NCHS Rapid Surveys System

NATIONAL CENTER FOR HEALTH STATISTICS

Rapid Survey Systems (RSS)

RSS-3 Cognitive Interviewing Report
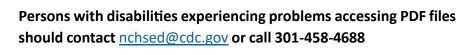
Last revised November 4, 2024

CDC
U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION

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Introduction

The National Center for Health Statistics (NCHS) seeks to evaluate questions included on the third round of the Rapid Surveys System (RSS-3). RSS is designed to produce timely estimates on emerging and relevant public health–related topics. Given the short timeline that RSS operates under, the more typical workflow of conducting cognitive interviews as a pretest before a survey is fielded is not possible. Rather, the cognitive interviews for RSS-3 were conducted shortly after the survey's field period, and the findings presented in this report can help inform interpretation of the survey results. For RSS-3, 20 interviews were completed several months after data collection.

This document was prepared for NCHS under Contract No. GS00F354CA with RTI International. Amy Brown served as the government project officer and as the contracting officer's representative. This study was granted approval by NCHS's Ethics Review Board and Information Collection Review clearance by the Office of Management and Budget.

Background

RSS is intended for situations in which decision makers' need for time-sensitive data of known quality about emerging and priority health concerns is a higher priority than their need for statistically unbiased estimates.

NCHS's traditional household surveys generate robust nationally representative statistics using methods that maximize relevance, accuracy, and reliability. Whereas NCHS's gold standard sampling, interviewing, and post-processing strategies are pivotal for examining national yearly trends in disease and behavioral risk factors and differences across demographic and geographic groups, they are less flexible when responding to short-term challenges to public health. As a result, the Centers for Disease Control and Prevention (CDC) uses other data sources to identify and track emerging public health threats, such as those associated with disease outbreaks. During the COVID-19 pandemic, the implications of unknown data quality from some public health surveillance approaches became clearer. In response, CDC is working to better understand the limits of its public health surveillance systems and to develop a mechanism that facilitates collection of time-sensitive survey data with known quality. To that end, the NCHS RSS has three major goals: (1) to provide CDC and partners with time-sensitive data of known quality about emerging and priority health concerns, (2) to increase NCHS's expertise in online panel use and to evaluate the quality of public health estimates generated from commercial online panels, and (3) to improve methods

to appropriately communicate the fitness for use of public health estimates generated from commercial online panels.

RSS will examine the ability of panel data to represent the U.S. adult population. Depending on the sample size, topic, and analytic goals, estimates for specific subpopulations defined by demographics or socioeconomic characteristics can be generated. RSS uses NORC's AmeriSpeak panel and Ipsos's KnowledgePanel, two commercially available probability-based online panels, to create a platform designed to produce national estimates from the combined results. RSS includes multiple mechanisms to evaluate the resulting survey data for its appropriateness for use in public health surveillance and research, including cognitive interviewing.

Four new, emerging, or supplemental topics from contributing agencies were specifically included on RSS-3, including:

- Family Health History
- Genetic Testing for Cancer and Heart Disease
- Employment
- Sexual Health

RSS-3 also included demographic questions such as age, race, ethnicity, and sex; calibration variables such as civic engagement and languages spoken at home; and benchmarking questions such as chronic conditions and access and use of medical care.

Methodology

Cognitive Interviewing

Cognitive interviewing focuses on participants' cognitive process while completing a survey.[1,2] Interviewers are interested in identifying survey elements that invoke unnecessary cognitive burden or that prevent respondents from effectively comprehending, recalling, judging, and reporting proper answers to questions. Interviewers are also interested in differences in the cognitive process by key subgroups and in how participant interpretation of the questions could impact results.

Cognitive interviewing consists of one-on-one interviews to assess general comprehension, clarity of question and response wording, effectiveness of skip logic,

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[1] Willis, G. (2005). *Cognitive Interviewing: A Tool for Improving Questionnaire Design*. Thousand Oaks, CA: Sage Publications.
[2] Miller, K., Willson, S., Chepp, V., and Padilla, J. (Eds.). (2014). *Cognitive Interviewing Methodology*. Hoboken, NJ: Wiley and Sons.

and visual aids in a survey. The goal is to gain an understanding of how well the questions work when administered to a sample of the survey's target population. The interviews follow a protocol with some general pre-scripted probes. Cognitive interviewers are trained to instruct the participant on thinking aloud and to encourage that behavior, and to use spontaneous probing to fully understand a participant's response. Cognitive interviewing works best for:

- Learning about the thought process respondents use in answering the questions
- Probing deeper into the response process
- Observing nonverbal, human reactions
- Testing navigation in self-administered modes
- Examining new items for potential for measurement error
- Gauging opinions on the survey as a whole

Sample and Respondent Recruitment

For RSS-3, recruitment for cognitive interviewing focused on building a demographically diverse, purposive qualitative sample and including participants who have had genetic testing for family history information, prenatal testing, and genetic disease risk factors.

Advertisements were placed online asking potential participants to fill out a screener online. This screening process allowed a diverse but nonrandom sample to be created for these interviews.

Data Collection and Analysis

Data Collection

All cognitive interviews were conducted virtually, using Zoom. Interviews lasted no more than 60 minutes, and all participants received a $50 electronic Visa gift card for participating even if they ended the interview early. Prior to beginning the interview, the interviewer reviewed the informed consent form with the participant and answered any questions they had about the form. Interviewers also obtained verbal consent for participation in the interview, consent for observation by RSS staff, and consent for audio and video recordings.

Interviewers shared their screen with participants, displaying the web version of the questionnaire. Participants were asked to read the questions aloud and tell the interviewer how they would respond if answering the survey on their own. Participants were asked to think aloud when answering the survey questions. Participants were

shown all questions in the web instrument; however, cognitive interviewers only probed on the four new, emerging, or supplemental topics specifically included in RSS-3. Interviewers probed these topics to better understand how participants decided on their answer and to assess participant understanding of the question. Participants could refuse to answer any question they did not want to answer.

Participants were assigned to either the Ipsos version or the NORC version of the instrument. Although the visual presentation of the web instrument differed between these two versions, the question text and response options were identical.

Data Analysis

To facilitate analysis, all interviews were video and audio recorded. Recordings allowed the interviewer to fully engage with the participant and concentrate during the interview without focusing on notetaking during the discussion. Using the recordings, interviewers created summary notes about how the participant answered the survey questions, how participants decided on their responses to survey questions, and their interpretation and understanding of the survey items, as evidenced by both summary and verbatim statements. Summary notes were entered into a template with each summary labeled with the participant ID. The notes did not contain any personally identifiable information, maintaining participant confidentiality throughout analysis. The summary notes were analyzed using thematic analysis, a method for analyzing qualitative data that involves reviewing a set of data and looking for patterns in the meaning of the data to identify themes.[3]

Table 1 displays the demographic characteristics of the 20 cognitive interview participants.

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[3] Clarke, V. & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, *12*(3), 297-298.

Table 1. Cognitive Interview Participant Characteristics

Participant Characteristic	Number of Participants	Participant Characteristic	Number of Participants
Race		**Education**	
American Indian or Alaska Native	0	Less than high school diploma	0
Asian	3	High school diploma or equivalent	5
Black or African American	5	Some college, no degree	3
Middle Eastern or North African	1	Associate's degree	3
Native Hawaiian and Pacific Islander	0	Bachelor's degree	7
Other	1	Post-bachelor's degree	2
White	10	No formal education	0
Hispanic or Latino (Yes)	2	**Genetic testing**	8
Age		Family history	8
18-29	6	Cancer	2
30-49	7	Heart disease	0
50+	7	**No genetic testing**	12
Sex			
Male	7		
Female	13		

Overall Findings

The cognitive interviews included survey questions and probes about selected questions from the four topics that were specifically included on RSS-3. The other health and demographic characteristics described previously are recurring across rounds of RSS and are used for calibration and other methodological purposes. This section provides an overview of the findings from the specific RSS topics.

1. *Family Health History.* Some participants did vary which family members they included in their responses to these questions. They reported on family members not listed in the introduction, did not include family members listed in the introduction, and changed which family members they were thinking of between questions. Although most participants had not actively collected health information to develop a family health history, there was consensus about the meaning of "actively collected health information." Participants defined this as "asking" or "having conversations" with biological relatives about their current and past conditions. Further, some participants mentioned these casual

conversations when thinking about sharing family health history with other relatives, but other participants did not consider these conversations as "sharing."

