



National Center for Health Statistics: Rapid Survey Systems (RSS)

RSS-1 Cognitive Interviewing Report

Prepared for:

Centers for Disease Control and Prevention
National Center for Health Statistics
3311 Toledo Road
Hyattsville, MD 20782

Prepared by:

RTI International
3040 E. Cornwallis Road
Research Triangle Park, NC 27709

Last Revised: April 5, 2024

Table of Contents

National Center for Health Statistics:	1
Rapid Survey Systems (RSS)	1
RSS-1 Cognitive Interviewing Report.....	1
Introduction	1
Background	1
Methodology.....	2
Cognitive Interviewing	2
Sample and Respondent Recruitment	2
Data Collection and Analysis.....	3
Data Collection	3
Data Analysis	3
Overall Findings.....	4
Question-by-Question Findings	5
Long COVID Questions	6
Breast Cancer Screening	10
Gynecological Medical Procedures	11
Genetic Tests Questions	12
Cancer Risks From Alcohol Questions	14
Sunscreen Questions.....	15
Chemical Hair Products Questions.....	18
Air Cleaners and Purifiers Questions.....	18
Intimate Partner Violence Questions.....	19

Introduction

The National Center for Health Statistics (NCHS) seeks to evaluate questions included on the first round of the Rapid Surveys System (RSS-1). 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-1 were conducted after the survey’s field period, and the findings presented in this report can help inform interpretation of the survey results.

For RSS-1, 15 interviews were completed after data collection, and the results should be used to inform the interpretation of survey results. This report documents the findings of the cognitive interviews conducted for RSS-1.

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 (OMB).

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.

Nine topics on a wide range of health concepts were specifically tested on RSS-1 including:

- Long COVID
- Breast Cancer Screening
- Gynecological Medical Procedures

- Genetic Tests
- Cancer Risks From Alcohol
- Sunscreen
- Chemical Hair Products
- Air Cleaners and Purifiers
- Intimate Partner Violence

A set of demographic and non–health related questions were also asked. These included questions about race and ethnicity, marriage and cohabitation, employment, internet access and health information technology, civic engagement, languages spoken at home, and telephone use. In response to recommendations of the OMB Interagency Technical Working Group on Race and Ethnicity Standards (<https://spd15revision.gov>), RSS-1 was used to test wording of questions for collection of detailed race and ethnicity.

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, 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-1, recruitment for cognitive interviewing focused on building a demographically diverse, purposive qualitative sample and including respondents who had used chemical hair straightening products. Use of chemical hair straightening products was the only specific recruitment criterion.

Advertisements were placed online asking potential respondents to email or call the project recruiter. The recruiter conducted a standardized phone screening with each potential respondent before they were selected for the interview. This screening process allowed a diverse but nonrandom sample to be created for these interviews.

¹ Willis, G. (2005). *Cognitive interviewing: A tool for improving questionnaire design*. Thousand Oaks, CA: Sage Publications.

² Miller, K., Willson, S., Chepp, V., & Padilla, J. (Eds.). (2014). *Cognitive interviewing methodology*. Hoboken, NJ: Wiley and Sons.

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 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. Additionally, after answering the test questions, interviewers probed to better understand how participants decided on their answer and to assess participant understanding of the question. The cognitive interviewer only probed on the nine topics described below. Participants could refuse to answer any question they did not want to answer.

Participants were assigned to either the Ipsos 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. For the race and ethnicity measurement items, participants were randomly assigned to a test group, although interviewers did not specifically probe on these items.

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

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

Table 1 displays the demographic characteristics of the 15 cognitive interview participants.

Table 1. Cognitive Interview Participant Characteristics

Participant Characteristics	Number of Participants
Race	
White	9
Black or African American	6
American Indian/Alaska Native	0
Asian	1
Middle Eastern and North African	0
Native Hawaiian/Pacific Islander	0
Other	0
Hispanic or Latino (Yes)	0
Age	
18-29	2
30-49	9
50+	4
Sex	
Male	2
Female	13
Education	
Less than high school diploma	0
High school diploma or equivalent	3
Some college, no degree	0
Associate's degree	2
Bachelor's degree	7
Post-bachelor's degree	3
No formal education	0
Chemical Straightener Use	6

Overall Findings

The cognitive interviews included survey questions and probes about selected questions from the nine topics that were specifically included on RSS-1. 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-1 topics.

