

## SUMMARY REPORT

# Testing Alternative Response Options for Spanish Translations of Sexual Identity Items for National Surveys

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## Executive Summary

At the request of the Office of Minority Health (OMH) at the Centers for Medicare & Medicaid Services (CMS) and the National Center for Health Statistics' (NCHS) Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER), NORC at the University of Chicago (NORC) engaged in research to explore the effectiveness of Spanish-language survey questions designed to measure sexual orientation.<sup>1</sup> This report builds and expands on previous research conducted by NORC on behalf of the Office of Enterprise Data and Analytics (OEDA) and the Office of Minority Health (OMH)—both at CMS—that showed Spanish speakers experienced comprehension problems with questions about sexual orientation.

For the previous research, NORC conducted a series of cognitive interviews in Spanish using two adaptations of the sexual orientation measure currently used in the National Health Interview Survey (NHIS) to understand the level of comprehension and answerability of these questions among Spanish-speaking individuals (Stern et al. 2016). In particular, the prior research revealed that Spanish speakers exhibited comprehension problems with the response options offered; of particular concern was the term “heterosexual.” Among Spanish-speaking respondents who struggled to comprehend this term, more than half stated either “I don’t know how to answer” or that they were “something else.”

The methodology and results of the previous work are the basis for this report. The cognitive interviews conducted for the current study focused on comprehension (e.g., definition of terms used in questions), decision-making (e.g., choosing the appropriate response from those offered), and ease in answering sensitive questions about one’s sexual orientation. Individuals eligible for this study were adults (aged 18 years or older) who spoke Spanish as their primary language. The 39 individuals with whom NORC completed interviews were of diverse backgrounds and included lesbian, gay, and bisexual (LGB) and non-transgender heterosexual respondents; individuals with a variety of national origins including Argentina, Belize, Chile, Colombia, Mexico, Panama, Puerto Rico, and Venezuela; and individuals of different education levels.

Based on the previous work, we tested two versions of the sexual orientation question where we varied the response options originally included in the NHIS version of the question. In the NHIS, the question in Spanish reads (presented in English for the reader’s convenience, as follows): *Which of the following best represents how you think about yourself?* 1) Gay (for male respondents) / Lesbian or Gay (for female

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<sup>1</sup> For the purposes of this report, we use sexual orientation and sexual identity synonymously.

respondents), 2) Heterosexual, that is, not gay (for male respondents) / Heterosexual, that is, not lesbian or gay (for female respondents), 3) Bisexual, 4) Something else, and 5) I don't know how to answer.

As reported in Stern et al. (2016), we noted issues with the translation of the response option phrased in English as “Straight, that is, not gay,” which translates to Spanish as “Heterosexual, o sea, no gay (for male) / Heterosexual, o sea, no gay o lesbiana (for female).” (The term “o sea” translates to “that is.”) The translation of “straight” as the more formal “heterosexual” can be as problematic for respondents to comprehend in Spanish as it is in English. Consequently, in the present study, we tested two alternatives. The first, “Version A,” reversed the order of the terms “gay” and “heterosexual” such that gay was presented first and read “Not gay, that is, heterosexual (for male respondents) / Not gay or lesbian; that is, heterosexual (for female respondents),” which in Spanish is “No gay, o sea, heterosexual” (for male) and “No gay o lesbiana, o sea, heterosexual” (for female respondents).

The second alternative, “Version B”—which was based on findings from Stern et al. (2016) suggesting that the term “heterosexual” can create confusion among Spanish speakers (especially among respondents with low levels of education)—eliminated the term “heterosexual” and included only “Not gay” (for male respondents) and “Not gay or lesbian” (for female respondents), which translate to Spanish as “No gay” (for male) and “No lesbiana o gay” (for female).

Results indicate that the response option for Version A (i.e., “not gay, that is, heterosexual”/ “No gay, o sea, heterosexual”) performs better than those for either Version B or the original NHIS question. It is more effective at minimizing inconsistency between screener and interview responses reporting sexual orientation. Version A also minimized the number of non-substantive responses such as “don't know” and “something else” that respondents provided in answer to the question on sexual orientation. Both of these patterns held true across respondents of different sexual orientations, gender, and education levels.

In other words, the major finding of this report indicates that Spanish speakers were able to respond more accurately to the measure of sexual orientation when the response option was phrased as “no [gay/lesbian], o sea, heterosexual.” Using the revised response options tested in the current effort, indeterminate responses such as “don't know” or “something else” were reduced to as low as 10 percent of total cases.

Based on these results, we recommend that if researchers decide to add Spanish-language versions of the sexual orientation measures to federal surveys, they use a modified version of the NHIS questions that includes response options that are not a direct translation of the English. We recommend replacing the response option for heterosexual that is currently translated in Spanish as “heterosexual, o sea, no

gay/lesbiana” with “no gay/lesbiana, o sea, heterosexual.” Our recommended translation is more readily understood by Spanish speakers because, although it is not a direct translation, it more effectively conveys the desired concept.

## Introduction

The purpose of this study is to provide guidance to the federal government in making informed decisions about including Spanish-language sexual orientation questions in federal surveys. This report provides qualitative evidence on the effectiveness of Spanish-language survey questions designed to measure sexual orientation—that is, lesbian, gay, and bisexual status. This report builds and expands on previous research conducted by NORC on behalf of OEDA and OMH, both at CMS. The previous research was conducted in the context of the Medicare Current Beneficiary Survey (MCBS) Task 8.2: Develop and Test Sexual and Gender Minority Status (LGBT) Items (hereafter, Stern et al. 2016) HHSM-500-2014-00035I, Task Order # HHSM-500-T0002. A key finding of the prior research was that Spanish speakers experienced comprehension problems with questions about sexual orientation more so than their English-speaking counterparts.

To build on the prior research and move toward a more research-based assessment of LGBT status in Spanish-speaking respondents, CMS OMH and the National Center for Health Statistics’ (NCHS) Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) joined efforts and commissioned NORC to conduct the present study: the NCHS and CMS Spanish Cognitive Interviewing Health Study. The current research was funded via CMS OMH through contract HHSM-500-2011-00002I task order HHSM-500-T0012.

## Motivation for Research

Individuals identifying as LGBT experience disparities in health status as well as in access to and utilization of health services. The available research highlights that LGBT men and women experience poorer health as compared to the general population in a number of areas. For example, the prevalence of sexually transmitted infections, mental health issues, and risk for diseases associated with being overweight and obese are higher among those who identify as LGBT compared to those who do not (Institute of Medicine 2011; Gay and Lesbian Medical Association and LGBT health experts 2001).

Data are not consistently collected on sexual orientation and gender identity in health care settings or population-based surveys and are generally not included as part of patient health care records (Cahill and Makadon 2014; IOM 2011; Gay and Lesbian Medical Association and LGBT health experts 2001). More consistent and detailed collection of sexual orientation and gender identity data would help us have a better understanding of the health disparities faced by LGBT people.

Among some members of the LGBT population, limited English proficiency may be an added barrier to obtaining complete information on their health status, health care needs, and access to care. According to data from the 2011 American Community Survey (ACS), 21 percent of the U.S. population ages five and older speak a language other than English at home, with Spanish being the most commonly reported (62 percent) among this group (Ryan 2013). Of those who reported Spanish as the language other than English that they speak at home, 44 percent were limited English proficient (LEP), reporting that they spoke English less than “very well.” In order to more adequately implement a measure of sexual orientation and gender identity, it is important to develop and include standard questions on this topic in federal surveys not only in English but in other languages as well. Research has demonstrated that survey questions, across a variety of topics, may be interpreted differently based on age (e.g., Haseldon and Joloza 2009), race, ethnicity, and/or minority status (Patterson 2000). As a result, the U.S. LEP population may interpret sexual orientation and gender identity questions differently than English-speaking respondents. Given the large percentage of the LEP population that speaks Spanish, the development of Spanish-language sexual orientation and gender identity items is a priority. Without an accurate means of measuring sexual orientation and gender identity in the Spanish-speaking population, a significant risk exists that the resulting estimates are biased due to a noticeable percentage of respondents misclassifying themselves.

## Conceptual Background

This report builds on the prior research in which NORC conducted cognitive interviews to test English- and Spanish-language sexual orientation and gender identity questions. That research found that whereas Spanish speakers were able to accurately answer questions about gender identity, sexual orientation items were not well understood. A review of the literature reveals that other studies exploring comprehension of specific translated survey items among Spanish speakers are limited; those that do exist suggest there may be several intersecting difficulties at work.

For example, terms used by social science researchers in English are not uniformly understood when directly translated to Spanish. A recent cognitive study conducted by Solorio and colleagues (2016) found that terms used in survey items that are not also used in everyday language create confusion among Spanish-speaking respondents. Specifically, cognitive testing of items designed to measure depression, anxiety, fatigue, and alcohol use among Hispanic respondents living with HIV revealed that terms explained in detail work better in Spanish compared to more general phrases such as “on average” (translated here in English). Also, phrases with double negatives or colloquial terms that are difficult to translate into Spanish (such as “high” in reference to substance abuse) represent a source of measurement error.

Researchers have also indicated that education level plays a role in deciding whether to answer in English or Spanish. For instance, Martinez, Marin, and Schoua-Glusberg (2016) suggest that foreign-born Hispanics with higher levels of education tend to learn English more quickly and consequently are more likely to answer survey questions in English than Spanish speakers with lower levels of education. They also suggest that Spanish speakers with lower levels of education appear to have lower levels of comprehension of survey questions in general.

Complicating matters further, Martinez et al. (2016) observe that, to be effective, survey items translated from English to Spanish need to be equally understood by individuals from different Spanish-speaking countries, regardless of education levels. Their work suggests this is hard to accomplish because even seemingly simple terms in English can be challenging to translate in ways that are effectively understood by a wide range of Spanish speakers from various cultural and ethnic backgrounds. For example, the authors cited that the word “messy” could be translated in Spanish as “reguero”; however, that term is not equally understood by Spanish speakers from various countries. The authors found through cognitive testing that a better option for translation, and for use in a questionnaire, is a combination of several terms: “reguero, cochino, sucio.”

In the context of LGBT survey metrics, important progress has been made in understanding the disparities in comprehension of key terms between English and Spanish speakers. For instance, Miller and Ryan (2011) report that English-speaking respondents may be able to understand colloquial terms such as “straight,” “gay,” or “not gay” more easily than formal terms such as “heterosexual” or “homosexual”—which tend to be perceived as more scientific in nature and therefore confusing. Spanish speakers, on the other hand, experience difficulty understanding the colloquial terms. This difficulty seems to arise because there are no equivalent colloquial expressions for words such as “straight” in Spanish. Comprehension issues are even more apparent among Spanish speakers when a negative syntactical

structure is utilized to refer to heterosexuality—namely, using the phrase “not gay.” Nonetheless, since the intent is to collect data with comparable measurement properties across both English- and Spanish-speaking respondents, Miller and Ryan (2011) propose an approach to measuring sexual orientation that combines both the colloquial and formal terms; that is, they suggest using “heterosexual, o sea, no es gay.” Based on this work, the NHIS developed metrics to measure LGBT status with the questions presented in Figure 1.

**Figure 1.** NHIS Measure of Sexual Orientation

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

[Response Options for Male Rs]:	[Response Options for Female Rs]:
1. Gay	1. Lesbian or gay
2. Straight, that is, not gay	2. Straight, that is, not lesbian or gay
3. Bisexual	3. Bisexual
4. Something else	4. Something else
5. I don't know how to answer	5. I don't know how to answer

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

[Response Options for Male Rs]:	[Response Options for Female Rs]:
1. Gay	1. Lesbiana o gay
2. Heterosexual, o sea, no gay	2. Heterosexual, o sea, no lesbiana o gay
3. Bisexual	3. Bisexual
4. Otra cosa	4. Otra cosa
5. No sé la respuesta	5. No sé la respuesta

As noted above, prior research conducted by NORC found that these sexual orientation items were not well understood by Spanish speakers. The current research aims to further test and refine the Spanish-language sexual orientation questions to improve comprehension among Spanish speakers. In the next section, we briefly review the main findings of the previous work, before proceeding to explain in more detail the options assessed in the present study.

**Summary of the Prior Research (Stern et al. 2016)**

The report “MCBS Task 8.2: Develop and Test Sexual and Gender Minority Status (LGBT) Items” (Stern et al. 2016) discusses measures of sexual orientation and gender identity, two dimensions of reporting LGBT status, primarily among Medicare beneficiaries. NORC conducted cognitive interviews in both English and Spanish using existing sexual orientation measures taken from the NHIS as well as new

gender-identity measures to understand the level of comprehension of these questions and their ability to be answered by Medicare-eligible individuals.

Cognitive interviews focused on:

- Comprehension of questions and terms and identifying sources of confusion or ambiguity in the questionnaire;
- The decision-making processes and embedded assumptions that respondents employ when answering questions of sexual orientation and gender identity; and
- Assessment of the ease in answering sensitive questions about one’s sexual orientation and gender identity.

Cognitive interviews were conducted using an abbreviated version of the MCBS questionnaire—56 questions in total. The sexual orientation and gender identity items were included in the demographic section near the end of the instrument as questions 52, 53, and 54, respectively (see Appendices A and B). Interviews were conducted using a retrospective probing technique, in which the interviewer administered a complete questionnaire to the respondent and then returned to the sexual orientation and gender identity items to conduct probing. The probing effort included questions such as: “Were there any words that you were uncertain about?”; “How did you decide on that answer?”; and “Did you have any trouble deciding on that answer?”.

NORC conducted cognitive interviews with 20 cisgender English-speaking respondents and 37 Spanish-speaking respondents between August 2015 and January 2016 in Chicago, IL; Atlanta, GA; and Washington D.C. The average age of respondents was 67 years old. Recruitment targeted Medicare beneficiaries. The sample included 22 males and 35 females; 48 heterosexual, non-transgender respondents; nine LGB respondents; and respondents of varying levels of education. There was also a diverse representation of national origins among the Spanish speakers.

The major finding of this cognitive study was that English speakers were able to comprehend questions about both sexual orientation and gender identity while Spanish speakers exhibited comprehension problems with translated questions about sexual orientation. Even though some English-speaking respondents expressed discomfort with the questions and a few did not understand the concept of “transgender,” these issues did not prevent English speakers from answering these questions accurately. Because the screener asked about sexual orientation in a way that allowed interviewers to clarify potentially confusing terminology, we had the opportunity to compare screener results that were presumed to be accurate with results from answers for the questionnaire items (when the actual wording

of the sexual orientation item was tested). All but two English respondents provided consistent responses about their sexual orientation during the screener and the cognitive interview.

Conversely, Spanish speakers, particularly women and those with low levels of education, did not understand the meaning of the sexual orientation response categories and were uncertain about the meaning of the term “heterosexual.” For more than half of the non-LGB Spanish-speaking respondents, lack of familiarity with and misunderstanding of the term “heterosexual” prevented them from selecting the appropriate response category, namely “heterosexual, that is, not gay” (i.e., the literal English translation of the Spanish response option).