2. *Genetic Testing for Cancer and Heart Disease.* There was some confusion between genetic testing and diagnostic testing for a few participants in this section. Some participants reported only diagnostic testing as if it were genetic testing and some participants seemed to report both types of tests simultaneously. When asked if they had ever had a genetic test for cancer or heart disease, many participants did not know if they had; some of these participants did not provide an answer and some of these participants said "No." There was some confusion for two participants around negatively framed questions (I do not…), and these participants had to expend more cognitive effort to figure out how to respond correctly.

3. *Employment.* The initial question asking about paid work in the last week caused confusion, particularly around the instruction to include work at a family business but not for pay. This confusion caused incorrect responses to be reported. Participants who were independent contractors or worked for themselves had difficulty reporting the number of jobs they currently work, the number of hours they work per week, and reporting whether taxes are deducted or withheld from their pay. Further, some participants who selected these responses of independent contractor and self-employed when answering the question about employment type reported being less certain about their responses and how to categorize their employment.

4. *Sexual Health*. There was some variation in the understanding of "sexual health" as participants proceeded through this section. There was also some discomfort among participants when answering this section and at least one participant chose not to answer most questions in this section. For those who reported receiving sexual health services, it was unclear for several participants if they received these services as part of general health care or specifically as sexual health services.

Question-by-Question Findings

Below are the cognitive interview findings for each topic probed on during the interviews. Findings include direct quotes from participants, where applicable. Questions were asked of all participants unless specified otherwise.

Family Health History Questions

The questions in this section asked about the importance of knowing family health history of immediate biological relatives, how much a participant knows about the health history of their biological relatives, and about the collection and sharing of family health history.

FHH_INTRO	**The next questions are about your family health history. This includes illnesses, past diagnoses, and health problems that your relatives had.** **Do not include relatives who you are related to by marriage or adoption. Include your biological parents, brothers, sisters, children, and grandparents.**

FHH_HISTIMP	**How important is knowing your family health history to your own health?**

Frequency distribution (N = 20)

Response Option	Count
Not at all important	0
Somewhat important	5
Very important	15

Participants understood this question was asking specifically about biological family. When asked what family members participants were thinking of while answering this question, one participant who was adopted mentioned that she thought of her biological mother, who she knows, when answering this question instead of her adoptive mother. Some participants took a broader view of the biological family that should be included in this question than the preceding introduction directed them to include. Three participants included aunts and uncles when answering this question, one included a great uncle, and one included a cousin she is particularly close to.

Five participants did not include their siblings. Reasons for excluding siblings included the siblings being deceased, not having a relationship with their siblings, and the assumption that because siblings are in the same generation as the participants, they would share similar conditions and health history. One participant did not include their grandparents when answering this question because they said that they did not know them well enough.

Although this question was generally well understood, four participants mentioned only thinking of relatives they knew to have hereditary health conditions when answering this question.

FHH_DISP1	How much do you know about the health history of your biological parents and grandparents?
FHH_MOM	Mother?
FHH_FATH	Father?
FHH_MATGP	Mother's parents, that is, either of your maternal grandparents?
FHH_PATGP	Father's parents, that is, either of your paternal grandparents?

Frequency distribution (N = 20)

Response Option	Count
Mother	
Nothing at all	0
Some	7
A lot	13
Father	
Nothing at all	1
Some	8
A lot	11
Mother's parents, that is, either of your maternal grandparents	
Nothing at all	8
Some	9
A lot	3
Father's parents, that is, either of your paternal grandparents	
Nothing at all	10
Some	8
A lot	2

Three participants mentioned managing their parents' or grandparents' health care or helping them with their medications or medical appointments. Other participants based their responses on health conditions they knew their relatives had, particularly as they grew older or passed away, and on what they had been told by other family members. Most participants' knowledge of their grandparents' health conditions came from conversations with their parents on other relatives. There was no apparent misunderstanding of these questions.

FHH_COLLECT	Have you ever actively collected health information from your <biological relatives> for purposes of developing a family health history?

Frequency distribution (N = 20)

Response Option	Count
Yes	2
No	18

Although most participants had not actively collected health information to develop a family health history, there was consensus about the meaning of "actively collected health information." Participants defined this as "asking" or "having conversations" with biological relatives about their current and past conditions. Participants saw this as something they would do themselves by going directly to their biological relatives.

Similar to the previous question, participants limited the family they considered for this question to biological family members, mostly parents and grandparents. Some participants mentioned siblings and aunts and uncles. One participant did mention excluding deceased relatives from this process but did not mention if they would ask for this health information from other, living relatives.

During probing, participants were asked if they had ever collected family health information for reasons other than creating a family history; five participants reported doing so. For these participants, this information often came up in regular conversation.

I feel like the answer would be yes, because it sounds really informal, like almost like saying 'have you had COVID or did you ever broken [sic] a bone in their body'. It feels super casual and like I'm just asking them how they're doing. Original question feels like a formal sit down, where this question is more of a casual conversation where you ask them how you're doing. As this was discussed during probing, participants did not consider this "actively" collecting health information and did not include it in their answer to this question.

FHH_OTHER	Have you ever shared your family health history with other relatives, to make them aware of their own health risks?

Frequency distribution (N = 20)

Response Option	Count
Yes	5
No	15

There was variation in how this question was understood by participants. The participants who said "Yes" to this question cited casual conversations with family members that included information about their shared family health history. Five of the participants who said "No" also mentioned similar casual conversation with family

members but did not consider this sharing family health history. Some participants seemed confused because there was no differentiation between a casual conversation that includes family health history and deliberately sharing this information.

I was going to say no because I don't think I've done that, but then you didn't mention formally doing it or not, this is just random. Also I'm not sure if I'm supposed to talk about my own health history in this question, or other relatives' health history. I can talk about my own, but it's kind of like saying "Did you know grandpa had cancer" when I'm talking to my sister. Does "family health history" include me or does it not, that's kind of confusing to me. My initial thing would be to say 'no', but now that we've had this discussion… I feel like I'd have to think about this question before I could answer yes or no. I'm going to say no because I can't think of an example, but I feel like if I really thought about it I could probably think of a time that I've done that.

Like the above respondent, two other participants expressed confusion about if they should include sharing information about their own health in this question. Two participants only mentioned sharing their own health history with other family members.

FHH_HCP	Have you ever shared your family health history with your doctor or health care provider, such as through forms you filled out during visits, patient portals, or conversations with your doctor?

Frequency distribution (N = 20)

Response Option	Count
Yes	16
No	4

This item was not probed on during the cognitive interviews. There was no apparent misunderstanding or confusion among participants.

FHH_DIFCOL	How difficult is it to collect information about the health history of your biological relatives?

Frequency distribution (N = 20)

Response Option	Count
Not at all difficult	5
Somewhat difficult	10
Very difficult	5

Four of the five participants who responded "very difficult" reported that their relatives were deceased or that they were no longer in contact. Those who selected "somewhat difficult" cited a variety of reasons causing difficulty including family's unwillingness or discomfort talking about health issues, not being in contact with some

family members, and not having information directly from health care providers and needing to trust what family told them. One participant was unsure how to respond because she was closer to one side of her family than the other.

> My mother passed away so I didn't get to find out much about family health history from her side. My aunt gives me bits and pieces but it's not really much information. My father's side, my father has given me a lot of information about my diet and how high blood pressure runs in the family, about schizophrenia, mental health. So with my father's side, somewhat difficult, but with my mother's side, there's not many more questions I could ask.

Several participants mentioned one side of their family when probed on how they decided on their answer but did not mention both sides.

FHH_DISP2	Do any of the following reasons make it difficult to collect information about the health history of your biological relatives?
FHH_KNWCOL	I do not know what information to collect.
FHH_ORG	I find it hard to organize or store the information.
FHH_NOCONT	I am not in contact with my relatives or they are no longer alive.
FHH_UNCOMF	I am uncomfortable asking my relatives.
FHH_DIFOTHER	Some other reason?

Frequency distribution (N = 20)

Response Option	Count
I did not know what information to collect	
Yes	9
No	11
I find it hard to organize or store the information	
Yes	5
No	15
I am not in contact with my relatives or they are no longer alive.	
Yes	12
No	8
I am uncomfortable asking my relatives.	
Yes	8
No	12
Some other reason?	
Yes	7
No	13

In this set of questions, only the last question (Some other reason) was probed on. There was no apparent misunderstanding or confusion among participants on any of these items.

