



NATIONAL CENTER FOR HEALTH STATISTICS

Rapid Survey Systems (RSS)

Round 7 Cognitive Interviewing Report



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Abstract

Introduction: The staff of the National Center for Health Statistics' (NCHS) Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) evaluated measurement properties of questions included on NCHS' Rapid Surveys System (RSS) Round 7 questionnaire. Five topics were evaluated in this round: Lyme disease prevention, complementary and integrative health, GLP-1 medication access, lung cancer screening, and fertility and reproductive health services.

Methods: Twenty cognitive interviews were conducted virtually to evaluate the question-response process and determine patterns of interpretation and response error. Respondents were purposively recruited, with an emphasis on four criteria: use of complementary and integrative health practices, use of GLP-1 medication, history of smoking, and women between the ages of 18 and 49.

Results: On the whole, respondents were able to answer questions in each section with minimal difficulty, and, to a large extent, interpretations fell within the scope of question intent. There were, however, some notable exceptions. In Section 1 (Lyme Disease Prevention Methods), respondents who had no direct experience with ticks were more likely to shift the construct to other types of bugs, particularly when the question itself omitted any reference to ticks. This pattern was observed not only among respondents who resided in low-prevalence states but also those from high-prevalence states. In Section 2 (Complementary and Integrative Health [CIH]) most respondents expressed limited or no knowledge of CIH and outwardly wondered if they were supposed to be aware of these practitioners and practices. Additionally, even respondents with some experience with CIH – including those who tried a modality only once – are not always fully educated on them and may, therefore, answer some questions incorrectly. Respondents were familiar with GLP-1s in Section 3, but access to this class of drugs is quickly evolving and growing more complex, making it difficult for respondents to answer some questions. The proliferation of acquisition methods, providers, types of GLP-1s (and GLP-1-like products), and drug delivery modes has broadened the field, making some respondents unsure whether their experience should be included in the questions. Additionally, respondents with experience in more than one mode of access may be unsure whether and how to include less conventional methods of GLP-1 access. In Section 4 (Lung Cancer Screening) it was difficult for light smokers to offer accurate answers about their patterns of use. Their patterns are random and sparse enough to make summarizing them into one answer difficult, especially when the question assumes a more regular habit. And finally, questions in Section 5 (Fertility and Reproductive Health Services) sometimes assume the person initiating a conversation on these topics is the respondent – or that the respondent was at least open to the conversation. This was not always the case. It is unclear whether conversations initiated and driven by the healthcare provider (not the

respondent/patient) should be included, especially when the respondent had no interest in such a conversation.

Keywords: Lyme disease prevention, complementary and integrative health, GLP-1 medication access, lung cancer screening, and fertility and reproductive health services.

Introduction

The staff of the National Center for Health Statistics' (NCHS) Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) evaluated questions included on the Rapid Surveys System (RSS) Round 7 as a quality improvement initiative. The RSS is a web-based survey platform designed to produce timely estimates for emerging health topics (1). The study received both Office of Management and Budget (OMB) and NCHS/Centers for Disease Control and Prevention Human Subjects approval and was determined to be exempted research for Institutional Review Board purposes.

The goal of the study was twofold - to document the constructs measured by the questions and to identify any question-response complications, including response error (2,3). Findings are intended to facilitate a better understanding of the meaning of survey estimates produced by RSS 7.

CCQDER conducted this study using cognitive interviewing. (The cognitive interview test instrument is included as Appendix II.) For RSS Round 7, there were five topics of interest for question evaluation: Lyme disease prevention, complementary and integrative health, GLP-1 medication access, lung cancer screening, and use of fertility and reproductive health services.

The research method is outlined in the next section. This is followed by a discussion of the findings and a conclusion. (Findings in a question-by-question format may be found in Appendix I.)

Methodology

Given the topics under investigation, there were four main groups recruited for cognitive study participation: those using complementary and integrative health practices, users of GLP-1 medication, those with a history of smoking, and women between the ages of 18 and 49. Within these groups, efforts were made to include respondents with a mix of age, race, and educational attainment. Respondents from a variety of geographic areas were also sought in order to reflect variation in the prevalence of Lyme disease in different regions. Recruitment was carried out through a combination of word-of-mouth and the CCQDER Respondent Database. Table 1 summarizes the demographic composition of the sample.

Table 1. Sample Demographics

Demographic Variables	Number (<i>n</i> = 20)
Race/Ethnicity ¹	
Black or African American	11

Hispanic or Latino	3
Native Hawaiian or Pacific Islander	1
White	6
Sex	
Female	16
Male	4
Age	
18 – 29	2
30 – 39	8
40 – 49	5
50 – 59	2
60 and older	3
Education	
High School Diploma or Equivalent	6
Some College	3
Associate's Degree	3
Bachelor's Degree	5
Graduate Degree	3
¹ Numbers do not add to 20 because respondents could choose more than one category. SOURCE: National Center for Health Statistics, Collaborating Center for Questionnaire Design and Evaluation Research, 2025.	

Interviews took place virtually using a video conference platform approved by NCHS and the Centers for Disease Control and Prevention Information Security Offices. Each interview lasted no longer than one hour. In order to capture respondents' initial reaction to the survey items, interviewers first read the questions to respondents and recorded their answers. The interviewer then followed up with retrospective probes to explore respondents' understandings of the questions, rationales for their answers, and whether any response difficulty occurred. A remuneration of fifty dollars (in the form of an electronic gift card) was provided to all participants at the interview's conclusion.

Qualitative data analysis was guided by the principles of grounded theory adapted to cognitive interviewing (4-6). Using the constant comparative method, analysts compared the rationale behind respondent answers across all participants for each question. This systematic comparison yielded patterns of question interpretation and response difficulties. These patterns are discussed next.

Overall Findings

This section discusses findings associated with each topic (a full question-by-question analysis is located in Appendix I). Some questions could not be fully evaluated due either to skip patterns in the questionnaire or time constraints of the one-hour interview. This is noted where applicable. The test instrument can be referenced in Appendix II, which includes variable names (for cross reference) and complete question wording.

Section 1: Lyme Disease Prevention Methods

All 20 respondents were administered the Lyme disease questions. Respondents came from a variety of states/jurisdictions including those with higher prevalence (states primarily in the northeast and mid-Atlantic areas) and lower prevalence (southern states) of Lyme disease. The questions (see Appendix 1) ask for a person's likelihood of 1) getting a vaccine to prevent Lyme disease (if it were available), 2) taking a single-dose antibiotic after a known tick bite, 3) using bug spray, and 4) wearing clothing pretreated with permethrin. Respondents expressed no difficulties with this set of questions and all were able to provide answers. However, there are some variations in the question-response process that draw into question the measurement construct.

Experience with ticks: First, there was minor variation in the underlying construct. When answering the questions, one group of respondents remained consistently focused on exposure to ticks and the potential for contracting Lyme disease. This group answered the questions in line with the underlying intent. However, another group of respondents answered the questions in terms of the avoidance of bugs in general, not ticks or the prevention of Lyme disease, per se. Answers from this group may not align as closely with question intent. This group variation was precipitated by two factors: respondent experience with ticks and question wording that omits reference to ticks.

Direct experience: The first group remained focused on ticks and Lyme disease across the four questions because of their direct experience with ticks. For example, in relaying her perspective, one respondent said, "I am, almost every weekend, out fishing with my family. And we've had a lot a scares with my little sisters where they would come home with ticks." This experience guided her answers. Another respondent also remained focused on ticks because he had a childhood experience that remained relevant to him. He said, "I was bitten by a tick as a child. They caught it before it got stuck on me. But I'm very cautious." In both cases, survey answers across all four questions were reflections of respondents' direct experience with ticks.

Lack of experience: The second group lacked any direct experience with ticks. As a result, they were prone to include experiences that were not specifically about ticks. Although respondents were recruited from a variety of states in order to take this phenomenon into account, experience with ticks was not contingent on geography alone. Some respondents in high-prevalence states had no direct experience with ticks and their interpretations were similar to those in low-prevalence states. For example, one respondent thought of her overall dislike of bugs in answering 'definitely' to using bug spray. She said, "I don't like bugs. I don't like bugs touching me, I don't like bugs on me and that's one of my key things is when I go out and I know there's a lot of mosquitoes." Another respondent was thinking about her exposure to bugs at work. She said, "I work at the front desk so when the doors open a lot of flies will come in the loading dock area...A lot of flies tend to get in and mosquitoes." Mosquitoes were

specifically cited by multiple respondents. In several cases respondents had negative reactions to mosquito bites. The salience of this experience caused them to interpret the last two questions through this lens. One respondent said she would ‘very likely’ use bug spray “because I’m allergic to mosquitoes, so I need to be careful of mosquito bites.” Similarly, another respondent said, “I have bad reactions to mosquito bites. So I’m always using Off and stuff like that. I don’t enjoy the smell but it’s not that big of a trade-off to prevent me from getting bit all over the place by mosquitoes so that’s why I said ‘definitely’ to that question.” For these respondents, the essence of the questions was avoidance of bugs not avoidance of ticks/Lyme disease.

In addition to absence of experience with ticks, it is likely that the lack of reference to ticks or Lyme disease in the last two questions in the series (LYM_PREVC and LYM_PREVD) further encouraged those with little direct experience with ticks to think more generally about avoiding bugs.

Variations in judgment: A second pattern emerged with variation among respondents in the judgment process. Respondents considered different factors when deciding how to answer. The likelihood of using any of the prevention methods hinged on familiarity with the method, prior use of the method, locations occupied (or visited) by the respondent, and activities of the respondent.

Familiarity: Some respondents answered based on the extent to which they were familiar with the prevention method. Antibiotics and bug spray were familiar to many respondents. Vaccines (specific to Lyme disease) and pretreated clothing were not as familiar. However, familiarity did not necessarily increase the likelihood that respondents would use a method. It simply informed the basis of their decision making. For example, when one respondent was asked about her answer of ‘very unlikely’ in using bug spray she said, “I don’t like the bug spray on my skin...The texture and the feeling...And it’s kinda hard to get off. I just don’t like bug spray at all.” Conversely, another respondent answered ‘definitely’ because “I’m just accustomed to using bug spray.”

Relatedly, although the questions are phrased as hypothetical behavior (“How likely are you to use each of the following methods...”), respondents answered certain questions based on their *actual* behavior. This was true for the question on the use of bug spray because, unlike vaccines or even pretreated clothing, most people have ample access to bug spray as a preventative measure and had, therefore, used it in the past. For example, one respondent thought about her use of bug spray at work. She said, “I use it every day at work. We have flies and stuff. So that’s why I picked definitely.”

Location and activities: Some respondents answered the questions on the basis of the chance they would be exposed to ticks to begin with. This was based on home environment, such as urban areas (“Because I’m more in a city-type area.”) or on their

participation in activities that typically put people in proximity to ticks (“I just assume you would get Lyme disease if you go hiking in the woods and I really don’t do that. I don’t even go to the local park.”). One respondent considered both location *and* activity. She explained:

“That also depends on the area you live in and what type of activity you do. I know Lyme disease is something that you get and it will stay for life, so it is something you do kinda want to prevent. But it also depends on the area and the activity that you’re in, so I’ll say ‘somewhat likely’ because I’m an outdoor person. Working outdoors, that [tick bites] can happen.”

Attitudes on vaccines and injections: Finally, the first question in this series asks about a hypothetical choice to get a vaccination for Lyme disease, if it were available (LYM_PREVA). Many respondents made their judgments based on trust in vaccines *writ large*. Some respondents rejected vaccines out of hand and answered on that basis alone. (“Definitely not. I don’t like vaccines.”) Others did not outright reject vaccines but did have a measured approach towards them, considering side effects for example. One respondent explained, “Before I run and get anything I like to hear experiences from other people of, oh, this new vaccine is giving everybody so-and-so [side effect]...That is where I’d make my decision.” A second respondent is only open to vaccines that target what she perceived to be serious illness. She said, “For me, I vaccinate if it’s a life-threatening disease. Not that Lyme disease isn’t potentially life threatening. But it’s not tuberculosis. Or malaria.” Another respondent weighed the chances of contracting Lyme disease against the need for vaccination:

“I just don’t see the need to be pre-vaccinated for something that might not happen. So the likelihood of me coming in contact with a tick is, I don’t know what the percentage is, but I would not agree to get vaccinated in advance because I *might* run into a tick. I’m not in agreement with that.”

Other respondents focused on their feelings about injections overall, often expressing a degree of trypanophobia, or fear of needles. One respondent said, “I’m kinda terrified of needles so I try to avoid them as much as I can. So as far as getting shots or vaccines, I try to avoid it.” Others were less “terrified” but still expressed dislike of needles. One respondent said, “I tend to have a small thing with needles anyway.” The central takeaway for the vaccine question is that judgments were not necessarily made on the basis of avoidance of Lyme disease but rather on the basis of trust in vaccines or openness to injections.

Section 2: Complementary and Integrative Health

This section contains questions on the use of complementary and integrative health (CIH) practitioners and practices in the past 12 months. All respondents were asked this set of questions; five reported using at least one of the methods in the past 12 months. Questions began with CIH *practitioners* (Ayurvedic doctor/Vaidya, curandero, hierbero/yerbera, native American healer, shaman, and sobador) followed by CIH *practices* (homeopathy, Reiki, acupuncture, Tai Chi, Qi Gong and music/art). Two patterns were observed in this section: respondent lack of knowledge and an ill-defined construct in the last question.

Lack of knowledge: Many respondents had never heard of most of the CIH practitioners or practices and as a result expressed a degree of perplexion. This was especially true of the practitioners in CIH_HLTH12M (specifically, Ayurvedic doctor or Vaidya, Curandero, Heirbero/Yerbera, and Sobador). A couple respondents were confused by the language and whether it should apply to them. One respondent said, “The Spanish sounding ones, I didn’t even know what you were talking about. I don’t even know what it is.” Another asked, “Should I be knowing this? [Laughs] Is this in a different language?” The interviewer replied that there were no definitions provided in the question, showed her the list of practitioners, and asked whether the respondent had ever visited any such practitioner. Seeing the names did not improve understanding. She replied, “I don’t know what that [Heirbero] is. I don’t know. I would need Google to translate what you’re saying.” Some respondents were confused to the point of forgetting that the questions were about health practitioners. For example, one respondent asked, “These are doctors you’re mentioning? These are types of doctors?”

Because many respondents explicitly stated their lack of knowledge in this section (“I have no clue what any of those are. I never heard of those before.”), interviewers retrospectively asked if respondents were familiar with any of the practices or practitioners. Acupuncture was by far the most recognized (“Acupuncture I definitely heard. It’s something that I always wanted to look into. But everything else I never heard of.”), followed by Tai Chi. Although respondent lack of knowledge prompted no response error (except in one case, discussed below), the significant confusion in this section could be offset by providing a sentence or two introducing the CIH topic, which was lacking in the cognitive interview test instrument. Findings here show the importance of orienting respondents to the CIH section and, perhaps, to the idea that they are not necessarily expected to be familiar with every CIH modality and the associated practitioners.

Despite the fact that respondents had never heard of many of the *practitioners* in this section (and no respondents mistakenly reported seeing any of the practitioners), five did answer ‘yes’ to using several *practices* in the past 12 months. However, when probed, all five respondents had minimal experiences, some engaging in the practice only once. For example, one respondent reported using Reiki one time because it was

provided by a friend. Three respondents tried Tai Chi but only once (“I tried it once, but I don’t regularly practice it, no.”) or very infrequently (“Yes. A little bit. On YouTube.”). Acupuncture was not only recognized by most respondents, but it was used by four of the five respondents who reported using any CIH in the past 12 months.

Although the questions were not extensively tested due to the small number of users, all of whom had only casually engaged in any of the practices, possible response error was observed in one case involving homeopathy and is worth noting. The respondent reported ‘yes’ but his description draws into question whether what he experienced was truly homeopathy. He explained:

“I was having some stomach issues. And my gastro, they also did Eastern medicine and they thought it was all connected with stress and all that stuff. So, it was too expensive – I couldn’t keep going – but they wanted me to do a bunch of things. They were like laying hands on me and doing pressure and all that stuff.”

This respondent illustrates that others with little knowledge of CIH practices could similarly offer false positive responses.

Ill-defined construct: In addition to respondents’ overall lack of knowledge, the final item in the series (CHI_MUSART) presented specific conceptual problems. It asks whether a respondent has, in the last three months, “created, practiced, or performed music or other art forms for your own health.” The construct here was unclear. As a result, some respondents included experiences that others excluded. For example, some respondents thought of the effect that art or music has on their mental health and answered ‘yes’. One respondent answered ‘yes’ because she “loves music.” When asked to elaborate, her description touches on the benefits music offers to mental health. She said, “I listen to a lot of gospel, like when I’m doing something. I’ll just sit and I’ll listen. Because I had a thing where I wouldn’t think before I reacted and I would just fly off the handle.”

This is similar to another respondent who uses painting to improve mental health. She said:

“I paint. I’ve been diagnosed with PTSD [post-traumatic stress disorder] and depression and anxiety. So I paint for my mental health. When I feel anxious or something I just go finish a painting or make something. I don’t know, I really be creative.”

While the previous two respondents’ answers seem reasonably in line with question intent, other respondents excluded similar experiences. One respondent answered ‘no’ but described a similar situation. In retrospective probing the interviewer asked if the respondent ever engaged in art or music. When she replied yes, the interviewer asked her to explain. She said (words in italics are interviewer speech):

"I would paint for my peace of mind. I've painted something for stress relief." *Why did you answer 'no' here?* "I wouldn't have thought of it." *Why is that?* "Given the line of questions, I think maybe I was thinking this was trying to solve some actual physical health problem. And it wasn't done for that particular thing."

Another respondent also excluded activities that the first two respondents included. During probing the interviewer asked the respondent if she did art of any kind. She said:

"I do. I started trying to color. I started doing DIY [do-it-yourself] projects to get my mind off of certain things. Because I suffer from anxiety and depression really bad. I do little projects here and there to soothe my mind." *Give me an example of a project.* "I do [phone] cases. I make hats." *Why did you answer 'no' to this question?* "I don't know. I think it was more the music part that I was focused on."