When probed, most Spanish-speaking respondents described a process in which they decided how to answer the question based on elimination of categories they did not understand or knew did not apply to them. Therefore, when presumably heterosexual (based on their screener response) Spanish speakers reviewed response categories for the sexual orientation question, they tended to select a category that was “not gay,” “not heterosexual,” and “not bisexual”—since they thought none of these categories described them. More than half of Spanish-speaking respondents were unable to select “heterosexual” during the interview even though they identified themselves as such in the screener. Among these respondents, about half answered, “I don’t know how to answer” and the other half selected “something else.” Even though Spanish speakers expressed discomfort with the gender identity questions, most often understanding gender identity as a “normal” or “self-evident” gender expression (i.e., the identity that conforms with the gender corresponding to their biological sex), they were able to accurately answer questions about their gender identity.

Based on these findings, NORC recommended using the English version of the NHIS sexual orientation question but suggested a minor revision to the Spanish translation. Our work suggested there were shortcomings in the current Spanish translation of the response options for the sexual orientation question that could potentially lead to measurement error, including discordance in results through misclassification, conflation between orientation and behavior, item nonresponse, and an overabundance of non-substantive responses (i.e., “don’t know” or “something else”). These results are in line with Miller and Ryan’s (2011) observations about Spanish-speaking respondents. Given the observed widespread lack of comprehension of the term “heterosexual” and respondents’ use of the process of elimination as a way of selecting their response, NORC recommended reversing the order of the term “heterosexual” and its explanation “that is, not gay” in the Spanish response option. Table 1 compares the current NHIS response options with the version recommended in Stern et al. 2016.

**Table 1.** Recommended Adjustment to NHIS Sexual Orientation Response Option (02)

	NHIS 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

Although we believed the recommended version would improve Spanish-speaking respondents’ ability to properly report their sexual orientation, the scope of the prior research did not afford us the opportunity to test this phrasing at the time. The current project carries out this additional testing, specifically evaluating this recommendation along with an alternative version of the sexual orientation question among Spanish speakers.

### Two Alternative Ways to Measure Sexual Orientation among Spanish Speakers

The present study tested two alternatives to the current Spanish translation of the NHIS sexual orientation question (see Figure 2). The first stems directly from NORC’s recommendation in Stern et al. 2016 and is referred to throughout the current report as Version A. Compared to the current NHIS question displayed in Figure 1, Version A reverses the order of the terms “heterosexual” and “not gay” or “not gay or lesbian” in the second response option so that “not gay” or “not gay or lesbian” is presented first and “heterosexual” is presented second. The second alternative of the sexual orientation question tested in this study is referred to throughout this report as Version B. Version B eliminates the term “heterosexual” altogether so that only “not gay” or “not gay or lesbian” is presented.

Version A aims to change the initial focus of the respondent’s attention from “heterosexual” to “not gay” or “not gay or lesbian” by reversing the order in which these terms are displayed. In contrast, Version B eliminates the source of confusion altogether and excludes the term “heterosexual” from the response option. This means that respondents who identify as “not gay” or “not gay or lesbian” as well as respondents who identify themselves as “heterosexual” would need to select the response option “not gay” or “not gay or lesbian.” Both of these edits are aimed at improving comprehension of this response option among respondents who are not familiar with the term “heterosexual,” as documented in Stern et al. 2016.

The exact wording of Versions A and B are presented in Figure 2 below. Please note that because we are testing alternatives to literal translations, the English wording of these questions represents an English translation of the Spanish wording, rather than the English versions that would be administered to English-speaking respondents. All cognitive testing conducted in this study was done in Spanish as detailed in the Methods section below.

**Figure 2.** Alternative Measures of Sexual Orientation and their Spanish Versions

**Version A. Which of the following best represents how you think about yourself? Gay; not gay, that is, heterosexual; bisexual; or something else? (English translation of Spanish version)**

[Response Options for Male Rs]:	[Response Options for Female Rs]:
1. Gay	1. Lesbian or gay
2. Not gay, that is, heterosexual	2. Not lesbian or gay, that is, heterosexual
3. Bisexual	3. Bisexual
4. Something else	4. Something else
5. I don't know how to answer	5. I don't know how to answer

**Version A. ¿Cuál de las siguientes mejor representa su manera de pensar en sí mismo? Gay; no gay, o sea, heterosexual; bisexual; o otra cosa?**

[Response Options for Male Rs]:	[Response Options for Female Rs]:
1. Gay	1. Lesbiana o gay
2. No gay, o sea, heterosexual	2. No lesbiana o gay, o sea, heterosexual
3. Bisexual	3. Bisexual
4. Otra cosa	4. Otra cosa
5. No sé la respuesta	5. No sé la respuesta

**Version B. Which of the following best represents how you think about yourself? Gay; not gay; bisexual; or something else? (English translation of Spanish version)**

[Response Options for Male Rs]:	[Response Options for Female Rs]:
1. Gay	1. Lesbian or gay
2. Not gay	2. Not lesbian or gay
3. Bisexual	3. Bisexual
4. Something else	4. Something else
5. I don't know how to answer	5. I don't know how to answer

**Version B. ¿Cuál de las siguientes mejor representa su manera de pensar en sí mismo? Gay; no gay; bisexual; o otra cosa**

[Response Options for Male Rs]:	[Response Options for Female Rs]:
1. Gay	1. Lesbiana o gay
2. No gay	2. No lesbiana o gay
3. Bisexual	3. Bisexual
4. Otra cosa	4. Otra cosa
5. No sé la respuesta	5. No sé la respuesta

We implemented two key changes to the interview protocol originally used in Stern et al. (2016). First, we eliminated the use of show cards to present the response options for the sexual orientation questions. In the prior research, the interviewer read the question, “Which of the following best represents how you think about yourself?” but did not read aloud the response options. Instead, the interviewer presented a

show card to the respondent, and the respondent selected an answer based on reading the response options. The show card (see Appendix C) had five response options listed: (1) Gay/Gay or lesbian; (2) Heterosexual, that is, not gay/Heterosexual, that is, not gay or lesbian; (3) Bisexual; (4) Something else; (5) I don't know how to answer. In the current study, per NCHS recommendation, the interviewer read, "Which of the following options best represents how you think about yourself?" and then read out loud the response options. The second change was the elimination of the "I don't know how to answer" response option as an explicitly offered response. While respondents could still answer "don't know," that response option was not read. In the prior research, this option was explicitly included among the response options on the show card. These protocol changes applied to both Versions A and B of the sexual orientation question.

## Methods

### Participant Eligibility and Recruitment

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Individuals eligible for this study were adults (age 18 years or older) who spoke Spanish as their primary language. An eligibility screening instrument (see Appendices D and E) was used to collect basic information—including gender, age, marital status, ethnicity, education, employment status, and income—about potential respondents. Respondent demographics were also used, when feasible, to enroll participants with varying education levels (less than high school and high school graduate), ages (less than 65 and 65 and above), and genders (men and women).<sup>2</sup> Respondents were rescreened onsite at the time of interview to reconfirm eligibility prior to the interview.

Using materials approved by the Office of Management and Budget (OMB) under clearance No. 0920-0222, exp. 07/31/2018, recruitment and interviewing was conducted in the Chicago metropolitan area. NORC staff was available to interview participants in our offices or to travel to a place that was more convenient for respondents. Recruitment materials consisted of a recruitment message (see Appendices F and G) and the eligibility screener (see Appendices D and E) discussed above.

Recruitment was conducted through multiple channels. First, the NORC team identified members of the public eligible to participate through personal networks; a total of eight participants were recruited via this method. A NORC team member who did not have any personal connection with the respondents interviewed them. Another 24 participants were recruited through a third-party vendor. Additionally,

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<sup>2</sup> Transgender respondents were not explicitly targeted for the purposes of this research.

NORC contacted a not-for-profit community organization that provides financial services to the Chicago-area Hispanic community. Through this organization, NORC recruited seven participants. Using these three different recruitment channels, NORC was able to conduct 39 interviews over the course of one week, starting on May 20, 2016, and ending on May 27, 2016. In a collaborative process, NCHS contractors recorded interviews while NORC staff conducted them.

### Participant Compensation

Respondents were provided with \$40 as a token of appreciation for participating in the study. Respondents were offered the token even if they did not choose to complete the full interview. In addition to the token of appreciation, respondents received a letter thanking them for their participation (Appendices H and I).

### Sample Information

Table 2 shows the distribution and measures of central tendency and dispersion of respondents by key demographic characteristics—namely gender, age, and education. Of the 39 respondents interviewed, 24 were women and 15 were men; 36 were younger than 65 years of age, and three were 65 years of age or older. The median age was 37 years of age, and women respondents were on average slightly older than men (39 versus 36 years of age). Although LGBT status was not part of the recruitment criteria, two of the 39 respondents identified as LGBT during the screener. Although nativity was also not a screening criterion, the pool of respondents included individuals from Argentina, Belize, Chile, Colombia, Mexico, Panama, Puerto Rico, and Venezuela.

**Table 2.** Demographic Characteristics of Recruited Sample

	Women		Men		Total
	<65 years	65+ years	<65 years	65+ years	
Less than high school graduate	6	2	1	0	9
High school graduate or more	16	0	13	1	30
<b>Total</b>	22	2	14	1	39
Median age	39.5		36.0		37.0
Average (mean) age	40.1		38.6		39.5
Minimum age	18		18		18
Maximum age	72		71		72

Based on scheduled interviewing order, respondents were alternatingly allocated to Version A or Version B of the sexual orientation question prior to the interview. This ensured an even distribution of respondents in each group. As a result, 20 respondents were exposed to Version A and 19 were exposed

to Version B. Tables 3 and 4 show the distribution of Version A respondents and Version B respondents by demographic characteristics. The distribution of respondents by key demographic variables was similar across the two versions of the question, with women respondents to Version B older on average than women respondents to Version A.

**Table 3.** Demographic Characteristics of Respondents Exposed to Version A of Sexual Orientation Question

	Women		Men		Total
	<65 years	65+ years	<65 years	65+ years	
Less than high school graduate	1	1	0	0	2
High school graduate or more	9	0	8	1	18
<b>Total</b>	10	1	8	1	20
Median age	31.0		29.0		29.5
Average age	35.7		34.1		35.0
Minimum age	18		18		18
Maximum age	65		71		71

**Table 4.** Demographic Characteristics of Respondents Exposed to Version B of Sexual Orientation Question

	Women		Men		Total
	<65 years	65+ years	<65 years	65+ years	
Less than high school graduate	5	1	1	0	7
High school graduate or more	7	0	5	0	12
<b>Total</b>	12	1	6	0	19
Median age	44.0		35.0		41.0
Average age	45.3		36.8		42.6
Minimum age	25		29		25
Maximum age	72		47		72

## Data Collection

The cognitive testing protocol and materials, including the recruitment script, eligibility screener questionnaire, participant consent form, cognitive interview protocol, and participant receipt form, were submitted by NCHS to OMB for review on April 25, 2016, under the Generic Clearance for CCQDER OMB No. 0920-0222, exp. 07/31/2018; OMB approved the test on May 4, 2016. NCHS’s Ethics Review Board (ERB) approved the protocol on April 13, 2016. NORC’s Institutional Review Board (IRB) approved the testing protocol on May 16, 2016.

## Data Collection Methods

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 sexual orientation items to be tested in the current study as well as the gender identity items tested as a part of the prior research.<sup>3</sup> The interviewer first administered the survey items using a paper-and-pencil instrument and then led the respondent through a series of retrospective probes to explore how the respondent understood the questions and arrived at a response. Some general probes used during the cognitive interviews on the sexual orientation 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 does bisexual mean to you?

This strategy was intended to uncover the decision-making processes and embedded assumptions that respondents employ when answering questions about sexual orientation. Probing was also designed to reveal differences in understanding and comprehension of terms in general, as well as to allow the analysis of responses based on demographic characteristics. NORC gathered data on specific interpretations and concerns such as the wording, concepts, and phrases used in draft questions and response categories.

The full cognitive interviewing protocol employed in the study is located in Appendices J and K. An interviewing worksheet and show cards, including a card with the sexual orientation response options, were only used during retrospective probing (Appendices L and M). Each interview lasted less than 60 minutes.

## Informed Consent

Cognitive interview respondents provided informed consent prior to their participation. As part of the consent process they were informed that their participation was voluntary and that the information they

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<sup>3</sup> The NHIS gender identity questions were included to preserve methodological parity between the current research and the research documented in Stern et al.

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 respondent confidentiality, respondents were assigned a unique identifier. The signed consent forms are kept by NCHS in a locked cabinet separate from the interview files. A copy of the informed consent forms, including consent for interviews conducted onsite at NORC's offices and offsite in the community, are located in Appendices N, O, and P.

## Results

This section provides a description of the results of our cognitive testing. We first present data in tabular form on the consistency between the sexual orientation the respondent reported in the screener with that reported during the cognitive interview. This consistency is analyzed by LGB status, gender, education, and non-substantive categories (i.e., “Don’t know” and “Something Else”). In addition, the analysis of sexual orientation by non-substantive categories is broken down by LGB status, gender, and education.

We then present a qualitative review of response verbatim as noted by cognitive interviewers. The review uses cognitive theory as a conceptual framework to investigate the survey answering process, including (1) question comprehension—that is, understanding of terms and phrases used in the question stem and response options; (2) retrieval of information—that is, remembering of relevant elements to formulate an answer; (3) decision making for response elaboration—the respondent’s judgment process related to the truthfulness and social adequacy of the answer; and (4) mapping of the answer into response categories offered in the question (Tourangeau 1984; Willis 2005).

In the qualitative review, we identify patterns and themes that emerged from 39 responses. For comparison purposes, we discuss our results with those from the prior testing on the NHIS translations along with Version A and B of the questions tested in this research. As noted above (see Figure 2), Version A refers to the question in which the response option included the option (in Spanish) of “not lesbian/gay, that is heterosexual” whereas Version B eliminated the term “heterosexual” and offered a response choice of “not gay” or “not lesbian or gay” only.

## Discordance between Screener and Interview

First, we examine the consistency between the way respondents defined themselves in the pre-interview screener, where interviewers asked “Do you, personally, identify as lesbian, gay, bisexual, or transgender” and could define potentially confusing terminology, and at the time of the interview. To provide a comprehensive view of results, Table 5 presents results that Stern et al. (2016) obtained using the NHIS question language, along with our results from Version A and Version B. The findings demonstrate that there is greater inconsistency between screener and interview responses when using the NHIS version of the sexual orientation questions as compared to Version A or Version B in the current study. When using the NHIS version of the sexual orientation question, 54 percent of respondents provided a response that was inconsistent with their screener response when interviewed (Stern et al. 2016), whereas in the current study the rate of inconsistency dropped to 37 percent for Version B and 15 percent for Version A.

