Cognitive Interview Evaluation of Select Questions for the National Survey of Family Growth

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Introduction

The Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) at the National Center for Health Statistics (NCHS) conducted a cognitive interviewing study to evaluate a variety of survey questions on the National Survey of Family Growth (NSFG) for the Division of Vital Statistics, Reproductive Statistics Branch at NCHS. The NSFG is a nationally representative household survey that gathers in-depth information on pregnancy, infertility, and reproductive health.¹ This study did not evaluate the entire NSFG questionnaire, but instead focused on a select subset of questions and topics. These topics included cohabitation, living on own before age 18, religion, male use of reproductive health services and family planning clinics, cervical cancer screening, sexual activity, and sex education.

Research Questions

Topics and questions were chosen for cognitive evaluation largely on the basis of incongruities or anomalies identified by NSFG staff in the data of previous survey administrations. As such, specific research questions guided retrospective probing in the cognitive interviews.

Cohabitation: Findings from the previous CCQDER cognitive evaluation of the NSFG Life History Calendar (LHC), a visual aid for recording and remembering chronology of certain events provided to female respondents, suggested that confusion existed among respondents over the concept of cohabitation.² Life experiences did not always conform to a straightforward classification as living or not living together. Because field interviewer notes from the NSFG corroborate this finding, respondent interpretations of the concept were explored further in this study.

Living away from home before 18: One question on the NSFG asks respondents whether they ever lived away from home before the age of 18. Survey field interviewer notes contain comments that suggest some confusion exists among respondents about how to answer this question. This may be especially true for respondents who have experienced a variety of (or unusual) living arrangements. This study explored how this question is interpreted by respondents and the nature of any response difficulties.

Religion: One goal for NSFG is to improve reporting of religious affiliation (both growing up and currently) as this has been shown to be problematic. For example, NSFG survey data currently

¹ Information on the NSFG may be found at https://www.cdc.gov/nchs/nsfg/about_nsfg.htm.

² For the full report, see https://wwwn.cdc.gov/qbank/report/Willson_2020_NCHS_NSFG.pdf

have a high number of Protestant responses in the 'other-specify' category. This study explored how respondents understood their own religiosity, how they interpreted the religious categories offered on the showcard, and how they chose a response. Based on these findings, modifications were made to improve the reporting of Protestant religions.

Male Use of Health Services and Family Planning Clinics: NSFG survey data suggests improvements could be made to the series on men's doctor visits in the last 12 months and their use of family planning clinics. For example, males who report seeing a doctor in the past 12 months are routed to a corresponding series of follow-up questions. However, some of those respondents report in the follow-up questions that they have *not* been to a doctor in the past 12 months. Interpretations of these questions and inconsistent answers were explored in the cognitive interviews.

Cervical Cancer Screening: NSFG survey data have shown some discrepancy in women's reporting of the timing of their last Pap and Human Papilloma Virus (HPV) tests. The cognitive interviews explored where the confusion might lie.

Sex Education and Sexual Activity: Because sexual intercourse and age at first sexual intercourse are important covariates for reproductive health outcomes, it is essential that respondents understand the concept 'sexual intercourse' as intended. This study explored respondents' interpretations to determine whether the questions function as intended.

Finally, there was also concern that question wording on sex education topics such as 'how to say no to sex' and 'waiting until marriage to have sex' may be unclear to respondents. These issues were explored in the cognitive interviews.

<u>Methodology</u>

Cognitive interviews were conducted in two parts. First, because the questions evaluated in this study are found in the interviewer-administered portion of the NSFG³, cognitive interviewers first read the questions to respondents and recorded their answers. In the second portion, interviewers followed-up with retrospective probes to ascertain respondent understandings of the questions, rationales for their answers, and whether any response error occurred. Interviews were a maximum of 60 minutes in length and took place virtually using the Zoom Internet meeting platform. The research design was iterative. Round 1 of testing included 17 interviews. Results from Round 1 informed question design modification that were then tested in a second round of 14 interviews.

Sampling and Respondent Demographics: As a qualitative evaluation, cognitive interviewing employs a purposive non-random sample. Rather than aiming for statistical representation, individuals are chosen on the basis of characteristics relevant to the questions under

³ The NSFG also uses computer-assisted personal interviewing (CAPI) for the more sensitive questions on the survey. Those were not included in this evaluation.

investigation while also aiming for a diverse demographic sample. A total of 31 Englishspeaking male and female respondents were interviewed. Some respondents self-identified as cisgender (that is, a person's sex assigned at birth matches their current gender identity) while other respondents reported another gender identity, such as transgender or non-binary. Males and females are asked different questions in the NSFG that are related to physical characteristics such as genitalia (for example, questions on cervical cancer screenings or testicular exams); therefore, self-reports of sex assigned at birth were used to determine which set of questions to administer. Because religiosity, access to family planning clinics, and sex education may vary geographically, respondents from different regions of the country (such as the Northeast, Mid-Atlantic, Southeast, Midwest, Southwest, and the West) were included. Further, a mix of adults both over 30 and under 30 were included, as questions on sex education are asked only of those under age 30. Finally, respondents represent a mix of race, ethnicity, and educational attainment. Table 1 summarizes the sample composition.

	Round 1	Round 2 Number (n = 14)	Total Number (N = 31)
Age			
18 – 29	9	3	12
30 – 39	4	4	8
40 and over	4	7	11
Education			
High School or less	3	7	10
2-year college degree	3	0	3
4-year college degree	8	5	13
Graduate degree	3	2	5
Race/Ethnicity			
Non-Hispanic	16	12	28
White	10	7	17
Black	4	5	9
Native Hawaiian/Pacific Islander	1	0	1
Multiple races	1	0	1
Hispanic	1	2	3
Region			
Mid-Atlantic	3	6	9
Southeast	4	4	8
Northeast	4	1	5
Midwest	1	0	1
Southwest	2	3	5
West	3	0	3
Gender Identity			
Cisgender	10	14	24

Female	4	8	12
Male	6	6	12
Non-cisgender	7	0	7

Analysis: Analysis of interview data included a process similar to the constant comparative method first developed by Glaser and Strauss (1967)⁴ and adapted to cognitive interviews by Miller et al. (2014).⁵ Data analysis was assisted by the use of Q-Notes⁶, a software application specifically designed for cognitive interview studies. Analysis first occurred within each interview. This involved analyzing a respondent's narrative during probing and comparing it to their survey answers to assess consistency, identify response error, and document the respondent's understanding of the questions. The second stage of analysis was a comparison of interpretations by question across interviews to identify larger patterns in the question-response process and forms of response error.

An overview of findings for the main research questions is described next and is followed by a detailed question-by-question analysis.

Overview of Findings for the Central Research Questions

Cohabitation: Two marital status questions were evaluated (see DEMO5 and DEMO6 in the question-by-question analysis). The first asks if respondents were married, cohabiting, or neither and the second question asks for legal marital status. These questions worked well together to the extent that all respondents in this sample answered correctly.

However, retrospective probing illustrated how life experiences did not always conform to a straightforward classification as living or not living together, which may offer insight into anomalies in NSFG survey data. Two examples that arose were arrangements associated with life on a college campus and one instance of a girlfriend temporarily taking in a boyfriend who fell on hard times and was briefly homeless. Respondents included these situations in their answer to DEMO5 although it might not be clear that they should have. On the other hand, DEMO6 – the question about legal marital status – was answered correctly by all respondents. Details of these patterns are offered in the question-by-question analysis.

Living away from home before 18: NSFG interviewer field notes contain comments suggesting that confusion sometimes exists among respondents about how to answer this question. The question contains lengthy instructions about what respondents should include and exclude from their answers (see ONOWN2 in the question-by-question analysis). This makes the

⁴ Glaser, B. and Strauss, A. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Hawthorne, NY: Aldine de Gruyter.

⁵ Miller, K., Willson, S., Chepp, V., & Padilla, J.-L. (2014) *Cognitive Interviewing Methodology: A Sociological Approach for Survey Question Evaluation.* Hoboken, NJ: Wiley.

⁶ Q-Notes: Analysis Software for Question Evaluation (cdc.gov)

administration of the question somewhat cumbersome for the interviewer and poses a higher cognitive burden on respondents who are required to process quite a bit of information before offering an answer. When one or the other of these conditions is not met (either the interviewer does not read the instructions exactly as written or the respondent does not listen to what is being read), confusion can ensue and response error may occur.

In this study, interviewers read the full question and respondents often heard and processed the information. As a result, respondents tended to answer the question correctly. However, a cognitive interview is more engaging of respondents – who are asked to explain the rationale behind their answers – than a survey interview perhaps is. Additionally, cognitive interviewers are careful to read the question exactly as worded – a focus that may not be as stringent among survey field interviewers whose job is not to evaluate the questions but rather to secure a completed interview. These factors may explain the higher rates of confusion among respondents in a survey setting.

Another explanation for respondent confusion is the inherent complexity associated with living arrangements. Some experiences defy simple categorization. Therefore, even when respondents heard and understood the instructions about what to include and exclude from their answers, some still found it difficult to judge whether their experienced counted as 'living away from home before 18.' These experiences are detailed in the question-by-question analysis.

Religion: Because the word 'Protestant' may not be universally understood, new categories of religious affiliation were developed in a bid to make it easier for respondents in Protestant religions to correctly classify themselves instead of relying on the 'other' category. Two iterations of the religious affiliation questions were tested (see the question-by-question analysis). The categories in Round 1 were not well understood by respondents and response error occurred as a result. The categories were modified in Round 2 and performed better – respondents tended to place themselves in the correct categories and all Protestant respondents chose the Protestant category because the examples included on the showcard resonated with respondents.

However, REL4, a new question in Round 2, contained categories that continued to be problematic. The categories are a subset of Christian religions, such as Born Again, Charismatic, Evangelical, and Fundamentalist. In Round 1 they were included along with other Christian options. In Round 2 they became their own question (REL4). In both Rounds they were the cause of much confusion on the part of respondents. These difficulties are discussed in the question-by-question section.

Male Use of Health Services and Family Planning Clinics: NSFG survey data suggests improvements could be made to the series on men's doctor visits in the last 12 months and their use of family planning clinics and reproductive health services. Males who report seeing a doctor in the past 12 months are routed to a corresponding series of follow-up questions.

However, some of those respondents report in the follow-up questions that they have *not* been to a doctor in the past 12 months. The opposite can occur as well – respondents report not seeing a doctor in the past 12 months and then, when asked why they have not, they report that they actually *have* seen a doctor in the past 12 months.

Results from the cognitive testing suggest that one reason for this discrepancy may be tied to inconsistent interpretations of the different questions, and of the first question in particular. The intent of that first question (ID-1) was to capture all types of visits to a doctor in the past year. It served as a filter question for the follow-ups that ask about reproductive healthcare services that may have been received during any of those healthcare visits in the past year.

Despite the variety of categories offered in ID-1 in Round 1 (which were: routine physical exam, physical exam for sports or work, and doctor visit when sick or hurt), respondents were uncertain what types of healthcare visits were intended by this question and false negative reports occurred. It was modified in Round 2 into a broadly worded question with a simple yes/no option in order to encourage respondents to report *all* types of visits to any healthcare provider, but some respondents still excluded certain types of visits, especially those that were routine check-ups or screenings. (Details are documented in the question-by-question section.)

Additionally, respondents often did not see the set of questions on reproductive health services as connected to the visits they reported in the first question, ID-1. In other words, questions in this section begin by asking about any type of healthcare visit and then follow up with questions about reproductive health services associated with any of these visits. Respondents do not always follow this logic and, as a result, did not always answer as intended.