Those that indicated "some other reason" gave reasons that could fit in the "I am uncomfortable asking my relatives" or "I am not in contact with my relatives or they are no longer alive" questions. One respondent discussed discomfort around sharing women's health issues with family while another was concerned her questions would make family members uncomfortable even if she was not. One participant noted a language barrier between herself and some older relatives that would prevent these conversations. One participant thought "uncomfortable" was not how he would describe his feelings. He said he felt more hesitant than uncomfortable.

"Uncomfortable" doesn't really fit. I think hesitant is better word. It's never going to be a simple, straightforward conversation. Could be long and emotionally draining.

The participants who said "No" to "some other reason" were asked if they could think of other reasons it may be difficult to collect family health history. Most reiterated reasons that were already listed but two participants cited their relatives' "apprehension" or "discomfort" as a reason it could be difficult to collect family health history.

Genetic Testing for Cancer and Heart Disease Questions

These questions asked about the participants' history with genetic testing, their knowledge of genetic testing, and their interest in seeking genetic testing.

GEN_INTRO	**The next questions are about genetic testing. This is when your blood or saliva is tested to see if you are at high risk of getting certain diseases in the future due to your genes. This does not include tests to determine if you have the disease now.** **Include genetic testing done by a health care provider or genetic counselor or from a home test, such as 23andMe or Color Genomics.**

While reviewing this introduction text, most participants found it clear and easy to understand. However, one participant found this introduction confusing because she used 23andMe to learn her ancestry and was confused about why it was included in a question about genetic testing. Further, although participants did not identify confusion about genetic testing while reviewing this introduction text, results from the questions in this section (described below) indicate that participants had confusion about the difference between genetic testing and diagnostic testing.

GEN_DISP1	Have you ever had a genetic test to determine if you have a greater risk of getting…
GEN_CANTST	Cancer?
GEN_HRTTST	Heart disease?

Frequency distribution (N = 20)

Response Option	Count
Cancer?	
Yes	1
No	16
I don't know	3
Heart disease?	
Yes	2
No	14
I don't know	4

There was variation in how participants decided to answer these questions. Five participants answered "I don't know" to at least one of the health conditions (cancer or heart disease) but during probing, three additional respondents who answered either yes or no indicated some uncertainty in their response. All of these participants said that either they had a test done but were not sure if it was for cancer/heart disease or were not sure if the test they had done was a genetic test.

Four participants mentioned diagnostic tests, like echocardiograms, blood tests for cholesterol levels, and allergy testing and were unsure if these were genetic tests or not. One participant cited 23andMe testing as the reason why she said "Yes" to both these questions because she knew they tested for genetic predispositions for certain conditions but was unsure if cancer and heart disease were included in that test.

GEN_CANKNW	Prior to taking this survey, did you know that genetic tests can be used to see if a person has a high risk of getting cancer in the future?

Frequency distribution (N = 19)

Response Option	Count
Yes	13
No	6

Participants who reported not having or being unsure if they had genetic testing for cancer (i.e., No or I don't know to GEN_CANTST) received this question. This item was not probed on during the cognitive interviews. There was no apparent misunderstanding or confusion among participants.

GEN_HRTKNW	Prior to taking this survey, did you know that genetic tests can be used to see if a person has a high risk of getting heart disease in the future?

Frequency distribution (N = 18)

Response Option	Count
Yes	10
No	8

Participants who reported not having or being unsure if they had genetic testing for heart disease (i.e., No or I don't know to GEN_HRTTST) received this question. This item was not probed on during the cognitive interviews. There was no apparent misunderstanding or confusion among participants.

GEN_CANINT	Are you interested in getting a genetic test to find out if you are at high risk of getting cancer in the future?

Frequency distribution (N = 19)

Response Option	Count
Yes	17
No	2

Participants who reported not having or being unsure if they had genetic testing for cancer (i.e., No or I don't know to GEN_CANTST) received this question. Those who said they were interested in having a genetic test to find out their risk of getting cancer in the future cited several reasons for this answer. Most commonly, participants thought getting a genetic test for cancer risk would cause no harm or they were just curious. Participants also mentioned a family history of having cancer as a reason for being interested in a genetic test.

I don't see it as a harm. If I'm getting genetic testing, if it's not going to harm my body or harm mentally or physically blah blah blah… um, then it shouldn't be a problem. It's better to stay safe.

I mean, it could only help not hurt so, yeah.

I think it's just interesting and everyone should do that if you can. The sooner you find something out, the easier it is to deal with it.

Three participants mentioned being afraid of their results or for the security of their health data but still being interested in having genetic testing.

The two participants who said they were not interested in genetic testing to assess cancer risk were older participants who don't see the value of a genetic test at their age.

No longer being 22 and cute, I do see my doctor not infrequently. I have asthma. I have CAT scans for that. I have blood work. He does an EKG every year or so. Those are more germane to me than a genetic test for cancer, though it's certainly great for breast cancer.

My mind might change in the future, but I don't want to know at the moment. I'm in the second half of my life or the next phase, and I want good 5-10 years of peace before I find out things like that.

GEN_HRTINT	Are you interested in getting a genetic test to find out if you are at high risk of getting heart disease in the future?

Frequency distribution (N = 18)

Response Option	Count
Yes	15
No	3

Participants who reported not having or being unsure if they had genetic testing for heart disease (i.e., No or I don't know to GEN_HRTTST) received this question. Participants answered this question in the same way they answered the previous question, mainly focusing on the lack of harm in a genetic test. One participant focused on their knowledge of family history as a reason they would be interested in a genetic test for heart disease.

I am now that I know they can test for that, since [my] family has a history of heart problems.

Contrastingly, one participant who said "No" to this question feels she already knows her risk without having a genetic test.

Because I already know that heart disease runs in my family so there really wouldn't be a reason for me to get tested.

GEN_DISP2	Why did you have genetic testing to find out if you are at high risk of getting [cancer/heart disease/cancer and heart disease] in the future?
GEN_SHRSLT1	I want to share the genetic test results with my relatives.
GEN_KNWDIFF1	Knowing my risk of [cancer/heart disease/cancer and heart disease] would make a difference in my health care decisions.
GEN_KNWCHG1	Knowing my risk of [cancer/heart disease/cancer and heart disease] would encourage me to change my health habits.
GEN_DRREC1	My doctor or health care provider recommended I get a genetic test for [cancer/heart disease/cancer and heart disease].

Frequency distribution (N = 3)

Response Option	Count
I want to share the genetic test results with my relatives.	
Yes	1
No	2
Knowing my risk of [cancer/heart disease/cancer and heart disease] would make a difference in my health care decisions.	
Yes	2
No	1
Knowing my risk of [cancer/heart disease/cancer and heart disease] would encourage me to change my health habits.	
Yes	3
No	0
My doctor or health care provider recommended I get a genetic test for [cancer/heart disease/cancer and heart disease].	
Yes	1
No	2

Participants who reported having a genetic testing for cancer and/or heart disease (i.e., Yes to GEN_CANTST and/or GEN_HRTTST) received this question.

When discussing the reasons for their answers to these questions, one participant mentioned lifestyle changes to lower her blood pressure after diagnostic medical tests. However, it was unclear if the participant who received these questions actually had genetic testing done. During probing of GEN_CANTST and GEN_HRTTST, this participant mentioned doing diagnostic medical testing after learning she had high blood pressure; this participant was unable to definitively answer whether this was a genetic test or diagnostic test.

One participant noted that she hadn't thought much about her reasons for getting tested but had been thinking about it more recently after the diagnosis of a close family member. During probing of GEN_CANTST and GEN_HRTTST, this participant said that they had done genetic testing through 23andMe and knew that there were some health components of that test but could not remember if she had been tested specifically for a predisposition for cancer or heart disease.

One participant was initially confused about the difference between "health care" and "health habits" in the second and third questions in this series. This participant decided that health care meant "doctor's visits" while health habits were her "lifestyle."

One participant said "Yes" to a doctor or health care provider recommending genetic testing but clarified a doctor or health care provider had not recommended this, but she would take their advice if they recommended it in the future.