**Table 5.** Consistency in Sexual Orientation Responses in Screener and Interview

	Consistent		Inconsistent		Total Interviews	
	N	%	N	%	N	%
NHIS (Stern et al.), only Spanish Rs (with the order “heterosexual; that is, not lesbian or gay” included in responses)	17	46%	20	54%	37	100%
Version A (with the order “not gay or lesbian, that is, heterosexual” included in responses)	17	85%	3	15%	20	100%
Version B (with only “not gay or lesbian”; the term “heterosexual” is excluded from responses)	12	63%	7	37%	19	100%

These results (Table 5) indicate that Version A (i.e., “not gay, that is, heterosexual”), the option recommended in Stern et al. (2016)—but not tested as a part of that research—is more effective than other options tested at minimizing inconsistency between screener and interview responses. It is possible that the reduction of inconsistency can be explained by the elimination of the explicit reading of the option “I don’t know how to answer” from Version A and B. However, it can also be posited that the reason for this finding could be found in the order of terms in which the respondent processes information. Namely, the respondent hears in Version A: “Which of the following best represents how you think about yourself? [By way of example, consider options for male respondents] (1) gay; (2) not gay, that is, heterosexual; (3) bisexual; or (4) something else?” Conceivably, respondents are able to immediately contrast “gay” (option 1) versus “not gay, that is, heterosexual” (option 2). When the lack of the trait is presented first—

with “Not gay or lesbian (female option)/Not gay (male option)” coming before the term “heterosexual” is introduced—the respondent comprehends that option 2 is about the lack of the trait, facilitating other cognitive processes. Specifically, since the comprehension of this response option is presumably based on the absence of the trait, the respondent is able to start the decision-making process with familiar terms, even if “heterosexual” is not fully comprehended.

As mentioned above, the interview protocol used for the prior research (i.e., Stern et al. 2016) is slightly different relative to Versions A and B. Notably, in the current study, we did not present show cards. Not using show cards (that is, no visual aids) strengthens the results reported here for the alternative measures of sexual orientation tested. The lower discordance rates, as compared to the results of the prior research, are not contingent on the use of show cards. Therefore, the results should apply across a variety of modes, including telephone interviews. Tables 6, 7, and 8 demonstrate that the same pattern of reduction in discordance holds for respondents of different sexual orientations, gender, and education levels.

**Table 6.** Consistency in Sexual Orientation Responses in Screener and Interview, by LGBT Status Reported in Screener

	Consistent	Inconsistent	Total Interviews
	N	N	N
NHIS, only Spanish Rs (Stern et al.)	17	20	37
Screener: LGBT	3	1	4
Screener: non-LGBT	14	19	33
Version A (with "heterosexual" included in response)	17	3	20
Screener: LGB	0	1	1
Screener: non-LGB	17	2	19
Version B (without "heterosexual" included in response)	12	7	19
Screener: LGB	1	0	1
Screener: non-LGB	11	7	18

**Table 7.** Consistency in Sexual Orientation Responses in Screener and Interview, by Gender Reported in Screener

	Consistent	Inconsistent	Total Interviews
	N	N	N
NHIS, only Spanish Rs (Stern et al.)	17	20	37
Male	9	4	13
Female	8	16	24
Version A (with "heterosexual" included in response)	17	3	20
Male	8	1	9
Female	9	2	11

Version B (without "heterosexual" included in response)	12	7	19
Male	6	0	6
Female	6	7	13

**Table 8.** Consistency in Sexual Orientation Responses in Screener and Interview, by Education Level Reported in Screener

	Consistent	Inconsistent	Total Interviews
	N	N	N
NHIS, only Spanish Rs (Stern et al.)	17	20	37
Less than high school graduate	10	16	26
High school graduate or more	7	4	11
Version A (with "heterosexual" included in response)	17	3	20
Less than high school graduate	1	1	2
High school graduate or more	16	2	18
Version B (without "heterosexual" included in response)	12	7	19
Less than high school graduate	2	5	7
High school graduate or more	10	2	12

### Respondent Use of “Don’t Know” or “Something Else” as a Response Option

Overall, there were fewer non-substantive responses (“don’t know” or “something else”) to the question on sexual orientation in the current study than there were in the prior research (Table 9). The prior research found that among those who received the NHIS question, 51 percent of respondents provided a “don’t know” or “something else” response as opposed to 37 percent for Version B and 10 percent for Version A in the current work.

**Table 9.** Identification of Sexual Orientation versus “Something Else”/“Don't Know” Responses

	Gay/lesbian, Heterosexual, or Bisexual: Response Options 1, 2, or 3		“Something Else” or “Don’t Know”: Response Options 4, 5, or Refusal		Total Interviews	
	N	%	N	%	N	%
NHIS (Stern et al.), only Spanish Rs (with the order “heterosexual, that is, not lesbian or gay” included in responses)	18	49%	19	51%	37	100%
Version A (with the order “not gay or lesbian, that is, heterosexual” included in responses)	18	90%	2	10%	20	100%

Version B (with only “not gay or lesbian”; the term “heterosexual” is excluded from responses)	12	63%	7	37%	19	100%
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Similar to previous patterns, these results indicate that Version A (i.e., “not gay or lesbian, that is, heterosexual”), the option recommended in Stern et al. (2006)—but not fully tested in said research—was more effective in this study at reducing the incidence of both “don’t know” and “something else” responses than the shortened Version B (i.e., “not gay” or “not gay or lesbian”). Similar to the explanation presented above for the screener, when we introduce “not gay” first, respondents start their decision-making process with familiar terms before getting to “heterosexual,” which may not be as familiar a term.

As previously discussed, a key protocol difference between the prior research and current Versions A and B was the elimination of the explicit offer of the response option “I don’t know how to answer.” One may argue that not reading out loud the option “I don’t know how to answer” is responsible for the reduced number of non-substantive responses obtained in the current study. While the authors acknowledge this change may explain part of the reduction of non-substantive responses in the current study versus the prior research using the NHIS response options, it does not explain the difference in the incidence of non-substantive responses between Versions A and B. Neither Versions A nor B included an explicit read-out-loud presentation of the option “I don’t know how to answer” and yet Version A still performed better, with 10 percent of respondents providing non-substantive responses as compared to 37 percent in Version B. Tables 10, 11, and 12 show that the same pattern holds true for respondents of different sexual orientations, gender, and education levels.

**Table 10.** Identification of Sexual Orientation versus “Something Else”/“Don’t Know” Responses, by LGBT Status Reported in Screener

	Gay/lesbian, Heterosexual, or Bisexual: Response Options 1, 2, or 3	“Something Else” or “Don’t Know”: Response Options 4, 5, or Refusal	Total Interviews
	N	N	N
NHIS, only Spanish Rs (Stern et al)	18	19	37
Screener: LGBT	3	1	4
Screener: non-LGBT	15	18	33
Version A (with "heterosexual" included in response)	18	2	20
Screener: LGBT	1	0	1
Screener: non-LGBT	17	2	19
Version B (without "heterosexual" included in response)	12	7	19
Screener: LGBT	1	0	1

Screener: non-LGBT	11	7	18
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**Table 11.** Identification of Sexual Orientation versus “Something Else”/“Don’t Know” Responses, by Gender Reported in Screener

	Gay/lesbian, Heterosexual, or Bisexual: Response Options 1, 2, or 3	“Something Else” or “Don’t Know”: Response Options 4, 5, or Refusal	Total Interviews
	N	N	N
NHIS, only Spanish Rs (Stern et al.)	18	19	37
Male	9	4	13
Female	9	15	24
Version A (with "heterosexual" included in response)	18	2	20
Male	9	0	9
Female	9	2	11
Version B (without "heterosexual" included in response)	12	7	19
Male	6	0	6
Female	6	7	13

**Table 12.** Identification of Sexual Orientation versus “Something Else”/“Don’t Know” Responses, by Education Level Reported in Screener

	Gay/lesbian, Heterosexual, or Bisexual: Response Options 1, 2, or 3	“Something Else” or “Don’t Know”: Response Options 4, 5, or Refusal	Total Interviews
	N	N	N
NHIS, only Spanish Rs (Stern et al.)	18	19	37
Less than high school graduate	11	15	26
High school graduate or more	7	4	11
Version A (with "heterosexual" included in response)	18	2	20
Less than high school graduate	1	1	2
High school graduate or more	17	1	18
Version B (without "heterosexual" included in response)	12	7	19
Less than high school graduate	2	5	7
High school graduate or more	10	2	12

## Qualitative Review of Responses

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In addition to examining the consistency between the sexual orientation reported in the screener versus the cognitive interview and the prevalence of non-substantive responses such as “don’t know” or “something else,” we conducted a qualitative review of respondent comprehension and reaction to the sexual orientation questions. This review explored patterns of response in the cognitive interviews that offer insight into the respondent answering process around the sexual orientation questions. The NORC team identified commonly occurring themes that were relevant to the analysis and subsequently labeled and coded them. In all, nine relevant themes were identified; we characterized them as:

- Respondent understanding of the intent of questions about sexual orientation;
- Conflation of sexual orientation and gender identity;
- Heterosexual sexual orientation as “normal”;
- Discomfort with sexual orientation question;
- Sexual orientation as a construct;
- Limited or objectionable response options;
- Comprehension problems with term “heterosexual”; and
- Version B respondents’ challenges regarding absence of term “heterosexual.”

In the following, we provide context in the opening paragraphs and verbatim responses from interviewees that best exemplify the theme. These examples are not exhaustive but instead representations of the theme<sup>4</sup>.

### Respondent Understanding of the Intent of Questions about Sexual Orientation

In general, we found that respondents had a well-defined understanding of the intent of the questions regarding their sexual orientation (“Which of the following options best represents how you think about yourself”)—regardless of whether they received Version A or B of the response options.

- R4736 [Female, 40, HS grad or more, Version A, non-LGBT/Not gay or lesbian, that is, heterosexual]: When asked “What did you think about when I asked that question?” respondent said, “My sexual orientation.”

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<sup>4</sup> All respondent quotations have been translated into English for the purposes of this report.

- R4750 [Male, 22, HS grad or more, Version A, non-LGBT/Not gay, that is, heterosexual]: When asked “What did you think about when I asked that question?” respondent said, “How I identify ... my sexual orientation and not just the physical.”
- R4762 [Male, 30, HS grad or more, Version B, non-LGBT/Not gay]: When asked “What did you think about when I asked that question?” respondent replied, “About sexual orientation.” When interviewer asked, “What did you think about in deciding on your answer?” respondent said, “My sexual preferences.”

It must be noted that some respondents felt that the topic of the question was not clear until the interviewer read the response options. That is, they did not understand the context for the question without seeing the response options. The following respondent reactions suggest that there seems to be some evidence of a comprehension issue leading to some measure of difficulty with decision-making. For instance:

- R4769 [Male, 30, HS grad or more, Version A, LGBT/Not gay, that is, heterosexual]: Respondent suggested the question may be improved by indicating it is about sexual orientation. He said, “You may want to ask something like, ‘How do you define your sexual orientation’ rather than ‘how you think about yourself.’ I got that the question was about sexual orientation when you started reading the options but not at the beginning.”
- R4733 [Male, 40, HS grad or more, Version B, non-LGBT/Not gay]: When asked “What did you think about when I asked that question?” respondent said, “I thought about sexual orientation.” When asked “What did you think about in deciding on your answer?” respondent said, “I thought about my likes and preferences. I thought that, similar to my father and son, I like women. I am one of seven siblings, so I assume my father liked women!” Respondent recommended to explicitly mention that the question is about sexual orientation “so that I know what the question is about.”

### **Conflation of Sexual Orientation and Gender Identity**

There were five respondents who conflated gender identity and sexual orientation. It is possible that this confusion is influenced, in part, by the inclusion of the gender identity questions in the survey instrument; however, federal surveys would include measures for both so this finding bears consideration.

Respondents stated the following, when asked about the sexual orientation item:

- R4734 [Male, 50, HS grad or more, Version A, non-LGBT/Not gay, that is, heterosexual]: When asked “What did you think about when I asked that question?” respondent said, “I thought about what I am. I was born a man. I was raised as a man; so that’s it.”
- R4739 [Female, 39, Less than HS, Version B, non-LGBT/Something else]: When interviewer asked, “What did you think about in deciding on your answer?” respondent said, “I’m a woman so I don’t see myself as gay or lesbian ... nothing against them; we are all different.” When interviewer asked, “How did you decide on that answer?” respondent said, “I’m what I am: a woman.”
- R4743 [Female, 37, Less than HS, Version B, non-LGBT/I don't know how to answer]: When interviewer asked, “What did you think about in deciding on your answer?” respondent paused for a long time and said, “It was not clear, if I am a 100 percent woman. If you asked me do you feel like a woman 100 percent then I would have known how to answer this.”

### Heterosexual Sexual Orientation as “Normal”

As has been noted in extant research, we found that respondents used a variety of terms to refer to their heterosexual orientation, including “normal,” “standard,” and “traditional.” While the results suggest a thorough understanding of the terms,<sup>5</sup> it is important to note that the latent construct is still part of the response process and thus we included it here.

- R4738 [Female, 37, Less than HS, Version A, non-LGBT/Not gay or lesbian, that is, heterosexual]: The first time the interviewer asked the question, respondent said (in English), “I’m straight.... I like my husband.... I am normal.”
- R4769 [Male, 30, HS grad or more, Version A, LGBT/Not gay, that is, heterosexual]: Respondent referred to heterosexual as “traditional” and “non-heterosexual” as “unusual” when asked what heterosexual meant to him. He said, “Heterosexual is the most common ... man and woman; nothing unusual—the traditional thing.”

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<sup>5</sup> It is likely that Stern et al. (2016) found more issues with the term given that the sample was skewed toward individuals age 65 and older, and many of them were of low educational attainment.

- R4741 [Female, 64, Less than HS, Version B, non-LGBT/Not gay or lesbian]: When interviewer asked, “What did you think about when I asked that question?” respondent said, “That I’m normal; that is, female.”

### **Discomfort with Sexual Orientation Question**

As we found in Stern et al 2016, we also see here that respondents who were both older and had lower levels of education tended to be more uncomfortable answering the question about their sexual orientation. Respondents’ discomfort centered on three commonly occurring themes: 1) not being accustomed to discussing issues regarding sexual orientation, 2) lack of familiarity with the response options, and 3) the desire not to offend anyone or say something offensive. Despite this discomfort, it should be noted that only one respondent refused to answer the question, and no respondent broke off the interview because of this question; that does not, however, suggest that levels of item nonresponse would be ameliorated in a self-administered context for these individuals. Still, as seen below in the verbatim responses, comprehension was not the most important issue.