Cervical Cancer Screening: NSFG survey data have shown some discrepancy in women's reporting of the timing of their last Pap and HPV tests. Most women in this sample were able to report the timing of their last cervical cancer screening. Any recall difficulty that arose was attributable either to the COVID-19 pandemic or to a recent pregnancy. The common thread in these two examples suggests that events or experiences that disrupt the schedule of routine visits make accurate recall of the last cervical cancer screening more difficult.

Another finding is that respondents were more familiar with the Pap test than they were the HPV test. This was cause for some confusion when these two tests were included along with the concept of cervical cancer screening in the first question, CERV1. Because respondents were aware of whether they had a Pap test, they often answered the question on that basis alone. However, there was evidence to suggest that some respondents were unaware of or unclear about the link between cervical cancer and Pap and HPV tests – in other words, those tests were not always understood as screenings for cervical cancer. As a result, CERV1 (which included language for cervical cancer screening, Pap tests and HPV tests) was confusing because it appeared double- or triple-barreled to respondents who did not understand the connection between those three topics. Details of this pattern are in the question-by-question section.

Sex Education and Sexual Activity: The question on sexual intercourse tested in Round 1 was generally understood by respondents as a question about penetration. While many respondents thought specifically of vaginal penetration by a penis (the intended meaning), there were some who included other forms of penetration. The question was modified in Round 2 to specify that other forms of penetration (for example, oral and anal) should not be included. This seemed to clarify the definition of sexual intercourse. Among the respondents in Round 2, the intent of the question was more obvious, and all answered as intended.

Finally, the topics for sex education were largely understood as intended. One example where this was not true was for the topic, 'how to say no to sex.' Two fundamentally different interpretive patterns emerged for this question. Some respondents understood it as asking about consensual sex, while others understood it as a question of abstinence or postponement of sexual activity. These patterns and others are discussed in more detail in the question-by-question analysis.

Question-by-Question Analysis

This section presents detailed findings for each question evaluated in the study. Based on the findings from Round 1, some questions were modified for Round 2. In those cases, both versions of the question are shown, along with the findings for each version, including the rationale for question modification and subsequent question performance.

Section 1

[DEMO5.] The next questions are about marriage and cohabitation. Are you now married, living with a partner together as an unmarried couple, or neither?

- 1. Married
- 2. Living with a partner together as an unmarried couple
- 3. Neither

[DEMO6.] What is your current legal marital status? [READ CATEGORIES]

- 1. Married
- 2. Widowed
- 3. Divorced
- 4. Separated
- 5. Never married

<u>Findings</u>: Cohabitation emerged as a confusing concept in the Life History Calendar (LHC) project. Respondents were often unsure what to include as cohabitation because experiences with it are sometimes complicated. All respondents, even those not currently cohabiting, were probed on the meaning of cohabitation.

Several respondents in this study demonstrated the complexity of 'living together.' For example, one respondent said he had lived with his girlfriend for a few weeks in the past

because he experienced temporary homelessness. She let him stay with her for a while until he was able to secure his own arrangements. He answered 'yes.' It is unclear, however, whether this would constitute cohabiting as intended by the question.

Another respondent talked about the notion of living together as a subjective judgment that can change over time. When trying to decide how to answer the question she said:

"I'd say [we lived together] off and on just because of work. So we would live together but it would be like truncated periods because he was traveling a lot. So I don't know if people consider that living together or not. But consistently, everyday...for the last five, six years." *In that phase, what was it like?*⁷ "I could be gone or he could be gone at maybe two- to three-month stretches. Which puts you in a sort of interesting relationship dynamic. Because you're not long distance, but then you are at times." *Who was on the lease? Did you see it as formally living together?* "It was initially my lease. But my lease was ending. So then we went into a lease together, so formally it would be seen as us living together from a leasing perspective. But in the actuality of the day-today, our apartment was more of a storage unit." *Did you think of it as living together?* "At the time we probably would've said living together. Because at first it just seemed like, oh, you're just away on a business trip. Until it started to become pretty regular. So now looking back, did it feel like living together? Not at all."

Another respondent was a college student living on campus with his girlfriend and other roommates. He said, "I was at home and then came on campus. I still have other roommates...There's actually six of us. In our apartment." Another respondent also included college-based living arrangements in his definition of cohabiting. He said, "And then like in college I had an off-campus apartment so my girlfriend, she lived there basically for a year or so [even though she had her own dorm room]." Both respondents did consider this cohabiting; however, college arrangements such as these might not fall within the intended scope of the question.

These examples – combined with similar findings from the previous LHC cognitive interviewing project – illustrate the complex nature of the experience of living together and reveal how response error could occur.

[ONOWN2.] Before you turned 18, did you ever live away from your parents or guardians? Please include times you were away at college or in the Armed Forces. But do not include times you were away at boarding school for elementary, middle, or high school, or living in an institution or jail or group home. Also, please do not include temporary supervised arrangements such as summer camp.

- 1. Yes
- 2. No

⁷ Text in italics denotes questions from the interviewer to the respondent during the cognitive interview.

<u>Findings</u>: Despite its length and cumbersome administration, the definition provided is important to this question. As one respondent said, "I'm trying to think about when I went away to college. I think technically yes because of when I started college [she was 17]. And I'm glad that you gave me the caveat because initially I would've included boarding school [in Nigeria during senior year of high school]."

However, even with the definition, experiences can be complicated and, therefore, difficult to align with the definition. For example, one respondent took the definition into account when thinking about boarding school during high school versus being away at college and answered 'no.' They said, "So that one kind of tripped me up a little bit. Because I went to an early college boarding school. So technically it was a high school program, but I was residing full-time on campus at a university. And I know one of the positive response options -- 'yes, you lived away -- was 'at university'?" The interviewer repeated the instructions. "Yeah. Honestly, thinking back I would have to respond affirmatively. Because it was full-time college enrollment. And it wasn't really a high school. It was more a program to let you skip high school. I earned an AA degree." It remains unclear what the correct response would be.

Another respondent also conveyed a complicated experience and vacillated on how to answer. She said, "I would say...[thinks]. This is a really hard question. Because I'm not 100% sure what qualifies. Under that definition I would say no, I didn't live away from my parents. But I don't know everything that happened when I was a kid. I might have spent a while in Malaysia, but I was supervised by a maid. So, 'no.'" *If it just asked the question with no definition what would you have said?* "Yes. Because there was a very short period...well, I'd say not sure because my recollection isn't that great of my entire childhood...I kind of moved out at 17, but my dad stayed with me for a while...but he would leave for months at a time to go back to Singapore...I might say 'yes' because it's more likely than not that I did spend some time unsupervised. Or alone." Again, it's unclear what constitutes 'living on own' in cases where a minor is left unattended at home by parents or guardians for months at a time, but not permanently and not officially.

This was similar to another respondent's experience. They said:

"When I was 15, I went to live with a friend for like a year and a half. Like I just went and stayed at his house all the time. By that I mean it was like I might go visit my parents once every other week or something. He had a couch in his room and he just let me crash on it for a little over a year." *Were your parents on board with it or were you doing this on your own?* "I told them what I was doing. And they were just kind of like, okay. They weren't really for or against it. I kind of laid it out as I'm going to be staying there...but there was no formal arrangement. We never talked to my friend's parents [to establish the arrangement]." *Were you just hanging out there a lot and then it sort of became full time?* "At first it was, where I was just staying over there most days. And then it got to the point where I wasn't going home but one day a month. All my clothes and stuff I had moved over to his house."

The respondent answered 'yes', which is probably the intended answer, but this experience demonstrates the complex and fluid nature of living arrangements and the potential difficulty of answering this question, even with the guidance provided by the definition.

Finally, though the instructions are important, their length may interfere with respondents' ability to take all factors into account. For example, one respondent did not factor all the caveats into his answer. Response error was the result, as he included summer camp. When he heard the question, he paused and said, "Well, I was away from home, but that was summer camp when I was 16 and 17." *Would you say yes or no for being away from home?* "Well, if summer camp counts, yes. Yes, I was away."

Section 2: Religion

Now I have a few questions about religion. These will include: what religion you were raised in and are now, if any; how often you attend religious services now and when you were younger; and how important religion is in your daily life. I'll ask each question one at a time.

[REL1.] Please look at Card 1. In what religion were you raised, if any?

- 1. Christianity
- 2. Jewish (Judaism) [Go to REL3]
- 3. Islam [Go to REL3]
- 4. Hinduism [Go to REL3]
- 5. Buddhism [Go to REL3]
- 6. Some other religion
- 7. No religion (agnostic, atheist) [Go to REL3]

{Ask only if R answers 1 or 6 to REL1

[REL2.] Please look at Card 2. Which of these were you raised as, if any?

- 1. Catholic
- 2. Mainline or Ecumenical Protestant, such as Episcopalian, Lutheran, Presbyterian, or Methodist
- 3. Mormon or Latter Day Saint
- 4. An Evangelical, Charismatic, Born Again, or Fundamentalist Christian
- 5. Something else, please specify_____

Round 1 Findings:

Definition of 'raised': One difficulty some respondents had with REL1 and REL2 was the definition of 'raised.' Most commonly this was because religious exposure was not always guided by parents or guardians but by other family members, such as grandparents. Respondents often wondered if 'being raised' is meant to be something done exclusively by parents. In other words, some respondents took the meaning of the question to focus more on

whether they were exposed to religion as a child in general, irrespective of how that exposure occurred. Others thought of 'being raised' as under the exclusive purview of parents.

One respondent weighed these different considerations and decided that exposure to religion in general was the intent of the question. She said, "Oh, okay. That's kind of hard [because mother wasn't religious at all]. But I stayed on the weekends at my grandma's place. And then I went to Christian church. So, in home, not raised religious but ended up coming up with Christianity. So, I guess Christianity."

Difficult categories: The categories did not function well for respondents. Confusion on how to answer arose when their specific religion was not shown on the card. For example, this resulted in response error for one respondent who said, "Protestant, but I don't see that on here. So, I guess six, 'some other religion' maybe."

Additionally, respondents often had a surprising lack of knowledge about the religions in which they were raised. This made it difficult to answer both REL1 and REL2. For example, one respondent said, "I just know straight Christianity. I'm not sure if it was fundamentalist. It was very standard." *None of those categories look familiar to you?* "No." *So, you would say number five [something else]?* "So, what is Fundamentalist?" The interviewer said she did not know and re-read all the categories to the respondent. "I guess number four [Fundamentalist]. I'm just shooting in the dark. It's Christian. There was a church." Another respondent chose 'something else' for REL2 and said, "I guess maybe like...it wouldn't have a specific name. It was more of a weird cult-like sect. I mean it was like 20 people who lived all beside each other and did everything together. They did the snake talking and talking in tongue stuff all the time. Very fringe, fringe Christianity. That would be the best way to describe it." *More fringe than, say, category four?* "I would say the talking to snakes makes it that way."

This confusion existed even among respondents who knew their childhood religious denomination but did not realize it was a Christian religion. One respondent said, "It was either Catholic or Christianity, I don't recall. Because I stopped going to church when I was around 14, no I mean like 10 years old or 12." Another respondent said, "Um, I know I should remember, but it was either Christianity or Catholic, one of those."

This type of confusion created difficulties in answering REL1. Another respondent explained, "I attended Catholic school all the way through 8th grade. We attended services throughout the school year but also Saturday or Sunday every week. We celebrated all the holidays." *So why not Christianity in the previous question? Do you see Christianity as a different category?* "I do see them as different categories." *How so?* "Just how the services are run, what the teachings are. A bit different. I also feel that Catholicism even more than Christianity, it's very organized. Whereas, I'm not saying Christianity isn't organized, but it's a little looser." However, respondents who were raised Catholic and answered in error for REL1 (typically they chose 'some other religion') did answer correctly in REL2 by choosing 'Catholic.'

