R interpret these questions and decide on their answer? Are there terms or words that cause any confusion? Even if there are words that they were uncertain about how did they decide which answer to give? For example, some respondents may not be sure about “transgendered” (“transgénero”). What process did they use to decide which response to give? If they said that “don’t know,” what would they want to know to be able to choose a response?</p> <p><b>Observations:</b></p>	

#	Question Text
55.	<p>Las dos siguientes preguntas son acerca de educación e ingresos.</p> <p>SHOW CARD DI7</p> <p>¿Cuál es el grado o nivel de escuela más alto que usted ha completado?</p> <p>[IF THE SAMPLE PERSON ATTENDED SCHOOL IN A FOREIGN COUNTRY, IN AN UNGRADED SCHOOL, HOME SCHOOLING, OR UNDER OTHER UNIQUE CIRCUMSTANCES, REFER THE RESPONDENT TO THE SHOWCARD AND ASK FOR THE NEAREST EQUIVALENT.]</p> <ol style="list-style-type: none"> <li>1. NO TIENE ESTUDIOS</li> <li>2. PREESCOLAR A 8°. GRADO</li> <li>3. 9° -12° GRADO, SIN DIPLOMA</li> <li>4. GRADUADO(A) DE HIGH SCHOOL (CON DIPLOMA DE HIGH SCHOOL O SU EQUIVALENTE)</li> <li>5. VOCACIONAL/TÉCNICO/DE NEGOCIOS/CERTIFICADO O DIPLOMA DE ESCUELA DE OFICIOS (MÁS ALLÁ DEL NIVEL DE HIGH SCHOOL)</li> <li>6. ALGO DE COLLEGE O UNIVERSIDAD, PERO SIN DIPLOMA</li> <li>7. GRADUADO DE UNIVERSIDAD DE 2 AÑOS CON GRADO DE ASOCIADO</li> <li>8. GRADUADO DE UNIVERSIDAD DE 4 AÑOS CON GRADO DE BACHILLERATO</li> <li>9. MAESTRÍA, TÍTULO PROFESIONAL O DOCTORAL</li> <li>10. DON'T KNOW</li> <li>11. REFUSED</li> </ol>
<b>Observations:</b>	
56.	<p>SHOW CARD DI8</p> <p>Mirando esta tarjeta dígame, ¿qué letra representa mejor el ingreso total (suyo y de su cónyuge/suyo) antes de impuestos durante los últimos 12 meses?</p> <p>Incluya ingresos de empleos, Seguro Social, Retiro de Ferroviarios, otro ingreso de retiro, y de las otras fuentes de ingreso de las cuales acabamos de hablar.</p> <p>[EXPLAIN IF NECESSARY:] El ingreso es importante para analizar la información que recolectamos. Por ejemplo, esta información nos ayuda a saber si las personas de un grupo de ingreso determinado usa cierto tipo de servicios de cuidado médico o tienen ciertas condiciones médicas más o menos frecuentemente que las personas de otros grupos.</p> <ol style="list-style-type: none"> <li>(01) A. Less than \$5,000</li> <li>(02) B. \$5,000 - 9,999</li> <li>(03) C. \$10,000 - 14,999</li> <li>(04) D. \$15,000 - 19,999</li> <li>(05) E. \$20,000 - 24,999</li> <li>(06) F. \$25,000 - 29,999</li> <li>(07) G. \$30,000 - 39,999</li> <li>(08) H. \$40,000 - 49,999</li> <li>(09) I. \$50,000 or more</li> <li>(-8) Don't Know</li> <li>(-9) Refused</li> </ol>
<b>Observations:</b>	

Appendix O: Worksheet and Showcards for Questionnaire Testing (Spanish)

---

AC1

- (01) Alergias / Inmunología (Alergias, Asma)
- (02) Anestesiología
- (03) Cardiología (Corazón)
- (05) Dermatología (Piel)
- (07) Endocrinología/Metabolismo (Diabetes, Tiroides)
- (08) Práctica Familiar
- (09) Gastroenterología (El Sistema Digestivo)
- (10) Medicina General
- (11) Cirugía General
- (12) Geriatria (Ancianos)
- (13) Ginecología - Obstetricia
- (14) Hematología (Sangre)
- (15) Morada de hospital
- (16) Medicina Interna (Internista)
- (17) Nefrología (Riñones)
- (18) Neurología (Sistema de los Nervios)
- (19) Medicina Nuclear
- (20) Oncología (Tumores, Cáncer)
- (21) Oftalmología (Ojos)
- (22) Ortopedia (Huesos, Articulaciones)
- (24) Osteopatía (DO)
- (25) Otorrinolaringología (Oído, Nariz, Garganta)
- (26) Patología
- (27) Medicina Física/Rehabilitación