- R4738 [Female, 37, Less than HS, Version A, non-LGBT/Not gay or lesbian, that is, heterosexual]: Respondent was uncomfortable discussing the general topic of sexual orientation but still responded to the question and was engaged in the prompts. Respondent identified herself multiple times as someone without a high level of education. She asked the interviewer what heterosexual meant and was genuinely interested in learning more about it.
- R4757 [Male, 71, HS grad or more, Version A, non-LGBT/Not gay, that is, heterosexual]: Respondent reported he had never been asked “this type of question before.” When asked “Were there any words that you were uncertain about?” respondent said, “These are terms that one is not used to, because of tradition and age. I get confused. I need to catch up!”
- R4742 [Female, 72, Less than HS, Version B, non-LGBT/Refused to answer]: Respondent paused for a while after the sexual orientation question and then said she wanted to skip the question. She said she did not want to answer. She said she knew about that (meaning, about the topic and the terms). Interviewer repeated the question for her. She said she didn’t have trouble with them and heard men and women did that and will now marry.

### **Sexual Orientation as a Construct**

Researchers have recognized that term “sexual orientation” is not in itself a unidimensional, measurable social construct. Instead, the term is a “conglomeration of aspects” that include sexual behavior, attraction

to others, and identity, all of which can be measured separately (Miller & Ryan 2011). In this section, we present responses to the question about sexual orientation divided into three basic themes: sexual attraction, sexual behavior, and relationship status.

### **Sexual Orientation as a Proxy for Sexual Attraction**

For most respondents, the question about sexual orientation was understood as referring to sexual attraction. This suggests that respondents define their own sexual orientation based on who they are attracted to and they define the question's response options of heterosexual, bisexual, gay, and lesbian as a matter of sexual attraction or sexual preference, rather than sexual behavior or gender expression.

- R4734 [Male, 50, HS grad or more, Version A, non-LGBT/Not gay, that is, heterosexual]: When interviewer asked, "What does heterosexual mean to you?" he defined heterosexual as "a person who likes the opposite gender."
- R4736 [Female, 40, HS grad or more, Version A, non-LGBT/Not gay or lesbian, that is, heterosexual]: When interviewer asked, "What did you think about in deciding on your answer?" respondent said, "I have always felt attraction for men and never for women, so it's clear that I am heterosexual." She also defined bisexual as somebody who "feels sexual attraction to men and women."
- R4768 [Male, 30, HS grad or more, Version B, non-LGBT/Not gay]: Respondent defined bisexual as "a person who feels attraction for both sexes" and heterosexual as "a person who feels attraction for the opposite sex."

### **Sexual Orientation as a Proxy for Sexual Behavior**

It is important to note that at least four of the respondents understood the question about sexual orientation as a question about sexual behavior. They defined heterosexual, bisexual, gay, and lesbian as a matter of individuals' observed behavior rather than emphasizing the issue of attraction. A subset of these respondents focused on relationship status and the orientation of members within that relationship, as a proxy for sexual behavior.

- R4757 [Male, 71, HS grad or more, Version A, non-LGBT/Not gay, that is, heterosexual]: Respondent defined heterosexual as "someone who maintains her sex. The man practices sex with his couple, his woman." Respondent indicated "bisexuals have sex with men and women."

- R4732 [Female, 43, HS grad or more, Version A, non-LGBT/Not gay or lesbian, that is, heterosexual]: When interviewer asked, “What does bisexual mean to you?” respondent said, “They can choose companions of the same or different sex for relations.”

### **Sexual Orientation as a Proxy for Relationship Status**

A small number of respondents took the question about sexual orientation to serve as a proxy for their relationship status. Thus, they interpreted the question to be about their past, current, or future relationships rather than their behavior, identity or attraction.

- R4771 [Male, 29, HS grad or more, Version A, non-LGBT/Not gay, that is, heterosexual]: When interviewer asked, “What did you think about when I asked that question?” respondent indicated, “I thought about my couple relationship.”

### **Limited or Objectionable Response Options**

Some respondents noted that the response options provided were limited and did not acknowledge the entire range of sexual orientations. A small number of respondents noted that the option “something else” was somewhat offensive. This finding suggests that a more exhaustive list of options may be needed.

- R4736 [Female, 40, HS grad or more, Version A, non-LGBT/Not gay or lesbian, that is, heterosexual]: Respondent suggested “asexual” should have been included as a response option.
- R4735 [Female, 41, HS grad or more, Version B, non-LGBT/Not gay or lesbian]: Instead of “something else,” respondent suggested using “other.” She said, “If I was another thing ... I would have liked to have that term ... not ‘something else.’ ... It sounds like an object to me. ... The person who lives the experience should choose how they are called.”

### **Comprehension Problems with Term “Heterosexual”**

Importantly, more than a dozen respondents had trouble comprehending the term “heterosexual.” This term has caused problems historically when translated, and we have demonstrated some better results here. It must be noted, however, that most of these respondents were able to answer the sexual orientation question by elimination—that is, by subtracting response options they did not think applied to them and, as a result, selecting the option they thought best matched their orientation. This means that even though respondents were not able to understand the term “heterosexual,” they could select options “not gay, that is, heterosexual” or “not gay or lesbian, that is, heterosexual,” which were consistent with their reported orientation in the screener (i.e., non-LGBT). Two bilingual respondents indicated they were aware of the

term “straight” and identified themselves as such but acknowledged they did not know how to translate “straight” into Spanish. These respondents were not familiar with using the term “heterosexual” in Spanish as a translation of “straight” in English.

- R4744 [Female, 18, HS grad or more, Version A, non-LGBT/Something else]: Respondent asked interviewer to repeat response options. When interviewer asked, “Were there any words that you were uncertain about?” respondent said, “Heterosexual. I didn’t know what that was.”
- R4764 [Female, 28, HS grad or more, Version B, non-LGBT/Something else]: When interviewer asked, “What did you think about when I asked that question?” respondent said, “Well, I didn’t understand the question. I got confused. The words, I am not that familiar.” When interviewer asked, “What did you think about in deciding on your answer?” respondent said, “I thought about what was the correct answer, what sex I am. I don’t know what to say; what’s the name for that? I like the opposite sex, not the same sex.”

### **Version B Respondents’ Challenges Regarding Absence of Term “Heterosexual”**

Respondents that received Version B, which did not include the term “heterosexual” in the sexual orientation question, indicated they would have preferred to see the response option of “heterosexual” included, either because it would have been easier to identify as heterosexual, because it was a more accurate term than “not gay” or “not gay or lesbian,” or because it was offensive or not politically correct to define heterosexuals as the negation of gays or lesbians. This request indicates that—despite the problematic nature of including the term “heterosexual”—not including it can seem overly limiting and problematic in its own regard.

- R4733 [Male, 40, HS grad or more, Version B, non-LGBT/Not gay]: Respondent was surprised to not see the term “heterosexual” as a response option and thought the term “not gay” was not politically correct. He said, “I was surprised to see the option ‘not gay’ because ‘not gay’ could mean a lot of different things. I was surprised that there was no option for ‘heterosexual,’ but political correctness is not my thing.” Respondent recommended that one way to improve this question would be to add the term “heterosexual” because “it is a more common word.”
- R4752 [Female, 47, Less than HS, Version B, non-LGBT/Something else]: Respondent selected “something else” even though she identified as heterosexual. When asked, “What did you think about in deciding on your answer?” she said, “That I am heterosexual. That I am not against gay or lesbians. I have a gay friend....”

- R4768 [Male, 30, HS grad or more, Version B, non-LGBT/Not gay]: When asked “What did you think about when I asked that question?” respondent said, “The options didn’t mention ‘heterosexual,’ so I had to go with ‘not gay.’”

## Summary and Recommendations

### Summary of Findings

Overall, the results of the current study are consistent with previous research (i.e., Stern et al. 2016) and provide helpful information to inform decisions about including Spanish-language sexual orientation questions in federal surveys. They indicate that Version A (i.e., “not gay, that is, heterosexual”) performs better than the other options tested. It is more effective at minimizing inconsistency between screener and interview responses reporting sexual orientation. Version A also minimized the number of non-substantive responses such as “don’t know” and “something else” that respondents provided in answer to the question on sexual orientation. Both of these patterns held true across respondents of different sexual orientations, gender, and education levels.

Several respondents who answered “not gay” in Version A of the sexual orientation question had trouble understanding the term “heterosexual” but were able to arrive at an answer consistent with their reported orientation in the screener by eliminating response options they did not think applied to them. Conversely, some respondents who answered “not gay” in Version B of the sexual orientation question indicated they would have preferred to see the response option of “heterosexual” included, either because it would have been easier to identify as heterosexual, because it was a more accurate term than “not gay” or “not gay or lesbian,” or because it was offensive or not politically correct to define heterosexuals as the negation of gays or lesbians.

Respondents had several ideas on ways to improve the response options, including a broader range of sexual orientations and changing the wording of the “something else” option. Some respondents noted that the response options provided were limited and did not acknowledge the entire range of sexual orientations. These respondents suggested the inclusion of response options such as “asexual” or options that would capture stages of transitioning. Similar to extant research, the results of the current study also show that some respondents find the response option “something else” offensive. However, it is the opinion of this research team that there were an insufficient number of these cases for us to recommend an alternative at this time. Future work may be warranted to examine this issue.

## Final Recommendations

Based on these findings, we recommend that any federal surveys that wish to more accurately enumerate the Spanish-speaking LGBT community use Version A (Figure 3) of the sexual orientation question, with the response option “not gay, that is, heterosexual.” Version A is superior to Version B in terms of consistency of responses and lower incidence of both “don’t know” and “something else” responses. In addition, some Version B respondents found it offensive to include “not gay” without a reference to the more formal “heterosexual.”

**Figure 3.** Alternative Measures of Sexual Orientation.

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

[Response Options for Male Rs]:	[Response Options for Female Rs]:
1. Gay	1. Lesbiana o gay
2. No gay, o sea, heterosexual	2. No lesbiana o gay, o sea, heterosexual
3. Bisexual	3. Bisexual
4. Otra cosa	4. Otra cosa
5. No sé la respuesta	5. No sé la respuesta

Our recommendation is based on the current study as well as previous work on the topic, including the Stern et al. report. The body of research on the topic of Spanish translation of English text has consistently shown that the direct translation of items from English to Spanish causes confusion among native Spanish speakers given that the Spanish translations of colloquial terms such as “straight” often have no cultural meaning outside of English. As a result, direct translations may fail to convey the desired concept to respondents. Our recommended adaptation of the translation is more readily understood by Spanish speakers because, although it is not a direct translation, it more effectively conveys the desired concept. Using the recommended phrasing in Spanish will help researchers gather more accurate data on the LGBT population because it will promote the more accurate identification of the LGBT population.

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## Appendices

### Appendix A: Stern et al.—Sexual Orientation and Gender Identity Questions (English)

52.	<p><b>SHOW CARD DI5</b></p> <p><b>[FOR MALE RESPONDENTS]</b>          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</p> <p><b>[FOR FEMALE RESPONDENTS]</b>          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>
<p><b>Probes</b></p> <ul style="list-style-type: none"> <li>• What did you think about when I asked that question?</li> <li>• What did you think about in deciding on your answer?</li> <li>• How did you decide on that answer?             <ul style="list-style-type: none"> <li>○ Can you tell me more about that?</li> </ul> </li> <li>• Did you have any trouble deciding on that answer?             <ul style="list-style-type: none"> <li>○ If YES, What were you concerned about?</li> </ul> </li> <li>• Were there any words that you were uncertain about?             <ul style="list-style-type: none"> <li>○ Which ones?</li> <li>○ How did this affect your answer?</li> </ul> </li> <li>• What does [Bisexual] mean to you?</li> <li>• [IF R ANSWERED: SOMETHING ELSE: ]             <ul style="list-style-type: none"> <li>○ What else would best represent how you think about yourself?</li> </ul> </li> <li>• [IF R ANSWERED: I don't know how to answer: ]             <ul style="list-style-type: none"> <li>○ What makes it difficult for you to answer this question?</li> </ul> </li> </ul> <p><b>Note to Interviewers</b>          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?</p> <p><b>Observations:</b></p>	

53.	<p>What sex were you assigned at birth, on your original birth certificate?</p> <p>(01) FEMALE</p> <p>(02) MALE</p>
<p><b>Observations:</b></p>	
54.	<p>SHOW CARD DI6</p> <p>How do you describe yourself? (select one)</p> <p>(01) Female</p> <p>(02) Male</p> <p>(03) Transgender</p> <p>(04) Do not identify as female, male, or transgender</p>
<p><b>Probes</b></p> <ul style="list-style-type: none"> <li>• What did you think about when I asked that question?</li> <li>• What did you think about in deciding on your answer?</li> <li>• How did you decide on that answer? <ul style="list-style-type: none"> <li>○ Can you tell me more about that?</li> </ul> </li> <li>• Did you have any trouble deciding on that answer? <ul style="list-style-type: none"> <li>○ If YES, What were you concerned about?</li> </ul> </li> <li>• Were there any words that you were uncertain about? <ul style="list-style-type: none"> <li>○ Which ones?</li> <li>○ How did this affect your answer?</li> </ul> </li> <li>• IF R ANSWERED “Do not identify as female, male, or transgender”: <ul style="list-style-type: none"> <li>○ How do you describe yourself?</li> <li>○ Is there some other term that you would use?</li> </ul> </li> <li>• What does [Transgender] mean to you?</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 “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?</p> <p><b>Observations:</b></p>	

## Appendix B: Stern et al.—Sexual Orientation and Gender Identity Questions (Spanish)

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>
<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>• ¿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> <p><b>Note to Interviewer</b>            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 lesbian”) 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> <p><b>Observations:</b></p>	

<p>52.</p>	<p><b>SHOW CARD DI5</b></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>
<p>53.</p>	<p>¿Qué sexo le asignaron al nacer, en su acta de nacimiento original?</p> <p>(01) MALE                  (02) FEMALE</p>
<p><b>Observations:</b></p>	
<p>54.</p>	<p><b>SHOW CARD DI6</b></p> <p>¿Se describe a sí mismo(a)?</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>	

52.	<p><b>SHOW CARD DI5</b></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>
<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>	

Appendix C: Stern et al.—Sexual Orientation Question Show Cards (Spanish)

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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

## Appendix D: Eligibility Screening Script (English)<sup>6</sup>

### Eligibility Screening Script

RESPONDENT NUMERIC IDENTIFIER: \_\_\_\_\_

The Public Health Service Act provides us with the authority to do this research (42 United States Code 242k). All information which would permit identification of any individual, a practice, or an establishment will be held confidential, will be used for statistical purposes only by NCHS staff, contractors, and agents only when required and with necessary controls, and will not be disclosed or released to other persons without the consent of the individual or the establishment in accordance with section 308(d) of the Public Health Service Act (42 USC 242m) and the Confidential Information Protection and Statistical Efficiency Act (PL-107-347).