Finally, the last substantive category in REL2 'An Evangelical, Charismatic, Born Again, or Fundamentalist Christian' was confusing. As seen in the previous example, some respondents asked what it meant. It prompted one respondent to choose two answers -- Protestant *and* Evangelical. During probing the interviewer asked if they could pick just one. "Probably Methodist because that was the formal denomination. And to me Evangelical and Fundamentalist are more broad categories more than they are denominations." Your church was a Methodist church that saw themselves as Evangelical? "Very Evangelical. Very Fundamentalist, yes."

As the previous example shows, confusion over this category can detract from choosing Protestant. One respondent said, "I wasn't sure what that category is. I'm pretty sure I was raised Baptist. That's probably number two then. I was just kind of confused." *You weren't sure what the church was*? "Just the categorization. I'm not sure we're Baptist." *But you think you might be*? "Yeah, there's a good chance. I grew up in the South in pretty conservative area. So, there's a strong chance it was Baptist." *Why did you think Fundamentalist at first*? "I'm not sure. I mean, I would just assume that's the baseline of Christianity or the most direct form. Although Baptist more than likely isn't that. I just wasn't sure of the definition of the word."

Because of these difficulties, the two questions were combined and the categories modified for Round 2. The question tested in Round 2 is as follows.

[REL1.] Now I have some questions about religion. Please look at Card 1. In what religion were you raised, if any? [mark all that apply]

- 1. Protestant (for example: Christian-no denomination, Baptist, Methodist, Lutheran, Presbyterian, Pentecostal, Episcopalian, and others)
- 2. Catholic
- 3. Church of Jesus Christ of Latter-day Saints (LDS/Mormon)
- 4. Jewish (Judaism)
- 5. Muslim (Islam)
- 6. Buddhist
- 7. Hindu
- 8. Other religion
- 9. No religion (agnostic, atheist)

[READ IF NECESSARY: This question asks about the religion in which you were raised, which may be different than your current religion.]

<u>Round 2 Findings</u>: The long introduction included in Round 1 seemed unnecessary to respondents' understandings of the religion questions. It was dropped in Round 2 in favor of a simpler version: 'Now I have some questions about religion.' No difficulties arose with the shorter introduction.

Definition of 'raised:' The concept of 'being raised' was still potentially problematic for some respondents. For example, one respondent answered 'Jewish' but said, "This is always so

confusing...raised number four [Jewish]." *Why was this question confusing?* "I know nothing about Judaism. My mom, all she ever did was make a nice dinner for Yom Kippur and Rash Hashanah. That was it. And we did eight gifts during Hanukkah. I don't know anything. She can't teach it to me." To this respondent, being raised in a religion means that one has a working knowledge of the basic tenets. Because she did not, she was reluctant to say she had been raised Jewish. Another respondent expressed a similar dilemma. He said, "I suppose I would be raised Protestant. But it wasn't really pushed on me or anything." When asked why he decided to answer 'Protestant' even though religion was not central to the household, he said, "Because we did decorate for Easter. We celebrated Christmas. I know there were pictures of Saints around the house. We had bibles. But we just didn't really attend a church." Both respondents decided to include the religion they associated with their parents even though the practice of religion was not incorporated into their childhood experience. However, judgments on this are not consistent, to the extent that other respondents with similar dilemmas chose 'no religion.' For example, one respondent chose 'no religion' and explained, "We celebrated Christmas and Easter and stuff. But we didn't really do anything to practice Christianity."

Improved categories: The categories in the revised question were such that it was easier for respondents – particularly those in the Protestant tradition – to choose a correct answer. The examples in the 'Protestant' category functioned well to categorize respondents accurately. This was especially true for respondents who were unfamiliar with the term 'Protestant.' For example, one respondent heard the question and said, "What I was raised? Christian. Which would be [studies showcard]. I guess Protestant." Another respondent also demonstrates that the examples were helpful. She looked at the showcard and said, "Uh...I was raised...Do I see it on here?...Methodist." *Would you have chosen Protestant if no examples followed it?* "Probably not. Because I never, I was never told growing up that we were Protestant. It was always Methodist." Another respondent who was unfamiliar with the word Protestant was also assisted by the examples. When asked if the examples helped her choose the correct category she said, "Yeah. I didn't know that it was called Protestant. Whenever I see a list, I never see the word Christian. I don't know what Protestant means."

As the previous respondent suggests, the new 'Protestant' category also worked well for respondents who simply thought of themselves as Christian. One respondent said, "Well, basically because I just know I'm Christian. There's no specialty to it." Another respondent did not answer with the word 'Protestant' but answered correctly because he saw the examples. He said, "I would just say I was a Christian...Christian, no denomination. It's a typical church."

In sum, modifications made to the categories in Round 2 were an improvement because Protestant respondents could more easily identify a category that resonated with their understandings.

[REL3.] Please look at Card 3. When you were 14, about how often did you usually attend religious services?

- 1. More than once a week
- 2. Once a week
- 3. 2-3 times a month
- 4. Once a month (about 12 times a year)
- 5. 3-11 times a year
- 6. Once or twice a year
- 7. Never

<u>Round 1 Findings</u>: There was no confusion over the meaning of this question. Recall did not seem to pose difficulty and respondents took the age of 14 into account. For example, one respondent who was raised Catholic and went to Catholic school thought specifically about how her church attendance varied over time. Because she had previously noted that she was in church multiple times a week as a child, the interviewer asked why she answered 'once a week' instead of 'more than once a week.' "The reason why I said once a week when I was 14 is because when I was 14 that's the first time I started going to public school. So I did make that distinction in my mind when you asked me the question. Because up until 14 I was in the same Catholic school. So, at that point, when I was 14, we [her family] would only go once a week on Sunday or Saturday." *And prior to 14?* "That would've been more than once a week."

Another respondent also shows how age was taken into account when answering. She said, "I was just thinking, when did I stop attending regularly? And it would've been just after that [age 14], honestly. So, yeah. At 14 I was still attending weekly services." Another respondent answered once a month and explained, "When I was younger, like 10 or so, I would go to church a lot more frequently. I'd go with my mother almost every Sunday. But the problem was, when I was around 14, I didn't really want to go. Not necessarily because of a lack of religion, but I had what I viewed as better things to do." These examples show that respondents were taking the age of 14 into account when answering this question.

<u>Round 2 Findings</u>: The only modification made to the question in Round 2 was to clarify what was meant by 'attend religious services.' This was done by adding an interviewer instruction:

[READ IF NECESSARY: Religious services mean official worship services, but not other nonworship types of meetings or church-related events.]

However, a 'read if necessary' instruction does not address any silent misunderstandings that occur. In Round 2 one respondent answered in error by including all church activities in her answer. The error was only discovered upon probing, where she explained her answer of 'more than once a week:' "My grandmother had us in church all the time. So it seems like I probably...growing up probably at least three times a week. Because there was choir rehearsal, we had prayer meeting -- actually more than that. We had Wednesday night bible study and then Sunday service. So it was definitely more than once a week." This respondent was including a variety of church activities in her answer. Her attendance at an actual service was only once a week. However, because she did not vocalize this during question administration,

the interviewer had no cause to read the additional instruction. As a result, this question may be prone to capture more activities than intended.

[REL4.] Please look at Card 1 again. What religion are you now?

- 1. Christian
- 2. Jewish (Judaism) [Go to REL6]
- 3. Islam [Go to REL6]
- 4. Hindu [Go to REL6]
- 5. Buddhist [Go to REL6]
- 6. Some other religion
- 7. No religion (agnostic, atheist) [GO TO Section 3]

[REL5.] Please look at Card 2 again. Which of these are you now?

- 1. Catholic
- 2. Mainline or Ecumenical Protestant, such as Episcopalian, Lutheran, Presbyterian, or Methodist
- 3. Mormon or Latter Day Saint
- 4. An Evangelical, Charismatic, Born Again, or Fundamentalist Christian
- 5. Something else, please specify_____

Round 1 Findings: Similar to REL1 and REL2 (religion raised), in REL4 and REL5 (current religion) respondents sometimes had difficulties classifying their religion. One respondent demonstrated such confusion. She said, "I consider myself spiritual, so I don't know if I should say 'some other religion' or 'no religion.' I don't know where that falls. But I don't follow a strict religion. So I guess we could go 'no religion' if that's okay. Probably the best bet." This respondent was referring to the Spiritualist Church and did not know how to classify it. Are you any specific religion now? "That would have to be 'something else.'" What would it be? "Kinda Spiritual. I actually go to services here and there at a Spiritualist church. It's hard to define so it puts it into the 'something else' category." Another respondent had similar trouble. He said, "Um, you can call it Ju—I am [pauses] you can call it Christianity. But I subscribe to what—most people would call it Judaism, but I call it Hebrew Israelite. So maybe you would call it number six [some other religion]? But it's a mix between one [Christianity] and two [Jewish]. So I believe in being born again, I believe in Jesus Christ, but I believe in the old Testament as well and that my people are probably from the 12 tribes of Israel. So I don't—I wouldn't call it Jewish or Judaism, but that would be the popular thing to call it. Judaism." If you had to pick one category, which would you choose? "Oh wow. Um, let's just say number six, 'some other religion."

Other respondents also had difficulty choosing a category, but for different reasons, including what it means to belong to a religion, lack of salience of religion in their life, and an internal tension between their beliefs versus behavior. These patterns are discussed next.

Definition of belonging to a religion: Sometimes classification was difficult because claiming a religion was linked to 'officially' joining a church or converting to a religion. One respondent

answered 'no religion' even though he regularly attends a Synagogue. He explained, "I'm going to give you a weird answer, but yeah, I feel like I'm just continuing on [with his parents' lack of religion growing up]. However, you probably jumped ahead [in the survey questions] because I said 'no religion' and there were probably some questions about attendance. And we do attend church services now. [Laughs.] Although COVID means that we're doing things online and not in person. But prior to COVID we were actually going to a Jewish Temple. And have joined a Jewish Temple in our area." *So what religion would you be now? Jewish?* "You know what? We haven't converted. My wife really wanted some spirituality, especially for the children. And they're very inviting and very welcoming. So, I enjoy going to the Jewish service, but I would not answer and say that I'm Jewish. That would not be a true answer. But we've observed holidays and stuff like that." This respondent answered the question based on not having officially converted to Judaism even though the practice in his daily life suggests that he does have a religion.

Religion not salient: Self-classification was sometimes difficult for those whose daily life was not firmly rooted in religion. For example, one respondent said, "I would consider myself maybe a Hindu atheist. Or just an atheist." *Could you pick just one?* "Maybe some other religion. I mean, honestly, I would vacillate [between 'other' and 'no religion']. I don't know which I would pick." She ultimately answered 'some other religion.'

Belief vs. behavior: Other respondents had difficulty because their personal religious identity did not necessarily match their religious behavior. Like the previous respondent, some respondents chose personal identity over behavior when answering this question. For example, one respondent answered Catholic even though she attends a Baptist church – which she attends regularly and to which she gives money. When asked about this discrepancy she said, "Yeah, I'm still Catholic. Some of what we watch online is technically a Baptist pastor, but so much of his theology often aligns with Catholicism -- minus the discussion of the Virgin Mary. But it really doesn't feel much different." The interviewer asked if this affected how she would answer the question. "Right now I think I'll stick with them [Baptists] because it really does feel like a church home." You chose Catholic for your answer. Because you don't think of yourself as Baptist or because you didn't officially join this church? "I mean technically they do have us on their list. And we tithe there and everything. But I still do my Catholic prayers and I still do the sign of the cross, still genuflect when I go into church. I still see myself as Catholic." It's unclear whether the intent of the question is to capture actual behavior or personal religious identity regardless of the extent to which a person practices religion. Either way it is not consistently capturing one or the other.