1. *Long COVID Questions.* Participants generally understood the concept of “Long COVID” and drew on articles or news stories they had read about Long COVID, conversations they had with their doctors about the illness, or the experiences of people they knew who had Long COVID to answer questions. However, some participants felt that more detail about definitions of Long COVID in the question stem would be helpful, and others felt that some wording around beliefs about Long COVID tended to minimize the conditions.
2. *Breast Cancer Screening Questions.* Although all participants who were asked these questions reported that it was easy for them to remember how long it had been since their most recent mammogram, there was more uncertainty about the responses to questions regarding whether information about having dense breasts had been received because of lack of recall about that specific information.
3. *Gynecological Medical Procedures Questions.* All participants asked these questions were certain of their responses to this series of questions regardless of whether they were able to explicitly describe the procedures.
4. *Genetic Tests Questions.* Participants felt the definition of genetic testing for cancer risk was helpful and provided enough information for them to provide an informed response. Participants also demonstrated that they generally understood the questions asking about concerns and differentiated between the need for concern depending on the questions.
5. *Cancer Risks From Alcohol Questions.* Most participants who responded that they think that alcohol increases cancer risk were very confident in their responses and drew on information they had read or seen about the effects of alcohol on one’s health, or they thought about people in their lives who were “drinkers” and developed cancer. Respondents provided mixed opinions about whether specifying how many drinks consumed per day would have made this question easier to answer.
6. *Sunscreen Questions.* While answering this series of questions, participants reflected on how often they use sunscreen in their day-to-day life and seemed to provide thoughtful responses based on their own experiences. However, some participants indicated that their responses to some questions might depend on seasonality, temperature, and type of activity level.
7. *Chemical Hair Products Questions.* Participants were easily able to provide responses to these questions and indicated in their responses the type of products the question intended to capture. Participants drew on experiences with regular occurrences of product use to answer the questions on frequency of use.
8. *Air Cleaners and Purifiers Questions.* Participants were confident in the reporting of portable air cleaners or air purifiers in their home and based their response on their routines and use patterns, although at least a couple of respondents expressed difficulty understanding the concept of an air purifier. Participants used information about their experiences with filter replacements to answer the question about whether their air purifiers used a HEPA filter specifically.
9. *Intimate Partner Violence Questions.* This set of questions was upsetting to some participants, and some opted to not answer them. Among those participants who responded to the intimate partner violence (IPV) questions, most were thinking of multiple people as they answered the questions as the question intended.

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 otherwise specified.

Long COVID Questions

Questions on Long COVID asked about awareness of Long COVID, agreement/disagreement with various opinions about Long COVID, experience with COVID-19, and action the participant would take if they wanted to learn more about Long COVID.

CVL_HEARDEV	When people have symptoms for weeks, months, or even years after COVID-19 infection, it is called Long COVID. Some people also refer to it as Post-COVID Conditions. Before today, had you ever heard of Long COVID?
--------------------	---

When participants read the phrase, “Long COVID,” they generally thought of COVID symptoms that were long-lasting and reached the point of being chronic. Several participants expressed how serious Long COVID is and that it can be life-altering and debilitating for some people.

- “Basically, just after an initial 2-4 weeks that someone is typically sick with COVID. Beyond that, I know people sometimes suffer with long conditions or don’t regain their sense of smell or taste. Or, just chronic tiredness, chronic exhaustion. Or, chronic coughs. I think of something that extends beyond the typical length of time you would think of for the symptoms to go away.”
- “People that have debilitating, long-term respiratory malfunction. Decrease in respiratory function for long periods of time after the viral infection. Sometimes lifelong symptoms. I’ve read about Long COVID from the World Health Organization, the Mayo Clinic, and a Reader’s Digest special article.”