Public reporting burden for this collection of information is estimated to average 10 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road, MS D-74, Atlanta, GA 30333, ATTN: PRA (0920-0222).

OMB #0920-0222; Expiration Date: 07/31/2018

### Sample screening script for respondent contact by NORC for the NCHS & CMS Spanish Cognitive Interviewing Study

**Dial respondent's telephone number [hereafter referred to as *R*] as indicated on voice mail system/email system.**

**Note: Speak only to *R*. If the number is answered by voice mail/answering machine, call back at another time.**

**NORC Recruiter/NORC Staff:** Good morning/afternoon, may I speak to (name)?

**If *R* is not available or not at home, say, "Thank you" and try again at another time.**

**If the person who answered the phone (NOT *R*) asks, "Who is calling?" or "What's this about?" say, "I am returning their call to me. I'll try to reach them at another time.**

**If *R* has been successfully contacted, continue...**

...Hello. My name is [NAME] and I work for NORC at the University of Chicago and we are conducting a health study on behalf of the National Center for Health Statistics and the Centers for Medicare and Medicaid Services. I'm calling about your interest in participating in the health study. Is this a good time?

**If not a good time to talk, schedule a time to call back.**

**If good time to talk, continue...**

[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, GO TO EXIT SCRIPT #1]

[IF YES] We are conducting a study to test questions that may be added to national surveys. If you agree to participate in this interview, an interviewer will ask you to fill out a questionnaire. Then the interviewer will ask you to explain what you were thinking as you answered the questions. Your answers

<sup>6</sup> English materials provided for reference only. Materials used in the field were Spanish-language materials.

will help us find out if the survey questions will be easy for other people to answer. Everything you say will be kept private. Some people may view some questions as sensitive – the questions you will be asked range from healthcare to basic 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.

➔ [IF YES] Great. In order to determine if you are eligible for our study, I'll need a few minutes of your time to ask some background questions. Then we can schedule an appointment time for you. Answering these questions is completely voluntary. We are required by law to use your information for statistical purposes only and to keep it confidential. The law prohibits us from giving anyone any information that may identify you without your consent.

➔ [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:**

- 
1. Are you male or female?
    1. MALE
    2. FEMALE
  
  2. 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.
  
  3. How old are you?
 

\_\_\_\_\_ years
  
  4. 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

5. Are you of Hispanic, Latino, or Spanish origin?
  1. YES
  2. NO
  
6. 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
  
7. 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. ]

**[If the recruitment needs for certain groups have been achieved, go to exit script 2].**

With your permission, we would like to record your interview. The recording is a record of what we asked and what you said about the questions. Do you give permission to have your interview audio recorded? Yes/No. [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

Do you have any questions at this point? *Pause to answer questions.* If (not/you have no other questions), then let's get you on the schedule, ok? We will be interviewing (Day, Month/Date) through (Day, Month/Date) from [fill] a.m. to [fill] p.m. Looking at your schedule, when would you be available to participate? *Schedule.* **[If date/times not available go to exit script 3.]**

A reminder call will be made to you a few days in advance. Should you have any questions or need to change your appointment, please feel free to contact me [name] at [phone number]. Thank you for responding to our ad, and I look forward to seeing you here at (DATE/TIME) *Get respondent to cite date & time if possible.*

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***Exit script 1:*** I am sorry, you have to be over the age of 18 to take part in this study and therefore we won't be able to use you at this time. We appreciate your call and thank you for your interest in our study.

***Exit script 2:*** Based upon your answers, it seems that we may already have a number of volunteers with very similar answers to yours. At this point we need to talk with people with some different characteristics. However, if we have cancellations or other slots open up, I may wish to call you back. Would it be okay if I kept your name, telephone number, and the information you provided in response to the eligibility questions until the end of this study? *If yes*, make notation. *If no*, OK, thank you for your time. We appreciate your call and thank you for your interest in our study.

***Exit script 3:*** I see...ok, we were hoping to complete this particular study between (Month/Date) and (Month/Date), so it looks like we won't be able to schedule you at this time. We appreciate your call and thank you for your interest in our study.

## Appendix E: Eligibility Screening Script (Spanish)

### Eligibility Screening Script

RESPONDENT NUMERIC IDENTIFIER: \_\_\_\_\_

El Acta del Servicio de Salud Pública nos otorga la autoridad para hacer este estudio (42, Código de Leyes de los Estados Unidos 242K). Toda información que pueda permitir identificar a algún individuo, práctica o establecimiento se mantendrá confidencial, será usada solo para propósitos estadísticos por el personal de NCHS, sus contratistas y agentes solamente cuando sea requerido y con los controles necesarios, y no será divulgada ni entregada a otras personas sin el consentimiento del individuo o establecimiento como lo establece la sección 308(d) del Acta del Servicio de Salud Pública (42 Código de Leyes de los Estados Unidos 242m) y el Acta de Protección de la Información Confidencial y Eficiencia Estadística (PL-107-347).

Se calcula que el tiempo que le llevará al público cumplir con este pedido de información es de un promedio de 10 minutos por participante, incluyendo el tiempo que tomará revisar las instrucciones, buscar fuentes de datos preexistentes, juntar y mantener los datos necesarios y completar y revisar el pedido de información. Ninguna agencia puede llevar a cabo o patrocinar un pedido de información a menos que tenga a la vista un número vigente de control de OMB, y a ninguna persona se le puede exigir que responda en ese caso. Envíe sus comentarios con respecto al cálculo de tiempo o de cualquier otro aspecto de este pedido de información, incluyendo sugerencias para reducir el tiempo que toma, a CDC/ATSDR Information Collection Review Officer; 1600 Clifton Road, MS D-74, Atlanta, GA 30333, ATTN: PRA (0920-0222).

Form Approved OMB #0920-0222; Fecha de Vencimiento: 07/31/2018

### Sample screening script for respondent contact by NORC for the NCHS & CMS Spanish Cognitive Interviewing Study

**Dial respondent's telephone number [hereafter referred to as R] as indicated on voice mail system/email system.**

**Note: Speak only to R. If the number is answered by voice mail/answering machine, call back at another time.**

**NORC Recruiter/NORC Staff:** Buenos días/Buenas tardes, ¿puedo hablar con (name)?

**If R is not available or not at home, say, "Gracias" and try again at another time.**

**If the person who answered the phone (NOT R) asks, "¿Quién habla?" or "¿Por qué llama?" say, "Le estoy regresando una llamada. Voy a tratar de llamarle en otro momento.**

**If R has been successfully contacted, continue...**

...Hola. Mi nombre es (NAME) y trabajo para NORC en la Universidad de Chicago y nosotros estamos conducting a health study on behalf of the Centro Nacional de Estadísticas de Salud and the Centers for Medicare and Medicaid Services. Estoy llamando sobre su interés en participar en el estudio de salud. ¿Ahora es un buen momento para hablar

**If not a good time to talk, schedule a time to call back.**

**If good time to talk, continue...**

[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, GO TO EXIT SCRIPT #1]

[IF YES] Estamos llevando a cabo un estudio para probar preguntas que se puedan añadir a encuestas nacionales. Si acepta participar en esta entrevista, el entrevistador le pedirá que llene un cuestionario. Luego, la entrevistadora le pedirá que usted explique lo que estaba pensando cuando contestó las preguntas. Sus respuestas nos ayudarán a saber si las preguntas de la encuesta serán fáciles de contestar para otras personas. Todo lo que usted diga se mantendrá en privado. 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.

- ➔ [IF YES] Muy bien. Para determinar si usted es elegible para nuestro estudio, voy a necesitar unos minutos de su tiempo para hacerle algunas preguntas sobre usted. Entonces podremos programar una cita para usted. Contestar estas preguntas es completamente voluntario. De acuerdo a las leyes, sólo tenemos permitido usar su información para hacer estudios estadísticos, y estamos obligados a mantenerla (su información) de forma confidencial. La ley nos prohíbe darle a otros cualquier información que pueda identificarle a usted sin su propio consentimiento.
- ➔ [IF NO] Esta bien, no hay problema. Apreciamos su interés. Pero para los propósitos de este estudio, nos gustaría saber por que 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:

-----

--

1. ¿Es usted hombre o mujer?
  1. HOMBRE
  2. MUJER
  
2. ¿Podría venir a una de nuestras oficinas en [fill city] para completar una entrevista?
  1. YES
  3. NO -> FIND OUT WHERE RESPONDENT WOULD LIKE TO BE INTERVIEWED; WE WILL DETERMINE IF TRAVEL ARRANGEMENTS CAN BE MADE; CONTINUE SCREENING.
  
3. ¿Cuántos años tiene?
 

\_\_\_\_\_ years
  
- 4.Cuál es el grado o nivel de estudios más alto que usted ha completado?
  1. NO TIENE ESTUDIOS
  2. PREESCOLAR A 8º. GRADO
  3. 9º -12º 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

5. Es usted de origen hispano, latino o español?
  1. YES
  2. NO
  
6. 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
  
7. ¿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 CORRESPONDA CON SU IDENTIDAD DE GÉNERO INTERNA. ALGUNAS PERSONAS TRANSGÉNERO TOMAN HORMONAS Y ALGUNAS SE SOMETEN A CIRUGÍAS. ]

[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. Sí
2. No

¿Tiene alguna pregunta por el momento? *Pause to answer questions.* Si (no/no tiene más preguntas), hagamos la cita para la entrevista, ¿Está bien? Estaremos haciendo entrevistas del (**día, mes/fecha**) al (**día, mes/fecha**) de [fill] a.m. a [fill] p.m. Por favor fíjese en su calendario y dígame cuándo estaría disponible para participar. *Schedule.* [**If date/times not available go to exit script 3.**]

Unos días antes, le llamaremos para recordarle de su cita. Si tiene alguna pregunta o necesita cambiar la cita, por favor no dude en llamarme; mi nombre es [**name**] y mi número de teléfono es [**phone number**]. Gracias por contestar a nuestro anuncio, y espero verle aquí el (**DATE/TIME**) *Get respondent to cite date & time if possible.*

-----  
**Exit script 1:** Lo lamento, pero tienes que ser mayor de 18 para participar en este estudio, y por lo tanto, no podemos entrevistarte en este momento. Agradecemos tu llamada y te agradecemos por tu interés en nuestro estudio.

**Exit script 2:** De acuerdo a sus respuestas, parece que ya tenemos suficientes voluntarios con respuestas muy semejantes a las de usted. En este momento necesitamos hablar con gente con algunas características diferentes. Sin embargo, si tenemos alguna cancelación o algún horario disponible, me gustaría volver a llamarle. ¿Está bien si guardo hasta el final de este estudio su nombre, número de teléfono y la información que nos dio al responder a las preguntas para ver si era elegible? *If yes, make notation. If no:* Bueno, gracias por su tiempo. Agradecemos tu llamada y te agradecemos por tu interés en nuestro estudio.

***Exit script 3:*** Ah, bueno. Teníamos pensado completar este estudio entre el (día) de (mes) y el (día) de (mes), así es que parece que no podremos hacer una cita con usted en este momento. Agradecemos tu llamada y te agradecemos por tu interés en nuestro estudio.

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## Appendix F: Recruitment Message (English)<sup>7</sup>

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On behalf of the National Center for Health Statistics (NCHS) and the Centers for Medicare and Medicaid Services (CMS), NORC at the University of Chicago is conducting research to test questions that may be added to national surveys. The question topics range from healthcare to general demographic questions such as race, and education. We are inviting individuals 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 individuals 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.

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<sup>7</sup> English materials provided for reference only. Materials used in the field were Spanish-language materials.

## Appendix G: Recruitment Message (Spanish)

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NORC en la Universidad de Chicago está llevando a cabo un estudio de parte del Centro Nacional para Estadísticas de Salud (NCHS por sus siglas en inglés) y los Centros para Servicios de Medicare y Medicaid (CMS por sus siglas en inglés), para probar preguntas que podrían agregarse a encuestas nacionales. Los temas de las preguntas van desde preguntas sobre el cuidado de salud, a preguntas de información demográfica como su raza y su educación. Estamos invitando a personas a participar en una entrevista; la entrevista consiste en primero completar una encuesta y hablar luego con el entrevistador sobre algunas de las preguntas de la encuesta. Escuchar lo que los individuos tienen que decir acerca de la encuesta nos ayudará a mejorar las preguntas. Si usted es elegible y decide participar, recibirá \$40 como un incentivo por participar en este estudio. Si usted está interesado(a) en saber más al respecto, por favor póngase en contacto con el Coordinador del estudio, NAME al [NAME@norc.org](mailto:NAME@norc.org).

## Appendix H: Thank You Letter (English)<sup>8</sup>

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DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service  
Centers for Disease Control and Prevention

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National Center for Health Statistics  
3311 Toledo Road  
Hyattsville, Maryland 20782

# Thank you!

...for the assistance you have given us in testing our questionnaire. After all testing and corrections have been completed, the final questionnaire will be used to collect information from persons throughout the country. The information will be used for many purposes that will benefit all Americans, such as providing information on the kinds of health conditions that affect most Americans, so that research funds can be best used, or developing screening or education programs to help prevent serious disabilities.

The information you provided will, of course, be held in confidence. When combined with information given by other volunteers, it will help us to identify and correct problems with question wording and order. This will improve the quality of the information collected in the national survey. We greatly appreciate your help in this effort.

A handwritten signature in black ink, appearing to read "Charles J. Rothwell".

Charles J. Rothwell  
Director  
National Center for Health Statistics

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<sup>8</sup> English materials provided for reference only. Materials used in the field were Spanish-language materials.

## Appendix I: Thank You Letter (Spanish)

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DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service  
Centers for Disease Control and Prevention

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National Center for Health Statistics  
3311 Toledo Road  
Hyattsville, Maryland 20782

# ¡Gracias!

...por la ayuda que nos ha prestado para probar el cuestionario. Después que se completen todas las pruebas y las correcciones, el cuestionario final será utilizado para recolectar información de personas en todo el país. La información se usará con muchos propósitos que beneficiarán a todas las personas en Estados Unidos, como proveer información acerca de los tipos de problemas de salud que afectan a la mayor parte de la población en Estados Unidos de manera que los fondos para investigaciones puedan usarse de la mejor manera, o para desarrollar programas de detección o de educación que ayuden a prevenir discapacidades graves.

La información que nos ha proporcionado será, claramente, mantenida confidencialmente. Cuando se combine esa información con la que nos hayan dado otros participantes voluntarios, eso nos ayudará a identificar y corregir problemas en la formulación de las preguntas y el orden en que ellas aparecen. Esto mejorará la calidad de la información que recolectamos en nuestra encuesta nacional. Apreciamos mucho su ayuda en este esfuerzo.

A handwritten signature in black ink, appearing to read "Charles J. Rothwell".