Finally, salience, belief, identity, and behavior can intersect to make choosing an answer difficult. This is demonstrated by one respondent who had trouble classifying herself. Her only experience in both childhood *and* adulthood has been with her mother's Presbyterian church. She still attends the Presbyterian church with her mother, but not very often and not to the extent that she thinks she should. This experience made it difficult for her to answer 'Protestant - Presbyterian,' despite the fact that 'Presbyterian' was specifically on the showcard

in REL5. Her exchange with the interviewer demonstrates her confusion. When first answering the question (REL4) she never even considered the category 'Presbyterian.' She said, "Oh, I guess number four [Fundamentalist]. I know I'm not Born Again. I know that doesn't apply. Yeah, I think so. Or wait, what's number two? What's the difference? Oh, they don't have Christianity. We're good. Number four. Never mind." During probing the interviewer asked if she chose number four based on the word 'Fundamentalist' (drawing on an earlier discussion with the respondent). "Pretty much. Exactly, yes." Explain what that means to you. "I could be totally wrong, but I am a Christian, so Fundamentalist would be somebody that practices Christianity. I just felt like that was the most fitting for me now compared to the others." So even though the card had number two [Protestant; Presbyterian], you didn't pick that because you're not technically a member of your mom's church? "No, that's really it. I'm not technically a member because I don't go like I should. I even watch church on TV which I probably shouldn't. I need to go in person too. But that's exactly why I picked number four." The respondent's story was so confusing that the interviewer could not firmly establish exactly why this respondent did not choose 'Christian' and then 'Protestant; Presbyterian,' but it is likely due to the tension and discord between the respondent's beliefs and behavior, combined with confusion over the term 'Fundamentalist.'

<u>Round 2 finding</u>: Modifications were made to the 'current religion' questions (REL4 and REL5 above) in relation to findings from Round 1. The new questions follow. Response categories were modified, some of which were incorporated into a new question (REL4 below).

[REL3.] Please look again at Card 1. What religion are you now?

- 1. Protestant (for example: Christian-no denomination, Baptist, Methodist, Lutheran, Presbyterian, Pentecostal, Episcopalian, and others)
- 2. Catholic
- 3. Church of Jesus Christ of Latter-Day Saints (LDS/Mormon)
- 4. Jewish (Judaism)
- 5. Muslim (Islam)
- 6. Buddhist
- 7. Hindu
- 8. Other religion (specify) [GO TO REL3a]
- 9. No religion (agnostic, atheist) [GO TO REL6]

[REL4.] Please look at Card 2. Which of these do you consider yourself to be, if any?

A born again Christian	1
A charismatic	
An evangelical	3
A fundamentalist	
None of the above	

REL3: The modified categories made REL3 easier for respondents to answer in Round 2. Fewer errors occurred. However, as was the case in Round 1, self-classification can still be difficult. For example, one respondent heard the question and said, "I'm still either one or...yeah, I guess I'd still say one [Protestant]." When asked why he hesitated he said, "Where I am now, I've

been sober 15 years, I think. Just before I was sober I was a Born Again Christian which is what started me down the path of being sober. But then I backtracked...I did shed some of what I learned of Christianity because I felt it was restrictive and you're either all or nothing when it comes to understanding other people's beliefs. So right now where I'm at, I guess I would describe it as 'other.' I can't say 'no religion' but I can't label me as Christianity. Because it's not all of it."

REL4: The categories in REL4 were not well understood by many respondents. Most appropriately chose 'none of the above' as a result. One respondent said, "I'm not familiar with some of these terms, so I'm going to go with 'none of the above.'" But getting to that answer was not always intuitive to or easy for respondents. For example, one respondent looked at both Born Again and Charismatic. She answered 'Born Again.' The interviewer asked why she had initially considered Charismatic. She said, "That was because I was trying to figure out what they meant about a Charismatic -- if that was some sort of a middle ground? I had not seen that term before. So I stalled a bit." She ultimately decided it was not relevant to her. Another respondent looked at the categories and said, "Um...Okay, what are all of these?" The interviewer said she did not have knowledge of all the categories. When the respondent was still unable to supply an answer, the interviewer pointed out the 'none of the above.'" It was the case that several respondents who were unfamiliar with the options did not immediately gravitate to 'none of the above.' The next respondent may offer a reason why.

Finally, one respondent completely misunderstood the categories and answered in error. He said, "I would probably say a Fundamentalist because I'm ready to fight anything....Like Huey Newton and those guys were considered Fundamentalists because they didn't like the establishment. They fought it. So they were always called Fundamentalists. I think about me. If I feel something is wrong, I'm going to say something. I'm going to voice my opinion, I'm going to fight hard about it. Regardless of the consequences. Like if I get fired or if I get in trouble or if they say we're going to throw you in jail if you don't shut the hell up. I'm like, alright, whatever. I need a vacation." Because the categories were so misunderstood, this respondent did not link the intent of this question to religion. This may be the case for other respondents as well – the question is not understood as a subset of Christian categories.

[REL6.] Currently, how important is religion in your daily life? Would you say it is very important, somewhat important, or not important?

- 1. Very important
- 2. Somewhat important
- 3. Not important

<u>Round 1 Findings</u>: The only respondents who had difficulty with this question were those who believed they fell somewhere between 'somewhat' and 'not' important. One respondent said, "Yeah, between 'somewhat important' and 'not important.'" When asked why they went with 'not important' after being pressed by the interviewer to pick one response, they explained,

"You won't see me waking up and praying before my meal and then praying before I go to bed. And saying Hail Mary's or having a rosary. I don't go to church every week. But religion has done a lot to teach me the basics of understanding what is right and what is wrong." Ultimately the judgment for their response was based on the extent to which they follow prescribed religious ritual in their daily life. Another respondent simply couldn't pick one answer when requested by the interviewer. They said, "I guess it depends on how much of my morality I credit to religion or how much I credit to what I think. So, I would say not really. But it feels wrong to say 'not important' because, so, if I was actually on a piece of paper, again, I would vacillate and end up on either somewhat or not important. I'm sorry if I'm being too fickle."

It seems some respondents will have trouble choosing a single option regardless of which vague quantifiers are offered by the question because they see a difference between the importance of abiding by prescriptive religious behavior verses morality associated with religion in general. It is not clear which dimension the question is asking about.

<u>Round 2 Findings</u>: Because of the judgment difficulties found in Round 1, a 'read if necessary' instruction was added to the question for Round 2. It read:

[READ IF NECESSARY: Religion refers to personal religious beliefs, not necessarily to a specific organized religion.]

This instruction helped clarify the judgment process for at least one respondent in Round 2. When he first heard the question, he was not sure how to answer because he (like others in the first round) was weighing the difference between practice and belief. He said, "I would say the aspect of going to church and being present in the actual community itself is not as important as it used to be. But the system of beliefs is still really important to me. So, I don't know – 'somewhat important' collectively." The interviewer picks up on the struggle, reads the clarifying instruction, and asks if that would change his answer. He said, "If it can be a construct that I created based on my beliefs, then I'd say it's really important. Because the word 'religious' now applies to things that I formulate." This example illustrates how the 'read if necessary' can change a respondent's judgment process.

However, when it is not immediately clear to the interviewer that judgment difficulties are occurring, the 'read if necessary' is not presented to the respondent. For example, during probing it became clear that there was some confusion on the part of one respondent. She said, "Yeah that was one question I wasn't quite sure how to answer because, while I don't practice religion, and it's not like—I'm not religious, it's still a part of my life because I was raised on it for so long. And I still have some of those like, some of that [makes a circular motion with hand] ideology...just the feelings that I have from it are still very much a huge part of my life...so it's kind of important, but not like, in the way I felt the question was asking." When asked what she thought the question was asking she said, "I felt it was asking, 'do you practice religion?'" The fact that respondents will not consistently receive the 'read if

necessary' instruction means that interpretations of what to consider and how to answer will vary.

[REL7.] Please look at Card 3 again. About how often do you attend religious services?

- 1. More than once a week
- 2. Once a week
- 3. 2-3 times a month
- 4. Once a month (about 12 times a year)
- 5. 3-11 times a year
- 6. Once or twice a year
- 7. Never

<u>Findings</u>: This question did not change between rounds. Respondents had no difficulty with recall, but two other issues arose.

Virtual attendance: A couple respondents questioned whether the intent of the question was to also capture virtual church attendance. However, because they saw virtual attendance as bona fide attendance, they did include that in their answers. One respondent asked, "So when you say 'attend' is that in person or virtual?" *What would you say*? "I'll include it because we make a point of watching service every week." Another respondent also included virtual attendance. She answered 'once a week' but said, "I normally stream it, though, just because the churches are still all over the place with COVID."

All church activities: In addition to including virtual attendance, one respondent included all kinds of church activity, not just religious service. She answered 'more than once a week' and said, "I was going to say once a week because I was thinking Sunday service. But with the pandemic and we've switched to virtual, now we have all of these different Zooms and different things that our Pastor's now doing. And so it's more than Sunday service. So I hop online and I might listen to -- he'll do, during the week, he'll have prayer or he may do a series of different things. Motivational week or something like that. Because I was going to say, as an adult, now that I'm married with children, it was just Sunday service for me because I didn't have time to do anything else. But now that it's virtual, I can tap into other things that are out there."

Section 3: Male Use of Health Services

VISIT12MO

[ID-1.] The next questions are about health care services you may have received. Please look at Card 4. In the past 12 months, that is, since [THIS MONTH LAST YEAR], did you have any of these types of visits to a doctor or health care provider? [ALL THAT APPLY]

- 1. A routine physical exam
- 2. A physical exam for sports or work
- 3. A doctor visit when you were sick or hurt
- 4. Did not have any visits to a doctor [Go to ID-9]

<u>Round 1 Findings</u>: The intent of this question is unclear, which is a primary motivator for response error in this and later questions on reproductive health for males. Respondents were unsure what the question was ultimately looking for, so they often did not include visits they may have had. For example, one respondent had multiple visits to a doctor that they did not see as fitting into the options provided. They asked, "Does a urine test count?" *You tell me.* "I wouldn't say it was a physical exam [so, no]." Another respondent was uncertain how to classify their medical visit. This person did not have a primary care physician (PCP) and only used urgent care or emergency rooms (ERs) when ill. She⁸ said, "I went to the ER last year." *So which choice would you make here?* "I think number three [doctor visit when sick or hurt] might apply." *What is your hesitation?* "I don't know if it applies is all." *So, I guess you were thinking...?* "I just don't have a primary care physician." The term 'doctor visit' implied a visit to ERs or Urgent Care – places where a person does not see the same doctor on a regular basis.

Another outcome of the unclear nature of this question was respondents being unsure how to classify or include certain types of visits. Mental health visits came up as an example. One respondent said, "And mental—psychological evaluations, I've added that to my list and being included in a clean bill of health. So, I don't see that question up there [indicating the card] because I wasn't sick or hurt, but I did have – and it wasn't routine – but I did decide to do it because I felt like I needed that. So, I guess you could add it on number three [a doctor visit when you were sick or hurt] for the psychological side."

Care for chronic conditions also came up as unclear. One respondent answered, "Number one - a routine exam." *That was it, then?* "I've had several doctor visits relating to being sick or hurt. I guess these are my only options. I wouldn't say I'm sick, but I do some follow-ups based on some blood work." *So, number three too?* "I guess one and three. I wouldn't describe myself as sick, but I necessitated a few follow-up visits with a few different kinds of doctors. And I do regularly see an endocrinologist. Chronic condition maintenance isn't on here."

These patterns may point to why some respondents report seeing a physician in one question and then report NOT seeing a physician in another – it depends on how they interpret the intent of each question. The question was modified in Round 2 to address some of this difficulty.

<u>Round 2 Findings</u>: In order to capture *all* types of medical visits, the question was modified in Round 2 to the following.

[ID-1.] In the past 12 months, that is, since [THIS MONTH LAST YEAR], did you have any visits to a doctor or health care provider? [SELECT 'Yes' even if visit was telehealth by phone or video]

1. Yes

⁸ The respondent was assigned male at birth and was read the male questions, but preferred pronouns were she/her.