One participant used the phrase “Post-COVID conditions” when discussing this question during probing. When the interviewer asked about the participant’s understanding of the difference between “Long COVID” and “Post-COVID conditions,” the participant stated that they felt the phrases were very similar but assumed there was a difference between them; however, the participant could not describe how they were different. This participant stated they preferred the phrase “Post-COVID conditions” because they were more familiar with that terminology.

Most participants felt the definition of Long COVID was helpful; however, four participants felt it could be improved by providing more information about the types of symptoms a person may experience with Long COVID and information on when a person may need to seek medical care if experiencing those symptoms.

- “I would need a little more...The type of symptoms I need to look out for and how long before I call the doctor.”
- “I think it’s helpful but it doesn’t give a lot of details. It could give more details on the symptoms it includes.”

Six participants reported that they had not heard of Long COVID before this interview.

CVL_REAL	Long COVID is a real illness.
-----------------	--------------------------------------

In deciding on their response to this question, participants reflected on articles or news stories they had read about Long COVID, conversations they had with their doctors about the illness, or the experiences of people they knew who had Long COVID.

- “My dad’s best friend. Ever since he caught COVID, he hasn’t been the same. He’s always tired. He actually has weird hair patches missing too. He feels terrible a lot. He never seemed to recover. It’s horrible. I’m really scared of it, to be honest.”
- “I’ve talked to my doctors about it.”
- “I’ve seen people debilitated by Long COVID.”

Participants understood the phrase “real illness” to refer to an illness that can be debilitating, one that can be diagnosed by a doctor or has a defined set of symptoms associated with it, and an illness that has serious symptoms or side effects that should be taken seriously.

- “[A real illness] means that it should be given validation and people should pay attention to it and understand the risk it poses. It’s not a myth, or made up, or a conspiracy. It’s here to stay with some people forever, like HIV.”
- “A doctor can diagnose it as such. I don’t think there’s a lot of diagnostic stuff you can do for Long COVID, but there is definitely a cluster of symptoms that are called Long COVID.”

One participant took issue with the phrase “real illness” because they felt it was vague and was leading them to agree with the statement:

- “The question is around the word ‘real.’ What does that even mean? I would leave my answer as ‘Don’t know’ because the vocabulary is confusing and maybe even...leading. A word like ‘illness’ is very objective and ‘real’ is very subjective...It’s leading me to agree that it is a real illness.”

CVL_SERIOUS	Long COVID can be debilitating and should be taken seriously.
--------------------	--

Most participants thought about people they knew who had Long COVID, or thought about their own experience with COVID, and tried to imagine what it would be like to have those symptoms last for an extended period of time.

- “People have died from having Long COVID, and have to be on ventilators and respirators. It’s serious.”
- “Because people who had it...I’ve seen people who’ve had serious infections from COVID and the recovery time can be gruesome. I don’t know anybody personally who has had Long COVID, but I’ve read enough about it to know it’s a real issue.”

One participant noted that the inclusion of the phrase “can be” in the question was necessary for them to answer the question. This participant felt the extent to which Long COVID could be debilitating and taken seriously would depend on the person because they feared some people may try to take advantage of a Long COVID diagnosis to earn special treatment.

- “Because of the phrase ‘can be.’ It does have the potential to be debilitating. I had a family member who had COVID and had a very bad case where she ended up in rehab and was unconscious for a while and had to do 14 weeks of rehab to get back to health. It can be debilitating and should be taken seriously. But, with anything, there are different levels of extremity. For some people, it may just be a little bit of memory loss and it may be more serious for others.”

Participants understood the term “debilitating” to mean an illness that takes over your everyday life and impacts your ability to do daily tasks—an illness that alters one’s “normal.”

- “Debilitating means that you are not able to perform at your normal capabilities...it’s something that limits your ability to function at the rate that you would deem as your average, as your normal, as your typical.”

CVL_DEPRESS	People with Long COVID may just be depressed.
--------------------	--

In responding to this question, participants differentiated between an individual being depressed *because* of an illness (i.e., depression as a side effect) and an individual just being depressed and not having Long

COVID. Overall, participants felt it was very likely that depression was a side effect of Long COVID, especially if one's symptoms became chronic, but that the illness could not be reduced to "just" being depressed. Several participants commented that the question, and especially the word "just," seemed to minimize the severity of Long COVID.