Charles J. Rothwell  
Director  
Centro Nacional para Estadísticas de Salud

## Appendix J. Cognitive Interviewing Protocol (English)<sup>9</sup>

RESPONDENT NUMERIC IDENTIFIER: \_\_\_\_\_

### **COGNITIVE INTERVIEW SURVEY ITEMS AND PROBES: ENGLISH TRANSLATION OF SPANISH VERSION OF SURVEY ITEMS 33 AND 34. For illustrative purposes only. Not to be used for administration**

The Public Health Service Act provides us with the authority to do this research (42 United States Code 242k). All information which would permit identification of any individual, a practice, or an establishment will be held confidential, will be used for statistical purposes only by NCHS staff, contractors, and agents only when required and with necessary controls, and will not be disclosed or released to other persons without the consent of the individual or the establishment in accordance with section 308(d) of the Public Health Service Act (42 USC 242m) and the Confidential Information Protection and Statistical Efficiency Act (PL-107-347).

Public reporting burden for this collection of information is estimated to average 60 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to CDC/ATSDR Information Collection Review Office; 1600 Clifton Road, MS D-74, Atlanta, GA 30333, ATTN: PRA (0920-0222).

Form Approved OMB #0920-0222; Expiration Date: 07/31/2018

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

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

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

<sup>9</sup> English materials provided for reference only. Materials used in the field were Spanish-language materials.

<p>1.</p>	<p>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?</p> <p>(01) YES (02) NO (-8) Don't Know (-9) Refused</p>
<p>4.</p>	<p>SHOW CARD SC1 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>
<p>5.</p>	<p>SHOW CARD SC1 [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>
<p>6.</p>	<p>SHOW CARD SC1 [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>

<p>1.</p>	<p>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?</p> <p>(01) YES (02) NO (-8) Don't Know (-9) Refused</p>
<p>7.</p>	<p>SHOW CARD SC1 [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>
<p>8.</p>	<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>
<p>9.</p>	<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>
<p>10.</p>	<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 (02) NO →GO TO Q21</p>

<p>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?</p> <p>(01) YES (02) NO (-8) Don't Know (-9) Refused</p>
<p>11. 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? IF SOME OTHER PLACE, ASK: Where is this?</p> <p>(01) DOCTOR'S OFFICE OR GROUP PRACTICE (02) MEDICAL CLINIC (03) MANAGED CARE PLAN CENTER/HMO (04) NEIGHBORHOOD/FAMILY HEALTH CENTER (05) FREESTANDING SURGICAL CENTER (06) RURAL HEALTH CLINIC (07) COMPANY CLINIC (08) OTHER CLINIC (09) WALK-IN URGENT CENTER (10) DOCTOR COMES TO SP'S HOME (11) HOSPITAL EMERGENCY ROOM (12) HOSPITAL OUTPATIENT DEPARTMENT/CLINIC (13) VA FACILITY (14) MENTAL HEALTH CENTER (91) OTHER (SPECIFY _____) (-8) DON'T KNOW (-9) REFUSED</p>
<p>12. What is the complete name of the place that you go to? WRITE NAME ON WORKSHEET</p>
<p>13. Is there a particular doctor you usually see at this place?</p> <p>(01) YES (02) NO →GO TO Q15 (-8) DON'T KNOW (-9) REFUSED</p>
<p>14. What is the complete name of that doctor? WRITE NAME ON WORKSHEET</p>

<p>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?</p> <p>(01) YES (02) NO (-8) Don't Know (-9) Refused</p>
<p>15. SHOW CARD US3 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 Q14/ PLACE NAME FROM Q12). For each statement, please tell me whether you strongly agree, agree, disagree, or strongly disagree.</p> <p>[(PROVIDER NAME FROM Q14) is/The doctors at (PLACE NAME FROM Q12) 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>
<p>16. SHOW CARD US3 [(PROVIDER NAME FROM Q14) is/The doctors at (PLACE NAME FROM Q12) 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>

<p>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?</p> <p>(01) YES (02) NO (-8) Don't Know (-9) Refused</p>
<p>17. SHOW CARD US3 [(PROVIDER NAME FROM Q14) has/The doctors at (PLACE NAME FROM Q12) 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>
<p>SHOW CARD US3 [(PROVIDER NAME FROM Q14) often seems/The doctors at (PLACEFROM Q12) 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>
<p>18. SHOW CARD US3 [Think about the care you receive from [(PROVIDER NAME FROM Q14)/(PLACE NAME FROM Q12)].]</p> <p>[(PROVIDER NAME FROM Q14) often does/The doctors at (PLACE NAME FROM Q12) 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>

<p>1.</p>	<p>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?</p> <p>(01) YES (02) NO (-8) Don't Know (-9) Refused</p>
<p>19.</p>	<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> <p>ALL RESPONSES →GO TO Q28</p>
	<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>
<p>20.</p>	<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>
<p>21.</p>	<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 Q25 (-8) DON'T KNOW →GO TO Q25 (-9) REFUSED →GO TO Q25</p>

<p>1.</p>	<p>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?</p> <p>(01) YES (02) NO (-8) Don't Know (-9) Refused</p>
<p>22.</p>	<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>
<p>23.</p>	<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>
<p>24.</p>	<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>
<p>25.</p>	<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>
<p>26.</p>	<p>I would like to get a little information about your background.</p> <p>Are you of Hispanic, Latino, or Spanish origin?</p> <p>(01) YES (02) NO →GO TO Q30 (-8) Don't Know →GO TO Q30 (-9) Refused →GO TO Q30</p>

<p>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?</p> <p>(01) YES (02) NO (-8) Don't Know (-9) Refused</p>
<p>27. SHOW CARD D11 Looking at this card, are you Mexican, Mexican American, or Chicano/Chicana, Puerto Rican, Cuban, or of another Hispanic, Latino/Latina or Spanish origin?</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>
<p>28. SHOW CARD D12 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 Q31. ELSE IF RACE INCLUDES NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER, GO TO Q32. ELSE GO TO Q33.</p>

<p>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?</p> <p>(01) YES (02) NO (-8) Don't Know (-9) Refused</p>
<p>29. SHOW CARD DI3 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.</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 AT Q30 INCLUDES NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER, GO TO Q32. ELSE GO TO Q33.</p>
<p>30. SHOW CARD DI4 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.</p> <p>(01) NATIVE HAWAIIAN (02) GUAMANIAN OR CHAMORRO (03) SAMOAN (91) OTHER PACIFIC ISLANDER GROUP (SPECIFY _____) (-8) Don't Know (-9) Refused</p>

<p>31. Sexual Identity Question – Version A          ½ of the respondents will receive Q33 Version A, and ½ of the respondents will receive Q34 version B. Please only read options 1-4. Do not read “I don’t know how to answer”.</p> <p>[FOR MALE RESPONDENTS]          Which of the following options best represents how you think about yourself? Gay; not gay, that is, heterosexual; bisexual; or something else?</p> <p>(01) Gay          (02) Not gay, that is, heterosexual          (03) Bisexual          (04) Something else          (05) I don’t know how to answer</p> <p>[FOR FEMALE RESPONDENTS]          Which of the following options best represents how you think about yourself? Lesbian or gay; not gay or lesbian, that is, heterosexual; bisexual; or something else?</p> <p>(01) Lesbian or Gay          (02) Not gay or lesbian, that is, heterosexual          (03) Bisexual          (04) Something else          (05) I don’t know how to answer</p>
<p>32. Sexual Identity Question – Version B          ½ of the respondents will receive Q33 Version A, and ½ of the respondents will receive Q34 version B. Please only read options 1-4. Do not read “I don’t know how to answer”.</p> <p>[FOR MALE RESPONDENTS]          Which of the following options best represents how you think about yourself? Gay; not gay; bisexual; or something else?</p> <p>(01) Gay          (02) Not gay          (03) Bisexual          (04) Something else          (05) I don’t know how to answer</p> <p>[FOR FEMALE RESPONDENTS]          Which of the following options best represents how you think about yourself? Lesbian or gay; not gay or lesbian; bisexual; or something else?</p> <p>(01) Lesbian or Gay          (02) Not gay or lesbian          (03) Bisexual          (04) Something else          (05) I don’t know how to answer</p>
<p><b>Probes for Q33 &amp; Q34</b></p> <ul style="list-style-type: none"> <li>• What did you think about when I asked that question?             <ul style="list-style-type: none"> <li>○ Can you give me an example of that?</li> </ul> </li> <li>• What did you think about in deciding on your answer?             <ul style="list-style-type: none"> <li>○ Can you give me an example of that?</li> </ul> </li> <li>• How did you decide on that answer?</li> </ul>

31. Sexual Identity Question – Version A

½ of the respondents will receive Q33 Version A, and ½ of the respondents will receive Q34 version B. Please only read options 1-4. Do not read “I don’t know how to answer”.

[FOR MALE RESPONDENTS]

Which of the following options best represents how you think about yourself? Gay; not gay, that is, heterosexual; bisexual; or something else?

- (01) Gay
- (02) Not gay, that is, heterosexual
- (03) Bisexual
- (04) Something else
- (05) I don’t know how to answer

[FOR FEMALE RESPONDENTS]

Which of the following options best represents how you think about yourself? Lesbian or gay; not gay or lesbian, that is, heterosexual; bisexual; or something else?

- (01) Lesbian or Gay
- (02) Not gay or lesbian, that is, heterosexual
- (03) Bisexual
- (04) Something else
- (05) I don’t know how to 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:**

31. Sexual Identity Question – Version A

½ of the respondents will receive Q33 Version A, and ½ of the respondents will receive Q34 version B. Please only read options 1-4. Do not read “I don’t know how to answer”.

[FOR MALE RESPONDENTS]

Which of the following options best represents how you think about yourself? Gay; not gay, that is, heterosexual; bisexual; or something else?

- (01) Gay
- (02) Not gay, that is, heterosexual
- (03) Bisexual
- (04) Something else
- (05) I don’t know how to answer

[FOR FEMALE RESPONDENTS]

Which of the following options best represents how you think about yourself? Lesbian or gay; not gay or lesbian, that is, heterosexual; bisexual; or something else?

- (01) Lesbian or Gay
- (02) Not gay or lesbian, that is, heterosexual
- (03) Bisexual
- (04) Something else
- (05) I don’t know how to answer

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

- (01) FEMALE
- (02) MALE

34. SHOW CARD DI6

How do you describe yourself?

- (01) Male
- (02) Female
- (03) Transgender
- (04) Do not identify as female, male, or transgender

35. 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.]

- (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

36. SHOW CARD DI8

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.

[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.]

- (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

## Appendix K. Cognitive Interviewing Protocol (Spanish)

RESPONDENT NUMERIC IDENTIFIER: \_\_\_\_\_

El Acta del Servicio de Salud Pública nos otorga la autoridad para hacer este estudio (42, Código de Leyes de los Estados Unidos 242K). Toda información que pueda permitir identificar a algún individuo, práctica o establecimiento se mantendrá confidencial, será usada solo para propósitos estadísticos por el personal de NCHS, sus contratistas y agentes solamente cuando sea requerido y con los controles necesarios, y no será divulgada ni entregada a otras personas sin el consentimiento del individuo o establecimiento como lo establece la sección 308(d) del Acta del Servicio de Salud Pública (42 Código de Leyes de los Estados Unidos 242m) y el Acta de Protección de la Información Confidencial y Eficiencia Estadística (PL-107-347).

Se calcula que el tiempo que le llevará al público cumplir con este pedido de información es de un promedio de 10 minutos por participante, incluyendo el tiempo que tomará revisar las instrucciones, buscar fuentes de datos preexistentes, juntar y mantener los datos necesarios y completar y revisar el pedido de información. Ninguna agencia puede llevar a cabo o patrocinar un pedido de información a menos que tenga a la vista un número vigente de control de OMB, y a ninguna persona se le puede exigir que responda en ese caso. Envíe sus comentarios con respecto al cálculo de tiempo o de cualquier otro aspecto de este pedido de información, incluyendo sugerencias para reducir el tiempo que toma, a CDC/ATSDR Information Collection Review Officer; 1600 Clifton Road, MS D-74, Atlanta, GA 30333, ATTN: PRA (0920-0222).

Form Approved OMB #0920-0222; Fecha de Vencimiento: 07/31/2018

1. 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?

- (01) YES
- (02) NO
- (-8) Don't Know
- (-9) Refused

2. Durante el año pasado, ¿fue usted a la clínica o departamento de pacientes externos o ambulatorios de un hospital?

NO INCLUYA HOSPITALIZACIONES.

- (01) YES
- (02) NO
- (-8) Don't Know
- (-9) Refused

3. A continuación, quiero preguntarle sobre sus visitas a médicos en el último año.

¿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.

[IF NECESSARY, SAY, 'Por favor mire la tarjeta AC1 para ver ejemplos de especialidades médicas.']

(01) YES

(02) NO

(-8) Don't Know

(-9) Refused

**SHOW CARD AC1**

1. ALERGIA/INMUNOLOGÍA

2. ANESTESIOLOGÍA

3. CARDIOLOGIA (CORAZÓN)

5. DERMATOLOGÍA (PIEL)

6. MÉDICO DE SALA DE EMERGENCIA

7. ENDOCRINOLOGÍA/METABOLISMO (DIABETES, TIROIDE)

8. PRÁCTICA FAMILIAR

9. GASTROENTEROLOGÍA

10. PRÁCTICA GENERAL

11. CIRUGÍA GENERAL

12. GERIATRÍA (ENVEJECIENTES)

13. GINECOLOGÍA - OBSTETRICIA

14. HEMATOLOGÍA (SANGRE)

15. RESIDENCIA EN HOSPITAL

16. MEDICINA INTERNA (INTERNISTA)

17. NEFROLOGÍA (RIÑONES)

18. NEUROLOGÍA

19. MEDICINA NUCLEAR

20. ONCOLOGÍA (TUMORES, CÁNCER)

21. OFTALMOLOGÍA (OJOS)

22. ORTOPEDIA

24. OSTEOPATÍA

25. OTORRINOLARINGOLOGÍA

26. PATOLOGÍA

27. FISIOLOGÍA/REHABILITACIÓN

28. CIRUGÍA PLÁSTICA

29. PROCTOLOGÍA

30. PSIQUIATRÍA/PSIQUIATRA

31. PULMONAR (PULMONES)

32. RADIOLOGÍA

33. REUMATOLOGÍA (ARTRITIS)

34. CIRUGÍA DEL TÓRAX (PECHO)

35. UROLOGÍA

36. OTRA ESPECIALIDAD MÉDICA

(91) OTHER DR SPECIALTY

(-8) DON'T KNOW

(-9) REFUSED

<p>4. 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> <ol style="list-style-type: none"><li>1. MUY SATISFECHO(A)</li><li>2. SATISFECHO(A)</li><li>3. INSATISFECHO(A)</li><li>4. MUY INSATISFECHO(A)</li><li>5. NO CORRESPONDE</li></ol> <p>(-8) Don't Know (-9) Refused</p>
<p>5. SHOW CARD SC1 [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> <ol style="list-style-type: none"><li>1. MUY SATISFECHO(A)</li><li>2. SATISFECHO(A)</li><li>3. INSATISFECHO(A)</li><li>4. MUY INSATISFECHO(A)</li><li>5. NO CORRESPONDE</li></ol> <p>(-8) Don't Know (-9) Refused</p>
<p>6. SHOW CARD SC1 [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> <ol style="list-style-type: none"><li>1. MUY SATISFECHO(A)</li><li>2. SATISFECHO(A)</li><li>3. INSATISFECHO(A)</li><li>4. MUY INSATISFECHO(A)</li><li>5. NO CORRESPONDE</li></ol> <p>(-8) Don't Know (-9) Refused</p>

<p>7. 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 CORRESPONDE (-8) Don't Know (-9) Refused</p>
<p>8. 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 CORRESPONDE (-8) Don't Know (-9) Refused</p>
<p>9. 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 CORRESPONDE (-8) Don't Know (-9) Refused</p>
<p>10. ¿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 Q21</p>

<p>11. ¿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>
<p>12. ¿Cuál es el nombre completo del lugar al que usted va? WRITE NAME ON WORKSHEET</p>
<p>13. ¿Hay un médico en particular que usted ve normalmente en este lugar?</p> <p>(01) YES          (02) NO →GO TO Q15          (-8) DON'T KNOW          (-9) REFUSED</p>
<p>14. ¿Cuál es el nombre completo de ese médico? WRITE NAME ON WORKSHEET</p>

15. SHOW CARD US3

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 Q14/ PLACE NAME FROM Q12)]. Para cada afirmación, por favor dígame si usted está totalmente de acuerdo, de acuerdo, en desacuerdo, o totalmente en desacuerdo.