GEN_DISP3	Why are you interested in having genetic testing to find out if you are at high risk of getting [cancer/heart disease/cancer and heart disease] in the future?
GEN_SHRSLT2	I want to share the genetic test results with my relatives.
GEN_KNWDIFF2	Knowing my risk of getting [cancer/heart disease/cancer and heart disease] would make a difference in my health care decisions.
GEN_KNWCHG2	Knowing my risk of [cancer/heart disease/cancer and heart disease] would encourage me to change my health habits.
GEN_DRREC2	My doctor or health care provider recommended I get a genetic test for [cancer/heart disease/cancer and heart disease].

Frequency distribution (N = 16)

Response Option	Count
I want to share the genetic test results with my relatives.	
Yes	11
No	5
Knowing my risk of [cancer/heart disease/cancer and heart disease] would make a difference in my health care decisions.	
Yes	15
No	1
Knowing my risk of [cancer/heart disease/cancer and heart disease] would encourage me to change my health habits.	
Yes	16
No	0
My doctor or health care provider recommended I get a genetic test for [cancer/heart disease/cancer and heart disease].	
Yes	2
No	14

Participants who reported being interested in genetic testing for cancer and/or heart disease (i.e., Yes to GEN_CANINT and/or GEN_HRTINT) received this question. Overall, participants were most concerned with how genetic testing could help them make better health care decisions and change their health habits.

Several participants who said "Yes" to sharing their test results with relatives would only do so in certain situations.

I think this is personal, if I'm just talking to relatives and it comes up in conversation then I don't mind sharing with them, but I'm not going to go out of my way to call them and share this information with them.

It would depend on what the test results are. If it's something like "I'm dying' that's a really hard subject to bring up to relatives. If I didn't have it then, I probably would. I would say more than likely I would probably choose yes.

One participant misinterpreted these questions to be asking about diagnostic testing rather than genetic testing. Another participant misinterpreted the last question in this series (My doctor or health care provider recommended I get a genetic test for [cancer/heart disease/cancer and heart disease]) and answered "Yes" because he would follow his doctor's advice if a doctor recommended genetic testing.

GEN_DISP4	**Why aren't you interested in having genetic testing to find out if you are at high risk of getting [cancer/heart disease/cancer and heart disease] in the future?**
GEN_STRESS	**Knowing that I have a high risk of [cancer/heart disease/cancer and heart disease] would make me anxious or stressed.**
GEN_NOHELP	**I do not think the genetic test results would be helpful to me.**
GEN_NOREC	**My doctor or other health care provider has not recommended genetic testing for [cancer/heart disease/cancer and heart disease] to me.**
GEN_KEEP	**I am concerned that my genetic test results could impact my ability to get or keep insurance or a job.**
GEN_MISUSE	**I am concerned that my genetic test results could be misused or shared with people who I do not want to see them.**
GEN_COST	**I am concerned about the cost of the test.**

Frequency distribution (N = 3)

Response Option	Count
Knowing that I have a high risk of [cancer/heart disease/cancer and heart disease] would make me anxious or stressed.	
Yes	1
No	2
I do not think the genetic test results would be helpful to me.	
Yes	1
No	2
My doctor or other health care provider has not recommended genetic testing for [cancer/heart disease/cancer and heart disease] to me.	
Yes	1
No	2
I am concerned that my genetic test results could impact my ability to get or keep insurance or a job.	
Yes	1
No	2

Response Option	Count
I am concerned that my genetic test results could be misused or shared with people who I do not want to see them.	
Yes	1
No	2
I am concerned about the cost of the test.	
Yes	1
No	2

Participants who reported not being interested in genetic testing for cancer and/or heart disease (i.e., No to GEN_CANINT and/or GEN_HRTINT) received this question. The three participants who answered this question were mostly concerned about data security and test results making them more anxious. One participant was concerned the survey was biased toward genetic testing.

I would say this survey is kind of pushing for genetic testing, like prodding you, like what's wrong with you, kind of thing.

Two participants were confused by the "double negative" in this question and some responses. They were confused about how to answer "I do not think the genetic test results would be helpful to me" when thinking about reasons they were NOT interested in genetic testing. These participants had to expend more cognitive effort to figure out how to respond correctly, as they had to reread the question several times.

Employment Questions

These questions asked participants about their current employment status, the number of jobs and hours worked, their type of employment, for example employed by a company or self-employed, paid and unpaid leave, and insurance coverage.

EMP_EMPLOY	Last week, did you work for pay at a job or business? If you work at a family business, but not for pay, select yes.

Frequency distribution (N = 20)

Response Option	Count
Yes	12
No	8

Variation emerged in what participants considered when deciding on their answer. Fourteen participants understood the question to be asking about working for pay or for a family business in the previous week.

Some participants reported being confused by the instruction about working for a family business and had to reread the item several times before responding. Three participants worked for pay in the previous week initially responded "No" because they did not do any unpaid work for a family business.

Two of these participants felt this item was asking two distinct questions—one about working for pay at a job or business, and one about not working for pay at a family business—and were confused as to why there was only one set of response options.

There's two questions but only one opportunity to answer.

[This] question was kind of confusing because "Did you work for pay at a job or business?" - there was no 'yes/no' there. I don't know why.

One participant responded "No" despite reporting "working for themselves" because they had not worked for a "job" since last December.

Well, I do work for myself. I haven't had a physical work from home job since last December, but I decided to do, for myself, like virtual assisting.

EMP_ABSENTWK	Did you have a job or business last week, but were temporarily absent due to illness, vacation, family or maternity leave, or some other reason?

Frequency distribution (N = 8)

Response Option	Count
Yes	2
No	5
Skipped	1

The eight participants who responded "No" to EMP_EMPLOY (i.e., did not work last week) received this question. One participant skipped this item without providing a response because they were unsure how to answer.

Most understood this item as being employed or self-employed but being temporarily absent from work. However, one participant who told the interviewer during probing that they were currently employed, but absent last week, responded "No" and explained that they did not have plans to return to this job.

EMP_WHYNOWRK	What is the main reason you were not working for pay at a job or business last week?

Frequency distribution (N = 5)

Response Option	Count
Unemployed, laid off, looking for work	1
Seasonal or contract work	0
Retired	0
Unable to work for health reasons or disabled	1
Taking care of house or family	0
Going to school	2
Working at a family-owned job or business, but not for pay	0
Other	0
Skipped	1

The five participants that reported not working last week (i.e., "No" to EMP_EMPLOY) and indicated that they were not temporarily absent from work (i.e., "No" to EMP_ABSENTWK) received this item.

One participant who misinterpreted EMP_EMPLOY and should have endorsed "Yes" (i.e., worked for pay last week) skipped this item without providing a response because it did not apply to them.

All participants that received this item understood the question to be asking about the reasons they did not work for pay during the reference period. No issues with question comprehension were reported or observed.

EMP_LOOK	Are you actively looking for work?

Frequency distribution (N = 5)

Response Option	Count
Yes	1
No	4

The five participants who reported not working last week (i.e., "No" to EMP_EMPLOY) and indicated that they were not temporarily absent from work (i.e., "No" to EMP_ABSENTWK) received this item.

Participants provided several examples of what "actively looking for work" meant to them, including going to online resources like Indeed, Zip Recruiter, and Craigslist to review job listings, applying to jobs, updating their resume, calling businesses to see if they are hiring, and inquiring with friends and family about potential opportunities.

EMP_NUMJOB	How many jobs do you currently work? If you are self-employed, count work with multiple customers, clients, or businesses as one job.

Frequency distribution (N = 14)

Open-End Response (Number of jobs)	Count
1	7
2	5
3	1
10	1

Fourteen participants who endorsed working (EMP_EMPLOY = 1) or having a job last week but being temporarily absent (EMP_ABSENTWK = 1) received this item.

Across the cognitive interviewing sample, variation emerged in what participants considered when deciding on their answer. Some participants considered all their jobs, including part-time, side jobs, or gig work they may do in addition to a primary job, while other participants did not. One participant who is employed by two companies reported having two jobs, but indicated they also occasionally do work as a freelancer that they did not include in their response. Another participant was not sure if they should count only their main source of employment, or if they should also count the "side work" they do with DoorDash and Instacart because this was not specified in the question. This participant decided to not include their side jobs in their answer.

I wasn't sure if they count your main job or if they count side jobs like DoorDash or Instacart… I would only count my main job because it doesn't mention anything about side jobs or gig work.