2. No

The revised question did capture a variety of healthcare visits such as dentists, COVID-19 testing/vaccinations, and routine check-ups for some respondents. For example, one respondent answered 'yes' because, "That would've been a dentist. I've been for a COVID test. I've had the vaccine. That's probably it for the last year."

However, some visits were still missed. A main cause was a misunderstanding by some respondents that the intent of the question was to capture visits prompted by illness, not necessarily screenings, vaccinations, or check-ups. For example, one respondent answered 'no' to this question but 'yes' to visiting a Planned Parenthood clinic in another question. When asked about this discrepancy he said, "I was going to get tested [for STDs] at Planned Parenthood." To him, this question (ID-1) was not asking about screenings.

Another respondent also answered 'no' in error, initially excluding the dentist and optometrist. When asked why, he explained his original rationale as hearing this as a general health question. However, upon reflection, he changed his understanding. He said, "For the dentist I realized I hadn't been in like six years, so I knew I had to go. And for the eye doctor I needed glasses." *Why did you answer 'no?*' "Because it led off with 'doctor.' I think there's a very specific way if you're a doctor, which is more in general health, which is a doctor's office or a hospital. [Thinks.] But then you said 'healthcare provider' so I realize I did go see a dentist and eye doctor." *Would you keep your answer as 'no?*' [Question is repeated.] "Well, I guess I would say 'yes.' Because I think the question might pertain to accessibility of health services. Because that I went there, it shows that I have access." While it may be the case that this revised question captures more experiences, the intent is still unclear to some respondents, which can prompt false negative responses.

SVC12MO

[ID-2.] Please look at Card 5. Did you receive any of the services shown on this card at those visits in the past 12 months?

- 1. A testicular exam (had your testicles examined)
- 2. Testing for sexually transmitted disease
- 3. Treatment for sexually transmitted disease
- 4. Information or advice about your partner using female methods of birth control
- 5. Information or advice about you getting a vasectomy (surgically sterilized)
- 6. Information or advice about HIV or AIDS
- 7. Information or advice about other sexually transmitted diseases, such as gonorrhea, chlamydia, syphilis, herpes or AIDS
- 8. Information or advice about using condoms to prevent pregnancy
- 9. Information or advice about using condoms to prevent STDs
- 10. None of the above [Go to ID-8b]

<u>Findings</u>: No changes were made to this question between rounds. Although it took some time for respondents to look over all the categories, most had no trouble indicating the services they

had received, if any. Only one category was potentially problematic: testicular exam. A couple of respondents were not sure whether what they received counted as an exam. One respondent said, "I would like to ask a question. When you say, 'testicles examined.' Looked at? Or felt?" *Whatever you think.* "All right. Number one [testicular exam]." During probing the interviewer asked the respondent to explain their confusion. "I've only had the one where -- if you'll pardon the image in your mind -- they reach down and basically just do a quick squeeze. They just make sure there's no tumors. And when someone says have you had an exam, I think to myself is that like, do they pull it down and look? Or...I only know my one way, so I'm going to assume that counts."

It is also possible for respondents to lose the connection between this question and the previous one. For example, one respondent asked for clarification. "So, when I visited the doctor, did I receive any information on any of this [on card five]? Is that the question?" *Yes, anything that's here.* "No."

Finally, some categories appropriate to transgender women could be added to this list. (Respondents who were assigned male at birth but who answered something different from that in the gender question received the male questions here if they had male genitalia.) One respondent remarked, "I would consider my hormone therapy a kind of reproductive healthcare just because it impacts that area of my life." The respondent explained that they are "chemically castrated" and have been receiving this care through hormone therapy implants.

NUMVISIT

[ID-3.] How many visits did you have in the last 12 months in order to receive these services from a doctor or other health care provider? _____number of visits

<u>Findings</u>: Recall is a possible problem with this question. One respondent answered "one time", but remarked, "But I would double check my medical history before I answered that question."

Similar to the previous question, another problem relates to respondents not realizing there is a line of questioning in these items and, therefore, not seeing the connection between ID-1, ID-2, and this question (which did not change between rounds). This creates confusion about which question this one refers to (ID-1 or ID-2). For example, one respondent asked, "Like literally only these things [in ID-2] or how many times did I go to the doctor [in general]?" The intent of ID-1 implies either visits to doctors or use of health care in general is the construct, while ID-2 implies that only the use of reproductive health services is the topic of interest. Confusion over whether this question (ID-3) is asking about any healthcare received or about reproductive services in particular was demonstrated by another respondent who needed clarification. He asked, "So for that service, or that [STD] testing? It was just part of the annual physical."

PLACEVIS

[ID-4.] Please look at Card 6. What place or places did you go for these service(s)? [all that apply]

- 1. Private doctor's office or HMO
- 2. Community health clinic, community clinic, public health clinic
- 3. Family planning or Planned Parenthood clinic
- 4. Employer or company clinic
- 5. School or school-based clinic
- 6. Hospital outpatient clinic
- 7. Hospital emergency room
- 8. Hospital regular room
- 9. Urgent care center, urgi-care, or walk-in facility
- 10. Sexually transmitted disease (STD) clinic
- 11. In-store health clinic (like CVS, Target, or Walmart)
- 12. Some other place

<u>Findings</u>: Similar to the previous question, respondents tended to lose the thread of meaning in this line of questioning, (e.g., is the intent to ask about the extent to which one visits a medical professional? Or is it about one's use of reproductive services in particular?). One respondent specifically asked for clarification: "So this is just in relation to what was asked in the previous question?" Another respondent was also confused and said, "I've been to the urgent care recently, but it wasn't for that [reproductive health]. I just had a concussion." They also included their PCP (category one) in their answer for a visit for a sinus infection. During probing they said, "Oh, yeah. I didn't actually receive any sexual health services from them [PCP]." When the respondent answered this question, they were thinking primarily about what kind of place they went to – not the reason for the visit. In essence, the categories ended up defining the meaning of the question.

Second, some of the categories were not clear. For example, one respondent asked, "What's the difference between an outpatient clinic and a regular room?" *What do you think the difference is?* "An outpatient clinic is a clinic, and a room is like a room. I'm assuming the room, you stay in the room, you sleep in the room whereas the outpatient clinic like you don't sleep in the room." Based on that, the respondent chose 'outpatient hospital clinic.' Another respondent asked, "A public health clinic is just your local hospital. Am I thinking that right?" *I don't know. Describe your place.* "I went to [local hospital system]. I'm not sure...give me sec." The respondent looked up his medical records and was shown the categories again. "I think it would be a public health clinic." (It was Kaiser.) But it was also his pediatrician which he's had since childhood (he is currently 20 years old).

SVCPAY

[ID-5.] Please look at Card 7. In which of the ways shown on this card was the bill for these visits paid? [all that apply]

- 1. Insurance
- 2. Co-payment
- 3. Out-of-pocket payment
- 4. Medicaid

- 5. No payment required
- 6. Some other way

<u>Findings</u>: There was no confusion over this question and respondents were generally able to answer, so no changes were made between rounds. However, the experience of one 18-year-old respondent suggests that younger respondents who are still on parental insurance may not have complete answers to this question. One respondent answered 'insurance.' When asked about co-pays or out-of-pocket payments during probing, they admitted, "I'm still under my family's plan. I have no idea of the finances."

Additionally, the response options lacked an important category: bill not paid. One respondent with no income and no insurance couldn't answer and said, "The bill wasn't paid. I have outstanding medical debt." This question may not function well for respondents who lack health insurance.

TALKSA

[ID-6.] During your visit(s) in the past 12 months did a doctor or health care provider ask you if you were sexually active?

- 1. Yes
- 2. No
- 3. If vol: Provider already knew R's status

<u>Findings</u>: The only problem with this question (which did not change between rounds) centers on the last category, 'provider already knew,' which is not proffered to the respondent. Interviewers marked that category only if volunteered by the respondent. Several respondents for whom this category was appropriate answered 'no' because they did not realize they could say that their provider knew their status. For example, one respondent who answered 'no' explained during probing. "They would've known, I guess. Actually, you know what? I'd had this doctor for years and years. And I'm pretty sure he asked at first but he's just kind of stopped asking because the answer has always been the same...And I was coming in for STD testing, so obviously he would've known." It might be better to simply read all the categories to respondents.

One respondent was not sure how to answer. The conversation took place, but it was initiated more by the respondent than the doctor. They said, "Ahh [pauses] maybe? I mean, I've volunteered the information too. Like 'oh this happened' and they're [the doctor] like 'well, you probably should get tested." Because the respondent told the doctor, this was seen as the doctor 'already knowing R's status,' so that was the category chosen by the interviewer.

TALKEC

[ID-7.] During your visit in the past 12 months, did a doctor or health care provider talk with you about emergency contraception?

- 1. Yes
- 2. No

<u>Findings</u>: This question did not change between rounds, but 'emergency contraception' might invoke various interpretations and be thought about more broadly than intended. For example, one respondent said, "I remember he mentioned birth control. But not going into detail about it. And that's why when the birth control questions came up. They're a little cloudy." What did he say? "He told me what methods were available but not necessarily where to find them, the pricing. I kind of had to learn that on my own." This respondent was thinking about birth control in general, not emergency contraception in particular. However, another respondent did have a good idea what this was. When asked about it he said, "I would assume it would be Plan B or something similar." Unfortunately, most respondents followed skip patterns out of this question, so extensive testing could not be done.

TALKDM

[ID-8.] During your visit in the past 12 months, did a doctor or health care provider talk with you about using a condom at the same time as a female method of contraception?

- 1. Yes
- 2. No

<u>Findings</u>: Like the previous question, most respondents followed the skips past this question so it could not be adequately evaluated and did not change between rounds. However, it may be problematic for transgender women. For example, one respondent said, "I find that question a little confusing. Are you saying they were suggesting I use both? Or they were suggesting I use the male one and the person would use the female one? The only thing that was mentioned to me [by the doctor] was using a condom. I don't have sex with women. And I think that's kind of obvious to my doctor."

WHYPSTD

[ID-8a.] Please look at Card 8. In the past 12 months you received a test for a sexually transmitted disease from [the place they gave in ID-4]. What is the <u>main</u> reason that you chose this place for care?

- 1. Could walk in or get same-day appointment
- 2. Cost
- 3. Privacy concern
- 4. Expert care here
- 5. Embarrassed to go to usual provider
- 6. Other

<u>Findings</u>: This question did not change between rounds in order to collect more data. Asking respondents why they have engaged in a particular behavior is often fraught with problems. It can be difficult for respondents to provide an answer that fits neatly into survey categories, rendering them neither mutually exclusive nor exhaustive. For example, one respondent did not see his answer and said, "Other -- just my usual provider." Another respondent thought of several reasons and said, "Um, cost. And, well, I guess expert care too." *What was the main reason?* "Okay, then, yeah, we'll go with number four [expert care]." Another respondent did

not reference the categories at all and simply answered in their own way. They said, "I use one medical [establishment] which is a concierge medical service and I can go online and ask if I can come in and get STD tested. And they were like, yeah, you can come in whenever you want. So, it's super easy and free." Since there was no obvious match in the categories, the interviewer marked 'other.'

This example highlights that when respondents answer in their own words, the burden is on the interviewer to interpret what the respondent said and map it onto the provided categories. This can introduce another source of error as interviewers impart their own judgments. For example, one respondent did not know how to answer. He said, "I don't know if this is an option, but it was just my doctor. My pediatrician since I was a kid. I trust him." *So...'other?'* "Oh, yeah. I would say number six, 'other.'" Another interviewer might have chosen number four (expert care) to which the respondent might have also said yes. The difficulty in arriving at a reason may, in fact, increase the number of responses in the 'other' category overall.