[(PROVIDER NAME FROM Q14) es /Los médicos en (PLACE NAME FROM Q12) son] muy cuidadoso(s) de chequear todo cuando lo examinan a (usted/él/ella).

- (01) TOTALMENTE DE ACUERDO
- (02) DE ACUERDO
- (03) EN DESACUERDO
- (04) TOTALMENTE EN DESACUERDO
- (05) NO CORRESPONDE
- (-8) Don't Know
- (-9) Refused

16. SHOW CARD US3

[(PROVIDER NAME FROM Q14) es /Los médicos en (PLACE NAME FROM Q12) son] competente(s) y bien capacitados.

- (01) TOTALMENTE DE ACUERDO
- (02) DE ACUERDO
- (03) EN DESACUERDO
- (04) TOTALMENTE EN DESACUERDO
- (05) NO CORRESPONDE
- (-8) Don't Know
- (-9) Refused

17. SHOW CARD US3

[(PROVIDER NAME FROM Q14) tiene /Los médicos en (PLACE NAME FROM Q12) tienen] una idea completa de los problemas de (usted/él/ella).

- (01) TOTALMENTE DE ACUERDO
- (02) DE ACUERDO
- (03) EN DESACUERDO
- (04) TOTALMENTE EN DESACUERDO
- (05) NO CORRESPONDE
- (-8) Don't Know
- (-9) Refused

18. SHOW CARD US3

[(PROVIDER NAME FROM Q14) con frecuencia parece/Los médicos en (PLACE NAME FROM Q12) con frecuencia parecen] estar apurados.

- (01) TOTALMENTE DE ACUERDO
- (02) DE ACUERDO
- (03) EN DESACUERDO
- (04) TOTALMENTE EN DESACUERDO
- (05) NO CORRESPONDE
- (-8) Don't Know
- (-9) Refused

19. SHOW CARD US3

Piense sobre el cuidado de salud que usted recibe de [(PROVIDER NAME FROM Q14)/(PLACE NAME FROM Q12)].

[(PROVIDER NAME FROM Q14)/Los médicos en ((PLACE NAME FROM Q12))] no le explica(n) a (usted/él/ella) sus problemas médicos.

- (01) TOTALMENTE DE ACUERDO
- (02) DE ACUERDO
- (03) EN DESACUERDO
- (04) TOTALMENTE EN DESACUERDO
- (05) NO CORRESPONDE
- (-8) Don't Know
- (-9) Refused

20. SHOW CARD US3

Frecuentemente usted tiene problemas de salud que deberían ser discutidos pero no se discuten.

- (01) TOTALMENTE DE ACUERDO
- (02) DE ACUERDO
- (03) EN DESACUERDO
- (04) TOTALMENTE EN DESACUERDO
- (05) NO CORRESPONDE
- (-8) Don't Know
- (-9) Refused

ALL RESPONSES →GO TO Q28

<p>21. [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>
<p>22. 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>
<p>23. 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 Q25  (-8) DON'T KNOW →GO TO Q25  (-9) REFUSED →GO TO Q25</p>
<p>24. ¿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>

<p>25. 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>
<p>26. 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>
<p>27. 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>
<p>28. 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 Q30  (-8) Don't Know →GO TO Q30  (-9) Refused →GO TO Q30</p>
<p>29. 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>

30. SHOW CARD DI2

Mirando esta tarjeta, ¿cuál es su raza?

[EXPLAIN IF NECESSARY: Para esta encuesta, los orígenes hispanos no son una raza.]

- (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

IF RACE INCLUDES ASIAN, GO TO Q31.

IF RACE INCLUDES NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER, GO TO Q32.

ELSE GO TO Q33.

31. SHOW CARD DI3

Mire esta tarjeta. ¿Es usted hindú, chino(a), filipino(a), japonés, coreano(a), vietnamita o de otro origen asiático?

Puede seleccionar más de un grupo.

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 Q30 INCLUDES NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER, GO TO Q32.

ELSE GO TO Q33.

32. SHOW CARD DI4

Mire esta tarjeta. ¿Es usted nativo de Hawái, guameño(a) o chamorro(a), samoano(a) o de otro origen de las Islas del Pacífico?

Puede seleccionar más de un grupo.  
CHECK ALL THAT APPLY.

- (01) NATIVE HAWAIIAN
- (02) GUAMANIAN OR CHAMORRO
- (03) SAMOAN
- (09) OTHER PACIFIC ISLANDER GROUP (SPECIFY \_\_\_\_\_)

(-8) Don't Know

(-9) Refused

33. Sexual Identity Question – Version A

**½ of the respondents will receive Q33 Version A, and ½ of the respondents will receive Q34 version B. Please only read options 1-4. Do not read “No sé la respuesta”**

[PARA HOMBRES PARTICIPANTES]

¿Cuál de las siguientes opciones representa mejor su manera de pensar en sí mismo? Gay; no gay, o sea, heterosexual; bisexual; o otra cosa?

- (01) Gay
- (02) No gay, o sea, heterosexual
- (03) Bisexual
- (04) Otra cosa
- (05) No sé la respuesta

[PARA MUJERES PARTICIPANTES]

¿Cuál de las siguientes opciones representa mejor su manera de pensar en sí misma? Lesbiana o gay; no gay o lesbiana, o sea, heterosexual; bisexual; o otra cosa?

- (01) Lesbiana o Gay
- (02) No gay o lesbiana, o sea, heterosexual
- (03) Bisexual
- (04) Otra cosa
- (05) No sé la respuesta

34. Sexual Identity Question – Version B  
**½ of the respondents will receive Q33 Version A, and ½ of the respondents will receive Q34 version B. Please only read options 1-4. Do not read “No sé la respuesta”**

[PARA HOMBRES PARTICIPANTES]

¿Cuál de las siguientes opciones representa mejor su manera de pensar en sí mismo? Gay; no gay; bisexual; o otra cosa?

- (01) Gay
- (02) No gay
- (03) Bisexual
- (04) Otra cosa
- (05) No sé la respuesta

[PARA MUJERES PARTICIPANTES]

¿Cuál de las siguientes opciones representa mejor su manera de pensar en sí misma? Lesbiana o gay; no gay o lesbiana; bisexual; o otra cosa?

- (01) Lesbiana o Gay
- (02) No gay o lesbiana
- (03) Bisexual
- (04) Otra cosa
- (05) No sé la respuesta

***Probes for Q33 & 34***

- ¿En qué pensó cuando le hice esta pregunta?  
o Me puede dar un ejemplo?
- ¿En qué pensó para decidir qué contestar?  
o Me puede dar un ejemplo?
- ¿Cómo decidió dar esa respuesta?  
o ¿Podría contarme un poco más sobre eso?
- ¿Tuvo algún problema para decidir qué contestar?  
o If YES, ¿Qué le preocupaba?
- ¿Hubo alguna palabra de la que no estuvo seguro(a)?  
o ¿Cuáles?  
o ¿Cómo influyó eso en su respuesta?
- ¿Qué quiere decir [bisexual] para usted?
- [IF R ANSWERED: SOMETHING ELSE: ]
  - o ¿En que otra manera mejor representaría cómo usted piensa sobre si mismo?
- [IF R ANSWERED: I don't know how to answer: ]
  - o ¿Qué le hace difícil para que usted pueda contestar esta pregunta?

***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:***

<p>35. ¿Qué sexo le asignaron al nacer, en su acta de nacimiento original?</p> <p>(01) Mujer (02) Hombre</p>
<p>36. SHOW CARD DI6</p> <p>¿Se describe a sí mismo(a)?</p> <p>(01) Hombre (02) Mujer (03) Transgénero (04) No me identifico como mujer, hombre ni transgénero</p>
<p>37. 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 8º. GRADO</li><li>3. 9º -12º 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>

38. SHOW CARD D18

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?

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.

[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.

(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

Appendix L: Worksheet and Show Cards for Questionnaire Testing (English)<sup>10</sup>

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## Worksheet for Questionnaire Testing

Place name from Q12:
Provider name from Q14:

---

<sup>10</sup> English materials provided for reference only. Materials used in the field were Spanish-language materials.

# 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)

*(continued)*

# AC1

- (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)

# 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-A

### Male Respondents

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

## DI5-A

### Female Respondents

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

## DI5-B

### Male Respondents

- Gay
- Not gay
- Bisexual
- Something else
- I don't know how to answer

# DI5-B

## Female Respondents

- Lesbian or Gay
- Not gay or lesbian
- 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 8<sup>TH</sup> Grade
- 9<sup>TH</sup>-12<sup>TH</sup> 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

**D18**

**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 +

# SC1

- Very Satisfied
- Satisfied
- Dissatisfied
- Very Dissatisfied

US3

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree

Appendix M: Worksheet and Show Cards for Questionnaire Testing (Spanish)

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## Worksheet for Questionnaire Testing

Place name from Q12:

Provider name from Q14:

# 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) Geriatría (Ancianos)
- (13) Ginecología - Obstetricia
- (14) Hematología (Sangre)
- (15) Morada de hospital
- (16) Medicina Interna (Internista)
- (17) Nefrología (Riñones)
- (18) Neurología (Sistema de los Nervios)

*(continúe)*

# AC1

- (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)

# 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-A

## Male Respondents

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

## DI5-A

### Female Respondents

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

DI5-B

## Male Respondents

- Gay
- No gay
- Bisexual
- Otra cosa
- No sé la respuesta

## DI5-B

### Female Respondents

- Lesbiana o Gay
- 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 8º Grado
- 9º - 12º 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 +

# SC1

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

US3

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

## Appendix N: Consent Form—Onsite (English)<sup>11</sup>

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RESPONDENT NUMERIC IDENTIFIER: \_\_\_\_\_



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service  
Centers for Disease Control and  
Prevention

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National Center for Health Statistics  
3311 Toledo Road  
Hyattsville, Maryland 20782

### Informed Consent Form for One-on-one Interviews

**You are being asked to take part in a research study. This consent form tells you about the study and what you will be asked to do. You can choose to take part in the study or not. If you choose to take part, you will need to sign this form.**

#### **Purpose of the Research**

The National Center for Health Statistics (NCHS) and the Centers for Medicare and Medicaid Services (CMS), NORC at the University of Chicago is conducting research to improve Federal surveys. For this research, NORC is testing new questions that may add important information about health disparities among small population groups. The question topics range from healthcare to basic demographic questions such as race, and education. If you agree to take part in this test, we will ask you to answer the survey questions. Then, we will ask you to explain what you were thinking and how you came up with your answers.

#### **Procedures**

An interviewer will ask you to fill out the questionnaire. Then, the interviewer will ask you to explain what you were thinking as you answered the questions. Then the interviewer will ask you if there were any words that were confusing and if you understood what was being asked.

The interview will last no more than 60 minutes, and we will give you \$40. You will also be asked to fill out a personal information sheet.

You may find that some of the questions we are testing are sensitive. You may choose not to answer any question for any reason. If you do not want to answer a question, say so, and we will move on to the next one. You may also stop the interview at any time.

If you have questions about how the project works, contact Ms. Karen Whitaker by phone at (301) 458-4569, or by mail at NCHS, Room 6330, 3311 Toledo Rd., Hyattsville, MD 20782.

#### **Recordings**

We would like to audio record your interview. The recording allows us to more carefully study and improve the questions. At the bottom of this form, you will be asked if you are willing to have the interview recorded. If you agree, you may still ask to stop the recording at any time, and we will turn off the machine. If you decide to stop recording, we will ask your consent to retain the portion already recorded.

---

<sup>11</sup> English materials provided for reference only. Materials used in the field were Spanish-language materials.

If you agree to record the interview, the recording will be stored electronically on NORCS' and NCHS' secure servers. Only NORC and NCHS staff directly involved in this research project will have access to the recording.

### Privacy

We are required by law<sup>1</sup> to tell you what we will do with the recording. We must also tell you how we will protect your privacy.

Audio recordings will be stored electronically on NORC's and NCHS' secure servers. Only NORC and NCHS staff directly involved in this research project will have access to the recording.

Materials with personal facts (such as names or addresses) are also stored in secured locked cabinets.

Your name or other personal facts that would identify you will not be used when we discuss or write about this study. People working on this project, however, may recognize your voice.

If you have questions about NCHS privacy laws and practices, contact Eve Powell-Griner, Ph.D., Confidentiality Officer at 1-888-642-4159.

### Benefits and Risks

There are no other direct benefits from taking part in this study. Your Medicare benefits will not be affected in any way by your decision whether to participate.

The possible risks of taking part in this study are minimal. We will take all possible steps to protect your privacy. You do not have to give us any information that you do not want to, and you can choose not to answer any question in the interview. You may also stop at any time and still receive the full \$40.

If you have any questions about this study, please call the office of the Ethics Review Board at the National Center for Health Statistics, toll-free at 1-800-223-8118. Please leave a brief message with your name and phone number. Say that you are calling about Protocol #2010-19-XX [Note: The amendment number will be inserted into the form once NCHS ERB approval has been received]. Your call will be returned as soon as possible.

### Please Read and Sign Below if You Agree

I freely choose to take part in this research study.

I allow NORC to audio record my interview.