One self-employed participant understood the instruction to count work with multiple customers or clients to mean they should count each customer or client as one job. They explained they had multiple contracts and the number of contracts they worked on varied, so they estimated they had "10 at the most" contracts and thus reported 10 jobs.

EMP_ALLHRS	In a typical week, about how many hours do you work at all your jobs or businesses combined?

Frequency distribution (N = 7)

Open-End Response (Hours worked; All jobs)	Count
10	1
25	1
30	2
40	2
65	1

Seven participants who reported having more than one job received this item.

Participants generally understood this item to be asking them to report the hours they worked across all the jobs they had previously reported. When asked how they decided on their response, four participants reported adding up the time they spend at each job, while three participants indicated that their hours varied and instead provided an estimated average of all hours worked across jobs.

Participants generally described a typical week as an average, normal week that did not include holidays or absences.

A week that excludes absences or significant changes in some way.

An average, not a hectic, week. Not counting holidays.

An average week, the norm.

However, one participant who reported not working a *"set schedule"* or being *"tied to a time clock"* and felt they did not have "typical weeks." This participant reported an estimated average of their time worked in a given week.

I don't think there are typical weeks unless you have a real 9 to 5 life.

EMP_HRSMAIN	In a typical week, [about how many hours do you work/about how many hours do you work at your main job or business, that is, the job at which you usually work the most hours]?

Frequency distribution (N = 14)

Open-End Response (Hours worked; Main job)	Count
5	1
20	1
25	2
30	2
35	2
37	1
40	3

Open-End Response (Hours worked; Main job)	Count
48	1
50	1

Fourteen participants who endorsed working (EMP_EMPLOY = 1) or having a job last week but being temporarily absent (EMP_ABSENTWK = 1) received this item.

Participants generally understood this item to be asking them to report the hours they work in a typical week at their job. Most participants who had two or more jobs reported their main job hours as a subset of the total hours they previously reported working across all their jobs (EMP_ALLHRS), with a few notable exceptions described below. Participants who had two or more jobs generally understood this item to be asking about their "main job," or the job where they spent the most time.

I'm thinking about not more of a gig or a side job, I'm thinking about main income… the place I spend most of my time at.

Job where you work most. I guess spend the most time on.

However, one participant indicated they work "equally at both jobs" and consider both jobs as a "main job." This participant initially answered the same as EMP_ALLHRS (10 hours), but during probing, changed their answer and split their total weekly hours between the two jobs; their final answer for EMP_HRSMAIN was 5 hours.

When participants were asked if they were including only work for pay, or if they included work for which they were not paid, all but one participant indicated they were only including work for pay. One self-employed participant explained that there is no easy division between the paid work they do for clients and other work they may do as part of their business that they are not directly paid for.

One self-employed participant who previously reported having 10 jobs because they counted each of their separate contracts as "one job" in EMP_NUMJOB reported hours worked across all of their contracts in this item. This participant reported the same number of hours worked in a typical week (30 hours) on EMP_ALLHRS and EMP_HRSMAIN.

EMP_HRSMORE	At your [job/main job, that is, the job at which you usually work the most hours,] would you like to work more hours, about the same hours, or fewer hours?

Frequency distribution (N = 14)

Response Option	Count
More hours	4
About the same number of hours	7
Fewer hours	3

Fourteen participants who endorsed working (EMP_EMPLOY = 1) or having a job last week but being temporarily absent (EMP_ABSENTWK = 1) received this item.

All participants who received this item understood the question to be asking about the desired number of hours they would like to work compared to the number of hours they are currently working. However, participants considered a variety of factors when deciding on their response. Participants who reported wanting to work more hours at their main job primarily considered finances, and the additional income more hours would provide, when deciding on their response. One participant who works more than one job also indicated that having more hours at their primary job would allow them to leave their part-time job. Two of the participants that indicated they would like to work fewer hours specifically noted they would like to work fewer hours, but for the same pay. Those who indicated they would like to work about the same amount of hours reported being content with the number of hours they were currently working.

EMP_TYPE	At your, [job/main job, that is, the job at which you usually work the most hours,] are you…

Frequency distribution (N = 14)

Response Option	Count
Employed directly by a business, company, government, or nonprofit organization?	7
Employed by a temporary employment agency?	0
Employed by a contract firm, other than a temporary employment agency?	0
An independent contractor?	3
Self-employed, not an independent contractor?	4
Other?	0

Fourteen participants who endorsed working (EMP_EMPLOY = 1) or having a job last week but being temporarily absent (EMP_ABSENTWK = 1) received this item.

Across the cognitive interviewing sample, participants generally understood this item to be asking about their employment classification (e.g., employed, self-employed, independent contractor), but some participants expressed confusion about the

difference between independent contractor and self-employed and were uncertain about how they should classify themselves.

I'm in-between independent contractor and self-employed because I kind of do both. But I guess I would just pick independent contractor for now.

I do find this one kind of confusing because I'm not sure. Like, I would be an independent contractor, but I'm not employed by one, so, I don't know. I would be self-employed.

Some participants who selected the independent contractor and self-employed options reported being less certain about their responses.

Two participants decided on their response based on how the entities they work for classify them. That is, one participant selected "independent contractor" and noted that is the way the websites they work for classified them; similarly, one participant selected "self-employed" and explained that DoorDash documents they read classified them as being "self-employed."

Participants who reported being employed directly by a business, company, government, or nonprofit understood this option to be about the type of employer they worked for and did not report any issues when responding. Two of these participants considered things like being on a payroll and having taxes taken out and receiving a W-2 when deciding on their response. All of the participants who selected this option noted they were "sure" of their response to this question when probed.

EMP_TAX	At your current [job/main job, that is, the job at which you usually work the most hours,] are taxes deducted or withheld from your pay?

Frequency distribution (N = 14)

Response Option	Count
Yes	9
No	5

Fourteen participants who endorsed working (EMP_EMPLOY = 1) or having a job last week but being temporarily absent (EMP_ABSENTWK = 1) received this item.

Participants' process for this item varied depending on whether they reported being employed by a company or business, or an independent contractor or self-employed. Participants who reported being employees responded "Yes" and most explained that they see the taxes deducted from their paychecks. The majority of participants who reported being self-employed or independent contractors selected "No" and indicated that they pay their own taxes. However, one participant who reported being self-employed selected "Yes" and explained they taxed themselves. Two other

participants who reported being independent contractors also selected "Yes"; both noted that they were uncertain about their response.

EMP_PDLEAVE	At your [job/main job, that is, the job at which you usually work the most hours,] do you receive paid leave?

Frequency distribution (N = 14)

Response Option	Count
Yes	7
No	7

Fourteen participants who endorsed working (EMP_EMPLOY = 1) or having a job last week but being temporarily absent (EMP_ABSENTWK = 1) received this item.

Across the participants who received this item, "paid leave" was generally understood as leave that if offered by an employer that you can take while still getting paid. Participants provided a variety of examples of paid leave they were familiar with, including vacation hours, sick leave, paid time off (PTO) hours, and maternity and paternity leave.

EMP_UPLEAVE	[In addition to your paid leave, are/Are] you allowed to take time off from work without pay?

Frequency distribution (N = 14)

Response Option	Count
Yes	12
No	2

Fourteen participants who endorsed working (EMP_EMPLOY = 1) or having a job last week but being temporarily absent (EMP_ABSENTWK = 1) received this item.

Across the participants who received this item, "unpaid leave" was generally understood as leave that an employee can take away from their job that they are not paid for. However, one participant who is a salaried employee was uncertain about how to respond and explained they can take time away from work, but they still receive their salary, so they selected "No."

Being "allowed" to take time away was generally understood as having the ability to request leave without pay and not be reprimanded or lose their job for doing so.

You don't have to work and don't receive consequences for that. [Like] getting demoted or fired.

You provide some sort of advanced notice and they let you without jumping through a lot of hurdles and hoops.

Some participants who reported being self-employed/independent contractors pointed out that taking unpaid time away from work was their own decision.

EMP_WHENWRK	When was the last time you worked for pay at a job or business, even if only for a few days?

Frequency distribution (N = 4)

Response Option	Count
Within the past 3 months (anytime less than 3 months ago)	2
Within the past 6 months (3 months but less than 6 months)	0
Within the past 12 months (6 months but less than 12 months)	1
Within the past 18 months (12 months but less than 18 months)	0
Within the past 5 years (18 months but less than 5 years)	0
Five years or more	0
Never worked	1

Four participants who reported not working last week (i.e., "No" to EMP_EMPLOY) and indicated they were not temporarily absent from work (i.e., "No" to EMP_ABSENTWK) received this item.