- "I think those are two unrelated conditions...You could insert any other word...could just be tired, hungry, sad. Any disease or illness or condition can often come with a series of depression. I don't think that just because one might feel an aftereffect of having Long COVID could lead to depression, that it can be claimed to the causation."
- "Just reading that made me mad to be totally honest. You can just hear a certain kind of news organization or a certain kind of person saying something like that. It's terrible. It's very invalidating, it's very minimizing. It's just wrong. A lot of people suffer from health conditions. Have some empathy! How would you like to have all those horrible symptoms with no end in sight or no treatment available?"

One of the participants who answered "Strongly agree" skipped over the word "just" when reading the question aloud. Overlooking that word changes the meaning of the question, and based on their responses to probes, had they read the question correctly their answer would likely change.

- "If I had Long COVID, I'd be depressed! Everyone's depressed when they have COVID. We don't want to have it."

The participant who answered "Don't know" did so because they did not want to "generalize about a population." However, during probing, this participant made clear that they felt depression could be a side effect of Long COVID because of necessary lifestyle changes. This participant felt bringing depression into the conversation turned Long COVID into a mental health issue instead of a viral issue, and they disagreed with that.

CVL_NORMPAIN	Long COVID symptoms are often just the normal aches and pains of life.
---------------------	---

Participants had similar reactions to this question as to CVL_NORMPAIN. In general, participants felt equating Long COVID with the "normal aches and pains of life" minimized the severity of the illness and was not a fair representation of what people with Long COVID experience.

- "I think to reduce it to the aches and pains of life is to diminish the epidemiology around the effects of Long COVID."
- "Nothing is normal about Long COVID. It felt like I got hit by a freight train when I had COVID in December."
- "This is too general. It doesn't give enough credit to the viral infection to compare it to normal aches and pains."

One participant felt that it was impossible to say Long COVID was just the normal aches and pains of life because the symptoms of Long COVID are specific to COVID-19, which did not exist before 2020.

- "It can't be the same as the normal aches and pains of life because Long COVID didn't exist before 2020."

As in CVL_SERIOUS, one participant noted that her response to this question would vary from person to person. This participant felt there were people who would exaggerate their symptoms or experience with Long COVID to give the impression that they were suffering more than they actually were. The participant suspected that for some people, Long COVID may be similar to the normal aches and pains of life. To

account for the fact that her answer would depend on the person, this participant answered “Somewhat agree” rather than “Somewhat disagree.”

- “It really depends on the person. There are definitely people who are going to make something into a bigger deal than it is. That’s a tricky one. Has this person always complained about being sick on a regular basis? Or is it new? I went with ‘Somewhat agree’ because I know people take off from work more often than what is normal. Part of this is due to me being so healthy and when I am sick, I push through things...I’m not saying it’s not a thing. I think it just depends on the person’s overall tendencies. Sometimes people use COVID as a crutch.”

When thinking of the “normal aches and pains of life,” participants thought about the normal “ups and downs of life” and included things such as headaches, muscle soreness, menstrual cramps, and feeling tired as the normal aches and pains of life.

CVL_EMPLOYER	Employers should provide reasonable accommodations for people with Long COVID.
---------------------	---

Participants felt “reasonable accommodations” included things such as remote work arrangements, flexible work schedules, working fewer days, limiting, or eliminating physical labor, allowing more breaks, and allowing more sick time off or time for doctor’s appointments.

As in previous questions, one participant noted that their response to this question would depend on the situation and the person diagnosed with Long COVID. This participant felt individuals are responsible for ensuring that the tasks and duties of their job are taken care of and should not receive certain kinds of special treatment because of a medical diagnosis.

- “It’s going to depend on the situation...If it’s something like being able to take off for a doctor’s appointment, absolutely. But, should you get significantly less work? No. It would depend on what the accommodations would be. ‘Reasonable’ is tricky because what’s reasonable to one person may not be reasonable to someone else.”