These examples are possible false negatives because the respondents' arts-and-crafts activities do help improve their mental health. However, while these respondents excluded applicable activities, another respondent included activities that might be seen as inapplicable. She was initially uncertain but ultimately answered affirmatively:

"Yes. Like a dance class?" (Interviewer repeats the question.) "Yes. I take music class." *This was the only one you said 'yes' to. Tell me about this.* "I take a dance class and a Pilates class and sometimes a hip-hop class. At my gym. And it helps my health because I get my heart rate going. That's why I take it."

This respondent included gym workouts because the classes are set to music and involve dance moves, all of which she associates with improving physical fitness/health. While her interpretation is reasonable, it is unclear whether a cardiovascular exercise class at a gym is meant to be captured by this question. In sum, in assessing the intent of the question and making judgments about what activities to include, respondents came to opposing conclusions.

Section 3: GLP-1 Medication Access

GLP_WEIGHT and GLP_LOSEWT: The GLP-1 section begins by asking two lead-in questions. The first asks how respondents would describe their weight (*GLP_WEIGHT*). Response options included, very overweight, slightly overweight, about the right weight, slightly underweight, very underweight.

Respondents easily answered this question. A common basis for response judgment was BMI ("My BMI. Even though they say BMI is not the most accurate in terms of health, it's the only measure that I have."). Another strategy was to compare current weight with a previous, more ideal weight ("Because I'm back at the same size before I had children."). However, people who see themselves in the process of losing weight

may have a different thought process. One respondent lost 15 pounds in the past six months through the use of Ozempic. Although indicating to the interviewer that she was still in the obese category, she answered 'slightly overweight' in this question. When asked why, she said, "Because I've been on a weight loss journey for a while now and I've been shedding pounds but I'm just not really where I want to be. So that's why I said 'slightly overweight'. But I am working on not being obese." Choosing 'slightly overweight' was her way of expressing that she is in the process of losing weight and is not as heavy as she once was, even if she is still obese by BMI standards.

The second lead-in question to the GLP-1 section asks whether a doctor or other health professional talked to the respondent in the past 12 months about losing weight to improve their health (GLP_LOSEWT). Most respondents were thinking of specific conversations they had with their health care provider. Sometimes the topic was raised by the physician. One respondent went in for a back problem and the doctor raised the weight issue. The respondent said:

"I stepped on the scale [at the Dr office] and it was in the 250's and they were like, yeah, it could be a little lower. It's obviously harder on your knees. Because I was complaining about some knee and back pain. And they were like if you brought the number down that would help."

Other times the respondent raised the issue. One respondent noted how he visited the doctor expressly for the purpose of addressing his weight:

"I went to the doctor specifically for that kind of review to see where my health was at. And based on the bloodwork and scale, it was like, okay, you're prediabetic and you're overweight."

GLP_MED12M: After the two introductory questions, respondents are asked if they have taken an oral or injectable medication for diabetes or weight loss, such as Ozempic (including other name brands and a 'read if necessary' with GLP-1 and drug names such as semaglutide) in the past 12 months. Eight respondents indicated that they had taken a GLP-1 in the past 12 months.

There was no error or confusion with this question. All respondents were aware of GLP-1 medications, even if they had never used them. Moreover, respondents were familiar with various name brands, especially Ozempic. For example, one respondent who never took a GLP-1 was asked if she heard of these medications. She said, "Yeah. Because Ozempic has incredible brand strategy. And advertising. How do you not know about it?" Those who were on GLP-1's were captured by the question as intended. This included those taking name-brand GLP-1s ("Yes, Zepbound.") and those taking compounds ("It was one of those generic GLP-1s through like HIMS or whatever."). Because respondents accurately understood the question, interviewers never had to follow up with the 'read if necessary' text.

However, one case did arise that demonstrates the shifting and increasingly complex nature of GLP-1 medications. New delivery methods and online services have broadened the field, making some respondents unsure whether their experience should be included. For example, one respondent answered ‘no’ but was uncertain if the question was about name-brand GLP-1s or also products marketed as GLP-1:

“I was a little questionable about answering this one. Because even though I don’t have any oral medication or injectable medication, there’s the GLP-1 patches from TikTok shop that I’ve been using. It’s helped me curb my appetite and lose some weight. I don’t know if there’s medicine in it or how it works but I’ve been using it and I’ve lost 15 pounds from it.”

This example shows that the evolution of weight loss products spawned by the increased popularity of GLP-1s adds potential for confusion. More research would be needed to explore this issue further, especially as the GLP-1 landscape continues to evolve.

GLP_MEDNOW: The second question in this series asks if respondents are *currently* taking GLP-1s. Six respondents answered ‘yes’. The remaining questions in this section were, therefore, tested on only six respondents.

GLP_MEDRX, GLP_MEDINTO, and GLP_MEDACT: This set of questions asks whether the respondent has a prescription from a doctor or other health professional for this medication (*GLP_MEDRX*), and if this person provided information about the type of nutrition (*GLP_MEDINTO*) and physical activity and exercise needed for those who take this medicine (*GLP_MEDACT*).

All six respondents answered ‘yes’ to having a prescription from a doctor or other health professional for this medication (*GLP_MEDRX*) and were, therefore, asked the two follow-up questions. When probed what they were thinking regarding doctor-provided information about diet and exercise, the examples respondents offered were commensurate with the intent of both questions. One respondent said, “She [doctor] mentioned to make sure that your protein intake is high – because you can lose a lot of muscle mass on this drug. And to keep an active lifestyle – try to find activity in whatever you can.” Another respondent shared all the information the doctor offered: “They [doctor] kind of ran me through the side effects first and informed me of that. And informed me that being active was important and eating a nutritious diet is important.” These questions were well understood and interviewers had no need for the ‘read if necessary’ text for either *GLP_MEDINTO* (diet) or *GLP_MEDACT* (exercise).

GLP_DISP2: The next set of questions asks from where respondents got their prescription or medication. Respondents answer ‘yes’ or ‘no’ to each of the following items:

GLP_RX12Ma	A primary care doctor or a specialist, filled at a pharmacy
GLP_RX12Mb	An online provider like Weight Watchers or Noom that provides medication and helps you plan a healthy diet and exercise routine
GLP_RX12Mc	An online company like Hims and Hers that only provides medication
GLP_RX12Md	A medical spa or cosmetic medical center
GLP_RX12Me	Somewhere else

Some respondents had straightforward experiences. They went to their doctor, got a prescription, and had it filled at a retail pharmacy. However, there are instances where the process deviates from this traditional process. This complicates the judgment process for respondents because the other options can seem to run together or do not quite fit their understandings. The following is an example of a respondent who has used multiple methods of obtaining GLP-1 medication. By her account, she has used a wellness spa, Ro, Remedy Meds, and Good Life. She answered ‘yes’ to all except GLP_RX12Ma (primary doctor, filled at a pharmacy). Her narrative is cited at length to convey the complexity of her experience:

“I went to multiple places.” *Tell me why and how.* “The first place I went was like a wellness spa. And how I ended up there I was coming from church and they had signs posted [on a lamppost]. I took a screenshot and I called. I had an online visit with their doctor. And they talked about all the weight loss and all that jazz. What ended up happening is some other company – I forgot the name of it – they [the initial wellness spa] ended up going out of business. I had to look for another place to go if I wanted to say on tirzepatide. From there I end up going to Ro because they sell the authentic version of Zepbound. And then their prices went up. Then next month would’ve been \$400 and I was like, ooh. So here I go again looking on the Internet. And then I found a plethora of places. I think the marketing of this stuff has increased. So, I went from Ro to some place called Remedy Meds or something like that. They offered it for \$199 [a month]. I was like, wow! And so that’s how these transitions happened.” *Earlier you said that now you use Good Life?* “They offer a higher dose [of tirzepatide] at a cheaper rate. I found that out on Reddit...And this one you don’t actually speak to a doctor. You just answer questions on a computer.”

The above respondent was probably correct to answer ‘yes’ to all except GLP_RX12Ma, but her story reveals all the factors she took into account to answer what, on the surface, seems like a straightforward question. Her experience may not be unique. The ongoing proliferation of options for obtaining GLP-1s makes it a challenge for survey

questions to reflect quickly evolving realities so that respondents can easily and accurately report their experiences.

GLP_COMPMED: The question asking whether a respondent has taken a generic, compounded version of GLP-1 seemed to create no confusion or response error. Three of the six respondents answered ‘yes,’ and their narrative supports their survey response. For example, one respondent reported that her doctor’s office orders the compound which she then picks up. She said, “They [doctor’s office] get shipments of their compound...they have a monthly option where they pre-fill the vials for you and that’s a fraction of the cost [of ordering three months at a time].”

GLP_DISP4: The next set of questions asks about respondents’ GLP-1 dosage patterns in the past 12 months. Respondents answer ‘yes’ or ‘no’ to each of the following items:

GLP_DOSEa	You skipped doses of this medication.
GLP_DOSEb	You took less of this medication than prescribed.
GLP_DOSEc	You delayed filling a prescription for this medication.
GLP_DOSEd	You stopped taking this medication entirely.

If the respondent answered ‘yes’ to any of the above, they were asked if it was because of cost and/or because it was not available or out of stock at their pharmacy.

Respondents were able to answer these questions easily, with one exception. One respondent had difficulty due to the manner in which she takes her compounded GLP-1. Rather than take the fully prescribed dose once a week (due to side effects), she takes a micro dose every three days. This difficulty resulted in response error because she answered ‘yes’ to GLP_DOSEd (stopped taking entirely). In describing her experience, the interviewer realized she never actually stopped taking the medication entirely. The respondent said:

“There was a period that I stopped taking it. I said I stopped taking it because it was not three days. I’m used to taking it every three days. So there was a period where I stopped taking it every seven days. And that period was just the transition period, one vendor to the next.” *What was the longest time you ever went between doses?* “Put three days. So I’ve been consistently taking it every week since February [laughs]. I just lost access to my every-three-days vial amount...So in my mind, when I heard that question, I was like, oh yeah, definitely that period. But I’ve only gone three days without the medication.”

This respondent was deciding her own schedule (and dosage) for taking GLP-1s. Her ability to obtain the medication on her own – without the assistance of a physician – was periodically interrupted, as she sought out different and more affordable sources of the

medication. Therefore, she initially answered ‘yes,’ because challenges with affordable access caused her to stop taking GLP-1s according to her self-determined timetable.

This is another example of the complexity of experiences that are emerging around the GLP-1 phenomenon – people have increasingly more ability to decide their own dosage amount and schedule.

GLP_INSPAY and GLP_SYMPTOMS: The final two questions in this section ask if health insurance paid for none, part, or all of the cost for GLP-1s and whether the respondent reduced or stopped taking the medication due to any side effects or symptoms. Neither question posed difficulty and no response error was detected. Only one respondent stopped taking the medication due to side effects. He attributed this need to sometimes having to reduce his dosage due to the unpredictable nature of compounded GLP-1s. He said:

“In the compounded world it’s different because you’re not dealing with somebody that has a name that you can go knock on [their] door. You’re trusting that a stranger that’s making this medicine is making it right. Not making it cheap. Not cutting any corners. And the effects are like hunger management. Sometimes I couldn’t get out of bed because just the thought of drinking water was making me nauseous. But at other times it’s like I can sit and eat ice cream all day and not bat an eye.”

Section 4: Lung Cancer Screening

This section is preceded by questions establishing whether respondents have ever smoked cigarettes. (These are standard questions on the National Health Interview Survey and were not evaluated here.) Of the 20 respondents in this study, 14 reported ever smoking and were, therefore, filtered into the lung cancer screening section.

LUN_AVERAGE, *LUN_AVGCIG*, and *LUN_AVGPACK*: The initial questions in this section seek to establish the extent to which a respondent smoked. The question, *LUN_AVERAGE* asks whether it would be easier for the respondent to report the average number of cigarettes or the average number of packs that they smoked per day. In the interviewer-administered format of the cognitive interview, most respondents misunderstood this as asking how many cigarettes or packs they smoked (not their preference for reporting by number of cigarettes or by number of packs). This confusion is unlikely to occur in a web format.

Estimates: In reporting the average number of cigarettes (or packs) that they smoked per day, most respondents could only provide an estimate, not an exact number (as formatted in the question). This was true irrespective of the frequency with which a respondent smoked. For example, one respondent answered seven cigarettes and said, “That’s an estimate. Because it can vary. I could be going through something that

day and I smoke a little more cigarettes.” Some of these estimates were very rough, to the point of being guesses. One respondent admitted, “I think I was just guessing. It might not be as many. I don’t even know where six came from. I just said six.” Other respondents arrived at their estimate by attempting to determine an overall average. During probing one respondent said, “How did I arrive at eight cigarettes? I just averaged it out. Sometimes it might have been a little bit more depending on if I was going out or something like that. You’re with friends or you’re having some cocktails, you’re gonna have more.” No respondent provided what they would call an exact number of cigarettes or packs.

Difficulties for light smokers: While all (including heavy) smokers gave estimates of daily smoking frequency, answering this question was more difficult for light smokers. This group smoked so little that the “per day” timeframe was inadequate. Some respondents compensated by simply reporting the number in a way that reflected their reality (“It’s like one cigarette a week.”) instead of the parameter given by the question. Others tried to fit their number into the timeframe by reporting fractions. One respondent answered ‘.005’ and explained, “It would be in the decimal. It was primarily in college, and it would be one or two a week.”

LUN_AVGCIG2 and LUN_AVGPACK2: Two follow-up questions were included in the event that respondents initially refused to report how many cigarettes or packs they smoked per day. The follow-up question read: *The answers people give us about their cigarette smoking are important to this study’s success. We know that this information is personal, but please remember your answer will be kept confidential.* In the cognitive interview setting, no one refused to answer questions about their cigarette smoking – it simply did not strike respondents as a sensitive question – so these questions could not be evaluated.

LUN_DOCASK and LUN_NOTSHARE: One question (LUN_DOCASK) asked respondents if their doctor ever asked them if they smoked cigarettes. In answering this question, respondents included questions on intake forms (“Just on the intake form. It was like, ‘have you ever smoked?’”) and actual discussions with their provider (“When they’re chatting with me, you know that’s one of the questions that they usually ask in the very beginning.”). Note that, while a ‘read if necessary’ is offered to clarify that respondents should include both paper or online forms completed before the health care visit *and* conversations held at the time of the visit, interviewers did not need to read this instruction. Respondents included both scenarios without being instructed.

LUN_NOTSHARE asks if respondents ever chose *not* to share with their doctor that they smoked cigarettes. Most respondents answered ‘no,’ many stating that they hide nothing from their doctor (“I tell him everything.”). A couple respondents noted that it’s difficult to hide smoking even if they wanted to. One respondent said, “I’ve always told them. First off, you can smell it on me [chuckles], you know? So why lie?”

Respondents who answer that they have chosen not to share with their doctor that they smoke cigarettes are then asked follow-up reasons why. Only one respondent answered 'yes' and proceeded through the follow-up questions (with no difficulty). As a result, these questions were unable to be evaluated.

LUN_CANCER and LUN_LCSCREEN: One question (LUN_CANCER) asks if the respondent has ever been told by a doctor or other health professional that they had lung cancer. All respondents answered 'no'. The next question begins with a list of lung cancer screening recommendations and then asks respondents if, before this survey, they knew the recommendations for who should get lung cancer screening. Most respondents answered 'no' ("No. This is the first time I heard it."). Some wondered why their physician never communicated to them these recommendations. One respondent said, "No I did not and that's very interesting...It's some good information. That's really good information. I think health professionals, primary care doctors, should tell you that."

For respondents who answered 'yes,' it was difficult to determine whether what they knew actually aligned with the official recommendations. Sometimes such an alignment seemed absent. For example, when asked who he thought should get screened and where he obtained this information, one respondent said, "I mean, just PSA announcements on TV and just general knowledge if you are a heavy smoker or around second-hand smoke or have a family history, then you should be getting screenings. Just absorbing general knowledge." Other respondents answered 'yes' but admitted to being uncertain whether they really knew what the recommendations were ("I think so, yes.").

Additionally, no respondents who answered 'yes' reported obtaining this information from a health care provider. The Internet and television were cited as sources of information ("Reading online and the news and just so on, you try to educate yourself and learn about these different procedures."). Friends were another source ("I know about it. I have a few friends that did it [got a CT scan]. They still smoke, they're heavy smokers.").

In sum, this question captures whether respondents think they know the recommendations for lung cancer screening. Importantly, most respondents did not arrive at an answer by 1) comparing what they thought they knew against the recommendations presented in the question and then 2) answering 'no' when their previous knowledge did not match these stated recommendations. They simply answered based on what made sense to them personally, without reflecting on the recommendations.

LUN_BENEFIT and LUN_HARMS: Two questions ask if, in the past 12 months, a doctor or other health professional talked with the respondent about the benefits and harms of having a scan to check for lung cancer. These could not be extensively tested because only one respondent answered 'yes.' No error was detected, even for one

respondent who answered ‘no’ but did have some form of lung cancer screening. She said, “The only doctor that mentioned it in all those years said, ‘What about getting a lung cancer screening?’ He gave me X-rays. And that’s what I did.”

LUN_LOWDOCT and *LUN_CTSCREEN*: *LUN_LOWDOCT* asks if the respondent ever had a low-dose CT scan of their chest area. Seven respondents answered ‘yes.’ The follow-up question (*LUN_CTSCREEN*) asks if the scan was to check for lung cancer; all respondents correctly answered ‘no.’ For example, probing revealed that the CT scans respondents reported were for other cancers (breast), accidents, bronchitis, and diagnosis for heart trouble.

Even though no response error was found, it is possible for a degree of uncertainty to occur, given the line of questions (prior to this one) that focus on lung cancer screening. For example, one respondent needed confirmation and asked, “Is just to check for lung cancer or is this just a procedure that I went through before?” The interviewer repeated the question and he said, “Yes, I did.”