Participants understood this item as asking them to report the last time they worked for pay. When probed about how easy or difficult it was to remember the last time they worked, participants said it was not difficult. One participant indicated they tracked when they work on a calendar, and another noted it was easy to recall because it was recent.

EMP_INSUR	Are you covered by any of the following types of health insurance or health coverage plans?
EMP_INSA	Insurance through a current or former employer or union of your own or another family member
EMP_INSB	Insurance purchased directly from an insurance company by you or another family member
EMP_INSC	Medicare, for people 65 and older or people with certain disabilities
EMP_INSD	Medicaid, Medical Assistance, or any kind of government-assistance plan for those with low incomes or a disability
EMP_INSE	TRICARE or other military health care
EMP_INSF	VA (enrolled for VA health care)
EMP_INSG	Indian Health Service
EMP_INSH	Any other type of health insurance or health coverage plan *(please specify)*

Frequency distribution (N = 20)

Response Option	Count*
Insurance through a current or former employer or union of your own or another family member	10
Insurance purchased directly from an insurance company by you or another family member	5
Medicare, for people 65 and older or people with certain disabilities	1
Medicaid, Medical Assistance, or any kind of government-assistance plan for those with low incomes or a disability	5
TRICARE or other military health care	0
VA (enrolled for VA health care)	0
Indian Health Service	0
Any other type of health insurance or health coverage plan (please specify)	1

*Responses do not sum to 20. Participants could endorse more than one type of insurance option.

Participants generally understood this question to be asking about what kind of health coverage, if any, they were covered by and the source of that insurance. However, three participants were unsure if the coverage they receive through their state health plan is actually through Medicare or Medicaid. Two of these participants selected the "Medicaid" option and the other selected "Any other type of health insurance" and typed in the name of the state-run plan. These participants cited being uncertain about their answers when probed about how sure/unsure they were of their responses.

Four participants who stated they were on their parents' plans also indicated that they were not certain about their responses and unsure about which of the first two options they should select (purchased through an employer or purchased through a health insurance company).

One participant interpreted "VA" as the state abbreviation for Virginia.

EMP_INSEMP	Did you obtain this coverage through your own employer or union?

Frequency distribution (N = 9)

Response Option	Count
Yes	6
No	3

Nine participants who endorsed working (EMP_EMPLOY = 1) or having a job last week but being temporarily absent (EMP_ABSENTWK = 1) and endorsed receiving

insurance through a current or former employer or union of your own or another family member (EMP_INSA) received this item.

Participants generally understood this item to be asking if they received the employer-provided insurance through their own employer. Five participants indicated they purchased coverage through their own employer, and one indicated it was through a union. Three participants indicated their insurance was through a family member.

EMP_OFFER	Does your employer or union offer health insurance?

Frequency distribution (N = 6)

Response Option	Count
Yes	0
No	6

Six participants that endorsed working (EMP_EMPLOY = 1) or having a job last week but being temporarily absent (EMP_ABSENTWK = 1) but did not endorse receiving insurance through their own current or former employer (EMP_INSA) received this item.

Participants generally understood this item as asking if their employer provided insurance. Four participants indicated they did not work for an employer (i.e., endorsed being self-employed or independent contractors) and as such this item did not apply to them. All four of these participants selected "No."

One participant indicated they were not certain if DoorDash provided insurance and selected "No." They indicated if there was a Don't Know option they would have selected that instead.

EMP_INSFAM	Did you obtain this coverage through a family member's employer or union?

Frequency distribution (N = 2)

Response Option	Count
Yes	2
No	0

Two participants received this item. This item was asked of participants who either reported that they were not working, but received employer provided insurance, or that they were working but their employer-provided insurance was not through their own employer. Both of these participants indicated that they were covered through a family member's policy.

Sexual Health Questions

These questions asked participants about their sexual relationships, sources of information on sexual health, comfort in discussing topics related to their sexual health with their partner(s), and frequency of sexual health discussions in the past 12 months.

SEX_INTRO	The next set of questions are about your sexual health. Sexual health means being comfortable in your body, having a sex life that satisfies you, and being in relationships that feel safe and supportive.

Overall, participants understood the definition of sexual health that was provided in the introduction and seemed to agree that these elements of sexual health included in the definition were in fact elements of sexual health. However, several participants mentioned that the definition did not align with their personal definition, did not include important aspects of sexual health like STIs, or was a "strange" definition from a government agency.

I thought it was really clear and very reasonable. In line with my own definition of sexual health.

Seems really clear because it gives you three different explanations. Doesn't exactly match personal definition – usually talks about medical aspect such as free from STDs, do you get regularly tested.

I think it's a narrow definition of sexual health and because this is CDC it seems a little authoritative. Feel like it should say "in this case, sexual health means" or for purposes of this survey we're defining sexual health as. Feel like it's super non-inclusive… I don't disagree that these things are part of sexual health, but I feel like it's a little limiting. I think sexual health could include trauma, reproductive rights, history, inequities in accessing sexual health resources, the laws of your state that impact access, culture, race, income – this is huge and you're saying it means these three things? That's small.

One participant questioned whether "being comfortable in your body" was part of sexual health, and felt it was more appropriately labeled as an element of self-image or mental health. Another participant wondered why the government would need to know about sexual health and questioned what it had to do with genetic testing.

SEX_REL	How much do you agree or disagree with the following statement? I have had a safe and supportive sexual relationship.

Frequency distribution (N = 20)

Response Option	Count
Strongly agree	12
Somewhat agree	5
Somewhat disagree	2
Strongly disagree	0
I have never had a sexual relationship	1

Participants had a broad understanding of "safe and supportive sexual relationship" that included elements of both physical and emotional safety. Examples included:

- Consensual and not abusive relationship
- Relationship in which they felt heard, respected, and loved
- Practicing safe sex
- Feeling comfortable discussing difficult issues
- Having access to medical care, contraceptives, and counseling
- A partner who is respectful of boundaries
- A relationship free of judgment

To select their response from the list of options, most participants thought about their relationship history and made a determination of whether they had a safe and supportive relationship. A few participants commented that they only needed to have had one safe and supportive sexual relationship in their lifetime to agree with this question, although determining their level of agreement could be more difficult depending on their relationship history. One participant who answered "Somewhat agree" discussed why they did not answer "Strongly agree":

Let me just go back, "I have had" so it's past tense, right. When deciding on answer, it just wasn't all that. It wasn't how I thought it should be. I never felt really fundamentally part of something important, didn't like the way I felt about my body. Didn't think partner at the time had any real emotional attachment or anything that had any depth.

SEX_FUL	How much do you agree or disagree with the following statement?
	My sexual relationships are fulfilling most of the time.

Frequency distribution (N = 18)

Response Option	Count
Strongly agree	8
Somewhat agree	4
Somewhat disagree	2
Strongly disagree	2
No response	2

This question was asked to all participants who answered anything other than "I have never had a sexual relationship" in SEX_REL. One participant was not eligible for this item, two participants who were eligible for this item chose not to answer (one of these participants answered cognitive probes), and one participant ended their interview at this point due to time. Thus, a total of 16 participants provided a response to this item and 17 participants answered cognitive probes.

All participants understood a sexual relationship that was "fulfilling most of the time" to mean that, in general, the sexual relationship was more often fulfilling than not. Some participants described this as the relationship having "good days and bad days." Others, labeled "most of the time" with a percentage, for example, 80% of the time the relationship was fulfilling.

The phrase "most of the time" combined with the response scale did seem to produce an unexpected result. The two participants who answered "Strongly disagree" did so because they felt their sexual relationships were fulfilling *all* of the time and not just *most* of the time.

However, in general, participants decided on a response to this item by reflecting on their current and past sexual relationships and gauging how fulfilling they had been as a whole.

SEX_DISP1	In your sexual relationships, how often do you talk about:
SEX_GETOUT	Your thoughts or feelings about the relationship and what you want to get out of it?
SEX_LIKE	What you like and dislike doing sexually?
SEX_BNDRS	Your sexual boundaries?
SEX_FEEL	How certain sexual situations make you feel both physically and emotionally?