CVL_MEDIA	The media and news reports exaggerate the problems that people with Long COVID face.
------------------	---

Some participants were thinking of specific media and news reports they had seen about Long COVID and assessed whether they felt those reports had been exaggerated. Others were thinking about their general perceptions of news and media reports and applied those perceptions to stories of Long COVID. For example, some participants discussed the need for media and news reports to exaggerate the stories they tell, or to tell extreme versions of stories, to capture the attention of their viewers. These participants assumed the media and news would do the same thing for stories about Long COVID.

- “It’s not that I don’t think there are problems with Long COVID, I just think the media and news in general are paid to find the biggest stories, or most impressive stories, or most bizarre stories to grab people’s attention.”
- “The media hasn’t given Long COVID the respect it deserves. Some are still speculating if it’s a real thing and being ignorant about it. Some may be exaggerated but overall there’s not enough for people to realize what they may be feeling or what a loved one may be going through.”

One participant had trouble deciding on a response to the question because they were unsure what the media and news were saying about Long COVID and mentioned that the source of news would be an important factor. Thus, they could not assess whether the reports were exaggerated. This participant

ultimately answered “Strongly disagree” because they felt reports needed to be extreme so people understood the severity of Long COVID. Additionally, this participant recommended the question be rephrased to ask, “Some media and news reports...” to make it easier to answer.

- “I don’t know what they’re saying. It depends on where you get your news. That’s a little tricky. Let’s assume this means that they are exaggerating it, then I would disagree with that because it’s horrible to have Long COVID”

Two participants answered “Don’t know”—one participant because they did not follow the news and the other because they didn’t feel they had a strong enough understanding of Long COVID to assess whether news and media reports were exaggerated.

- “Since I’m not a doctor and don’t know the ins and outs of Long COVID, I can’t then assess whether the media has exaggerated or diminished the effects of Long COVID.”

CVL_PASSED	Long COVID can be passed from one person to another.
-------------------	---

Most participants disagreed with this statement and were sure of their response. However, two participants responded with “Somewhat agree.” These participants could not think of a reason one person would not be able to pass Long COVID to another person.

- “I don’t know a lot about Long COVID, but if COVID can be passed from one person to another, why can’t Long COVID?”

One participant indicated during probing that they were torn between “Strongly disagree” and “Somewhat disagree.” This participant decided to answer “Somewhat disagree” because, although they felt mostly certain that Long COVID could not be passed from one person to another, they were not 100 percent sure.

- “I’m not 100% certain it can’t be passed on. Unless I’m 100% sure, I’ll answer “Somewhat.””

Breast Cancer Screening

Breast cancer screening questions asked about experience with mammograms, amount of time since the most recent mammogram, information received about dense breasts after the most recent mammogram, and the format of that information. Breast density questions were only asked of female participants ages 30 or older.

CAN_RECENTM	About how long has it been since your <u>most recent</u> mammogram?
--------------------	--

All participants reported that it was easy for them to remember how long it had been since their most recent mammogram. This was because they have their mammogram done at the same time each year, or because some scheduling or insurance issues they experienced for their last mammogram made it particularly memorable.

- “Very easy because it was extremely difficult to get a mammogram because insurance wouldn’t approve it.”
- “I get it every October and I remember because the month is pink.”

CAN_BDENSITY	After your most recent mammogram, did you <u>receive</u> any information about whether or not you had dense breasts?
---------------------	---

Some participants were unsure whether they had received information about whether they had dense breasts because they did not remember receiving results that included that terminology. These participants answered “No” because they had not seen that phrase in their results or they did not receive any test results that were abnormal.

- “I don’t know if that phrase was used but I did receive information about the results. My results were positive...nothing was found.”

Those who did receive information about whether they had dense breasts recalled the communications they received from their doctor or information they learned about their breast tissue after receiving a cancer diagnosis.

- “When I was diagnosed with breast cancer it was a really tiny spot. I read up about the kind of breast cancer and they said you couldn’t necessarily feel it because I have dense breast tissue.”
- “I know I have dense breasts from previous mammograms and I get notified if that’s still true each year.”

Participants received communications about their mammogram results in a variety of ways: two participants through the mail, two participants through discussions with their doctor, and one participant through a health portal app on their phone.