LUN_DISP3: The next set of questions ask respondents why they have not had a low-dose CT scan for lung cancer screening. They are offered a list of reasons, to which they answer ‘yes’ or ‘no’ to each. These include:

LUN_NOREC	My health care provider never recommended a lung cancer screening to me.
LUN_HEALTHY	I am healthy.
LUN_BLAEMD	I am afraid of being judged or blamed for smoking.
LUN_NOTIME	It is hard to find time to get a lung cancer screening.
LUN_TRANSPO	It is hard for me to get reliable transportation to get a lung cancer screening
LUN_EXPOSE	I am concerned about being exposed to radiation from a low-dose CT scan.
LUN_CONCERN	I am concerned about other harms from getting a low-dose CT scan.
LUN_NORISK	I am at low or no risk of getting lung cancer.
LUN_ANXIOUS	Knowing the results would make me anxious or stressed.
LUN_COST	I am concerned about the cost of screening.
LUN_SCOTHER	Some other reason.

Respondents had no trouble with this list of reasons, except one. *LUN_NORISK* operated as a double-barreled question because it implicitly assumes respondents agree they are low risk. As such, an answer could reflect a respondent’s agreement or disagreement with being low risk of developing lung cancer or the answer could mean (as intended) that a perceived low-risk level influenced their decision not to have a lung cancer screening. This is notably problematic for those who believe they have a high risk of developing lung cancer because they must disagree with (i.e., answer ‘no’ to) *LUN_NORISK*. This leaves them with no ability to answer whether this high-risk level is

a reason they have not gotten a CT scan. For example, one respondent asked, “How do I answer that? Yes? I am [at risk]?” Similarly, another respondent said, “No, because I guess I am [at risk] because I smoke cigarettes. So, I’m at risk, right? Is that...So I don’t know if I should say ‘yes.’ I guess I’ll put ‘yes’ because I am [at risk].” In essence, the question is double-barreled because it inadvertently presupposes that a respondent believes they are at a low risk of getting lung cancer.

LUN_DISP6: The final set of questions in this section includes a series of statements about smoking and lung cancer, to which respondents are asked whether they strongly agree, somewhat agree, somewhat disagree, or strongly disagree. The statements are:

LUN_BLAKE	People with lung cancer are to blame for their illness.
LUN_CHOICES	People with lung cancer have made poor lifestyle choices.
LUN_STILLRISK	You are still at risk of getting lung cancer even if you do not smoke.
LUN_ASSUME	If someone told me they had lung cancer I would assume it was because they smoked.

No difficulties were observed with respondents answering these questions. Respondents’ judgments were based on one of three patterns. One group linked smoking directly to lung cancer. For example, one respondent answered ‘strongly agree’ to LUN_BLAKE and explained, “The information I’ve been made aware of, as far as lung cancer, you only see that related to cigarette smoking or smoking in general.” Another respondent thought of her personal experience when she answered ‘strongly agree’ to LUN_CHOICE. She said, “I take responsibility. No one shoved a cigarette in my mouth. I took it upon myself to smoke. I could’ve stopped a lot earlier than I did. It’s a lifestyle choice, almost like being an alcoholic.”

However, another group of respondents understood that smoking was not the only possible cause of lung cancer. This group tended to strongly disagree with the statements (or strongly agree for LUN_STILLRISK). Environmental factors (“People do get lung cancer from other issues, maybe asbestos or whatnot, who knows?”), second-hand smoke (“I do know people that have died from lung cancer from secondhand smoke. They never smoked a cigarette in their life.”), and heredity (“Sometimes cancer runs in your family, so it could be hereditary. So that’s why I disagree with all of that.”) were identified as possible causes of lung cancer.

A third group may be described as seeing lung cancer as likely caused by smoking but acknowledged that there can be other reasons, such as those cited above. This group, rather than answer ‘strongly agree,’ tended to answer ‘somewhat agree’ or ‘somewhat disagree’ as a way to make room for that uncertainty. The interesting point is that agreement could go either way. It’s the word ‘somewhat’ that is the important qualifier in these instances. For example, one respondent who answered ‘somewhat agree’ explained, “That’s if they smoked cigarettes or if they worked around asbestos. There’s been a lot of work – about 40, 50 years – that smoking causes cancer. And other

occupations working around chemicals.” Conversely, using the same logic another respondent answered ‘somewhat *disagree*.’ She said:

“I slightly disagree because – it’s crazy I was just watching a documentary the other day about Christopher Reeve and I saw that his wife contracted lung cancer and she didn’t smoke a day in her life. So sometimes that’s not the case...You can’t just assume that [smoking caused cancer] because there’s many different factors. It isn’t just a one-way street. There are many different ways to get there.”

For respondents in this group, there is no discernable line between agree and disagree. Therefore, by opting for a response that includes ‘somewhat,’ these respondents are conveying the idea that multiple factors can play a role in precipitating lung cancer, including but not limited to smoking.

Section 5: Fertility and Reproductive Health Services

Ten respondents were asked the questions in this section (the other ten were either male or over 49).

FER_PERAGE and *FER_PREG*: The first two questions in this section ask how old the respondent was when she had her first menstrual period (*FER_PERAGE*) and if she is currently pregnant (*FER_PREG*). Most respondents gave an estimate of their age at first menses (“I believe I was 13. I might have been 12. Are you in 6th grade when you’re 12? I think 12.”), but one remembered exactly (“I remember the day it happened too. It was the day I bought [new album]. And I was looking at the booklet in the bathroom and I was like, whoa!”). All respondents answered ‘no’ to being currently pregnant and expressed absolute certainty with their answer.

FER_PREGNUM, *FER_LIVENUM*, *FER_SURGERY* and *FER_PHYSPOS*: The first question in this grouping (*FER_PREGNUM*) asks how many times a respondent has been pregnant in her life. Generally, respondents answered without issue, even when they had potentially sensitive experiences. For example, one respondent had no reservations about explaining her difficult experience to the interviewer. She said:

“I was pregnant and I found out when I fell out on the floor, passed out, at work, in orientation week. Ended up being where it was not the right time because my grandmother was pretty much dying. COVID was high and coming in hot during that time and there was a lot of respiratory problems with patients. I was pretty much scared that I would either get COVID and possibly die trying to give birth to a child or give birth and the child have a lot of respiratory problems because of the COVID situation...The stress of life, that was not a quality of life that I think I would be able to carry a child successfully through. So I did have an abortion and, yeah.”

However, at least one respondent reacted with more awkwardness. When asked the question she first gave an extended nervous laugh and said, “I’m sorry.” [Pauses and

thinks.] “I want to say eight.” Interviewers were largely able to develop rapport with respondents, such that most answered this question without hesitation. However, the sensitivity of the question may be diminished even further in a self-administered web format.

On the other hand, no difficulty or obvious discomfort arose when respondents answered the number of babies that were born alive (FER_LIVENUM) or whether they ever had surgery or other medical procedures to make it impossible to have children (FER_SURGERY). Hysterectomy and tubal ligation were cited as procedures that several respondents had. Respondents also had no difficulty answering whether, as far as they knew, it was physically possible for them to have a baby (FER_PHYSPOS).

FER_PLANS, FER_INTEND and FER_EXPECT: Respondents seemed to understand the difference between the first two questions – wanting to have a baby versus intending to have a baby. Several respondents answered these two questions differently (for example, yes to one and no to the other). Their rationale was tied to health concerns and physical limitations. For example, one respondent answered ‘probably yes’ to wanting to have another child and ‘no’ to intending to have another child. She said:

“I do want to have kids, but I also think about being 36 and in the healthcare field they said that’s geriatric age for women to have children. And when I worked in ICU at the hospital, I saw firsthand how it can affect women...I do want kids, but I don’t want to lose my life or to jeopardize a child’s life in the process of something like that.”

Another respondent also answered ‘probably yes’ to wanting to have another child but ‘no’ to intending to have another child. In explaining the difference, she said:

“I love children. But I wouldn’t do it again, though, because I had three C-sections and it would have to be another C-section. So that’s really why when I went and got my surgery. But if someone else could have the baby for me, I would take it [laughs].”

The third question, FER_EXPECT, asks respondents when they expected their next child to be born (within the next two years, 2-5 years from now, or more than 5 years from now) but it could not be adequately evaluated because only four respondents filtered into this question. However, no response difficulty was observed for those four. When answering the question, respondents thought about when their life circumstances may be optimal for having a child. For example, one respondent said:

“I’m 27 and I don’t feel like right now I’m financially stable to even take care of another human being. I have enough for me, I can’t add a little person right now. Once I get more stable and have my career where I want it to be, I will take the steps to having a child.”

FER_SEXMALE and FERSEX12M: The first question asks if the respondent, at any time in her life, had sexual intercourse with a male. The second question asks whether the respondent had sexual intercourse with a male partner in the last 12 months. These questions, in the interest of time and because similar questions were evaluated in another study (7), were not evaluated.

FER_PREVENT, FER_WANTPREG, and FER_WHYNOBC: The first question begins by stating that there are a variety of methods that some people use to prevent pregnancy or to prevent sexually transmitted disease [STDs] and then asks respondents if they used any method the last time they had sexual intercourse with a male partner. In addition, the interviewers were provided a fairly comprehensive list of methods, with instructions to show the list to respondents if needed. However, this list proved to be unnecessary. The root question stood well on its own – in no case did respondents express confusion or uncertainty and need to see the list. Moreover, probing revealed no response error. For example, some respondents thought of their use of these methods for STD protection (“Yes, we used condoms [for STD prevention].”) while others cited birth control purposes (“I also think that [birth control pills] contributed to a lot of the imbalance I had. And my weight fluctuation.”).

For respondents who answered ‘no,’ the next two questions ask about reasons for not using a method of birth control. The first question (*FER_WANTPREG*) asks if the reason was because the respondent, herself, wanted to become pregnant. The second (*FER_WHYNOBC*) provides a list of reasons for not using birth control and asks the respondent for the *main* reason. Only four respondents filtered into these questions, so they could not be fully evaluated. However, it is important to note that the list in *FER_WHYNOBC* did miss two reasons that might be worth including. One was religious reasons (“I would say ‘other reason.’ Um, religious reasons.”) and the other was infertility in the respondent’s partner (“There’s a zero percent possibility to conceive because of a procedure that was done, not on my end. But the person in question.”)

FER_DISP: The next set of questions ask about recent medical visits for family planning services and other types of pregnancy and health care services for women. Each of the following questions asks if the respondent received the service in the past 12 months.

<i>FER_BCDOC</i>	Have you received a method of birth control or a prescription for a method from a doctor or medical care provider?
<i>FER_TESTBC</i>	Have you received a check-up or medical test related to using a birth control method?
<i>FER_INFOBC</i>	From a doctor or other medical care provider, have you received counseling or information about birth control?
<i>FER_INFOSTER</i>	Have you received counseling or information about getting sterilized?
<i>FER_PLANB</i>	From a doctor or other medical care provider, have you received emergency contraception pills, a prescription for emergency

	contraception pills, or counseling or information about emergency contraception pills?
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Most respondents answered ‘no’ to the above questions so they could not be fully evaluated. However, one finding is that the initiation of these services may not always be prompted by the respondent. For example, one respondent answered ‘yes’ to FER_TESTBC. When asked why, she explained that during a well-woman visit her doctor suggested she go on birth control – it was not her idea. She said, “They were trying to put me on birth control and I was telling them, no, I don’t want to go on birth control. I don’t want to get the shot [Depo-Provera].” The respondent made it clear in the interview that the health care provider was pressing her on something she did not want. The wording of the question does not specify but does suggest that birth control services were received at the behest of the patient/respondent. This may not always be the case.

The only other notable finding was for FER_INFOSTER. One respondent was uncertain of the meaning (“Sterilized? What do you mean?”). This prompted the interviewer to refer to the ‘read if necessary’ instruction (“This includes counseling about a surgical procedure that makes female pregnancy impossible, most commonly a tubal ligation.”), which clarified the confusion and allowed the respondent to correctly answer ‘no’. This suggests that including the instruction on the screen in a web-based format may be beneficial.

FER_PAPTEST, FER_PELVEXAM, and FER_STDTEST: Respondents had no difficulty answering whether they received a Pap test or pelvic exam in the past 12 months. Extensive probing was not used in the interest of time and because similar questions have been tested in the past (7, 8) which have consistently shown that women understand these types of questions. Respondents also had no difficulty answering if they had been tested for an STD in the past 12 months. All reported receiving this test as part of a routine checkup (“I get a full panel testing every year.”).

FER_FERTILITY, FER_FERTNOW, and FER_DOCPREV: FER_FERTILITY asks if the respondent has ever gone to a medical provider to talk about ways to help her become pregnant. Only two respondents answered ‘yes’ to this question, so it could not be adequately evaluated. One respondent who answered ‘yes’ described a straightforward experience. She said, “We’re just getting counseling, trying to find out what days and how many eggs [at age 45], just checking that out. But we’re trying to do it naturally.” However, the other respondent who answered ‘yes’ described a situation that might not track with question intent. She explained, “It was my annual. They were asking me, ‘Do you want to get pregnant?’ No, no, no. Because of all the pain I was going through with my menstrual...but they were like your age, you’re still young, you’re not married. No, no, no.” This is likely response error because the respondent did not, herself, seek out ways to assist getting pregnant. Instead, her health care provider was suggesting that, despite her protestations, the respondent will eventually want to become pregnant.

Further evaluation of this question may be beneficial to the extent that the ‘read if necessary’ instruction may prove helpful when provided on-screen in a web format.

FER_FERTNOW could not be evaluated – only two respondents were asked this question; both answered ‘no.’ Similarly, FER_DOCPREV also could not be evaluated because only one respondent answered ‘yes.’ She was including this topic in the same conversation she had with her health care provider about ways to help her get pregnant at age 45. (“Yeah, getting all the information I could get so, yeah, that [preventing miscarriage] was part of it.”)

Conclusion

Overall, respondents were able to answer questions in each section with little error and minimal difficulty, and, to a large extent, interpretations fell within the scope of question intent. However, a few noteworthy issues arose in each section of the questionnaire. A few main points are summarized below.

Section 1: Lyme Disease Prevention Methods

Different constructs were measured by the questions on Lyme disease prevention. Respondents who had no direct experience with ticks were more likely to shift the construct to other types of bugs, particularly when the question itself omitted any reference to ticks. Interestingly, this pattern was observed not only among respondents who resided in low-prevalence states but also those from high-prevalence states. In other words, living in a state with higher rates of Lyme disease does not automatically translate into having direct exposure to ticks or awareness of Lyme disease.

Section 2: Complementary and Integrative Health

Most respondents expressed limited or no knowledge of CIH and outwardly wondered if they were supposed to be aware of these practitioners and practices. Additionally, even respondents with some experience with CIH – including those who tried a modality only once – are not always fully educated on them and may, therefore, answer some questions incorrectly.

Section 3: GLP-1 Medication Access

While respondents were familiar with GLP-1s, access to this class of drugs is quickly evolving and growing more complex, making it difficult for respondents to answer some questions. The proliferation of acquisition methods (direct home delivery vs. scripts for retail pharmacies), providers (on-line questionnaires on TikTok vs. in-office physician oversight), types of GLP-1s (name brand vs. compounded and counterfeit versions), and drug delivery modes (injection, pill, patches) have broadened the field, making some respondents unsure whether their experience should be included in the questions. Additionally, respondents with experience in more than one mode of access may be unsure whether and how to include less conventional methods of GLP-1 access. The

speed of this evolution, as new opportunities emerge, poses a challenge to question design.

Section 4: Lung Cancer Screening

It was difficult for smokers to offer accurate answers about smoking frequency because the interval/ratio response option of daily use assumes a regular and somewhat frequent behavioral pattern. This is particularly true for light smokers. Their patterns are random and sparse enough to make answering on the basis of daily use difficult if not impossible.

Section 5: Fertility and Reproductive Health Services

Questions on fertility and reproductive health focus on the respondent as the person initiating a conversation on these topics. Some evidence in this study suggests other types of experiences may be captured, particularly without the benefit of the 'read if necessary' instruction. It is unclear whether conversations initiated and driven by the healthcare provider (not the respondent/patient) will be captured, especially when the respondent had no interest in such a conversation and, therefore, found the experience to be salient enough to include.

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Appendix I: Question-by-Question Analysis

LYM – LYME DISEASE PREVENTION METHODS

LYM_DISP

Lyme disease is an infection spread by the bite of a black-legged tick. How likely are you to use each of the following methods for preventing Lyme disease? Would you say definitely, very likely, somewhat likely, somewhat unlikely, very unlikely, or would you definitely not do this?

Findings: All 20 respondents were administered the Lyme disease questions, expressed no comprehension difficulties, and all were able to provide answers. Respondents came from a variety of states/jurisdictions, including areas with higher and lower prevalence of Lyme disease. Experience with ticks did influence the interpretation of the questions.

Respondents who had experience with ticks remained focused on ticks and Lyme disease across the four questions. For example, in relaying her perspective, one respondent said, “I am, almost every weekend, out fishing with my family. And we’ve had a lot a scares with my little sisters where they would come home with ticks.” This experience guided her answers. Another respondent also remained focused on ticks because he had a childhood experience that remained relevant to him. He said, “I was bitten by a tick as a child. They caught it before it got stuck on me. But I’m very cautious.” In both cases, survey answers across all four questions were reflections of respondents’ direct experience with ticks. However, those with little-to-no experience tended to think about bugs in general or the chances that they would be exposed to ticks to begin with. This was based on home environment (“Because I’m more in a city-type area.”) or on participation in activities that typically put people in proximity to ticks (“I just assume you would get Lyme disease if you go hiking in the woods and I really don’t do that. I don’t even go to the local park.”).

LYM_PREVA

If it were available, getting an annual vaccine to prevent Lyme disease.