Frequency distribution (N = 17)

Response Option	Count
SEX_GETOUT	
Always	6
Usually	5
Sometimes	2
Rarely	2
Never	0
No response	2
SEX_LIKE	
Always	6
Usually	6
Sometimes	3
Rarely	0
Never	1
No response	1
SEX_BNDRS*	
Always	7
Usually	5
Sometimes	3
Rarely	0
Never	1
No response	1
SEX_FEEL*	
Always	3
Usually	6
Sometimes	4
Rarely	2
Never	1
No response	1

*For the questions in this set, interviewers asked probes only about SEX_BNDRS and SEX_FEEL. One participant was ineligible for these questions, one participant chose not to answer these questions, and two participants ended the interview at this point (or earlier) because of time. Therefore, 17 participants saw these questions.

In answering SEX_BNDRS, all participants understood "sexual boundaries" to be referring to the sexual activities they were comfortable performing and those they were not.

The activities that you are or are not willing to participate in.

What you like and don't like and what you're not going to do.

In responding to SEX_FEEL, participants were able to easily select their response from the list of provided response options. Participants determined the appropriate response by reflecting on their relationship and how they have communicated with their partner(s) in the past. Some participants had more difficulty responding to this question because their comfort with these conversations has changed over time or because these were not frequent or common conversations they had with their partner.

Actually, I had to think about it because early in our relationship it was not easy for me to communicate what I wanted. But as time goes on if you're not used to doing it, it's something you're going to have to learn.

We don't often talk about these things, so it's not like a yes or no answer.

One participant was unsure what SEX_GETOUT was asking and chose not to answer because of this; it was unclear why the participant was confused.

SEX_COMFTLK	Would you say you are comfortable talking to your sexual partners about your sexual health?

Frequency distribution (N=17)

SEX_COMFTLK	
Yes	14
No	3

One participant was ineligible for this question and two participants ended the interview at this point (or earlier) because of time. Therefore, 17 participants saw these questions and answered cognitive probes.

In answering SEX_COMFTLK, nearly all participants understood "sexual health" to be an umbrella term to capture any topic related to their sexual relationship—this could include STIs, sexual likes and dislikes, health issues or physical limitations, and emotional response to sexual situations. Those participants who answered "Yes" to SEX_COMFTLK indicated that they were comfortable having these conversations with their partner(s) because they trusted each other, were comfortable with each other, and they were necessary conversations.

One participant had a very difficult time answering this question and was unsure if people would have these types of conversations with their partner(s), unless they were discussing STIs.

I don't even… to me that's just a strange question. I don't know if anyone that talks to their partner about their sexual health. Don't even know what that conversation would include unless you think she gave you something or have some suspicions. That question… for me it's an oddity.

SEX_DISP2	Are you <u>ever</u> hesitant to talk to your sexual partners about your sexual health for any of the following reasons?
SEX_HURTPTR	I do not want to offend them or hurt their feelings.
SEX_HONEST	I do not trust my partner to be honest with me.
SEX_DESCFEEL1	I do not know how to describe my feelings.
SEX_PUNDSTD	I do not think my partner would understand me.

Frequency distribution (N =17)

Response Option	Count
SEX_HURTPTR	
Yes	5
No	11
No response	1
SEX_HONEST	
Yes	3
No	13
No response	1
SEX_DESCFEEL1	
Yes	2
No	14
No response	1
SEX_PUNDSTD	
Yes	1
No	15
No response	1

One participant was ineligible for this question and two participants ended the interview at this point (or earlier) because of time. Therefore, 17 participants saw these questions.

All participants understood these questions to be asking about the reasons they may be hesitant to speak with a partner about their sexual health and reflected on the conversations they have had surrounding sexual health in the past. Some participants only discussed these topics with partners when there was a need to do so. Other

participants mentioned that they were very open and honest in their relationships, so they felt very comfortable having these conversations.

I don't have this conversation because I think they are needs-based conversation. But I wouldn't have a problem having them.

I trust him completely, he's been really honest. I don't see much reason except for sometimes I don't have a way with words, it's hard for me to describe.

We have pretty open dialog about sexual health.

Eight participants answered "No" to SEX_HURTPTR through SEX_PUNDSTD and were asked if there were any reasons they were ever hesitant to talk to their partner about their sexual health. Two of these participants indicated that there were times when they were hesitant to talk to their partners. One participant stated they would be hesitant if their partner were hesitant or felt some shame surrounding the conversation. The other participant felt they would be more hesitant to discuss their sexual health with their partner if it were a new relationship and they did not yet feel comfortable with their partner.

SEX_HLTSVS	In the past 12 months, did you receive any sexual health services like sexually transmitted infection (STI) or HIV testing, STI treatment, HIV PrEP (pre-exposure prophylaxis), or birth control?

Frequency distribution (N = 18)

Response Option	Count
Yes	5
No	12
Don't know	0
No response	1

All participants were asked this question, but one refused to answer (although they were open to discussing the probes); two participants ended the interview at this point (or earlier) due to time. Thus, 18 participants saw this question and answered cognitive probes. All participants thought back to the health services they had received during the past 12 months and recalled if they had received any of the services listed in the question. Most participants showed no difficulty answering this question. One participant answered "Yes" but during probing explained they had their blood tested for the purposes of donating blood and not for any sexual health services. However, because they had their blood tested, they felt they should answer "Yes" and were asked the follow-up question (SEX_DISP3), to be discussed next.

Participants were also asked for examples of other kinds of sexual health services one could receive. Responses included:

- Pregnancy health services
- Hepatitis A, B, C testing and treatment
- Counseling or therapy
- Abortion
- Condoms or other contraceptives
- Annual gynecological exams
- Vaccinations for HPV
- Family planning
- Urinary tract infection treatment
- Sexual abuse/domestic violence screenings

SEX_DISP3	Did you receive sexual health services at any of the following locations?
SEX_DR	A doctor's office?
SEX_CLINIC	A community or public health clinic?
SEX_HOSP	A hospital including the emergency room and outpatient clinics?
SEX_URGCLIN	An urgent care or in-store health clinic?
SEX_TELHLTH	A telehealth appointment?

Frequency distribution (N = 4)

Response Option	Count
SEX_DR	
Yes	3
No	1
SEX_CLINIC	
Yes	1
No	3
SEX_HOSP	
Yes	1
No	3
SEX_URGCLIN	
Yes	1
No	3
SEX_TELHLTH	
Yes	0
No	4

This question was asked of those participants who answered "Yes" to SEX_HLTSVS (i.e., they received sexual health services in the past 12 months). One of these participants had to stop the interview at this point due to time. Thus, four participants responded to this series of questions.

Participants were asked if there were any other places they received sexual health services in the past 12 months that were not included in SEX_DR through SEX_TELHLTH. Only one participant indicated that there was an additional place—this participant had their blood drawn at a center that collects blood, platelets, and plasma. This is the same participant discussed in above, who answered "Yes" to SEX_HLTSVS and said that they had their blood tested for the purpose of donating blood, not for an STI test.

SEX_TLKDR	Are you comfortable talking to <u>any</u> healthcare providers about your sexual health, relationships, and behaviors?

Frequency distribution (N = 16)

Response Option	Count
Yes	11
No	4
No response	1

Four participants ended the interview at this point (or earlier) due to time. Thus, 16 participants saw this question and answered cognitive probes.

One participant could not answer this question due to confusion about why "any" was emphasized. This participant thought this question was asking if they were comfortable talking about these things with any of their health care providers, including those whose professions do not necessarily relate to sexual health, like podiatrists and chiropractors. They also said that they would talk about health, relationships, and behaviors with different kinds of health professionals.

I'm not going to talk about behavior with any old doctor. It's something I might talk about with a therapist, that seems more relational. But also think about describing a sexual act and describing if it's risky. I feel like these should be three separate questions—sexual health is different from relationships which is different from behaviors.

When asked, all participants interpreted "healthcare providers" to be referring to any medical professional and gave examples that included primary care providers, OBGYNs, nurses, and specialists, such as HIV and fertility specialists. Some participants had a broader interpretation of "healthcare providers" to also include psychologists and mental health professionals.

When asked, participants also shared a common understanding of "behaviors"—in the context of this question—to refer to the types of sexual activity a person may engage in and any actions a person takes (or does not take) to mitigate risks associated with that sexual activity.