Yes       No

---

**Respondent Signature**

---

**Print name**

---

**Date**

<sup>1</sup>The Public Health Service Act provides us with the authority to do this research (42 United States Code 242k). All information which would permit identification of any individual, a practice, or an establishment will be held confidential, will be used for statistical purposes only by NCHS staff, contractors, and agents only when required and with necessary controls, and will not be disclosed or released to other persons without the consent of the individual or the establishment in accordance with section 308(d) of the Public Health Service Act (42 USC 242m) and the Confidential Information Protection and Statistical Efficiency Act (PL-107-347).

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Public reporting burden for this collection of information is estimated to average 60 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road, MS D-74, Atlanta, GA 30333, ATTN: PRA (0920-0222).

OMB #0920-0222; Expiration Date: 07/31/2018

## Appendix O: Consent Form—Onsite (Spanish)



RESPONDENT NUMERIC IDENTIFIER: \_\_\_\_\_

DEPARTAMENTO DE SALUD Y SERVICIOS HUMANOS

Servicio de Salud  
Pública  
Centros para el Control y la  
Prevención de  
Enfermedades

Centro Nacional para Estadísticas de Salud  
3311 Toledo Road  
Hyattsville, Maryland 20782

### Formulario de Consentimiento Informado para Entrevistas Individuales

**A usted se le está pidiendo que participe en un estudio. Este formulario de consentimiento explica en qué consiste el estudio y qué se le pedirá a usted que haga. Usted puede decidir si desea participar en el estudio o no. Si usted decide tomar parte, tendrá que firmar este formulario.**

#### Propósito del estudio

En nombre del Centro Nacional de Estadísticas de Salud (NCHS por sus siglas en inglés) y los Centros para Servicios de Medicare y Medicaid (CMS por sus siglas en inglés), NORC en la Universidad de Chicago está llevando a cabo un estudio para mejorar las encuestas federales. Para este estudio, NORC está probando nuevas preguntas que puedan añadir información importante acerca de las disparidades de salud entre pequeños grupos de población. Los temas de las preguntas van desde preguntas sobre el cuidado de salud, a preguntas de información demográfica como su raza y su educación. If you agree to take part in this test, we will ask you to answer the survey questions. Then, we will ask you to explain what you were thinking and how you came up with your answers.

#### Procedimientos

Una entrevistadora le pedirá que llene el cuestionario. Luego, el entrevistador le pedirá que explique lo que estaba pensando al contestar las preguntas. El entrevistador le preguntará si hubo palabras confusas y si entendió lo que le estaban preguntando.

La entrevista no durará más de 60 minutos y le daremos \$40. También se le pedirá que complete una hoja de información personal.

Tal vez algunas de las preguntas que estamos probando a usted le resulten delicadas. Puede decidir no contestar cualquier pregunta que quiera, por cualquier motivo. Si no quiere contestar alguna pregunta, dígalos y pasaremos a la siguiente. Usted también puede parar la entrevista en cualquier momento.

Si tiene cualquier pregunta acerca de cómo funciona el proyecto, puede ponerse en contacto con Karen Whitaker llamando al teléfono (301) 458-4569, o por correo a NCHS, sala 3215, 3311 Toledo Rd., Hyattsville, MD 20782.

#### Grabación

Nos gustaría grabar en audio su entrevista. Grabar nos permite estudiar las preguntas con más atención. Al pie de este formulario, se le preguntará si está dispuesto(a) a que grabemos la entrevista. Si está de acuerdo, usted puede pedir en cualquier momento que interrumamos la grabación, y apagaremos la

máquina. Si decide parar la grabación, le pediremos su consentimiento para quedarnos con la parte que ya grabamos.

Si está de acuerdo en que grabemos la entrevista, la grabación se almacena electrónicamente en los servidores seguros de NORC y NCHS. Sólo los empleados de NORC y NCHS directamente involucrados en este proyecto de investigación tendrán acceso a la grabación.

### **Privacidad**

Tenemos por ley<sup>1</sup> la obligación de decirle qué vamos a hacer con la grabación. También debemos decirle cómo protegeremos su privacidad.

Grabaciones de audio se almacenan electrónicamente en los servidores seguros de NORC y NCHS. Sólo los empleados de NORC y NCHS directamente involucrados en este proyecto de investigación tendrán acceso a la grabación.

Los materiales con los hechos personales (tales como nombres o direcciones ) también se almacenan en armarios cerrados con llave.

No usaremos ni su nombre ni ningún otro dato personal que podría permitir identificarle a usted cuando hablemos o escribamos informes sobre este estudio. Es posible, sin embargo, que alguna de las personas que trabajan en el proyecto lo/la reconozca a usted o a su voz.

Si tiene cualquier pregunta sobre las leyes y prácticas de privacidad de NCHS, por favor póngase en contacto con Eve Powell-Griner, Ph.D., Oficial de Confidencialidad, llamando al 1-888-642-4159.

### **Beneficios y Riesgos**

No hay otros beneficios directos por participar en este estudio. Su decisión de participar o no, no afectará de ninguna manera sus beneficios de Medicare.

Son mínimos los riesgos posibles al participar en este estudio. Tomaremos todos los recaudos posibles para proteger su privacidad. Usted no tiene que darnos ninguna información que prefiera no darnos, y puede decidir no contestar cualquiera de las preguntas en la entrevista. También puede parar la entrevista en cualquier momento e igualmente recibirá los \$40.

Si tiene alguna pregunta sobre este estudio, por favor llame a la oficina del Comité de Revisión Institucional en el Centro Nacional para Estadísticas de la Salud, al teléfono gratis 1-800-223-8118. Por favor deje un mensaje breve con su nombre y su número de teléfono. Diga que está llamando acerca del Protocolo N° 2010-19-53. Se le devolverá la llamada lo antes posible.

### **Por favor lea y firme a continuación si está de acuerdo**

He decidido por propia voluntad participar en este estudio.

Autorizo a NORC a grabar el audio de mi entrevista.

Sí

No

---

**Firma del participante**

---

**Nombre en letra de molde**

---

**Fecha**

<sup>1</sup>El Acta del Servicio de Salud Pública nos otorga la autoridad para hacer este estudio (42, Código de Leyes de los Estados Unidos 242K). Toda información que pueda permitir identificar a algún individuo, práctica o establecimiento se mantendrá confidencial, será usada solo para propósitos estadísticos por el personal de NCHS, sus contratistas y agentes solamente cuando sea requerido y con los controles necesarios, y no será divulgada ni entregada a otras personas sin el consentimiento del individuo o establecimiento como lo establece la sección 308(d) del Acta del Servicio de Salud Pública (42 Código de Leyes de los Estados Unidos 242m) y el Acta de Protección de la Información Confidencial y Eficiencia Estadística (PL-107-347).

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Se calcula que el tiempo que le llevará al público cumplir con este pedido de información es de un promedio de 60 minutos por participante, incluyendo el tiempo que tomará revisar las instrucciones, buscar fuentes de datos preexistentes, juntar y mantener los datos necesarios y completar y revisar el pedido de información. Ninguna agencia puede llevar a cabo o patrocinar un pedido de información a menos que tenga a la vista un número vigente de control de OMB, y a ninguna persona se le puede exigir que responda en ese caso. Envíe sus comentarios con respecto al cálculo de tiempo o de cualquier otro aspecto de este pedido de información, incluyendo sugerencias para reducir el tiempo que toma, a CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road, MS D-74, Atlanta, GA 30333, ATTN: PRA (0920-0222).

OMB #0920-0222; Fecha de Vencimiento: 07/31/2018

## Appendix P: Consent Form—Offsite (Spanish)

RESPONDENT NUMERIC IDENTIFIER: \_\_\_\_\_



DEPARTAMENTO DE SALUD Y SERVICIOS HUMANOS

Servicio de Salud  
Pública  
Centros para el  
Control y la  
Prevención de  
Enfermedades

Centro Nacional para  
Estadísticas de Salud  
3311 Toledo Road  
Hyattsville,  
Maryland 20782

### Formulario de Consentimiento Informado para Entrevistas Individuales

**A usted se le está pidiendo que participe en un estudio. Este formulario de consentimiento explica en qué consiste el estudio y qué se le pedirá a usted que haga. Usted puede decidir si desea participar en el estudio o no. Si usted decide tomar parte, tendrá que firmar este formulario.**

#### Propósito del estudio

En nombre del Centro Nacional de Estadísticas de Salud (NCHS por sus siglas en inglés) y los Centros para Servicios de Medicare y Medicaid (CMS por sus siglas en inglés), NORC en la Universidad de Chicago está llevando a cabo un estudio para mejorar las encuestas federales. Para este estudio, NORC está probando nuevas preguntas que puedan añadir información importante acerca de las disparidades de salud entre pequeños grupos de población. Los temas de las preguntas van desde preguntas sobre el cuidado de salud, a preguntas de información demográfica como su raza y su educación. Si usted está de acuerdo en participar en esta prueba, le pediremos que conteste las preguntas de la encuesta. Luego, le pediremos que explique lo que estaba pensando y cómo decidió responder a las preguntas.

#### Procedimientos

Una entrevistadora le pedirá que llene el cuestionario. Luego, el entrevistador le pedirá que explique lo que estaba pensando al contestar las preguntas. El entrevistador le preguntará si hubo palabras confusas y si entendió lo que le estaban preguntando.

La entrevista no durará más de 60 minutos y le daremos \$40. También se le pedirá que complete una hoja de información personal.

Tal vez algunas de las preguntas que estamos probando a usted le resulten delicadas. Puede decidir no contestar cualquier pregunta que quiera, por cualquier motivo. Si no quiere contestar alguna pregunta, dígalos y pasaremos a la siguiente. Usted también puede parar la entrevista en cualquier momento.

Si tiene cualquier pregunta acerca de cómo funciona el proyecto, puede ponerse en contacto con Karen Whitaker llamando al teléfono (301) 458-4569, o por correo a NCHS, sala 3215, 3311 Toledo Rd., Hyattsville, MD 20782.

#### Grabación

Nos gustaría grabar en audio su entrevista. Grabar nos permite estudiar las preguntas con más atención. Al pie de este formulario, se le preguntará si está dispuesto(a) a que grabemos la entrevista. Si está de acuerdo, usted puede pedir en cualquier momento que interrumamos la grabación, y apagaremos la

máquina. Si decide parar la grabación, le pediremos su consentimiento para quedarnos con la parte que ya grabamos.

Si usted está de acuerdo con que se grabe la entrevista, NCHS lo mantendrá entrevista en un espacio cerrado, ya sea en un gabinete de almacenamiento o en una computadora protegida por contraseña que no está conectada al internet. Cuando sean utilizadas, todas las grabaciones estarán guardadas bajo la responsabilidad del personal del NCHS.

### **Privacidad**

Tenemos por ley<sup>1</sup> la obligación de decirle qué vamos a hacer con la grabación. También debemos decirle cómo protegeremos su privacidad.

Grabaciones de audio se almacenan electrónicamente en los servidores seguros de NCHS. Cuando sean utilizadas, todas las grabaciones estarán guardadas bajo la responsabilidad del personal del NCHS.

Los materiales con los hechos personales (tales como nombres o direcciones) también se almacenan en armarios cerrados con llave. Sólo el personal de NCHS tiene acceso a este material. Los investigadores NORC puede ver el material de la NCHS Centro para el Diseño de Cuestionarios e Investigación de Evaluación para fines estadísticos.

No usaremos ni su nombre ni ningún otro dato personal que podría permitir identificarle a usted cuando hablemos o escribamos informes sobre este estudio. Es posible, sin embargo, que alguna de las personas que trabajan en el proyecto lo/la reconozca a usted o a su voz.

Si tiene cualquier pregunta sobre las leyes y prácticas de privacidad de NCHS, por favor póngase en contacto con Eve Powell-Griner, Ph.D., Oficial de Confidencialidad, llamando al 1-888-642-4159.

### **Beneficios y Riesgos**

No hay otros beneficios directos por participar en este estudio. Su decisión de participar o no, no afectará de ninguna manera sus beneficios de Medicare.

Son mínimos los riesgos posibles al participar en este estudio. Tomaremos todos los recaudos posibles para proteger su privacidad. Usted no tiene que darnos ninguna información que prefiera no darnos, y puede decidir no contestar cualquiera de las preguntas en la entrevista. También puede parar la entrevista en cualquier momento e igualmente recibirá los \$40.

### **Realización de la entrevista en un sitio por mutuo acuerdo**

Para que usted participe en el estudio de hoy, nos pusimos de acuerdo para reunirnos en este sitio. Reunirnos en este sitio ha sido su preferencia. Sin embargo, se le aconseja escoger un lugar privado para que se sienta cómodo(a) contestando las preguntas. NCHS protegerá los materiales que contienen su información personal y los trasladaremos al NCHS.

Si tiene alguna pregunta sobre este estudio, por favor llame a la oficina del Comité de Revisión Institucional en el Centro Nacional para Estadísticas de la Salud, al teléfono gratis 1-800-223-8118. Por favor deje un mensaje breve con su nombre y su número de teléfono. Diga que está llamando acerca del Protocolo N° 2010-19-61. Se le devolverá la llamada lo antes posible.

**Por favor lea y firme a continuación si está de acuerdo**

He decidido por propia voluntad participar en este estudio.

Autorizo a NCHS a grabar el audio de mi entrevista.

Sí     No

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**Firma del participante**

**Nombre en letra de molde**

**Fecha**

<sup>1</sup>El Acta del Servicio de Salud Pública NCHS otorga la autoridad para hacer este estudio (42, Código de Leyes de los Estados Unidos 242K). Toda información que pueda permitir identificar a algún individuo, práctica o establecimiento se mantendrá confidencial, será usada solo para propósitos estadísticos por el personal de NCHS, sus contratistas y agentes solamente cuando sea requerido y con los controles necesarios, y no será divulgada ni entregada a otras personas sin el consentimiento del individuo o establecimiento como lo establece la sección 308(d) del Acta del Servicio de Salud Pública (42 Código de Leyes de los Estados Unidos 242m) y el Acta de Protección de la Información Confidencial y Eficiencia Estadística (PL-107-347).

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Se calcula que el tiempo que le llevará al público cumplir con este pedido de información es de un promedio de 60 minutos por participante, incluyendo el tiempo que tomará revisar las instrucciones, buscar fuentes de datos preexistentes, juntar y mantener los datos necesarios y completar y revisar el pedido de información. Ninguna agencia puede llevar a cabo o patrocinar un pedido de información a menos que tenga a la vista un número vigente de control de OMB, y a ninguna persona se le puede exigir que responda en ese caso. Envíe sus comentarios con respecto al cálculo de tiempo o de cualquier otro aspecto de este pedido de información, incluyendo sugerencias para reducir el tiempo que toma, a CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road, MS D-74, Atlanta, GA 30333, ATTN: PRA (0920-0222).  
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