- 1 Definitely
- 2 Very likely
- 3 Somewhat likely
- 4 Somewhat unlikely
- 5 Very unlikely
- 6 Definitely not

Findings: Many respondents made their judgments based on trust in vaccines in general. Some respondents rejected vaccines out of hand and answered on that basis alone. (“Definitely not. I don’t like vaccines.”) Others did not outright reject vaccines but did have a measured approach towards them. One respondent explained, “Before I run and get anything I like to hear experiences from other people of, oh, this new vaccine is giving everybody so-and-so [side effect]...That is where I’d make my decision.” A second respondent is only open to vaccines that target what she perceived to be serious illness. She said, “For me, I vaccinate if it’s a life-threatening disease. Not that Lyme disease isn’t potentially life threatening. But it’s not tuberculosis. Or malaria.” Another respondent weighed the chances of contracting Lyme disease against the need for vaccination:

“I just don’t see the need to be pre-vaccinated for something that might not happen. So the likelihood of me coming in contact with a tick is, I don’t know what the percentage is, but I would not agree to get vaccinated in advance because I *might* run into a tick. I’m not in agreement with that.”

Other respondents focused on their feelings about injections overall, often expressing a fear of needles. One respondent said, “I’m kinda terrified of needles so I try to avoid them as much as I can. So as far as getting shots or vaccines, I try to avoid it.” Others were less “terrified” but still expressed dislike of needles. One respondent said, “I tend to have a small thing with needles anyway.” The central takeaway for the vaccine question is that judgments were not necessarily made on the basis of avoidance of Lyme disease but rather on the basis of trust in vaccines or openness to injections.

LYM_PREVB

Taking a single dose of antibiotics within 72 hours of a known tick bite.

- 1 Definitely
- 2 Very likely
- 3 Somewhat likely
- 4 Somewhat unlikely
- 5 Very unlikely
- 6 Definitely not

Findings: Respondents had no difficulty with this question and because all were familiar and comfortable with antibiotics (versus a hypothetical Lyme vaccine), they answered in some range of ‘likely’. One respondent answered ‘definitely not’ to vaccines but ‘definitely’ to this question. She explained the difference, “I’m very cautious. I’d rather take medicine [antibiotic] before I take a vaccine.” Another respondent also answered definitely and explained, “If I were to come into contact with a tick, I definitely would want to have some type of antibiotic as a result of being bitten.”

LYM_PREVC

Using bug spray on your skin or clothing.

- 1 Definitely
- 2 Very likely
- 3 Somewhat likely
- 4 Somewhat unlikely
- 5 Very unlikely
- 6 Definitely not

Findings: Some respondents lacked any direct experience with ticks. This influenced their interpretation of this question (and the next). Specifically, they were prone to include experiences that were not about ticks. For example, one respondent thought of her overall dislike of bugs in answering ‘definitely’ to using bug spray. She said, “I don’t like bugs. I don’t like bugs touching me, I don’t like bugs on me and that’s one of my key things is when I go out and I know there’s a lot of mosquitoes.” In fact, mosquitoes were cited by multiple respondents. In several cases respondents discussed their negative reactions to mosquito bites. One respondent said she would ‘very likely’ use bug spray “because I’m allergic to mosquitoes, so I need to be careful of mosquito bites.” Similarly, another respondent said, “I have bad reactions to mosquito bites. So I’m always using Off and stuff like that. I don’t enjoy the smell but it’s not that big of a trade-off to prevent me from getting bit all over the place by mosquitoes so that’s why I said ‘definitely’ to that question.” For these respondents, the essence of the questions was avoidance of bugs in general not avoidance of ticks/Lyme disease.

Relatedly, although the questions are phrased as hypothetical behavior (“How likely are you to use each of the following methods...”), respondents often answered this question based on their *actual* behavior. For example, one respondent thought about her use of bug spray at work. She said, “I use it every day at work. We have flies and stuff. So that’s why I picked definitely.”

Finally, the lack of reference to ticks or Lyme disease in this question (and the next) along with the use of the generic term ‘bug spray’ (or ‘bug repellent’ in the next question) may have further encouraged those with little direct experience with ticks to think more generally about avoiding bugs.

LYM_PREVD

Wearing clothing that has been pretreated with a long-lasting permethrin [pr-MEH-thruhn] bug repellent.

- 1 Definitely
- 2 Very likely
- 3 Somewhat likely
- 4 Somewhat unlikely

-
- 5 Very unlikely
 - 6 Definitely not

Findings: Because respondents were less familiar with the method of repellent, they were less likely to agree with this than with the previous question on bug spray. For example, one respondent answered 'somewhat unlikely' and explained, "I would have to do research. And see what are the effects, what are the risk factors. It's the skeptical person-slash-hypochondriac in me."

CIH - COMPLEMENTARY AND INTEGRATIVE HEALTH

CIH_HLTH12M

During the past 12 months, have you seen any of the following practitioners for health reasons? [Mark all that apply – SHOW SCREEN IF NEEDED SO R CAN SEE NAMES]

- Ayurvedic Doctor or Vaidya
- Curandero
- Hierbero or Yerbera
- Native American Healer or Medicine Man
- Shaman
- Sobador

Findings: All 20 respondents were asked this set of questions. Many respondents had never heard of most of the CIH practitioners and as a result expressed a degree of perplexion. A couple respondents were confused by the language and whether it should apply to them. One respondent said, "The Spanish sounding ones, I didn't even know what you were talking about. I don't even know what it is." Another asked, "Should I be knowing this? [Laughs] Is this in a different language?" The interviewer replied that there were no definitions provided in the question, showed her the list of practitioners, and asked whether the respondent had ever visited any such practitioner. Seeing the names did not improve understanding. She replied, "I don't know what that [Heirbero] is. I don't know. I would need Google to translate what you're saying." Some respondents were confused to the point of forgetting that the questions were about health practitioners. For example, one respondent asked, "These are doctors you're mentioning? These are types of doctors?"

Although respondent lack of knowledge prompted no response error, the confusion could be offset by providing a sentence or two introducing the CIH topic, which was lacking in the cognitive interview test instrument. Findings here show the

importance of orienting respondents to the CIH section and, perhaps, to the idea that they are not necessarily expected to be familiar with every CIH modality and the associated practitioners.

CIH_HOMEO

During the past 12 months...Did you see a practitioner of Homeopathy for your health?

- 1 Yes
- 0 No

Findings: This question was not extensively tested due to only one user. Like the previous question, though, many respondents had never heard of homeopathy. For example, one respondent said, “Yes. I’m all for you being able to get better at-home [care] and using holistics. But I’m like, I’ve never heard of any of those terms. But homeopathy sounds pretty cool.” Never hearing the word before, she understood it to mean getting medical treatment at home. While she correctly answered ‘no,’ another respondent demonstrates the potential for response error when people are unfamiliar with CIH practices but try to make sense of the questions. His description draws into question whether what he experienced was truly homeopathy. He explained:

“I was having some stomach issues. And my gastro, they also did Eastern medicine and they thought it was all connected with stress and all that stuff. So, it was too expensive – I couldn’t keep going – but they wanted me to do a bunch of things. They were like laying hands on me and doing pressure and all that stuff.”

This respondent illustrates how others with little knowledge of CIH practices could similarly offer false positive responses.

CIH_REIKI

Did you see a practitioner for energy healing or Reiki for your health?

- 1 Yes
- 0 No

Findings: Only one respondent reported using Reiki because it was provided by a friend. Moreover, he only attended one session and understood little about the practice. He said, “It was provided by a friend of mine. They are a licensed professional but they did it for free. But I didn’t notice much of a difference.”

CIH_ACUPUN

Did you see a practitioner for acupuncture for your health?

- 1 Yes
- 0 No [GO TO CIH_TAICHI]

Findings: Acupuncture was by far the most recognized CIH practice, even among respondents who never used it (“Acupuncture I definitely heard. It’s something that I always wanted to look into. But everything else I never heard of.”). Acupuncture was not only recognized by most respondents, it was used by four of the five respondents who reported using any CIH in the past 12 months. No response error was detected. For example, one respondent reported, “[My doctor] wanted me to do acupuncture in my ankles because I pulled a ligament.” Similarly, another respondent said, “I had a severe car accident. So I had acupuncture in my neck.”

CIH_ACU12M

During the past 12 months, how many times did you see a practitioner for acupuncture?

- 1 Only one time
- 2 2-5 times
- 3 6-10 times
- 4 11-15 times
- 5 16-20 times
- 6 More than 20 times

Findings: This question could not be fully evaluated because it was tested on only four respondents. Respondents gave a range of answers and no response error was found.

CIH_ACUCOST

During the past 12 months, were any of the costs of seeing a practitioner for acupuncture covered by health insurance?

- 1 Yes
- 0 No

Findings: This could not be fully evaluated because it was tested on only four respondents; however, no response error was detected. Two answered ‘no’ (“With my old insurance it did not cover. They said it’s not part of the network or something like that, so it’s out of pocket.”) and two answered ‘yes’ (one who was covered by the Affordable Care Act).

CIH_TAICHI

During the past 12 months...Did you practice Tai Chi for your own health?

- 1 Yes
- 0 No

Findings: Tai Chi was the second-most recognized practice (behind acupuncture). Additionally, three respondents tried Tai Chi but only once (“I tried it once, but I don't regularly practice it, no.”) or very infrequently (“Yes. A little bit. On YouTube.”).

CIH_QIGONG

Did you practice Qi Gong for your own health?

- 1 Yes
- 0 No

Findings: This question could not be evaluated. All respondents answered 'no' and were unfamiliar with the term.

CIH_MUSART

During the last three months, did you create, practice, or perform music or other art forms for your own health?

- 1 Yes
- 0 No

Findings: In addition to respondents' overall lack of knowledge in this section, this item presented specific conceptual problems because the construct is unclear. As a result, some respondents included experiences that others excluded. For example, some respondents thought of the effect that art or music has on their mental health and answered 'yes'. One respondent answered 'yes' because she "loves music." When asked to elaborate, her description touches on the benefits music offers to mental health. She said, "I listen to a lot of gospel, like when I'm doing something. I'll just sit and I'll listen. Because I had a thing where I wouldn't think before I reacted and I would just fly off the handle."

This is similar to another respondent who uses painting to improve mental health. She said:

"I paint. I've been diagnosed with PTSD [post-traumatic stress disorder] and depression and anxiety. So I paint for my mental health. When I feel anxious or something I just go finish a painting or make something. I don't know, I really be creative."

While the previous two respondents' answers seem reasonably in line with question intent, other respondents excluded similar experiences. One respondent answered 'no' but described a similar situation. In retrospective probing the interviewer asked if the respondent ever engaged in art or music. When she replied yes, the interviewer asked her to explain. She said (words in italics are interviewer speech):

"I would paint for my peace of mind. I've painted something for stress relief." *Why did you answer 'no' here?* "I wouldn't have thought of it." *Why is that?* "Given the line of questions, I think maybe I was thinking this was trying to solve some actual physical health problem. And it wasn't done for that particular thing."

Another respondent also excluded activities that the first two respondents included. During probing the interviewer asked the respondent if she did art of any kind. She said:

“I do. I started trying to color. I started doing DIY [do-it-yourself] projects to get my mind off of certain things. Because I suffer from anxiety and depression really bad. I do little projects here and there to soothe my mind.” *Give me an example of a project.* “I do [phone] cases. I make hats.” *Why did you answer ‘no’ to this question?* “I don’t know. I think it was more the music part that I was focused on.”

These examples are possible false negatives because the respondents’ arts-and-crafts activities do help improve their mental health. However, while these respondents excluded applicable activities, another respondent included activities that might be seen as inapplicable. She was initially uncertain but ultimately answered affirmatively:

“Yes. Like a dance class?” (Interviewer repeats the question.) “Yes. I take music class.” *This was the only one you said ‘yes’ to. Tell me about this.* “I take a dance class and a Pilates class and sometimes a hip-hop class. At my gym. And it helps my health because I get my heart rate going. That’s why I take it.”

This respondent included gym workouts because the classes are set to music and involve dance moves, all of which she associates with improving physical fitness/health. While her interpretation is reasonable, it is unclear whether a cardiovascular exercise class at a gym is meant to be captured by this question. In sum, in assessing the intent of the question and making judgments about what activities to include, respondents came to opposing conclusions.

GLP – GLP-1 MEDICATION ACCESS

GLP_WEIGHT

How would you describe your weight?

- 1 Very overweight
- 2 Slightly overweight
- 3 About the right weight
- 4 Slightly underweight
- 5 Very underweight

Findings: Respondents easily answered this question. A common basis for response judgment was BMI (“My BMI. Even though they say BMI is not the most accurate in terms of health, it’s the only measure that I have.”). Another strategy was to compare current weight with a previous, more ideal weight (“Because I’m back at the same size

before I had children.”). However, people who see themselves in the process of losing weight may have a different thought process. One respondent lost 15 pounds in the past six months through the use of Ozempic. Although indicating to the interviewer that she was still in the obese category, she answered ‘slightly overweight’ in this question. When asked why, she said, “Because I’ve been on a weight loss journey for a while now and I’ve been shedding pounds but I’m just not really where I want to be. So that’s why I said ‘slightly overweight’. But I am working on not being obese.” Choosing ‘slightly overweight’ was her way of expressing that she is in the process of losing weight and is not as heavy as she once was, even if she is still obese by BMI standards.

GLP_LOSEWT

In the past 12 months, has a doctor or other health professional talked to you about losing weight to improve your health?

- 1 Yes
- 0 No

Findings: Respondents were correctly thinking of specific conversations they had with their health care provider. Sometimes the topic was raised by the physician. One respondent went in for a back problem and the doctor raised the weight issue. The respondent said:

“I stepped on the scale [at the Dr office] and it was in the 250’s and they were like, yeah, it could be a little lower. It’s obviously harder on your knees. Because I was complaining about some knee and back pain. And they were like if you brought the number down that would help.”

Other times the respondent raised the issue. One respondent noted how he visited the doctor expressly for the purpose of addressing his weight:

“I went to the doctor specifically for that kind of review to see where my health was at. And based on the bloodwork and scale, it was like, okay, you’re prediabetic and you’re overweight.”

GLP_MED12M

In the past 12 months, have you taken an oral or injectable medication for diabetes or weight loss, such as Ozempic, Rybelsus, Wegovy, Mounjaro, Zepbound, Saxenda, Victoza, Trulicity, Byetta, or Bydureon BCise? [Read if necessary: These are also known as GLP-1 medications and may contain semaglutide, tirzepatide, liraglutide, dulaglutide, or exenatide.]

- 1 Yes
- 0 No [GO TO NEXT SECTION – CIGARETTES]

Findings: Eight respondents indicated that they had taken a GLP-1 in the past 12 months and no error or confusion was observed. All respondents were aware of GLP-1 medications, even if they had never used them. Moreover, respondents were familiar with various name brands, especially Ozempic. For example, one respondent who never took a GLP-1 was asked if she heard of these medications. She said, “Yeah. Because Ozempic has incredible brand strategy. And advertising. How do you not know about it?” Those who were on GLP-1’s were captured by the question as intended. This included those taking name-brand GLP-1s (“Yes, Zepbound.”) and those taking compounds (“It was one of those generic GLP-1s through like HIMS or whatever.”). Because respondents accurately understood the question, interviewers never had to follow up with the ‘read if necessary’ text.

However, one case did arise that demonstrates the shifting and increasingly complex nature of GLP-1 medications. New delivery methods and online services have broadened the field, making some respondents unsure whether their experience should be included. For example, one respondent answered ‘no’ but was uncertain if the question was about name-brand GLP-1s or also products marketed as GLP-1:

“I was a little questionable about answering this one. Because even though I don’t have any oral medication or injectable medication, there’s the GLP-1 patches from TikTok shop that I’ve been using. It’s helped me curb my appetite and lose some weight. I don’t know if there’s medicine in it or how it works but I’ve been using it and I’ve lost 15 pounds from it.”

This example shows that the evolution of weight loss products spawned by the increased popularity of GLP-1s adds potential for confusion.

GLP_MEDNOW

Are you now taking this medication?

- 1 Yes
- 0 No [GO TO NEXT SECTION – CIGARETTES]

Findings: Six respondents answered ‘yes’. The remaining questions in this section were, therefore, tested on only six respondents. Respondents understood this question similar to the previous and no error was found.

GLP_MEDRX

In the past 12 months, did you have a prescription from a doctor or other health professional for this medication?

- 1 Yes
- 0 No [GO TO GLP_COMPMED]

Findings: All six respondents answered ‘yes’ to having a prescription from a doctor or other health professional for this medication. Probing was administered in the next two follow-up questions.

GLP_MEDINFO

Did the person prescribing your medication provide information about the type of nutrition needed for those who take this medicine? [Read if necessary: For example, eating enough protein and fiber, staying well-hydrated, or eating small portion sizes to reduce stomach discomfort.]

1 Yes

0 No

Findings: When probed what they were thinking regarding doctor-provided information about diet and exercise (this question and the next were probed as a set), the examples respondents offered were commensurate with the intent of both questions. One respondent said, “She [doctor] mentioned to make sure that your protein intake is high – because you can lose a lot of muscle mass on this drug. And to keep an active lifestyle – try to find activity in whatever you can.” Another respondent shared all the information the doctor offered: “They [doctor] kind of ran me through the side effects first and informed me of that. And informed me that being active was important and eating a nutritious diet is important.” Both questions were well understood and interviewers had no need for the ‘read if necessary’ text for either question.

GLP_MEDACT

Did the person prescribing your medication provide information about the physical activity and exercise needed for those who take this medicine? [Read if necessary: For example, getting moderate intensity exercise throughout the week or incorporating resistance or strength training into your routine.]

1 Yes

0 No

Findings: See previous question.

GLP_RX12Ma

In the past 12 months, did you get your prescription or medication from...A primary care doctor or a specialist, filled at a pharmacy.