- (28) Cirugía Plástica
- (29) Proctología
- (30) Psiquiatría/Psiquiatra (Salud Mental)
- (31) Pulmonar (Pulmones)
- (32) Radiología
- (33) Reumatología (Artritis)
- (34) Cirugía Torácica (Pecho)
- (35) Urología (Tracto Urinario)

# SC1

- Muy Satisfecho(a)
- Satisfecho(a)
- Insatisfecho(a)
- Muy Insatisfecho(a)

## SC2

- Pensó Que el Problema No Era Serio
- Pensó Que Costaría Mucho
- Tuvo Problemas Para Encontrar o Conseguir un Médico
- Tiempo, Horario o Conflictos Personales
- Pensó que el Médico no Podía Hacer Mucho Acerca del Problema
- Tenía Miedo de Descubrir lo que Tenía
- El Médico no Aceptaría Mi Seguro

## SC3

- Pensó que Costaría Mucho
- Pensó que la Medicina no Ayudaría para la Afección
- Tenía Temor de las Reacciones o Contraindicaciones de la Medicina
- No le Gusta Tomar Medicinas
- Pensó que la Medicina No Era Necesaria
- La Medicina no Estaba Cubierta por el Seguro o no Estaba en el Formulario del Plan
- Tuvo Problemas para Obtener la Medicina
- Obtuvo o Usó Muestras
- Usó Otra Medicina Como Substituto



## SC4

- Frecuentemente
- Algunas Veces
- Nunca

## US1

- Menos de Un Año
- De 1 Año a Menos de 3 Años
- De 3 Años a Menos de 5 Años
- De 5 Años a Menos de 10 Años
- 10 Años o Más

## US2

- Nunca
- Algunas Veces
- Usualmente
- Siempre

US3

- Totalmente de Acuerdo
- De Acuerdo
- En Desacuerdo
- Totalmente en Desacuerdo

# DI1

- Mexicano(a), mexicano(a) americano(a),  
chicano(a)
- Puertorriqueño(a)
- Cubano(a)

## DI2

- Indio Americano o Nativo de Alaska
- Asiático
- Negro o Afroamericano
- Nativo de Hawái u Otra Isla del Pacífico
- Blanco

## DI3

- Hindú
- Chino(a)
- Filipino(a)
- Japonés
- Coreano(a)
- Vietnamita

# DI4

- Nativo(a) de Hawái
- Guameño(a) o chamorro(a)
- Samoano(a)



# DI5

## Male Respondents

- Gay
- Heterosexual, o sea, no gay
- Bisexual
- Otra cosa
- No sé la respuesta

# DI5

## **Female Respondents**

- Lesbiana o Gay
- Heterosexual, o sea, no gay o lesbiana
- Bisexual
- Otra cosa
- No sé la respuesta

## DI6

- Hombre
- Mujer
- Transgénero
- No me identifico como mujer, hombre ni transgénero

## DI7

- Ninguna Escolaridad Completada
- Jardín Infantil a 8° Grado
- 9° - 12° Grado, Sin Diploma
- Graduado(a) de Escuela (Superior/Secundaria)  
- Diploma de Escuela (Superior/Secundaria) o el Equivalente
- Certificado o Diploma de Escuela Vocacional/Técnica/Negocios/Comercial  
[Superior al Nivel de Escuela (Superior/Secundaria)]
- Algo de Universidad, Pero Sin Grado
- Grado Asociado
- Grado Universitario
- Grado de Maestría, Profesional o Doctorado

DI8

**Ingreso Anual**

A. Menos de \$5,000
B. \$5,000 - 9,999
C. \$10,000 - 14,999
D. \$15,000 - 19,999
E. \$20,000 - 24,999
F. \$25,000 - 29,999
G. \$30,000 – 39,999
H. \$40,000 - 49,999
I. \$50,000 +

## Appendix P: Participant Receipt Form (Spanish)

---

### National Opinion Research Center (NORC) Recibo para Participantes

**Instrucciones:** Por favor marque el cuadro de abajo. Con su firma, usted indica que ha leído este Recibo y ha recibido 40 dólares como incentivo por participar en esta encuesta.

He recibido \$40.00 dólares (en efectivo) del personal de NORC como incentivo por participar en esta encuesta.

---

Firma del/de la Participante

\_\_\_\_|\_\_\_\_|\_\_\_\_|\_\_\_\_|\_\_\_\_|\_\_\_\_|  
**Mes                      Día                      Año**