WHYNOSTD

[ID-8b.] In the past 12 months you <u>did not</u> receive a test for a sexually transmitted disease. Please look at Card 9. Which one of these reasons would you say is the <u>MAIN</u> reason why you have not been tested for a sexually transmitted disease?

- 1. Didn't want parents to find out
- 2. Concerned about confidentiality
- 3. Doctor or health care provider never suggested it
- 4. Embarrassed or difficult to ask to be tested
- 5. Cost or lack of insurance
- 6. Other

<u>Findings</u>: If asking respondents reasons for behaviors is difficult in survey questions, asking for reasons why respondents have NOT done something is even more so. One respondent illustrates this difficulty. He looked at the hand card and said, "I mean, I would say it's a combination of number three [doctor never suggested] and number six [other] because I'm in a monogamous married relationship. But the doctor never suggested it. Probably because I have no symptoms and no reason to suggest [an STD is present]...Previously I've had a vasectomy too." *Can you pick one?* "I guess I would say 'other.' 'Other' meaning 'in a monogamous relationship.' But the doctor never mentioned it to me either. There might need to be another option, 'long-term committed relationship' or something like that." Ultimately, the respondent could not settle on a main reason. This left the interviewer with the task of deciding which option to mark (she chose 'other').

Additionally, the categories are not exhaustive. Some respondents were not sexually active in the past 12 months and had to choose 'other.' For example, one respondent explained, "I just don't have a reason to because I've not had sex. So, I have no reason. None of my parents have STDs that I might be spreading or whatever. I think it's interesting that the option isn't here. They make it sound like it's mandatory to get an STD test. But the STD is an optional test."

Another respondent said, "Just unnecessary. I'm not sexually active. I mean, I am now but I wasn't in that time period." Similarly, another respondent answered 'other' because, "I wasn't having sex." However, while 'other' might be the best option, it is misleading because the question assumes sexual activity in the past 12 months.

Finally, some error occurred here as respondents did not fully understand the intent of all the questions asked. Some respondents got to this question and reevaluated the meaning the second question, ID-2. For example, one respondent said, "Uh, [category] three. [Pause.] I do donate blood regularly and they do test it for HIV and other things, so, although I'm straight, but they still test for HIV and other stuff." He answered in error in question ID-2 because he understood that question as asking about healthcare services that he initiated, not those that were undertaken for other reasons. Another respondent demonstrated a similar error pattern. He heard this question and said, "Well, okay. Actually, I had a physical and they did run just like as part of the standard blood work and stuff, um, some STD checks. So I guess I didn't consider [that when he answered 'none' to ID-2]." The interviewer showed him the card again from ID-2. He said, "I guess what I heard you say was did I go for any of those reasons [on the card]." After hearing ID-2 again, the respondent changed his answer and explained, "Okay, so yeah. I misunderstood that because just as part of a physical, number two [STD check] would be covered. So I should've said 'yes' there." The error generated here is linked to a misunderstanding of question intent and a failure to see a connection between the questions.

BARRIER

[ID-9.] You reported that you did not go to a doctor in the past 12 months. Please look at Card 10. Which of the reasons shown on this card explain why you did not see a doctor? [all that apply]

- 1. I did not need to see a doctor in the last year
- 2. I did not know where to go for care
- 3. I could not afford to pay for a visit
- 4. I was afraid to hear bad news
- 5. I had privacy/confidentiality concerns
- 6. I could not take time off from work
- 7. Something else (specify)

<u>Findings</u>: Most respondents followed skips past this question, so it could not be thoroughly evaluated and did not change between rounds. However, one respondent chose 'something else' because this was the year of COVID-19. They said, "So I'm a cancer survivor and, uh, I was concerned that going to a doctor might expose me to COVID. Because that's pretty much where sick people go." It is reasonable to expect that other respondents might cite the pandemic (especially during the years 2020 and 2021) as their reason for avoiding medical establishments.

Section 4: Male Use of Family Planning Clinics

YOUGOFPC

[IB-1.] Now please look at Card 11, which shows some family planning and health services. Have you, yourself, ever received services such as these from a family planning clinic or Planned Parenthood clinic?

- 1. Yes
- 2. No

Round 1 Findings: This question is problematic to the extent that respondents were unclear about the intent, which is framed differently by the card versus the question. The card focuses on reproductive health services but the terms in the question suggest a slightly different intent. Specifically, the term 'family planning clinic' introduced confusion. (Most respondents heard of Planned Parenthood and were at least vaguely aware of their services.) The word 'clinic' in the term 'family planning clinic' invoked notions of health care provided to underserved populations. By mixing the two terms, it was unclear whether the question was asking about birth control and fertility or about use of free or reduced-cost clinics. For example, one respondent said, "Well, what exactly is a family planning clinic?" The interviewer said she did not know. "I've never been to Planned Parenthood and I've never been to anything that's specifically for family planning. So I'm going to say 'no.'" Another respondent also asked, "Like a clinic that's specifically for family planning? Or for that kind of stuff?" If that's how you interpret it. "That how I interpret it. But I'd be a little confused at first because family planning sounds a little too close to family physician." But ultimately you think ...? "Fertility clinic. But some of the clinics I went to when I was young were publicly funded women's clinics. I don't know if those are...So I'd teeter on the edge of 'yes' or 'no' again." You went to one in the past? "Yes. For HIV testing. For testing sexually transmitted diseases." How long ago? "This would've been four years ago maybe. No -- it was as proximate as 2020 because I was on Medicaid for a while." And these were publicly funded women's clinics? "Yeah. They're made specifically for women and transgender people." So would you say 'yes?' "Well, that's the thing. I wouldn't know if that would count as a family planning clinic." Ultimately the respondent answered 'no' and said, "I would have to know why are they asking this question. Are they trying to figure out if people are using family planning clinics or publicly funded clinics? Maybe I should answer 'yes' because they'll get more funding." Another respondent also focused on the 'clinic' aspect and said, "I've received some [services] from a community clinic for low-income people for these issues, so I think it would be the same thing [as what the question is asking]. Because I've got HIV testing, for sexually transmitted diseases, strategies to prevent HIV. I go to a free clinic." It was unclear whether this clinic was specifically a family planning clinic.

Additionally, the categories on the card can shift the meaning of the question away from where these services were obtained. For example, one respondent answered 'yes' according to the services received, irrespective of where. He said, "I don't remember exactly. I think it was a general hospital. I may have just walked into an emergency room"

<u>Round 2 Findings</u>: To address some of the confusion in Round 1, the question was changed to deemphasize the type of service received and focus more on the place of service. In Round 2 the question was as follows.

[IB-1.] Have you ever received services for yourself from a family planning clinic or Planned Parenthood clinic?

- 1. Yes
- 2. No

This question seemed to cause less confusion for respondents. Most focused on the type of place (instead of the type of service) and generally thought about Planned Parenthood as defining the intent of the question. When asked their understanding of the type of place this question was asking about, most had reasonably accurate descriptions. One respondent said, "I was thinking about an abortion clinic or a clinic that gives advice to people considering it." Another respondent said, "I've never been to one of those, so I don't really know what it's like there...I know they do abortions. I know they do a bunch of educational stuff. And I'm not sure, maybe they do birth control stuff. I haven't really received any education about what they do." One other respondent said, "If you say Planned Parenthood then I'm thinking a Planned Parenthood clinic which is a variety of health services, a lot of them focused on reproductive health and women's health. But I know planned parenthood has services for men too."

While all gave accurate answers, two respondents did express the idea that the question seemed inapplicable to men. One respondent answered, "Maybe. I hadn't really thought about it. As a male, the primary birth control would've been condoms, which you can just buy at the drug store. So it's not having to go get something prescribed for me. Or monitored while I'm taking it. So it's a privilege. It's a lot easier in that regard." Another respondent expressed more confusion over being asked about something he thought was under the exclusive purview of women. He said, "Well I just didn't know if you were—see...Planned Parenthood I always associate with the providing of, you know, early abortions and so forth, plus other counseling about sexually—about sexual behavior or whatever. And family planning clinics I always just picture them like, you know, just distributing condoms or stuff like that, you know? I mean, just-just, I mean, [struggling to find words] see, to me, those kind of questions, because it's the woman who bears the responsibility of carrying a child and so forth, it's much more—much more invested in getting particular answers in places like that, so."

WHENGOFP

[IB-2.] When was the last time you received services from a family planning clinic or Planned Parenthood clinic? Was it within the last 12 months, that is, since [THIS MONTH LAST YEAR], or more than 12 months ago?

- 1. Within the last 12 months
- 2. More than 12 months ago

<u>Findings</u>: Most respondents followed the skip pattern out of this question, so it could not be adequately evaluated and did not change between rounds. Respondents had no difficulty with timeframe recall, although one respondent may have demonstrated telescoping recall by including experiences outside of the 12-month timeframe. He said, "Ooh, that's close. I guess

for the sake of this I would say 'within the last 12 months.'" He acknowledged that his visit may have been up to 14 (not 12) months ago, but thought that, for the purposes of this survey, it would be better to report his visit than not.

YOUFPSVC

[IB-3.] Please look again at Card 11. Which of these services did <u>you</u> receive at that visit? [all that apply]

- 1. Physical exam
- 2. HIV testing
- 3. Testing for sexually transmitted diseases other than HIV
- 4. Treatment for sexually transmitted diseases other than HIV
- 5. Information or advice on strategies to prevent pregnancy, for example, birth control methods
- 6. Information or advice on strategies to prevent STDs or HIV, for example, using condoms or reducing your number of partners
- 7. Some other service

<u>Findings</u>: Most respondents followed skips past this question, so it could not be evaluated and did not change between rounds. The few respondents on whom the question was tested did not demonstrate any error.

Section 5: Cervical Cancer Screening

CERVICEV_A

[CERV1.] There are two different kinds of tests to check for cervical cancer. One is a Pap smear or Pap test and the other is the HPV or Human Papillomavirus test. Have you ever had a test to check for cervical cancer?

[Read if necessary: These are routine tests for women in which a doctor or other health professional takes a sample from the cervix with a swab or brush and sends it to the lab.]

- 1. Yes
- 2. No

<u>Findings</u>: Respondents were able to answer this question (which remained the same between rounds) without any apparent response error; however, the question may be more complicated than it needs to be by incorporating multiple topics. Respondents did not always understand the difference between the two tests or their connection to cervical cancer. The following are examples of respondents' varying levels of knowledge.

I don't know when you have a Pap smear if it automatically screens you for cervical cancer. And if it doesn't, maybe that's a screening that is an additional sector of wellness exams. I don't know.

In my opinion, I think they [Pap and HPV tests] are the same because what they do [it with] the swab, they get the swab to test for the virus. I think they are the same...In my understanding, but I am not very sure.

The Pap smear is, to me, like an annual commitment to yourself, as far as your wellness. So I don't know what is under that Pap smear umbrella. Because the way you're asking me, you're like, hey, you got a Pap smear, did you have a cervical [cancer] screening? I'm confused with that question. Am I getting a Pap smear because I need a cervical screening? Or is the cervical screening part of the Pap smear. I'm lost. So if I understood all what was tested in a Pap smear, then maybe it's one and the same. I don't know that.

Despite partial or inaccurate understandings of cervical cancer screening tests, respondents were able to say that they had one – especially the Pap test – because they knew it by name. But their knowledge of whether they had an HPV test was not as certain. This pattern became more obvious in the subsequent questions.

CERVICWHEN_A

[CERV2.] Please look at Card 12. When did you have your MOST RECENT test to check for cervical cancer?