1 Yes

0 No

Findings: This set of questions (GLP_RX12Ma – GLP_RX12Me) were probed together. Some respondents had straightforward experiences. They went to their doctor, got a prescription, and had it filled at a retail pharmacy. However, there are instances where the process deviates from this traditional process. This complicates the judgment process for respondents because the other options can seem to run together or do not quite fit their understandings. The following is an example of a respondent who has used multiple methods of obtaining GLP-1 medication. By her account, she has used a wellness spa, Ro, Remedy Meds, and Good Life. She answered ‘yes’ to all except this question (GLP_RX12Ma). Her narrative is cited at length to convey the complexity of her experience:

“I went to multiple places.” *Tell me why and how.* “The first place I went was like a wellness spa. And how I ended up there I was coming from church and they had signs posted [on a lamppost]. I took a screenshot and I called. I had an online visit with their doctor. And they talked about all the weight loss and all that jazz. What ended up happening is some other company – I forgot the name of it – they [the initial wellness spa] ended up going out of business. I had to look for another place to go if I wanted to say on tirzepatide. From there I end up going to Ro because they sell the authentic version of Zepbound. And then their prices went up. Then next month would’ve been \$400 and I was like, ooh. So here I go again looking on the Internet. And then I found a plethora of places. I think the marketing of this stuff has increased. So, I went from Ro to some place called Remedy Meds or something like that. They offered it for \$199 [a month]. I was like, wow! And so that’s how these transitions happened.” *Earlier you said that now you use Good Life?* “They offer a higher dose [of tirzepatide] at a cheaper rate. I found that out on Reddit...And this one you don’t actually speak to a doctor. You just answer questions on a computer.”

The above respondent was probably correct to answer ‘yes’ to all questions in this set except GLP_RX12Ma, but her story reveals all the factors she took into account to answer what, on the surface, seems like a straightforward question. Her experience may not be unique and points to the need for further investigation.

GLP_RX12Mb

An online provider like Weight Watchers or Noom that provides medication and helps you plan a healthy diet and exercise routine.

1 Yes

0 No

Findings: No specific difficulties were found for this item. See GLP_RX12Ma for how the question set functioned.

RX12Mc

An online company like Hims and Hers that only provides medication

- 1 Yes
- 0 No

Findings: No specific difficulties were found for this item. See GLP_RX12Ma for how the question functioned.

GLP_RX12Md

A medical spa or cosmetic medical center

- 1 Yes
- 0 No

Findings: No specific difficulties were found for this item. See GLP_RX12Ma for how the question functioned.

GLP_RX12Me

Somewhere else

- 1 Yes
- 0 No

Findings: No specific difficulties were found for this item. See GLP_RX12Ma for how the question functioned.

GLP_COMPMED

Compounded medications include the same active ingredients as popular name brand drugs but are not FDA-approved. They are made by specialized pharmacies and are often used as an alternative when a medication is in short supply. In the past 12 months, have you taken a generic, compounded version of this medication?

- 1 Yes
- 0 No
- 9 Don't know

Findings: No difficulties were found with this question. Three of the six respondents answered 'yes,' and their narrative supports their survey response. For example, one respondent reported that her doctor's office orders the compound which she then picks up. She said, "They [doctor's office] get shipments of their compound...they have a

monthly option where they pre-fill the vials for you and that's a fraction of the cost [of ordering three months at a time]."

GLP_DOSEa

During the past 12 months, were any of the following true for you? You skipped doses of this medication.

- 1 Yes
- 0 No

Findings: GLP_DOSEa through GLP_DOSEd were probed together. Respondents were able to answer these questions easily, with one exception, GLP_DOSEd, which is discussed below.

GLP_DOSEb

You took less of this medication than prescribed.

- 1 Yes
- 0 No

Findings: GLP_DOSEa through GLP_DOSEd were probed together. Respondents were able to answer these questions easily, with one exception, GLP_DOSEd, which is discussed below.

GLP_DOSEc

You delayed filling a prescription for this medication.

- 1 Yes
- 0 No

Findings: GLP_DOSEa through GLP_DOSEd were probed together. Respondents were able to answer these questions easily, with one exception, GLP_DOSEd, which is discussed below.

GLP_DOSEd

You stopped taking this medication entirely.

- 1 Yes
- 0 No

Findings: One respondent had difficulty due to the manner in which she takes her compounded GLP-1. Her example is discussed at length as it reveals the complexity in the evolving GLP-1 landscape. Rather than take the fully prescribed dose once a week

(due to side effects), she takes a micro dose every three days. This difficulty resulted in response error because she answered 'yes' to this question. In describing her experience, the interviewer realized she never actually stopped taking the medication entirely. The respondent said:

“There was a period that I stopped taking it. I said I stopped taking it because it was not three days. I’m used to taking it every three days. So there was a period where I stopped taking it every seven days. And that period was just the transition period, one vendor to the next.” *What was the longest time you ever went between doses?* “Put three days. So I’ve been consistently taking it every week since February [laughs]. I just lost access to my every-three-days vial amount...So in my mind, when I heard that question, I was like, oh yeah, definitely that period. But I’ve only gone three days without the medication.”

This respondent was deciding her own schedule (and dosage) for taking GLP-1s. Her ability to obtain the medication on her own – without the assistance of a physician – was periodically interrupted, as she sought out different and more affordable sources of the medication. Therefore, she initially answered 'yes,' because challenges with affordable access caused her to stop taking GLP-1s according to her self-determined timetable.

[IF R SKIPPED DOSES]

GLP_DOSEWHYa

Did you skip doses of this medication...Because of the cost

1 Yes

0 No

Findings: This question could not be fully evaluated because only one respondent filtered into it. However, his answer suggests no difficulty or error. He said, “Because at \$400 a dose, it was like, okay, I can’t afford \$400 every month. That’s too much to spend.”

GLP_DOSEWHYb

Because it was not available or out of stock at your pharmacy

1 Yes

0 No

Findings: This question could not be evaluated because respondents either skipped or answered 'no'.

[IF R TOOK LESS OF THE MEDICATION]

GLP_LESSWHYa

Did you take less of this medication... Because of the cost

- 1 Yes
- 0 No

Findings: This question could not be evaluated because all respondents skipped out.

GLP_LESSWHYb

Because it was not available or out of stock at your pharmacy

- 1 Yes
- 0 No

Findings: This question could not be evaluated because all respondents skipped out.

[IF R DELAYED FILLING A PRESCRIPTION]

GLP_DELAYa

Did you delay filling a prescription for this medication...Because of the cost

- 1 Yes
- 0 No

Findings: This question could not be evaluated because all respondents skipped out.

GLP_DELAYb

Because it was not available or out of stock at your pharmacy

- 1 Yes
- 0 No

Findings: This question could not be evaluated because all respondents skipped out.

[IF R STOPPED TAKING THE MEDICATION ENTIRELY]

GLP_STOPa

Did you stop taking this medication entirely...Because of the cost

- 1 Yes
- 0 No

Findings: This question could not be evaluated because it was tested on only one respondent. This is the respondent discussed at length in GLP_DOSEd who mistakenly

reported that she stopped taking GLP-1s altogether (she did not). Here she answered 'no' and stated, "No. I stopped because of CDC or some sort of issues with the company. So I had to find someplace else to go."

GLP_STOPb

Because it was not available or out of stock at your pharmacy

- 1 Yes
- 0 No

Findings: This question could not be evaluated because respondents skipped out (except for the above respondent who had given her explanation in the previous question).

[SHOW ALL CURRENTLY TALKING GLP-1s]

GLP_INSPAY

In the past 12 months, how much did your health insurance pay for this medication? Did insurance pay for none, part, or all of the cost?

- 1 None of the cost
- 2 Part of the cost
- 3 All of the cost

Findings: This question did not pose any comprehension issues, however, the 'part of the cost' category may present some definitional difficulties. When insurance pays almost all or almost none, choosing 'part of the cost' can feel incorrect – or at least misleading. For example, one respondent who answered 'part of the cost' did answer correctly but wanted to explain that the category did not quite fit because the portion covered by insurance seemed so trivial to her:

"I didn't really feel like it was part, it was like [audio cuts off]...Insurance, to me, they really don't help with anything. Especially with me being an adult and I don't have kids. I really don't feel like they help us they just give us the bare minimum...They paid \$25, I paid the remaining balance."

GLP_SYMPTOMS

Have you reduced or stopped taking this medication due to any side effects or symptoms? [Read if necessary: Side effects or symptoms can include low blood sugar, nausea, vomiting, diarrhea, abdominal pain, dehydration, or pancreatic, kidney, and gallbladder issues.]

1 Yes

0 No

Findings: This question could not be fully evaluated because only one respondent stopped taking the medication due to side effects. He had no difficulties with the question and attributed the need to sometimes having to reduce his dosage to the unpredictable nature of compounded GLP-1s. He said:

“In the compounded world it’s different because you’re not dealing with somebody that has a name that you can go knock on [their] door. You’re trusting that a stranger that’s making this medicine is making it right. Not making it cheap. Not cutting any corners. And the effects are like hunger management. Sometimes I couldn’t get out of bed because just the thought of drinking water was making me nauseous. But at other times it’s like I can sit and eat ice cream all day and not bat an eye.”

LUN – LUNG CANCER SCREENING

[IF R EVER SMOKED]

LUN_AVERAGE

Thinking about the entire time that you have smoked, we want to know the average number of cigarettes that you smoked per day. What would be the easiest way for you to tell us the average number of cigarettes that you smoked per day? [Read if necessary: A typical pack is 20 cigarettes.]

- 1 Average number of cigarettes
- 2 Average number of packs

Findings: Fourteen respondents reported ever smoking and were, therefore, asked this question. In the interviewer-administered format of the cognitive interview, most respondents misunderstood this as asking how many cigarettes or packs they smoked (not their preference for reporting by number of cigarettes or by number of packs). However, this confusion is unlikely to occur in a web format.

[IF R REPORTS AS # OF CIGARETTES]

LUN_AVGCIG

Over the entire time that you have smoked, what is the average number of cigarettes that you smoked per day? [Read if necessary: A typical pack is 20 cigarettes.]

_____ cigarettes smoked per day

Findings: Most respondents reported number of cigarettes (only two reported number of packs). In reporting the average number of cigarettes that they smoked per day, most respondents could only provide an estimate, not an exact number (as formatted in the question). This was true irrespective of the frequency with which a respondent smoked. For example, one respondent answered seven cigarettes and said, “That’s an estimate. Because it can vary. I could be going through something that day and I smoke a little more cigarettes.” Some of these estimates were very rough, to the point of being guesses. One respondent admitted, “I think I was just guessing. It might not be as many. I don’t even know where six came from. I just said six.” Other respondents arrived at their estimate by attempting to determine an overall average. During probing one respondent said, “How did I arrive at eight cigarettes? I just averaged it out. Sometimes it might have been a little bit more depending on if I was going out or something like that. You’re with friends or you’re having some cocktails, you’re gonna have more.” No respondent provided what they would call an exact number of cigarettes or packs.

Difficulties for light smokers: While all (including heavy) smokers gave estimates of daily smoking frequency, answering this question was more difficult for light smokers. This group smoked so little that the “per day” timeframe was inadequate. Some respondents compensated by simply reporting the number in a way that reflected their reality (“It’s like one cigarette a week.”) instead of the parameter given by the question. Others tried to fit their number into the timeframe by reporting fractions. One respondent answered ‘.005’ and explained, “It would be in the decimal. It was primarily in college, and it would be one or two a week.”

[IF LUN_AVGCIG = DK or refused]

LUN_AVGCIG2

The answers people give us about their cigarette smoking are important to this study’s success. We know that this information is personal, but please remember your answer will be kept confidential.

Over the entire time that you have smoked, what is the average number of cigarettes that you smoked per day? [Read if necessary: A typical pack is 20 cigarettes.]

_____ cigarettes smoked per day

Findings: In the cognitive interview setting, no one refused to answer questions about their cigarette smoking – it simply did not strike respondents as a sensitive question – so these questions could not be evaluated.

[IF REPORTS AS # OF PACKS]

LUN_AVGPACK

Over the entire time that you have smoked cigarettes, what is the average number of packs that you smoked per day? [Read if necessary: A typical pack is 20 cigarettes.]

_____ packs smoked per day

Findings: See LUN_AVGCIG for findings.

[IF LUN_AVGPACK = DK or refused]

LUN_AVGPACK2

The answers people give us about their cigarette smoking are important to this study's success. We know that this information is personal, but please remember your answer will be kept confidential.

Over the entire time that you have smoked cigarettes, what is the average number of packs that you smoked per day? [Read if necessary: A typical pack is 20 cigarettes.]

_____ packs smoked per day

Findings: In the cognitive interview setting, no one refused to answer questions about their cigarette smoking – it simply did not strike respondents as a sensitive question – so these questions could not be evaluated.

[ALL]

LUN_DOCASK

Has a doctor or other health professional ever asked you if you smoked cigarettes?

[Read if necessary: The question could have been asked on a paper or online form you completed before the health care visit or during a conversation at the visit.]

1 Yes

0 No

Findings: In answering this question, respondents included questions on intake forms (“Just on the intake form. It was like, ‘have you ever smoked?’”) and actual discussions with their provider (“When they’re chatting with me, you know that’s one of the questions that they usually ask in the very beginning.”). Note that, while a ‘read if necessary’ is offered to clarify that respondents should include both paper or online forms completed before the health care visit *and* conversations held at the time of the visit, interviewers did not need to read this instruction. Respondents included both scenarios without being instructed.

LUN_NOTSHARE

Have you ever chosen not to share that you smoke cigarettes with a doctor or health professional?

- 1 Yes
- 0 No [GO TO LUN_CANCER]

Findings: All respondents answered 'no,' many stating that they hide nothing from their doctor ("I tell him everything."). A couple respondents noted that it's difficult to hide smoking even if they wanted to. One respondent said, "I've always told them. First off, you can smell it on me [chuckles], you know? So why lie?"

[IF R HAS NOT TOLD A DR ABOUT SMOKING]

LUN_INSUR

What were the reasons why you did not share that you smoke cigarettes with them? It might have negatively affected the cost of my health insurance, life insurance, or long-term care insurance.

- 1 Yes
- 0 No

Findings: This question could not be evaluated. All respondents skipped out.

LUN_JUDGED

I would have been judged negatively by the doctor or health professional.

- 1 Yes
- 0 No

Findings: This question could not be evaluated. All respondents skipped out.

LUN_TREAT

I would have been treated differently by the doctor or health professional.

- 1 Yes
- 0 No

Findings: This question could not be evaluated. All respondents skipped out.

LUN_LECTURE

I did not want a lecture about smoking from the doctor or health professional.

- 1 Yes
- 0 No

Findings: This question could not be evaluated. All respondents skipped out.

LUN_ASHAME

I felt ashamed about smoking.

1 Yes

0 No

Findings: This question could not be evaluated. All respondents skipped out.

LUN_READY

I was not ready to quit smoking.

1 Yes

0 No

Findings: This question could not be evaluated. All respondents skipped out.

LUN_SHOTHER

Some other reason.

1 Yes

0 No

Findings: This question could not be evaluated. All respondents skipped out.

[ALL]

LUN_CANCER

Have you ever been told by a doctor or other health professional that you had lung cancer?

1 Yes

0 No

Findings: All respondents answered 'no' to this question. No difficulty or response error was detected.

[ALL]

LUN_LCSCREEN

Lung cancer screenings are recommended for people who...

- Are between the ages of 50 and 80,
- Smoke now or have quit smoking in the past 15 years,

-
- Have smoked at least “20 pack years,” such as smoking one pack of cigarettes a day for 20 years, or two packs a day for 10 years, or four packs a day for five years.

Before this survey, did you know the recommendations for who should get lung cancer screening?

1 Yes

0 No

Findings: Most respondents answered ‘no’ (“No. This is the first time I heard it.”). Some wondered why their physician never communicated to them these recommendations. One respondent said, “No I did not and that’s very interesting...It’s some good information. That’s really good information. I think health professionals, primary care doctors, should tell you that.”

For respondents who answered ‘yes,’ it was difficult to determine whether what they knew actually aligned with the official recommendations. Sometimes such an alignment seemed absent. For example, when asked who he thought should get screened and where he obtained this information, one respondent said, “I mean, just PSA announcements on TV and just general knowledge if you are a heavy smoker or around second-hand smoke or have a family history, then you should be getting screenings. Just absorbing general knowledge.” Other respondents answered ‘yes’ but admitted to being uncertain whether they really knew what the recommendations were (“I think so, yes.”).

Additionally, no respondents who answered ‘yes’ reported obtaining this information from a health care provider. The Internet and television were cited as sources of information (“Reading online and the news and just so on, you try to educate yourself and learn about these different procedures.”). Friends were another source (“I know about it. I have a few friends that did it [got a CT scan]. They still smoke, they’re heavy smokers.”).

In sum, this question captures whether respondents think they know the recommendations for lung cancer screening. Importantly, most respondents did not arrive at their answer by 1) comparing what they initially thought they knew against the recommendations presented in the question and then 2) answering ‘no’ when their previous knowledge did not match these stated recommendations. They simply answered based on what made sense to them personally, without reflecting on the recommendations provided by the survey.

[IF R IS 40 OR OLDER; ELSE WOMEN GO TO FERTILITY; MEN END INTERVIEW]

LUN_BENEFIT

During the past 12 months, did a doctor or other health professional talk with you about the benefits of having a scan to check for lung cancer?

1 Yes

0 No

Findings: This question and the next were probed together but could not be extensively tested because only one respondent answered 'yes.' No error was detected, even for one respondent who answered 'no' but did have some form of lung cancer screening. She said, "The only doctor that mentioned it in all those years said, 'What about getting a lung cancer screening?' He gave me X-rays. And that's what I did."

LUN_HARMS

During the past 12 months, did a doctor or other health professional talk with you about the harms of having a scan to check for lung cancer?

1 Yes

0 No

Findings: See previous question.

LUN_LOWDOCT

Have you ever had a low-dose CT scan of your chest area? During this test, you are lying down and moved through a donut-shaped x-ray machine while holding your breath.

1 Yes

0 No [GO TO LUN_DISP3]

Findings: Seven respondents answered 'yes'. No response error was found, however, probing occurred in the next question.

LUN_CTSCREEN

Was your most recent low-dose CT scan of your chest area done to check or screen for lung cancer?