SEX_DISP4	Are you hesitant to talk to healthcare providers about your sexual health, relationships, and behaviors because:
SEX_JUDGE	I fear they would judge me.
SEX_TRUST	I do not feel like I can trust them.
SEX_DESCFEEL2	I do not know how to describe my feelings.
SEX_HCPUST	I do not think my health care provider would understand.

Frequency distribution (N = 16)

Response Option	Count
SEX_JUDGE	
Yes	7
No	9
SEX_TRUST	
Yes	1
No	15
SEX_DESCFEEL2	
Yes	2
No	14
SEX_HCPUST	
Yes	3
No	13

Both participants who answered "Yes" to SEX_DESCFEEL2 indicated that they were looking for a way to answer "Sometimes" rather than "Yes" or "No."

Four participants ended the interview at this point (or earlier) due to time. Thus, 16 participants saw these questions and answered cognitive probes.

Nine participants answered "No" to SEX_JUDGE through SEX_HCPUST and were asked if there were any reasons they would be hesitant to talk to their healthcare providers about their sexual health, relationships, or behaviors. All of these participants indicated they would not be hesitant to talk to their healthcare providers about these topics unless they were generally uncomfortable with that provider, for example, because they were a new patient, the provider was intimidating, or because the provider acted inappropriately. One of these participants noted that when they were younger,

they were uncomfortable asking their healthcare providers for information on these topics because their providers were "too conservative"; however, this participant indicated that they do feel comfortable with their current providers.

SEX_DISP5	Which of the following sources do you typically turn to for information about sexual health?
SEX_SOURCEA	Your family?
SEX_SOURCEB	Your partner?
SEX_SOURCEC	Your peers or friends?
SEX_SOURCED	Your therapist?
SEX_SOURCEE	Your doctor or health care provider?
SEX_SOURCEF	The Internet or social media?
SEX_SOURCEG	Another source?

Frequency distribution (N =16)

Response Option	Count
SEX_SOURCEA	
Yes	1
No	15
SEX_SOURCEB	
Yes	8
No	8
SEX_SOURCEC	
Yes	5
No	11
SEX_SOURCED	
Yes	5
No	11
SEX_SOURCEE	
Yes	13
No	3
SEX_SOURCEF	
Yes	13
No	3
SEX_SOURCEG	
Yes	4
No	12

Four participants ended the interview at this point (or earlier) due to time. Thus, 16 participants saw these questions and answered cognitive probes.

All participants reflected on the sources they have gone to in the past to discuss their sexual health when deciding on their answers to these questions. Most participants indicated they would assess their comfort level with each source before having a conversation about their sexual health. Others also mentioned cultural and religious factors that influenced whether they were comfortable speaking with friends and family about their sexual health. One participant mentioned that the severity of the topic would determine the source they chose—for less serious issues they may speak with friends or family, but for more serious issues, they would speak with their doctor or healthcare provider.

I would just talk to someone rather than get advice. If it was something that was serious, dealing with disease, no I would not talk to a family member. If it was something menial or small then yeah. But if it's something that's serious.

I come from a religious and cultural background where I would be shamed for asking my family.

All participants interpreted the phrase "turn to a source for information" to mean the source they would go to for more information, whether that be a place they look, like the internet or a person they ask like friends or family. Several participants noted that "the Internet" and "social media" are different things. They would be comfortable turning to the internet through known websites and organizations but not getting information from unverified social media posts.

The four participants who indicated they turn to another source (answered "Yes" to SEX_SOURCEG) said they would turn to WebMD, books, scientific research papers, or government institutions for more information on this topic.

SEX_RELST	Are you currently:

Frequency distribution (N = 15)

Response Option	Count
In a sexual relationship with <u>one</u> person?	8
In a sexual relationship with <u>more than one</u> person?	0
Not in a sexual relationship	6
No response	1

Four participants ended the interview at this point (or earlier) because of time and one participant refused to answer. Thus, 15 participants saw these questions and answered cognitive probes.

All participants understood a "sexual relationship" to be one in which they were engaging in any kind of sexual activity or "intimacy" with a person. Participants noted that this relationship could be a casual relationship or a more serious, committed relationship.

SEX_RELST2	Is this relationship…? Select all that apply.

Frequency distribution (N = 8)

Response Option	Count
A casual sexual relationship	0
A committed sexual relationship	7
An open relationship	0

This question was asked of all participants who answered "In a sexual relationship with <u>one</u> person" for item SEX_RELST. One of the eight participants who were eligible for this question refused to provide a response, but did provide responses to the probes.

Overall, participants understood a "casual sexual relationship" to be one in which the individuals did not consider themselves to be in a dating relationship and/or did not have any long-term goals of developing a dating relationship. A couple participants used the phrase "friends with benefits" to describe a casual sexual relationship.

That I'm not in a relationship with that person, just someone I have sex with every now and then.

Someone you hook up with more than once, like occasionally or frequently.

Participants described a "committed sexual relationship" as one that was "monogamous," "between two people," or one in which there are "shared feelings that extended beyond sex." Several participants named marriage as an example of a committed sexual relationship.

Marriage, monogamy, where there are shared feelings.

Something serious that can extend beyond sexuality.

Interpretation of an "open relationship" was more varied across the participants. Some participants defined an open relationship as a committed sexual relationship in which both partners agreed to having sex with other people. Other participants did not specify that an open relationship would be a part of a committed relationship, but simply stated it meant an individual was having sex with multiple people. One participant used the phrase "sister wives" to describe an open relationship.

Being in a committed sexual relationship but also exploring other options with other people.

You're having sex with multiple people.

SEX_RELST3	**Are any of your relationships…? Select all that apply.**

No participants answered this question, as it was only applicable to those who answered "In a sexual relationship with <u>more than one</u> person" for item SEX_RELST.

SEX_DISP6	**In the past 12 months, have you had vaginal, oral, or anal sex with someone who is…**

Frequency distribution (N = 15)

Response Option	Count
A man?	
Yes	5
No	9
No response	1
A woman?	
Yes	4
No	10
No response	1
Nonbinary, genderqueer, transgender, or did not identify as only male or only female?	
Yes	1
No	13
No response	1
I have not had sex in the past 12 months	
Yes	5
No	9
No response	1

Five participants ended the interview at this point (or earlier) due to time and one participant refused to answer these questions. Thus, 15 participants received and answered these questions but these items were not probed on during the cognitive interviews.

SEX_NEWPTR	**In the past 12 months, have you had sex with a new partner?**

Frequency distribution (N = 9)

Response Option	Count
Yes	1
No	8

   The nine participants who answered "Yes" to at least one item in SEX_DISP6 were asked SEX_NEWPTR. All participants who answered this question generally understood a "new partner" to be someone they had sex with for the first time during the past 12 months. Participants further defined "new partner" based on their personal relationship. For example, one participant, who had been in a committed relationship for longer than the past 12 months defined a "new partner" to be "someone other than [their] significant other."

SEX_DISC	In the past 12 months, before you had sex with any <u>new</u> partner, did you discuss the following topics?
Q7_a	**Using condoms**
Q7_b	**Hormonal birth control or IUDs**
Q7_c	**HIV PrEP (pre-exposure prophylaxis)**
Q7_d	**HIV Testing**
Q7_e	**Sexually transmitted infection (STI) testing**

Frequency distribution (N =1)

Response Option	Count
Using condoms	
Yes	0
No	1
Hormonal birth control or IUDs	
Yes	0
No	1
HIV PrEP (pre-exposure prophylaxis)	
Yes	0
No	1
HIV Testing	
Yes	0
No	1
Sexually transmitted infection (STI) testing	
Yes	0
No	1

The only participant to answer this series of questions was the one participant who indicated they had sex with a new partner in the past 12 months (i.e., answered "Yes" to item SEX_NEWPTR). This participant reported that it was easy to answer this series of questions as it was "not a problem that pertained to [her]."

SEX_DISP8	In the past 12 months, how often **did you discuss the following topics with any of your new sex partners?**
SEX_CONDOM	Using condoms
SEX_BC	Hormonal birth control or IUDs
SEX_HIVPREP	HIV PrEP (pre-exposure prophylaxis)
SEX_HIVTST	HIV Testing
SEX_STITST	Sexually transmitted infection (STI) testing

No participants answered this question as it was only applicable if a respondent indicated that they had discussed any of these topics with new sex partners in the past 12 months (i.e., answered "Yes" to any of the items in Q7_a – Q7_e).