- 1. Within the past year (anytime less than 12 months ago)
- 2. Within the past 2 years (1 year but less than 2 years ago)
- 3. Within the past 3 years (2 years but less than 3 years ago)
- 4. Within the past 5 years (3 years but less than 5 years ago)
- 5. Within the past 10 years (5 years but less than 10 year ago)
- 6. 10 years ago or more

<u>Findings</u>: Recall was not an issue for most respondents. Only one respondent had trouble remembering when her Pap test was. This was due to both the COVID-19 pandemic altering patterns for doctor visits along with a pregnancy she experienced during the pandemic. As a result, it took her quite a bit of work to get to the correct answer. Her first answer was 'within the past year,' but then she said, "Wait, you know what? For that last one I think, to be honest, COVID has thrown me off. And I just also had a baby, so it throws things [normal GYN visits] off. It's actually...it should be less than two years because I would've had my last Pap while I was pregnant. And for last cervical exam. So it would be the second one [response option]. And then what was the next question?" The interviewer repeated CERV3. "I'm trying to make sure I'm being honest. I'm trying to think with the baby, if that was the intention of it. [Thinks.] So now I gotta push this back even further. Pregnant 2019. So that means it was at least two years ago but less than three years -- for Pap smear related to cervical screening."

Another respondent had difficulty understanding the question due to the lack of knowledge referenced in the previous question. Specifically, she did not fully understand that Pap and HPV tests were checks for cervical cancer – despite the previous question explicitly stating that they are. As a result, she was unclear about this question. She said, "So I don't know how to explain this. I've had a Pap smear but it hasn't been indicative of checking for cervical cancer. So I don't

know how to answer that. I've never been checked for cervical cancer specifically. But I've had a Pap smear in the past year." *So would you include that here?* "Yes. Because I imagine that if anything came back abnormal, including cervical cancer, that's what that test would result [in]."

TELLCERVIC

[CERV3.] At your most recent cervical cancer test, did a doctor or other health professional tell you which type of test(s) you received?

- 1. Yes
- 2. No

<u>Findings</u>: Some response error occurred with this question. One source of error was the notion of the need for a conversation with the healthcare provider. A second source was the confusing context created by the first question, CERV1, which included both Pap and HPV tests.

Conversation unnecessary: Respondents who answered 'yes' were not always thinking about specific conversations with their healthcare provider. When asked what the doctor told her, one respondent said, "To be honest, I can't remember that information being communicated to me, so I hope I didn't answer that incorrectly. But I think in my mind I was under the impression it was going to check for cervical cancer." It was also unclear what – if anything – the doctor told a second respondent. When asked she said, "Oh, wow, I should pay more attention. It was just your typical Pap smear exam...but it went quick. So that's all." Similarly, another respondent answered 'yes,' not because her physician had that conversation with her, but because the respondent made an appointment specifically for a routine Pap test. She said, "I knew going in that I was getting a Pap smear. That's something that's discussed when I make my appointment every year. So she doesn't really say a whole lot now because I just know that that's the test I'm going in for." The physician would have no cause to tell the respondent she was receiving a Pap test – yet the respondent still knew she was getting one.

Because many women initiate appointments for Pap tests on their own, it stands to reason that this question could be confusing. In these cases, the question makes the false assumption that the respondent would need to be informed by the physician of the type of test being performed.

Inclusion of both Pap and HPV: Several respondents answered 'no' when the conversation they had included a discussion of only one test but not *both* Pap and HPV. For example, one respondent answered 'no' but during probing mentioned that her physician did tell her she was getting a Pap test. When asked why she answered 'no' to this question, the respondent explained, "She told me it would be a Pap test but I think you had asked me about PV...D? Right? I don't think she ever discussed with me that -- if I was getting tested for that. At the same time [as the Pap]." So you were thinking of the very first question [interviewer repeats CERV1]? "Right. Yeah, I never had an HPV that I know of. It's always been the Pap test." Another respondent had the same interpretation – that the conversation had to include both Pap and HPV tests. She said, "What my understanding is, when they do the Pap smear they

check for everything -- HPV or any cancer. So she didn't specify and use the word HPV." Because the first question in this series (CERV1) discusses both Pap and HPV tests, some respondents thought both conditions had to be true in order to answer 'yes.'

[CERV4.] At your most recent cervical cancer screening, did you have a Pap test?

- 3. Yes
- 4. No

<u>Findings</u>: This question did not change between rounds. It appeared straightforward and well understood. All respondents were able to say whether or not they had a Pap test. There was no confusion on their part and no response error was detected.

HPVTEST_A

[CERV5.] At your most recent cervical cancer screening, did you have an HPV test?

- 1. Yes
- 2. No

<u>Findings</u>: While Pap tests were very familiar to respondents in this sample, the HPV test was much less so. As a result, some respondents were less confident about receiving the HPV test in relation to the Pap test. Several respondents answered 'don't know' as a result. One respondent explained, "I only heard of it when I moved in 1998. Maybe 2000. I never knew what it was. So I'm 47. Maybe HPV wasn't even around. Or the test that they give to girls, like teenagers, maybe?"

Another respondent hesitated before answering 'don't know.' When asked why she said, "Well, because I think they probably test for HPV at the same time as the cervical cancer. And I think she [the physician] would probably notify me if I tested positive for that. She just doesn't specify that they're testing for that." Similarly, another respondent said, "They ask about it, but I don't remember them saying this test is going to include an HPV test. They may have, I just don't know."

CERVIC_FU

[CERV6.] In the PAST 5 years, did any of your cervical cancer screening tests require follow-up to check for cancer or precancerous cells?

- 1. Yes
- 2. **No**

<u>Findings</u>: All respondents seemed to provide accurate answers to the question and to take the timeframe into account. For example, several respondents did have follow-up tests and procedures (for example, colposcopy and LEEP) but answered 'no' because they were outside the five-year window.

Self_test

[CERV7.] If an easy-to-use kit was available for you to collect your own vaginal sample for the HPV test, would you prefer this option rather than having the test done by a doctor or nurse?

- 1. Yes
- 2. No
- 3. Have no preference

<u>Round 1 Findings</u>: This version was tested on only four respondents, as the rest followed skips past it. However, an early pattern was suggested that aligns with opinion/attitude questions in general. Answers to this question were conditional. That is, answering 'yes' or 'no' depended on certain additional factors not addressed by the question. Each respondent had various concerns surrounding the nature of the test. The way they answered the question depended on the degree to which they understood the question as implicitly taking their concerns into account.

Question does not account for concerns: For example, one respondent saw the question as *not* taking her concerns into account and answered on that basis. She said, "I would lean toward no." *Why is that?* "When it comes to something like that, I just get nervous in terms of what if I don't do it right? I get nervous, too, when I go to the doctor but at least I can trust that my medical professional knows what they're doing, even if it is a little uncomfortable for me. I want the results to be correct." The ability to perform the test correctly on oneself influenced her preference of doing so. However, not seeing this concern addressed by the question, she answered 'no.'

Another respondent who did not see her concerns addressed by the question answered 'no preference' because she was unsure of the conditions surrounding the test and was offered no guidance in this regard by the question. She answered 'no preference,' not because she did not care one way or the other, but because her concerns were not addressed by the question. She said, "Would it be done at home or would it be done at a clinic?" The interviewer repeated the question. "I guess no preference." Why no preference? "I was thinking I don't have any insurance. So, if an at-home kit would be a little bit easier -- easily available -- and maybe it wouldn't have me jump through so many hoops of trying to schedule a thing and all that. Then I would do it at home. It's purely financial and convenient. [But] if I had access to insurance and all that and it was no issue to make an appointment, I wouldn't care. Then I would go to the clinic. They can do it, I won't mess that up. But for someone who doesn't have access, if that was an easier option and I could do this, I would." Cost, scheduling, and accuracy were important aspects of whether this respondent would want to do the test herself. The question did not make mention of any of these conditions, causing the respondent to answer 'no preference' as a way of conveying the idea that, lacking important information, she could not say 'yes' or 'no.'

Question does account for concerns: One respondent who had additional concerns not mentioned in the question assumed – unlike the previous respondents – that these concerns were implicitly accounted for. Like the others, she had concerns over the accuracy of self-testing and answered by assuming the test would take this into account. She said, "I wouldn't

say I'm a prudish person, but I am a private person. And it [the HPV test] is awkward. Even though you know this doctor sees various women's bodies all the time, it's very intimate. And, yeah, I prefer to do it myself. My only concern would be doing it incorrectly. If you don't take the proper sample from the proper place. But if there was a way to be more foolproof, yeah I would prefer to do it myself." Another respondent also assumed her concerns would be met without having to see it stated explicitly in the question. She said, "Why not? Yes. As long as I did it properly. And it's easy. I would do it. Something simple."

Clearly women can have a variety of concerns and questions surrounding the nature of an unfamiliar do-it-yourself test. A single survey question cannot take every concern into account. The important finding here is that respondents did not have consistent interpretations. Some answered on the basis of assuming their concerns were implicitly accounted for by the question, while others did not make that assumption. The result is that answers of 'yes', 'no,' and 'no preference' do not have consistent meanings among respondents. In particular, answers of 'no' and 'no preference' can mean 'I need more information' or they can mean 'all else being equal, this is my answer.'

<u>Round 2 Findings</u>: Modifications were made to the question based on findings from Round 1. Too many unknowns existed in some respondents' minds. This caused different reactions to the question in Round 1. Taking this into account, the question in Round 2 incorporated the notion that, not only would the test be easy to administer, the results would be accurate. The new question follows.

[CERV7.] In the future, you may have the option to use a simple kit to test for HPV infection yourself. To use, you insert a swab about an inch into your vagina and rotate it for 30 seconds. It is easy to use the kit correctly and the results are accurate. If available, would you prefer this option rather than having the test done by a doctor or nurse?

- 1. Yes
- 2. No [GO TO Section 6]
- 3. Have no preference

Respondents in Round 2 were more sure of their answers and less likely to mention caveats. This may be because the biggest concern mentioned in Round 1 - accuracy - was incorporated into the question for Round 2.

Additionally, the first round of testing suggested that respondents who had concerns not addressed by the question might answer 'no preference' as a way of conveying their uncertainty and need for more information. In Round 2, answers of 'no preference' fell more within the scope of the category. For example, one respondent explained that she answered 'no preference' because, "I've done the at-home test kit to check for diabetes, like for a blood kit. And I'm perfectly fine with that. Convenience-wise I think it's good to be able to test for those things. I don't want to say I feel like it's more accurate if you have it done in a doctor's office. So I really don't have a preference either way."

Self_test2 [CERV8.] Would you prefer to do this test at home or in a clinic?

- 1. Home
- 2. Clinic
- 3. Have no preference

<u>Findings</u>: There was not enough information to warrant a change in this question between rounds. In Round 1 answers depended on certain conditions that were lacking in the previous question. For example, one respondent answered 'no preference' because it was not clear that her concerns would be addressed. She said, "Part of me would want to do it at home for the awkward factor. But then another part of me is like at a clinic are you more likely to do it correctly? So, I think that means they cancel each other out -- you're neutral."

However, no one expressed this concern in Round 2. Only one respondent had difficulty in Round 2 because she was not clear on the word 'clinic.' At first she said, "Clinic is a weird word. When you say 'clinic', do you mean like a women's health center? Or like my GYN?" The interviewer said there was no definition provided, so the respondent answered 'no preference.' When asked about this confusion during probing, the respondent said, "It [clinic] sounded cold. Sounded more like, hey, wanna just go stop by Planned Parenthood and let them do an HPV test? That's different than making an appointment with my doctor at my doctor's office. So the word 'clinic' made me think 'cold,' like I wouldn't have a relationship with the person doing it." Ultimately, however, the respondent understood the intent of the question to distinguish between home and a professional setting.

Section 6: Sex Education/Sexual Activity

The final set of questions are about sex education and sexual activity. [SEX1.] At any time in your life, have you ever had sexual intercourse with a [man/woman], that is, made love, had sex, or gone all the way?