1 Yes

0 No

Findings: All respondents answered 'no', with no discernable response error. For example, probing revealed that the CT scans respondents reported were for other cancers (breast), accidents, bronchitis, and diagnosis for heart trouble. Even though no response error was found, it should be noted that it is possible for a degree of uncertainty to occur, given the line of questions (prior to this one) that focus on lung cancer screening. For example, one respondent needed confirmation and asked, "Is just to check for lung cancer or is this just a procedure that I went through before?" The interviewer repeated the question and he said, "Yes, I did."

LUN_DISP3

What are the reasons you have not had a low-dose CT scan for lung cancer screening?

LUN_NOREC

My health care provider has never recommended a lung cancer screening to me.

- 1 Yes
- 0 No

Findings: Respondents generally had no difficulty with these questions. Eight respondents said 'yes' to this item. Note that even though this is posed as a double negative (an answer of 'no' means 'yes, a provider HAS recommended it'), respondents were able to answer. For example, one respondent answered 'yes' and explained, "No they haven't really mentioned that. I think if you bring it up then they bring it up or something like that...it's not like 'according to your history you should get this' it wasn't like that."

LUN_HEALTHY

I am healthy.

- 1 Yes
- 0 No

Findings: Seven respondents answered 'yes' to this item. A few linked 'being healthy' specifically to their smoking status (versus other benchmarks such as the presence or absence of chronic disease). One respondent said, "Because I would assume it was based on some need from smoking, which I can't imagine I've smoked enough to warrant a CT scan." Similarly, another respondent said, "I guess because I don't smoke anymore. It's been about 10 years and I have good breathing, luckily."

LUN_BLMED

I am afraid of being judged or blamed for smoking.

- 1 Yes
- 0 No

Findings: Respondents generally had no difficulty with this item. Only two answered 'yes'. However, one respondent did express confusion over the intent. She asked, "Afraid of being judged? By who?" [Interviewer repeats the introduction and the question.] "I guess no. I'm a little confused by that one, sorry."

LUN_NOTIME

It is hard to find time to get a lung cancer screening.

- 1 Yes

0 No

Findings: No respondents answered 'yes' to this question so it could not be evaluated.

LUN_TRANSPO

It is hard for me to get reliable transportation to get a lung cancer screening.

1 Yes

0 No

Findings: Respondents had no difficulty with this question and most answered 'no'. Only one respondent answered 'yes' due largely to mobility challenges. She said, "I'm in a power chair and I also live in an area that is not too accessible as far as public transportation. So I need to have a period of time knowing that I'm going so I can arrange transportation."

LUN_EXPOSE

I am concerned about being exposed to radiation from a low-dose CT scan.

1 Yes

0 No

Findings: No respondents answered 'yes' to this question so it was not evaluated.

LUN_CONCERN

I am concerned about other harms from getting a low-dose CT scan.

1 Yes

0 No

Findings: No respondents answered 'yes' to this question so it was not evaluated.

LUN_NORISK

I am at low or no risk of getting lung cancer.

1 Yes

0 No

Findings: This item operated as a double-barreled question because it implicitly assumes respondents agree they are low risk. As such, an answer could reflect a respondent's agreement or disagreement with being low risk of developing lung cancer or the answer could mean (as intended) that a perceived low-risk level influenced their decision not to have a lung cancer screening. This is notably problematic for those who believe they have a high risk of developing lung cancer because they must disagree with (i.e., answer 'no' to) this question. This leaves them with no ability to answer

whether this high-risk level is a reason they have not gotten a CT scan. For example, one respondent asked, “How do I answer that? Yes? I am [at risk]?” Similarly, another respondent said, “No, because I guess I am [at risk] because I smoke cigarettes. So, I’m at risk, right? Is that...So I don’t know if I should say ‘yes.’ I guess I’ll put ‘yes’ because I am [at risk].” In essence, the question is double-barreled because it inadvertently presupposes that a respondent believes they are at a low risk of getting lung cancer.

[IF R NEVER HAD A CT SCAN OR HAD A SCAN THAT WAS NOT FOR LUNG CANCER]

LUN_DISP5

Are any of the following a reason why you have not had a low-dose CT scan for lung cancer screening?

LUN_ANXIOUS

Knowing the results would make me anxious or stressed.

- 1 Yes
- 0 No

Findings: The intent of this question may not be consistently understood because the construct is vague. For example, only one respondent answered ‘yes’ and explained the rationale behind her answer. She said, “I guess I’m too sure of myself that I don’t have it. Maybe I don’t want to think too much because otherwise they might come up with something. You start digging around for something, you find it. Ignorance is bliss.” It’s notable that the explanation of another respondent seems to be similar, but she chose to answer ‘no’. In describing the reasons in her own words, she said, “I don’t know that I want to know. I’m-a be honest with you. I just don’t know if I want to know that.” The discrepancy in how these two respondents with similar rationales chose to answer differently suggests that this item might capture respondents who do not want to know the results for *any* reason, not just because it would lead to anxiety or stress.

LUN_COST

I am concerned about the cost of screening.

- 1 Yes
- 0 No

Findings: Only one respondent answered ‘yes’ to this item. However, upon probing, she did not mention cost as a factor. Unfortunately, it was unclear why she initially chose cost as a factor.

LUN_SCOTHER

Some other reason.

1 Yes

0 No

Findings: Most respondents answered ‘no’ to this question. However, one respondent answered ‘yes’ and explained, “Some other reason. I mean, I didn’t think about it.”

[ALL]

LUN_DISP6

How much do you agree or disagree with the following statements? Would you say you strongly agree, somewhat agree, somewhat disagree, or strongly disagree?

Findings: The below set of attitude questions were probed together, as a group – not individually. No difficulties were observed, but respondents did exhibit different judgment patterns, each of which is grounded in beliefs in the cause(s) of lung cancer. One group linked smoking as the direct cause of lung cancer. For example, one respondent answered ‘strongly agree’ to LUN_BLAKE and explained, “The information I’ve been made aware of, as far as lung cancer, you only see that related to cigarette smoking or smoking in general.” Another respondent thought of her personal experience when she answered ‘strongly agree’ to LUN_CHOICE. She said, “I take responsibility. No one shoved a cigarette in my mouth. I took it upon myself to smoke. I could’ve stopped a lot earlier than I did. It’s a lifestyle choice, almost like being an alcoholic.”

However, a second group of respondents understood that smoking was not the only possible cause of lung cancer. This group tended to strongly disagree with the statements (or strongly agree for LUN_STILLRISK). Environmental factors (“People do get lung cancer from other issues, maybe asbestos or whatnot, who knows?”), second-hand smoke (“I do know people that have died from lung cancer from secondhand smoke. They never smoked a cigarette in their life.”), and heredity (“Sometimes cancer runs in your family, so it could be hereditary. So that’s why I disagree with all of that.”) were identified as possible causes of lung cancer.

Finally, a third group may be described as seeing lung cancer as likely caused by smoking but acknowledged that there can be other reasons, such as those cited above. This group, rather than answer ‘strongly agree,’ tended to answer ‘somewhat agree’ or ‘somewhat disagree’ as a way to make room for that uncertainty. The interesting point is that agreement could go either way. It’s the word ‘somewhat’ that is the important qualifier in these instances. For example, one respondent who answered ‘somewhat agree’ explained, “That’s if they smoked cigarettes or if they worked around asbestos. There’s been a lot of work – about 40, 50 years – that smoking causes cancer. And other occupations working around chemicals.” Conversely, using the same logic another respondent answered ‘somewhat disagree.’ She said:

“I slightly disagree because – it’s crazy I was just watching a documentary the other day about Christopher Reeve and I saw that his wife contracted lung cancer and she didn’t smoke a day in her life. So sometimes that’s not the case...You can’t just assume that [smoking caused cancer] because there’s many different factors. It isn’t just a one-way street. There are many different ways to get there.”

For respondents in this group, there is no discernable line between agree and disagree. Therefore, by opting for a response that includes ‘somewhat,’ these respondents are conveying the idea that multiple factors can play a role in precipitating lung cancer, including but not limited to smoking.

LUN_BLAME

People with lung cancer are to blame for their illness.

- 1 Strongly agree
- 2 Somewhat agree
- 3 Somewhat disagree
- 4 Strongly disagree

LUN_CHOICES

People with lung cancer have made poor lifestyle choices.

- 1 Strongly agree
- 2 Somewhat agree
- 3 Somewhat disagree
- 4 Strongly disagree

LUN_STILLRISK

You are still at risk of getting lung cancer, even if you do not smoke.

- 1 Strongly agree
- 2 Somewhat agree
- 3 Somewhat disagree
- 4 Strongly disagree

LUN_ASSUME

If someone told me they had lung cancer, I would assume it is because they smoked.

- 1 Strongly agree
- 2 Somewhat agree
- 3 Somewhat disagree
- 4 Strongly disagree

FER – FERTILITY AND REPRODUCTIVE HEALTH SERVICES

[ASK WOMEN 18-49; ELSE MEN END INTERVIEW]

FER_PERAGE

The next section is about your experience with childbearing and pregnancy. The first question asks when you started having your menstrual periods. How old were you when you had your first menstrual period?

_____ years

Findings: Most respondents gave an estimate of their age at first menses (“I believe I was 13. I might have been 12. Are you in 6th grade when you’re 12? I think 12.”) and, as a result, some offered ranges rather than a discrete number (“I think 10 or 11. I don’t remember.”).

Only one respondent remembered enough detail to provide an age (she answered ‘14’) with confidence (“I remember the day it happened too. It was the day I bought [new album]. And I was looking at the booklet in the bathroom and I was like, whoa!”).

FER_PREG

Are you pregnant now?

- 1 Yes
- 0 No
- 9 Don’t know

Findings: All respondents answered ‘no’ to being currently pregnant and expressed absolute certainty with their answer.

FER_PREGNUM

The next question asks about any pregnancies you have had -- whether they resulted in babies born alive, stillbirth, abortion, miscarriage, or ectopic or tubal pregnancy.

[Including this pregnancy, how / How] many times have you been pregnant in your life?

_____ # times [IF 0, GO TO FER_SURGERY]

Findings: Generally, respondents answered without issue, even when they had potentially sensitive experiences. For example, one respondent had no reservations about explaining her difficult experience to the interviewer. She said:

“I was pregnant and I found out when I fell out on the floor, passed out, at work, in orientation week. Ended up being where it was not the right time because my grandmother was pretty much dying. COVID was high and coming in hot during that time and there was a lot of respiratory problems with patients. I was pretty much scared that I would either get COVID and possibly die trying to give birth to a child or give birth and the child have a lot of respiratory problems because of the COVID situation...The stress of life, that was not a quality of life that I think I

would be able to carry a child successfully through. So I did have an abortion and, yeah.”

However, at least one respondent reacted with more awkwardness. When asked the question she first gave an extended nervous laugh and said, “I’m sorry.” [Pauses and thinks.] “I want to say eight.” Interviewers were largely able to develop rapport with respondents, such that most answered this question without hesitation. The sensitivity of the question may be diminished even further in a self-administered web format.

[IF R HAS EVER BEEN PREGNANT] FER_LIVENUM

The next question asks about any live births you have had. How many babies did you have that were born alive? Please include babies that may have died shortly after birth and babies that you placed for adoption.

_____ # of babies

Findings: No difficulty or obvious discomfort arose when respondents answered the number of babies that were born alive.

FER_SURGERY

Have you ever had surgery or other medical procedures that make it impossible for you to get pregnant [again] or carry [a / another] baby?

- 1 Yes [GO TO FER_PLANS]
- 0 No

Findings: Respondents had no difficulty answering this question. Hysterectomy and tubal ligation were cited as procedures that several respondents had.

FER_PHYSPOS

Some women are not physically able to have children. As far as you know, is it physically possible for you, yourself, to have [a / another] baby?

- 1 Yes
- 0 No

Findings: Respondents also had no difficulty answering whether, as far as they knew, it was physically possible for them to have a baby.

FER_PLANS

The next question is about your feelings about having [a / another] baby, whether or not you are able to, or plan to have one. Looking to the future, [if it were possible,] would

you, yourself, want to have [a / another] baby at some time? [If you are currently pregnant, please consider some time after this pregnancy is over.] Would you say...

- 1 Definitely yes
- 2 Probably yes
- 3 Probably no
- 4 Definitely no

Findings: This question and the next (FER_INTEND) were probed together. Respondents seemed to understand the difference between the two questions – wanting to have a baby versus intending to have a baby. Several respondents answered these two questions differently (for example, yes to one and no to the other). Their rationale was tied to health concerns and physical limitations. For example, one respondent answered ‘probably yes’ to wanting to have another child and ‘no’ to intending to have another child. She said:

“I do want to have kids, but I also think about being 36 and in the healthcare field they said that’s geriatric age for women to have children. And when I worked in ICU at the hospital, I saw firsthand how it can affect women...I do want kids, but I don’t want to lose my life or to jeopardize a child’s life in the process of something like that.”

Another respondent also answered ‘probably yes’ to wanting to have another child but ‘no’ to intending to have another child. In explaining the difference, she said:

“I love children. But I wouldn’t do it again, though, because I had three C-sections and it would have to be another C-section. So that’s really why when I went and got my surgery. But if someone else could have the baby for me, I would take it [laughs].”

FER_INTEND

Sometimes what people want and what they intend are different because they are not able to do what they want. The next questions are about your intentions to have [a / another] baby in the future. Looking to the future, do you intend to have [a / another] baby at some time? [Read if necessary: Intend refers to what you are actually going to try to do. Do not count intended adoptions or stepchildren.]

- 1 Yes
- 0 No [GO TO FER_SEXMALE]

Findings: See previous question (FER_PLANS). Note that because respondents understood the question as intended, it was unnecessary to read the additional instruction.

FER_EXPECT

When do you expect your [first / next] child to be born? [If you are currently pregnant, please consider some time after this pregnancy is over.] Would you say...

- 1 Within the next 2 years
- 2 2-5 years from now
- 3 More than 5 years from now

Findings: This item could not be adequately evaluated because only four respondents filtered into the question. However, no response difficulty was observed for those four. When answering the question, respondents thought about when their life circumstances may be optimal for having a child. For example, one respondent said:

“I’m 27 and I don’t feel like right now I’m financially stable to even take care of another human being. I have enough for me, I can’t add a little person right now. Once I get more stable and have my career where I want it to be, I will take the steps to having a child.”

[IF R HAS NEVER BEEN PREGNANT; ELSE GO TO FER_SEXM12M]

FER_SEXMALE

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

- 1 Yes
- 0 No [END INTERVIEW]

Findings: This question, in the interest of time and because similar questions were evaluated in another study (7), was not probed. No obvious error was detected, but one 37-year-old respondent answered ‘no’ (all others answered ‘yes’). To ensure accuracy, the interviewer did, in this case, explore her rationale. She said, “Abstinence is where I am with that. And I gotta be honest. Religious aspects too. You don’t have premarital sex. And I’m fairly religious, so...”. This answer seemed in line with question intent.

FER_SEXM12M

During the last 12 months, that is, since [MONTH] 2024, have you had sexual intercourse with a male partner? [Read if necessary: Do not count oral sex, anal sex, or other forms of sexual activity that do not involve vaginal penetration.]

- 1 Yes
- 0 No [END INTERVIEW]

Findings: This question, in the interest of time and because similar questions were evaluated in another study (7), was not evaluated.

[IF R HAS HAD SEX WITH A MALE IN PAST 12 MONTHS]

FER_PREVENT

I have a list of methods that some people use to prevent pregnancy or to prevent sexually transmitted disease [If it would be helpful for me to provide specific examples of these methods, I can read those.] [SHARE SCREEN IF NEEDED]

- Birth control pills
- Condoms or rubbers
- Hormonal implant (READ IF NECESSARY: Norplant, Implanon, or Nexplanon)
- IUD (READ IF NECESSARY: for example, Copper-T, Paragard, Mirena, Skyla, Liletta, Kyleena)
- Emergency contraception pills [READ IF NECESSARY: for example: Plan B, Preven, Ella, Next Choice, Julie, "Morning after" pills]
- Female sterilization (READ IF NECESSARY: tubal ligation, hysterectomy, other)
- Partner's vasectomy
- Depo-Provera injectables (shot every 3 months)
- Withdrawal, pulling out
- Calendar rhythm method
- Standard Days or CycleBeads method
- Safe period by temperature or cervical mucus test (READ IF NECESSARY: for example: Two Day Method, Billings Ovulation Method, Symptothermal Method)
- Natural Cycles app
- Contraceptive patch (READ IF NECESSARY: Ortho-Evra or Xulane)
- Vaginal contraceptive ring (READ IF NECESSARY: NuvaRing, EluRyng, or Annovera)
- Other methods [READ IF NECESSARY: for example, Vaginal contraceptive film, diaphragm, female condom, foam, jelly or cream, cervical cap, suppository, insert, Today sponge, Phexxi Gel, Lunelle (monthly shot)]

The last time you had intercourse with a male partner, did you or he use any method?

1 Yes [GO TO FER_DISP]

0 No

Findings: No difficulties were found with this question. Interviewers were provided with a fairly comprehensive list of methods (shown above) and instructions to show the list to respondents if needed. However, this list proved to be unnecessary. The root question

stood well on its own – in no case did respondents express confusion or uncertainty and need to see the list. Moreover, probing revealed no response error. For example, some respondents thought of their use of these methods for STD protection (“Yes, we used condoms [for STD prevention].”) while others cited birth control purposes (“I also think that [birth control pills] contributed to a lot of the imbalance I had. And my weight fluctuation.”).

[IF NO BIRTH CONTROL WAS USED; ELSE GO TO FER_DISP]

FER_WANTPREG

Is the reason you did not use a method of birth control because you, yourself, wanted to become pregnant?