- 1. Yes
- 2. No

<u>Round 1 Findings</u>: Most respondents generally understood the intent of this question as asking about sexual penetration. Some respondents thought specifically of vaginal intercourse. For example, when asked what they were thinking here, one respondent said, "High-risk sexual behavior." *What kind of behavior is that?* "PIV. Penis-in-vagina intercourse. That was my first sexual contact." *Would you think of that activity always, or does other stuff count too?* "That's [penis-in-vagina] not what immediately comes to mind, but that's the broad cultural assumption that I assumed the survey was informed by." Another respondent said, "Yes, there was an instance in which I inserted my wee-wee into a woman's hoo-ha. That happened. In real life. And that is how I knew to answer the question, yes." Another respondent also saw this as the basis of the question. They said, "When I hear 'sexual intercourse' I think of penis in vagina and not necessarily the other [i.e., oral or anal.]" One respondent had a direct way of putting it: "I'd say I have a clear distinction in my head between what constitutes sexual activity and what constitutes sexual intercourse...When someone asks you if you've lost your virginity, you don't say you've lost your virginity after you've got a blow job. You say you've lost your virginity after you [expletive] someone. Or got [expletive]. And losing virginity is sexual intercourse."

However, other respondents included additional forms of sexual penetration, not just penis-invagina. One respondent said, "When I think of sexual intercourse, I believe it's the involvement directly of two genitals in one way or another. Or the insertion of one's genitals into someone's orifices. Anything involving hands -- that's not intercourse to me. You could say it is, but it's a bit of stretch. Because it's not really intercourse. Now full-on penetration, that's sexual intercourse." And is this oral, anal, or vaginal? "Oral, anal, all that. Because I know I consider any way an STD can be spread with that exchange of fluid, THAT I can count as sexual intercourse." Another respondent was also thinking of a broader definition of penetration and explained, "At that point I was thinking of the first time you have full penetrative sex with someone else." Would it be any kind? Oral, vaginal, anal? "I would say, yeah. That's what came to my mind, as long as it was penetrative. So, anything beyond touching of some kind." Similarly, when asked what they thought sexual intercourse meant in this question, one respondent said, "What I think qualifies as sexual intercourse instead of sexual activity would be a penis going into a vagina or a penis going into someone's butt." So, you answered based on that definition? "Yeah. And then I'd say sexual activity would be a different thing, which might include stuff like oral sex or touching." And finally, another respondent said, "I would say allthe-way penetration. I would assume that's primarily what it means." Just vaginal? Or oral, anal or any penetration counts? "I would say vaginal or anal." But not oral? "No."

The additional clarification of 'made love, had sex, or gone all the way' might not always work as intended and might, in fact, introduce a variety of unintended sexual activities. For example, when asked about the meaning of this question, one respondent said, " The reason why I answered 'yes' unambiguously is because at 18 -- you mentioned 'you went all the way' -- that's why I said 'yes.' If it just said sexual intercourse, I might've said something like...well, 18." *If it just said sexual intercourse what would you think*? "For me that would be anal or vaginal intercourse." *But then 'going all the way' is more like anything at all*? "Yeah, like oral." *Was your answer based on anal/vaginal or any sexual activity*? "I was thinking of oral sex."

<u>Round 2 Findings</u>: Even though many respondents interpreted the question in Round 1 as asking about vaginal intercourse, there were instances when respondents were thinking of other types of sexual activity that were not intended to be included. In Round 2 the question was modified to offer specific guidance on what was meant by sexual intercourse – or, more precisely – what was *not* meant. The question tested in the second round follows.

[SEX1.] At any time in your life, have you ever had sexual intercourse with a male/female, that is, made love, had sex, or gone all the way? Please do *not* count oral sex, anal sex, or other forms of sexual activity that do not involve vaginal penetration.

- 1. Yes
- 2. No [go to SEXED1]

Because Round 2 included more respondents over 30 (who were instructed to skip the last set of questions), the new version could not be fully evaluated. However, the few respondents on whom the question was tested had accurate interpretations. For example, when asked what kind of sex the question was asking about, one respondent said, "Well the way that you phrased the question was simply penis in vagina penetrative intercourse, so that's what I was going off of."

[SEX2.] That very first time that you had sexual intercourse with a [man/woman], how old were you?

_____Age in years

<u>Findings</u>: This question was not extensively tested and did not change between rounds. All respondents under 30 were asked this question and none had recall difficulty.

[SEX3.] At the time you last had sexual intercourse with your most recent partner, how would you describe your relationship with him/her? [Open ended – code answer.]

- 1. Single and not dating
- 2. Single and dating/hanging out
- 3. In a relationship but not living together
- 4. Living together but not married
- 5. Married and living together
- 6. Married but not living together

<u>Findings</u>: This question was initially administered as an open-ended question, where the interviewer was to pick a response option based on the answer given by the respondent. While sometimes this was straightforward ("We're legally married"), it often was not.

After hearing the question some respondents waited, seeming to expect categories to be read. It was unclear to them how they were expected to classify their partner or how much detail was required. For example, one respondent said, "Uh, [expletive] buddy. Am I supposed to come up with a fancy term for that?" In later interviews, the question wording was not modified, but interviewers read the list of options aloud to the respondent. This seemed to work better. Respondents were able to choose an option they felt was accurate.

[SEXED.] Now I'm interested in knowing about formal sex education you may have had. Before you were 18, did you ever have any formal instruction at school, church, a community center or some other place about:

how to say no to sex? methods of birth control? where to get birth control? how to use a condom? sexually transmitted diseases? how to prevent HIV/AIDS?

waiting until marriage to have sex?

<u>Findings</u>: The root of this question was read prior to each topic (as a different question) and did not change between rounds. Most respondents associated these topics with sex education in school, which was often part of a general health class. A few also mentioned church.

Two general patterns were found in relation to this section. First, several of the topics produced different interpretations among respondents. Second, even though some topics were not covered in great detail in their classes, respondents tended to include them in (rather than omit them from) their answers.

Interpretive differences for certain topics: The first topic on the list was interpreted in slightly different ways by respondents. 'How to say no to sex' could be seen as teaching abstinence. For example, one respondent said 'yes' because, "There was this Catholic teacher who was teaching the science classes and he would tell abstinence...He would say look how much effort people go through when they could just not have sex. But that wasn't school policy. That was just him...That was the only time I got 'to say no to sex.'" Another respondent said 'yes' and explained, "Fornication was a big no-no. I heard it ever since I was born. I went to church for a long time. But there was a kid's class or like a teen class and one day they talked about it. They took one Saturday. The services were usually two hours. To just talk about fornication and how you'll go to hell if you fornicate. It was one class but you heard it all the time."

However, 'how to say no to sex' was also seen as consensual sex. One respondent said, "I don't think so. I wish that they would've taught consent." Similarly, another respondent said she thought this question was about "how to assert yourself in a situation where someone's coming at you with the force of a thousand suns and you're like 'holy [expletive], get away from me."" She went on to explain that her school never taught "how to defend yourself against unwanted advances." Another respondent also said, "It was: sex is something between two consenting adults. And both people should be okay with it." One respondent answered 'yes' because school covered the many issues surrounding consensual sex. They said, "If you're drinking and want to have sex and someone says yes and you're both drunk, does that count as consent? No. They were very into that." Another respondent answered 'no' because although the topic was covered, it was not directed toward him as a male. He said the content was, "How could women walk away...As a male, I don't think I was told how to say no to sex, actually." When asked what should have been covered for males he replied, "Like if a woman were to express interest, how would you be able to walk out of that situation and not put yourself in danger. It's not normally seen as a man being in danger, but who's to say?"

'Methods of birth control' could also be interpreted different ways. For example, condoms were sometimes excluded from this category. For example, one respondent answered 'no' and said, "I didn't know much about birth control. I heard about birth control but my real education about birth control was during college talking to girls and asking questions about it." In school they only covered condoms, which he did not classify as birth control. Respondents often

associated condom use exclusively with the prevention of STIs. One respondent said, "They'd show us a bunch of pictures of people with sexually transmitted diseases and be like, this will be you if you don't wear a condom. It's like the absolute worst case ever recorded. Just pure scare factor stuff."

'How to prevent HIV/AIDS' was sometimes interpreted with a focus on transmission more than prevention, per se. One respondent said, "I'd say 'yes,' I guess. 7th grade health class. I'm not going to say it was super specific, but they said how it could be transmitted." *Did they say how it could be prevented?* "I think it was just assumed. The church implied I could get it from having gay sex...in school they said it was transmitted through bodily fluids."

However, there were some respondents who specifically remember being told how to avoid HIV/AIDS. One respondent said, "I remember they said not to share razors because you can spread AIDS through razors [raises eyebrows and laughs to indicate that this is ridiculous] and that's all I got." Another respondent said, "If you want to avoid them [HIV/AIDS] then you need to use a condom."

Level of detail: Respondents thought of the level detail in which topics were covered, but usually did include even those that were not explained to them in great detail. This was true for all the topics asked about. For example, one respondent said, "I knew methods existed. I did not have instruction on how to use said methods. I was just told what they were called." Another respondent said, "They didn't go into what they were. It was essentially, if you do not use a condom, you'll get chlamydia, gonorrhea, HIV...it was very much a black-and-white, binary." One respondent answered 'yes' to birth control but said, "It was all very vague though." *How so*? "They taught us about the different methods and mentioned them. But they didn't really go into detail." One respondent stopped to think before answering 'yes' to 'where to get birth control.' When asked what she was thinking she said, "The way they did it was sometimes a little weird. They would be scarce about it. They were trying not to overstep something your parents would want to handle. You have to sign a consent form to be part of this, but if girls raised their hands and had questions, they would tell us, [but] they tended to be kind of vague."

[SEXED2.] Looking at Card 13, where did you receive that instruction about _____? [all that apply]

- 1. School
- 2. Church
- 3. A community center
- 4. Some other place

<u>Findings</u>: A potential problem with this question is that the response categories might redefine the intent of this line of questioning. The first question in the sex education series asks whether the respondent ever received formal sex education. However, the addition of 'some other place' as a response option here may serve to widen the scope of intent such that informal sources of information are now included. Some respondents began to understand the questions as asking whether they had been exposed to the material from *any* source, and experiences of 'formal' encompassed more scenarios.

For example, respondents who chose 'some other place' were thinking of parents, friends, and the Internet. When asked what he would include as 'formal' one respondent said, "I would say in a setting with someone who is trusted...or the information is trusted on the Internet." Another respondent who answered 'some other place' thought about their parents. When asked about this they said, "To me it's formal. It's my parents but..." *What made it formal?* "They didn't do the whole birds and bees reference stuff. They were very up front in saying things. Things like HIV & AIDS are there, they exist. They didn't do it in a scary way. They walked a fine line with it." *So it's formal because...?* "It was thorough, well-explained. If I had a program, it would be like the same way."

In sum, the word 'formal' in the previous question may be interpreted a variety of ways to begin with, and this question opens the door to even greater variation by including the vague category of 'some other place.'

[SEXED3.] What grade were you in when you first received instruction on _____?

GRADE_____

<u>Findings</u>: This question did not change between rounds. Most respondents could recall the information with reasonable accuracy, although sometimes they would remember only within a couple years, such as 7th grade or 8th grade. One point that came up several times was in relation to those topics that were covered in church. This had sometimes occurred so early (particularly with 'waiting until marriage to have sex') that respondents could not pinpoint the grade they were in. As one respondent said, she first received that message "as soon as I could understand what the pastor was saying. [Laughs.] Yeah, that was always the message." Other respondents conveyed the same experience – being exposed to the topic in church as far back as they could remember.

[SEXED4.] Did you receive instruction about ______ before or after the first time you had sex?

- 1. Before
- 2. After

<u>Findings</u>: This question did not change between rounds and was not extensively probed because all respondent answers matched the age at which they said they first had sexual intercourse.