- 1 Yes
- 0 No

Findings: Only four respondents filtered into this question, so it could not be fully evaluated. Probing occurred largely in the next question. However, one respondent answered ‘yes’ and explained, “Um yes. I never use birth control. I don’t believe in birth control.” In the context of this topic, the respondent explained that she (and her husband) was not specifically trying to get pregnant but that she was living her life according to God’s plan. She said, “I want to see God’s work and the only way I can do that is if I let him work.” In other words, pregnancy is an outcome decided by God (not her), which she accepts either way. It’s unclear if her rationale resonates with the intent of this question, which assumes a belief in personal agency with regard to fertility.

FER_WHYNOBC

Which one of these is the main reason that you did not use birth control?

- 0 You did not expect to have sex
- 1 You did not think you could get pregnant
- 2 You didn’t really mind if you got pregnant
- 3 You were worried about the side effects of birth control
- 4 Your male partner did not want you to use a birth control method
- 5 Your male partner himself did not want to use a birth control method
- 6 Other reason

Findings: Only four respondents filtered into this question, so it could not be fully evaluated. However, it is important to note that the list did miss two reasons that might be worth including. One was religious reasons (“I would say ‘other reason.’ Um, religious reasons.”) and the other was infertility in the respondent’s partner (“There’s a zero percent possibility to conceive because of a procedure that was done, not on my end. But the person in question.”)

[ALL]

FER_DISP

The questions in this section are about recent medical visits for family planning services, as well as other types of pregnancy and health care services for women.

FER_BCDOC

In the past 12 months, that is since [MONTH] 2024, have you received a method of birth control or a prescription for a method from a doctor or medical care provider? [Read if necessary: This includes getting pills, or a new prescription for pills, a new diaphragm or IUD, or a new supply of condoms, from a doctor or medical care provider. Do not count visits to drug stores or other stores or pharmacies, to refill prescriptions or to buy supplies.]

1 Yes

0 No

Findings: Most respondents answered ‘no’ to this question so it could not be fully evaluated. No obvious difficulties were observed. However, one respondent who answered ‘yes,’ is noteworthy. This respondent receives a prescription for birth control during her doctor visits, even when she has no intention of taking them. Her objective is to have medication on hand in case she needs, but can’t afford, medication in the future. She explained:

“I don’t take it because I’m not [sexually] active. But when I pick up my prescriptions every month, I do get birth control.” *You mean like the pill?* “Yeah. And I fill up my cabinet with all kinds of things just in case I fall off of insurance one day. Everything's getting expensive. I do have prescription medications that I don't take.”

This respondent was stockpiling GLP-1s in addition to birth control pills. The last portion of the ‘read if necessary’ instruction (“Do not count visits to drug stores or other stores or pharmacies, to refill prescriptions or to buy supplies.”) – which this respondent did not hear during question administration – may help to clarify such experiences, provided respondents read the on-screen instructions. Even so, the additional instruction may not address those who hoard medication for possible future use. It is unclear how they are expected to answer.

FER_TESTBC

In the past 12 months, have you received a check-up or medical test related to using a birth control method? [Read if necessary: This includes procedures or lab tests used to detect medical conditions or problems. These may refer to routine visits or visits made because of specific problems related to contraceptive use.]

1 Yes

0 No

Findings: Most respondents answered ‘no’ to this question so it could not be evaluated. No obvious difficulties were observed. However, one finding is that the initiation of these services may not always be prompted by the respondent. For example, one respondent answered ‘yes’ to this question. When asked why, she explained that during a well-woman visit her doctor suggested she go on birth control – it was not her idea. She said, “They were trying to put me on birth control and I was telling them, no, I don’t want to go on birth control. I don’t want to get the shot [Depo-Provera].” The respondent made it clear in the interview that the health care provider was pressing her on something she did not want. The wording of the question does not specify but does imply that birth control services were received at the behest of the patient/respondent. This may not always be the case.

FER_INFOBC

In the past 12 months, from a doctor or other medical care provider, have you received counseling or information about birth control? [Read if necessary: Includes counseling or information related to whether to use birth control methods, how to get them, information about different methods, and how they are used]

1 Yes

0 No

Findings: Most respondents answered ‘no’ to this question so it could not be evaluated. No obvious difficulties were observed.

FER_INFOSTER

In the past 12 months, have you received counseling or information about getting sterilized? [Read if necessary: Includes counseling about a surgical procedure that makes female pregnancy impossible, most commonly a tubal ligation.]

1 Yes

0 No

Findings: Most respondents answered ‘no’ to this question so it could not be evaluated. No obvious difficulties were observed. The only notable finding was for one respondent who was uncertain of the meaning (“Sterilized? What do you mean?”). This prompted the interviewer to refer to the ‘read if necessary’ instruction, which clarified the confusion and allowed the respondent to correctly answer ‘no’. This suggests that including the instruction on the screen in a web-based format may be beneficial.

FER_PLANB

In the past 12 months, from a doctor or other medical care provider, have you received emergency contraception pills, a prescription for emergency contraception pills, or counseling or information about emergency contraception pills? [Read if necessary: Emergency contraception pills are also known as "Plan B" or the "Morning-after pill." Include counseling, information, or a prescription for the pills, whether or not you obtained the pills.]

1 Yes

0 No

Findings: Most respondents answered 'no' to this question, so it could not be fully evaluated. However, one respondent did express some uncertainty with the language. She heard the question and said, "I have not. Well contraception is birth control, right? Pretty much?" Interviewer reads the 'read if necessary' instruction. Once the respondent heard 'Plan B' she recognized the intent of the question and was more confident in her answer of 'no.' Given the vocabulary in this item ('emergency contraception'), it might be beneficial to ensure that the 'read if necessary' instruction appears on the page.

FER_PAPTEST

In the past 12 months, have you received a Pap test – where a doctor or nurse put an instrument in the vagina and took a sample to check for abnormal cells that could turn into cervical cancer?

1 Yes

0 No

Findings: Respondents had no difficulty answering whether they received a Pap test in the past 12 months. Extensive probing was not used in the interest of time and because similar questions have been tested in the past (7, 8) and consistently show that women understand questions about Pap tests.

FER_PELVEXAM

In the past 12 months, have you received a pelvic exam – where a doctor or nurse puts one hand in the vagina and the other on the abdomen?

1 Yes

0 No

Findings: Respondents had no difficulty answering whether they received a pelvic exam in the past 12 months. Extensive probing was not used in the interest of time and

because similar questions have been tested in the past (7, 8).

FER_STDTEST

In the past 12 months, have you been tested for a sexually transmitted disease? [Read if necessary: Includes medical exams, blood tests, or cultures taken to determine whether someone has a sexually transmitted disease or STD. Some sexually transmitted diseases include herpes, gonorrhea, chlamydia, and HIV.]

1 Yes

0 No

Findings: Respondents had no difficulty answering if they had been tested for an STD in the past 12 months. All reported receiving this test as part of a routine checkup (“I get a full panel testing every year.”).

FER_FERTILITY

Have you ever gone, either alone or with a spouse or partner, to a doctor or other medical care provider to talk about ways to help you become pregnant? Please include telehealth visits by video or phone. [Read if necessary: If main purpose of visit was for something other than seeking help to become pregnant, please select no.]

1 Yes

0 No [GOT TO FER_DOCPREV]

Findings: Only two respondents answered ‘yes’ to this question, so it could not be adequately evaluated. One respondent who answered ‘yes’ described a straightforward experience. She said, “We’re just getting counseling, trying to find out what days and how many eggs [at age 45], just checking that out. But we’re trying to do it naturally.”

However, the other respondent who answered ‘yes’ described a situation that might not track with question intent. She explained:

“It was my annual. They were asking me, ‘Do you want to get pregnant?’ No, no, no. Because of all the pain I was going through with my menstrual...but they were like your age, you’re still young, you’re not married. No, no, no.”

This is likely response error because the respondent did not, herself, seek out ways to assist getting pregnant. Instead, her health care provider was suggesting that, despite her protestations, the respondent will eventually want to become pregnant. The ‘read if necessary’ instruction may prove helpful when provided in a web format.

FER_FERTNOW

Are you currently pursuing medical help for you to become pregnant? [Read if necessary: If you or your spouse/partner plan to visit the doctor or clinic again, please select yes.]

1 Yes

0 No

Findings: This question could not be evaluated – only two respondents were asked this question; both answered ‘no.’

FER_DOCPREV

Not counting routine check-ups, prenatal care, or advice about a pregnancy, have you ever been to a doctor or other medical care provider to help you prevent miscarriage or pregnancy loss? Please include telehealth visits by video or phone.

1 Yes

0 No

Findings: This question could not be evaluated because only one respondent answered ‘yes.’ She was including this topic in the same conversation she had with her health care provider about ways to help her get pregnant at age 45. (“Yeah, getting all the information I could get so, yeah, that [preventing miscarriage] was part of it.”)

Appendix II: Cognitive Interview Test Instrument

CHR - CHRONIC CONDITIONS [NOT TESTED]

CHR_HYPEV

Have you ever been told by a doctor or other health professional that you had hypertension, also called high blood pressure?

[Read if necessary: If you take medication to control your hypertension, please answer yes.]

- 1 YES
- 0 NO

CHR_HYPSTILL

Do you still have hypertension, also called high blood pressure?

[Read if necessary: If you take medication to control your hypertension, please answer yes.]

- 1 YES
- 0 NO

CHR_CHLEV

Have you ever been told by a doctor or other health professional that you had high cholesterol?

[Read if necessary: If you take medication to control your high cholesterol, please answer yes.]

- 1 YES
- 0 NO

Do you still have high cholesterol?

- 1 YES
- 0 NO

CHR_CAREV

Have you ever been told by a doctor or other health professional that you had cardiovascular disease, including coronary heart disease, angina, a stroke, or a heart attack?

[Read if necessary: If you take medication to control your cardiovascular disease, please answer yes.]

- 1 YES
- 0 NO

CHR_CARSTILL

Do you still have cardiovascular disease, including coronary heart disease, angina, a stroke, or a heart attack? [Read if necessary: If you take medication to control your cardiovascular disease, please answer yes.]

- 1 YES
- 0 NO

CHR_OBEV

Have you ever been told by a doctor or other health professional that you had obesity? [Read if necessary: If you take medication to control your obesity, please answer yes.]

- 1 YES
- 0 NO

CHR_OBSTILL

Do you still have obesity?

[Read if necessary: If you take medication to control your obesity, please answer yes.]

- 1 YES
- 0 NO

CHR_SLAPEV

Have you ever been told by a doctor or other health professional that you had sleep apnea?

[Read if necessary: If you use a medical device such as a positive airway pressure or PAP machine to control your sleep apnea, please answer yes.]

- 1 YES
- 0 NO

CHR_SLAPSTILL

Do you still have sleep apnea?

[Read if necessary: If you use a medical device such as a positive airway pressure or PAP machine to control your sleep apnea, please answer yes.]

- 1 YES
- 0 NO

CHR_CANEV

Have you ever been told by a doctor or other health professional that you had cancer or a malignancy of any kind?

- 1 YES
- 0 NO

CHR_COPDEV

Have you ever been told by a doctor or other health professional that you had Chronic Obstructive Pulmonary Disease, C.O.P.D., emphysema, or chronic bronchitis?

1 YES

0 NO

CHR_ASEV

Have you ever been told by a doctor or other health professional that you had asthma?

1 YES

0 NO

[SHOW IF CHR_ASEV=yes]

CHR_ASTILL

Do you still have asthma?

1 YES

0 NO

[SHOW IF CHR_ASTILL=yes]

CHR_AS12M

During the past 12 months, have you had an episode of asthma or an asthma attack?

1 YES

0 NO

DIB – DIABETES [NOT TESTED]

[SHOW ALL]

DIB_PREDIB

Has a doctor or other health professional ever told you that you had prediabetes or borderline diabetes?

1 Yes

0 No

[ALL WOMEN]

DIB_GESDIB

Has a doctor or other health professional ever told you that you had gestational diabetes, a type of diabetes that only occurs during pregnancy?

Gestational diabetes is a diabetes that you did not have prior to being pregnant and goes away after you are pregnant. Pregnant women are usually screened for gestational diabetes during the 24th to 28th week of pregnancy.

-
- 1 Yes
 - 0 No

[SHOW ALL]

DIB_DIBEV

[Not including prediabetes / gestational diabetes] Has a doctor or other health professional ever told you that you had diabetes?

- 1 Yes
- 0 No

[IF R HAS DIABETES]

DIB_DIBSTILL

Do you still have diabetes?

[Read if Necessary] If you take medication to control your diabetes, please answer yes.

- 1 Yes
- 0 No

[IF R HAS PREDIABETES OR BORDERLINE]

DIB_PDIBSTILL

Do you still have prediabetes or borderline diabetes?

- 1 Yes
- 0 No

DIB_DIBTYPE

According to your doctor or other health professional, what type of diabetes do you have? Is it type 1, type 2, or some other type? If you don't remember or weren't told, that's OK.

- 1 Type 1
- 2 Type 2
- 3 Some other type
- 9 I don't know what type I have

LYM – LYME DISEASE PREVENTION METHODS [PROBED]

[SHOW ALL]

LYM_DISP

Lyme disease is an infection spread by the bite of a black-legged tick. How likely are you to use each of the following methods for preventing Lyme disease? Would you say definitely, very likely, somewhat likely, somewhat unlikely, very unlikely, or would you definitely not do this?

LYM_PREVA

If it were available, getting an annual vaccine to prevent Lyme disease.

- 1 Definitely
- 2 Very likely
- 3 Somewhat likely
- 4 Somewhat unlikely
- 5 Very unlikely
- 6 Definitely not

LYM_PREVB

Taking a single dose of antibiotics within 72 hours of a known tick bite.

- 1 Definitely
- 2 Very likely
- 3 Somewhat likely
- 4 Somewhat unlikely
- 5 Very unlikely
- 6 Definitely not

LYM_PREVC

Using bug spray on your skin or clothing.

- 1 Definitely
- 2 Very likely
- 3 Somewhat likely
- 4 Somewhat unlikely
- 5 Very unlikely
- 6 Definitely not

LYM_PREVD

Wearing clothing that has been pretreated with a long-lasting permethrin [pr-MEH-thruhn] bug repellent.

- 1 Definitely
- 2 Very likely
- 3 Somewhat likely
- 4 Somewhat unlikely
- 5 Very unlikely
- 6 Definitely not

CIH - COMPLEMENTARY AND INTEGRATIVE HEALTH [PROBED]

[SHOW ALL]

CIH_HLTH12M

During the past 12 months, have you seen any of the following practitioners for health reasons? [Mark all that apply – SHOW SCREEN IF NEEDED SO R CAN SEE NAMES]

- Ayurvedic Doctor or Vaidya
- Curandero
- Hierbero or Yerbera
- Native American Healer or Medicine Man
- Shaman
- Sobador

During the past 12 months...

CIH_HOMEO

Did you see a practitioner of Homeopathy for your health?

- 1 Yes
- 0 No

CIH_REIKI

Did you see a practitioner for energy healing or Reiki for your health?

- 1 Yes
- 0 No

CIH_ACUPUN

Did you see a practitioner for acupuncture for your health?

- 1 Yes
- 0 No [GO TO CIH_TAICHI]

CIH_ACU12M

During the past 12 months, how many times did you see a practitioner for acupuncture?

- 1 Only one time
- 2 2-5 times
- 3 6-10 times
- 4 11-15 times
- 5 16-20 times
- 6 More than 20 times

CIH_ACUCOST

During the past 12 months, were any of the costs of seeing a practitioner for acupuncture covered by health insurance?

- 1 Yes
- 0 No

CIH_TAICHI

During the past 12 months...

Did you practice Tai Chi for your own health?

- 1 Yes
- 0 No

CIH_QIGONG

Did you practice Qi Gong for your own health?

- 1 Yes
- 0 No

CIH_MUSART

During the last three months, did you create, practice, or perform music or other art forms for your own health?

- 1 Yes
- 0 No

GLP – GLP-1 MEDICATION ACCESS [PROBED]**GLP_WEIGHT**

How would you describe your weight?

- 1 Very overweight
- 6 Slightly overweight
- 7 About the right weight
- 8 Slightly underweight
- 9 Very underweight

GLP_LOSEWT

In the past 12 months, has a doctor or other health professional talked to you about losing weight to improve your health?

- 1 Yes
- 0 No

The next questions are about medications for diabetes and weight loss.

GLP_MED12M

In the past 12 months, have you taken an oral or injectable medication for diabetes or weight loss, such as Ozempic, Rybelsus, Wegovy, Mounjaro, Zepbound, Saxenda, Victoza, Trulicity, Byetta, or Bydureon BCise? [Read if necessary: These are also known as GLP-1 medications and may contain semaglutide, tirzepatide, liraglutide, dulaglutide, or exenatide.]

- 1 Yes
- 0 No [GO TO NEXT SECTION – CIGARETTES]

GLP_MEDNOW

Are you now taking this medication?

- 1 Yes
- 0 No [GO TO NEXT SECTION – CIGARETTES]

GLP_MEDRX

In the past 12 months, did you have a prescription from a doctor or other health professional for this medication?

- 1 Yes
- 0 No [GO TO GLP_COMPMED]

GLP_MEDINFO

Did the person prescribing your medication provide information about the type of nutrition needed for those who take this medicine? [Read if necessary: For example, eating enough protein and fiber, staying well-hydrated, or eating small portion sizes to reduce stomach discomfort.]

- 1 Yes
- 0 No

GLP_MEDACT

Did the person prescribing your medication provide information about the physical activity and exercise needed for those who take this medicine? [Read if necessary: For example, getting moderate intensity exercise throughout the week or incorporating resistance or strength training into your routine.]

- 1 Yes
- 0 No

In the past 12 months, did you get your prescription or medication from...

GLP_RX12Ma

A primary care doctor or a specialist, filled at a pharmacy

- 1 Yes
- 0 No

GLP_RX12Mb

An online provider like Weight Watchers or Noom that provides medication and helps you plan a healthy diet and exercise routine

1 Yes

0 No

RX12Mc

An online company like Hims and Hers that only provides medication

1 Yes

0 No

In the past 12 months, did you get your prescription or medication from...?

GLP_RX12Md

A medical spa or cosmetic medical center

1 Yes

0 No

GLP_RX12Me

Somewhere else

1 Yes

0 No

GLP_COMPMED

Compounded medications include the same active ingredients as popular name brand drugs but are not FDA-approved. They are made by specialized pharmacies and are often used as an alternative when a medication is in short supply. In the past 12 months, have you taken a generic, compounded version of this medication?

1 Yes

1 No

9 Don't know

During the past 12 months, were any of the following true for you?

GLP_DOSEa

You skipped doses of this medication.

1 Yes

0 No

GLP_DOSEb

You took less of this medication than prescribed.

1 Yes

0 No

GLP_DOSEc

You delayed filling a prescription for this medication.

1 Yes

0 No

GLP_DOSEd

You stopped taking this medication entirely.

1 Yes

0 No

[SHOW IF R SKIPPED DOSES]

Did you skip doses of this medication...

GLP_DOSEWHYa

Because of the cost

1 Yes

0 No

Because it was not available or out of stock at your pharmacy

1 Yes

0 No

[SHOW IF R TOOK **LESS** OF THE MEDICATION]

Did you take less of this medication...

GLP_LESSWHYa

Because of the cost

1 Yes

0 No

GLP_LESSWHYb

Because it was not available or out of stock at your pharmacy

1 Yes

0 No

[SHOW IF R **DELAYED FILLING** A PRESCRIPTION]

Did you delay filling a prescription for this medication...

GLP_DELAYa

Because of the cost

1 Yes

0 No

GLP_DELAYb

Because it was not available or out of stock at your pharmacy

1 Yes

0 No

[SHOW IF R **STOPPED TAKING** THE MEDICATION ENTIRELY]

Did you stop taking this medication entirely...

GLP_STOPa

Because of the cost

- 1 Yes
- 0 No

GLP_STOPb

Because it was not available or out of stock at your pharmacy

- 1 Yes
- 0 No

[SHOW ALL CURRENTLY TALKING GLP-1s]

GLP_INSPAY

In the past 12 months, how much did your health insurance pay for this medication? Did insurance pay for none, part, or all of the cost?

- 1 None of the cost
- 2 Part of the cost
- 3 All of the cost

GLP_SYMPTOMS

Have you reduced or stopped taking this medication due to any side effects or symptoms?

[Read if necessary: Side effects or symptoms can include low blood sugar, nausea, vomiting, diarrhea, abdominal pain, dehydration, or pancreatic, kidney, and gallbladder issues.]

- 1 Yes
- 0 No

CIG - CIGARETTE SMOKING [NOT TESTED]

CIG_SMKEV

Have you smoked at least 100 cigarettes in your entire life?

- 1 Yes
- 0 No [GO TO LUN_CANCER]

CIG_AGE1

How old were you when you first started to smoke cigarettes fairly regularly?
_____ age

Do you now smoke cigarettes every day, some days, or not at all?

- 1 Every day
- 2 Some days
- 3 Not at all

[SHOW IF R IS NOT A CURRENT SMOKER]

CIG_AGE2

How old were you when you last smoked cigarettes regularly? _____ age

LUN – LUNG CANCER SCREENING [PROBED]

[SHOW IF R **EVER** SMOKED]

LUN_AVERAGE

Thinking about the entire time that you have smoked, we want to know the average number of cigarettes that you smoked per day. What would be the easiest way for you to tell us the average number of cigarettes that you smoked per day? [READ IF NECESSARY: A typical pack is 20 cigarettes.]

- 3 Average number of cigarettes
- 4 Average number of packs

[SHOW IF R REPORTS AS # OF CIGARETTES]

LUN_AVGCIG

Over the entire time that you have smoked, what is the average number of cigarettes that you smoked per day? [READ IF NECESSARY: A typical pack is 20 cigarettes.]

_____ cigarettes smoked per day
[SHOW IF LUN_AVGCIG = DK or refused]

LUN_AVGCIG2

The answers people give us about their cigarette smoking are important to this study's success. We know that this information is personal, but please remember your answer will be kept confidential.

Over the entire time that you have smoked, what is the average number of cigarettes that you smoked per day? [Read if necessary: A typical pack is 20 cigarettes.]

_____ cigarettes smoked per day

[SHOW IF REPORTS AS # OF PACKS]

LUN_AVGPACK

Over the entire time that you have smoked cigarettes, what is the average number of packs that you smoked per day? [Read if necessary: A typical pack is 20 cigarettes.]

_____ packs smoked per day

[SHOW IF LUN_AVGPACK = DK or refused]

LUN_AVGPACK2

The answers people give us about their cigarette smoking are important to this study's success. We know that this information is personal, but please remember your answer will be kept confidential.

Over the entire time that you have smoked cigarettes, what is the average number of packs that you smoked per day? [Read if necessary: A typical pack is 20 cigarettes.]

_____ packs smoked per day

[SHOW ALL]

LUN_DOCASK

Has a doctor or other health professional ever asked you if you smoked cigarettes?
[Read if necessary: *The question could have been asked on a paper or online form you completed before the health care visit or during a conversation at the visit.*]

1 Yes

0 No

LUN_NOTSHARE

Have you ever chosen not to share that you smoke cigarettes with a doctor or health professional?

1 Yes

0 No [GO TO LUN_CANCER]

[SHOW IF R HAS **NOT** TOLD A DR ABOUT SMOKING]

What were the reasons why you did not share that you smoke cigarettes with them?

LUN_INSUR

It might have negatively affected the cost of my health insurance, life insurance, or long-term care insurance.

1 Yes

0 No

LUN_JUDGED

I would have been judged negatively by the doctor or health professional.

1 Yes

0 No

LUN_TREAT

I would have been treated differently by the doctor or health professional.

1 Yes

0 No

LUN_LECTURE

I did not want a lecture about smoking from the doctor or health professional.

1 Yes

0 No

LUN_ASHAME

I felt ashamed about smoking.

1 Yes

0 No

LUN_READY

I was not ready to quit smoking.

1 Yes

0 No

LUN_SHOTHER

Some other reason.

1 Yes

0 No

[SHOW ALL]

LUN_CANCER

Have you ever been told by a doctor or other health professional that you had lung cancer?

1 Yes

0 No

[SHOW ALL]

LUN_LCSCREEN

Lung cancer screenings are recommended for people who...

- Are between the ages of 50 and 80,
- Smoke now or have quit smoking in the past 15 years,
- Have smoked at least “20 pack years,” such as smoking one pack of cigarettes a day for 20 years, or two packs a day for 10 years, or four packs a day for five years.

Before this survey, did you know the recommendations for who should get lung cancer screening?

1 Yes

0 No

[SHOW IF R IS 40 OR OLDER; ELSE WOMEN GO TO FERTILITY; MEN END INTERVIEW]

LUN_BENEFIT

During the past 12 months, did a doctor or other health professional talk with you about the benefits of having a scan to check for lung cancer?

- 1 Yes
- 0 No

LUN_HARMS

During the past 12 months, did a doctor or other health professional talk with you about the harms of having a scan to check for lung cancer?

- 1 Yes
- 0 No

LUN_LOWDOCT

Have you ever had a low-dose CT scan of your chest area? During this test, you are lying down and moved through a donut-shaped x-ray machine while holding your breath.

- 1 Yes
- 0 No [GO TO LUN_DISP3]

LUN_CTSCREEN

Was your most recent low-dose CT scan of your chest area done to check or screen for lung cancer?

- 1 Yes
- 0 No

LUN_DISP3

What are the reasons you have not had a low-dose CT scan for lung cancer screening?

LUN_NOREC

My health care provider has never recommended a lung cancer screening to me.

1 Yes

0 No

LUN_HEALTHY

I am healthy.

1 Yes

0 No

LUN_BLAAMED

I am afraid of being judged or blamed for smoking.

1 Yes

0 No

LUN_NOTIME

It is hard to find time to get a lung cancer screening.

1 Yes

0 No

LUN_TRANSPO

It is hard for me to get reliable transportation to get a lung cancer screening.

1 Yes

0 No

LUN_EXPOSE

I am concerned about being exposed to radiation from a low-dose CT scan.

1 Yes

0 No

LUN_CONCERN

I am concerned about other harms from getting a low-dose CT scan.

- 1 Yes
- 0 No

LUN_NORISK

I am at low or no risk of getting lung cancer.

- 1 Yes
- 0 No

[SHOW IF R NEVER HAD A CT SCAN **OR** HAD A SCAN THAT WAS NOT FOR LUNG CANCER]

LUN_DISP5

Are any of the following a reason why you have not had a low-dose CT scan for lung cancer screening?

LUN_ANXIOUS

Knowing the results would make me anxious or stressed.

- 1 Yes
- 0 No

LUN_COST

I am concerned about the cost of screening.

- 1 Yes
- 0 No

LUN_SCOTHER

Some other reason.

- 1 Yes
- 0 No

[SHOW ALL]

LUN_DISP6

How much do you agree or disagree with the following statements? Would you say you strongly agree, somewhat agree, somewhat disagree, or strongly disagree?

LUN_BLAAME

People with lung cancer are to blame for their illness.

- 5 Strongly agree
- 6 Somewhat agree
- 7 Somewhat disagree
- 8 Strongly disagree

LUN_CHOICES

People with lung cancer have made poor lifestyle choices.

- 5 Strongly agree
- 6 Somewhat agree
- 7 Somewhat disagree
- 8 Strongly disagree

LUN_STILLRISK

You are still at risk of getting lung cancer, even if you do not smoke.

- 5 Strongly agree
- 6 Somewhat agree
- 7 Somewhat disagree
- 8 Strongly disagree

LUN_ASSUME

If someone told me they had lung cancer, I would assume it is because they smoked.

- 5 Strongly agree
- 6 Somewhat agree
- 7 Somewhat disagree
- 8 Strongly disagree

FER – FERTILITY AND REPRODUCTIVE HEALTH SERVICES [PROBED]

[ASK WOMEN 18-49; ELSE MEN END INTERVIEW]

The next section is about your experience with childbearing and pregnancy. The first question asks when you started having your menstrual periods.

FER_PERAGE

How old were you when you had your first menstrual period? _____ years

FER_PREG

Are you pregnant now?

- 1 Yes
- 5 No
- 9 Don't know

FER_PREGNUM

The next question asks about any pregnancies you have had -- whether they resulted in babies born alive, stillbirth, abortion, miscarriage, or ectopic or tubal pregnancy.

[Including this pregnancy, how / How] many times have you been pregnant in your life?

_____ # times [IF 0, GO TO FER_SURGERY]

[SHOW IF R HAS EVER BEEN PREGNANT]

FER_LIVENUM

The next question asks about any live births you have had. How many babies did you have that were born alive? Please include babies that may have died shortly after birth and babies that you placed for adoption.

_____ # of babies

FER_SURGERY

Have you ever had surgery or other medical procedures that make it impossible for you to get pregnant [again] or carry [a / another] baby?

- 1 Yes [GO TO FER_PLANS]
- 0 No

FER_PHYSPOS

Some women are not physically able to have children. As far as you know, is it physically possible for you, yourself, to have [a / another] baby?

- 1 Yes
- 0 No

FER_PLANS

The next question is about your feelings about having [a / another] baby, whether or not you are able to, or plan to have one.

Looking to the future, [if it were possible,] would you, yourself, want to have [a / another] baby at some time? [If you are currently pregnant, please consider some time after this pregnancy is over.] Would you say...

- 1 Definitely yes
- 2 Probably yes
- 3 Probably no
- 4 Definitely no

FER_INTEND

Sometimes what people want and what they intend are different because they are not able to do what they want. The next questions are about your intentions to have [a / another] baby in the future. Looking to the future, do you intend to have [a / another] baby at some time?

[Read if necessary: Intend refers to what you are actually going to try to do. Do not count intended adoptions or stepchildren.]

- 1 Yes
- 0 No [GO TO FER_SEXMALE]

FER_EXPECT

When do you expect your [first / next] child to be born? [If you are currently pregnant, please consider some time after this pregnancy is over.] Would you say...

- 1 Within the next 2 years
- 2 2-5 years from now
- 3 More than 5 years from now

[SHOW IF R HAS NEVER BEEN PREGNANT; ELSE GO TO FER_SEXM12M]

FER_SEXMALE

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

- 1 Yes
- 0 No [END INTERVIEW]

FER_SEXM12M

During the last 12 months, that is, since [MONTH] 2024, have you had sexual intercourse with a male partner? *[Read if necessary: Do not count oral sex, anal sex, or other forms of sexual activity that do not involve vaginal penetration.]*

- 1 Yes
- 0 No [END INTERVIEW]

[SHOW IF R HAS HAD SEX WITH A MALE IN PAST 12 MONTHS]

FER_PREVENT

I have a list of methods that some people use to prevent pregnancy or to prevent sexually transmitted disease [If it would be helpful for me to provide specific examples of these methods, I can read those.] [SHARE SCREEN IF NEEDED]

- Birth control pills
- Condoms or rubbers
- Hormonal implant (READ IF NECESSARY: Norplant, Implanon, or Nexplanon)
- IUD (READ IF NECESSARY: for example, Copper-T, Paragard, Mirena, Skyla, Liletta, Kyleena)
- Emergency contraception pills [READ IF NECESSARY: for example: Plan B, Preven, Ella, Next Choice, Julie, "Morning after" pills]
- Female sterilization (READ IF NECESSARY: tubal ligation, hysterectomy, other)
- Partner's vasectomy
- Depo-Provera injectables (shot every 3 months)
- Withdrawal, pulling out
- Calendar rhythm method
- Standard Days or CycleBeads method
- Safe period by temperature or cervical mucus test (READ IF NECESSARY: for example: Two Day Method, Billings Ovulation Method, Symptothermal Method)
- Natural Cycles app
- Contraceptive patch (READ IF NECESSARY: Ortho-Evra or Xulane)
- Vaginal contraceptive ring (READ IF NECESSARY: NuvaRing, EluRyng, or Annovera)
- Other methods [READ IF NECESSARY: for example, Vaginal contraceptive film, diaphragm, female condom, foam, jelly or cream, cervical cap, suppository, insert, Today sponge, Phexxi Gel, Lunelle (monthly shot)]

The last time you had intercourse with a male partner, did you or he use any method?

- 1 Yes [GO TO FER_DISP]
- 0 No

[SHOW IF NO BIRTH CONTROL WAS USED; ELSE GO TO FER_DISP]

FER_WANTPREG

Is the reason you did not use a method of birth control because you, yourself, wanted to become pregnant?

- 1 Yes
- 0 No

FER_WHYNOBC

Which one of these is the main reason that you did not use birth control?

- 7 You did not expect to have sex
- 8 You did not think you could get pregnant
- 9 You didn't really mind if you got pregnant
- 10 You were worried about the side effects of birth control
- 11 Your male partner did not want you to use a birth control method
- 12 Your male partner himself did not want to use a birth control method
- 13 Other reason

[ASK ALL]

FER_DISP

- The questions in this section are about recent medical visits for family planning services, as well as other types of pregnancy and health care services for women.

FER_BCDOC

In the past 12 months, that is since [MONTH] 2024, have you received a method of birth control or a prescription for a method from a doctor or medical care provider?

[Read if necessary: *This includes getting pills, or a new prescription for pills, a new diaphragm or IUD, or a new supply of condoms, from a doctor or medical care provider.*

Do not count visits to drug stores or other stores or pharmacies, to refill prescriptions or to buy supplies.]

- 1 Yes
- 0 No

FER_TESTBC

In the past 12 months, have you received a check-up or medical test related to using a birth control method?

[Read if necessary: This includes procedures or lab tests used to detect medical conditions or problems. These may refer to routine visits or visits made because of specific problems related to contraceptive use.]

- 1 Yes
- 0 No

FER_INFOBC

In the past 12 months, from a doctor or other medical care provider, have you received counseling or information about birth control?

[Read if necessary: Includes counseling or information related to whether to use birth control methods, how to get them, information about different methods, and how they are used]

- 1 Yes
- 0 No

FER_INFOSTER

In the past 12 months, have you received counseling or information about getting sterilized?

[Read if necessary: Includes counseling about a surgical procedure that makes female pregnancy impossible, most commonly a tubal ligation.]

- 1 Yes
- 0 No

FER_PLANB

In the past 12 months, from a doctor or other medical care provider, have you received emergency contraception pills, a prescription for emergency contraception pills, or counseling or information about emergency contraception pills? *[Read if necessary: Emergency contraception pills are also known as "Plan B" or the "Morning-after pill." Include counseling, information, or a prescription for the pills, whether or not you obtained the pills.]*

- 1 Yes
- 0 No

FER_PAPTEST

In the past 12 months, have you received a Pap test -- where a doctor or nurse put an instrument in the vagina and took a sample to check for abnormal cells that could turn into cervical cancer?

- 1 Yes
- 0 No

FER_PELVEXAM

In the past 12 months, have you received a pelvic exam -- where a doctor or nurse puts one hand in the vagina and the other on the abdomen?

- 1 Yes
- 0 No

FER_STDTEST

In the past 12 months, have you been tested for a sexually transmitted disease?

[Read if necessary: Includes medical exams, blood tests, or cultures taken to determine whether someone has a sexually transmitted disease or STD. Some sexually transmitted diseases include herpes, gonorrhea, chlamydia, and HIV.]

- 1 Yes
- 0 No

FER_FERTILITY

Have you ever gone, either alone or with a spouse or partner, to a doctor or other medical care provider to talk about ways to help you become pregnant? Please include telehealth visits by video or phone. *[Read if necessary: If main purpose of visit was for something other than seeking help to become pregnant, please select no.]*

- 1 Yes
- 0 No [GOT TO FER_DOCPREV]

FER_FERTNOW

Are you currently pursuing medical help for you to become pregnant? *[Read if necessary: If you or your spouse/partner plan to visit the doctor or clinic again, please select yes.]*

1 Yes

0 No

FER_DOCPREV

Not counting routine check-ups, prenatal care, or advice about a pregnancy, have you ever been to a doctor or other medical care provider to help you prevent miscarriage or pregnancy loss? Please include telehealth visits by video or phone.

1 Yes

0 No

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