Gynecological Medical Procedures

The gynecological medical procedures questions asked about experience with the following procedures: fallopian tubes tied, fallopian tubes cut, both fallopian tubes removed, and both ovaries removed. Only female participants received these questions.

OVA_TUBETIED	Have you ever had any of the following procedures: Fallopian tubes tied?
---------------------	---

OVA_TUBECUT	Have you ever had any of the following procedures: Fallopian tubes cut?
--------------------	--

OVA_TUBEREM	Have you ever had any of the following procedures: Both fallopian tubes removed?
--------------------	---

OVA_OVARIES	Have you ever had any of the following procedures: Both ovaries removed?
--------------------	---

All participants were certain of their responses to this series of questions. Regardless of whether participants were able to explicitly describe what is done during these procedures, participants understood that all of these procedures would result in a person being unable to get pregnant, and they knew whether they had had these procedures. Only one participant was unsure of what was being asked, but they guess that it had to do with vaginal health. Additionally, most participants were familiar or very familiar with the term “fallopian tubes.”

- “I would know if I’d had [these procedures]. These were the easiest questions yet.”
- “To not get pregnant. The fallopian tubes are connected to the little egg thingies at the top that go down to your uterus. They tie the tubes so the egg doesn’t get through. Has nowhere to go...You can either have them tied or cut. I know cut – they can accidentally grow back together and you

can accidentally get pregnant and not plan on it. They're both sterilization procedures, but one is more permanent than the other."

- "None of these were procedures that I ever had done during my pregnancy or after. I know that's sometimes what that's associated with, especially having your tubes tied. But, my husband had a vasectomy done and we decided to go with that option just because we heard that there's more risk associated with females for these procedures as opposed to males."

Genetic Tests Questions

The genetic tests questions asked about awareness of genetic testing to determine whether a person is at greater risk of developing cancer, and the level of concern about the results of genetic testing impacting one's ability to get or keep various kinds of insurance or employment.

GEN_INTRO	<p>The next few questions refer to genetic testing for cancer risk where your blood or saliva is tested to see if you carry genes which may predict a greater chance of developing cancer at some point in your life. This does <u>not</u> include tests to determine if you have cancer now.</p> <p>Have you ever heard of genetic testing to determine if a person is at greater risk of developing cancer?</p>
------------------	---

Overall, participants found this question clear and easy to answer. Participants felt the definition of genetic testing for cancer risk was helpful and provided enough information for them to provide an informed response.

- "I've had the BCRA test because my mother has had breast cancer twice."
- "It was very helpful because when I read "blood or saliva test" it was exactly how my doctor explained it to me and I knew that I'd had that done."
- "It was very helpful because listing all the cancer risks that these tests can test for may downplay other cancers or could cause attention to be focused on some cancers instead of others. I like that the description wasn't specific."

However, two participants experienced some confusion when reading the question and selecting their response. One of these participants did not initially realize the question was asking about genetic tests specifically for cancer risk. The other participant was unsure if the types of test the question referred to were specific to different types of cancer or if it was a generic test for various types of cancer.

- "I initially said yes because I've done genetic testing for Parkinson's. I haven't heard of genetic testing for cancer specifically so I changed it to no...the definition was helpful but I think emphasizing the cancer part would make it more helpful."
- "I thought it was more specific – like you could get tested for breast cancer. I don't know if it's generic testing for all types of cancer or just specific types."

Those who answered "Yes" were thinking about blood tests, saliva swabs, urine tests, PCR tests, XY chromosomal testing, and BCRA tests.

GEN_HLTHINS	<p>How concerned are you that the results of genetic testing for cancer risk would impact your ability to get or keep...health insurance?</p>
--------------------	--

Participants who expressed concerns over their ability to get or keep health insurance were thinking about the cost associated with the additional tests and doctor's appointments that would be necessary if the test determined they were high risk. These participants were concerned that health insurance companies could use the results of their genetic test to deny them coverage or raise their insurance rates.

- “It would be a lot of money. A lot of out-of-pocket costs. I would think like, health insurance doesn’t really pay. You still have to pay in cash.”
- “Health insurance companies are supposed to be there to help you, but really they’re not making money if they are providing services. I know a lot of times they want to know if you have preexisting conditions.”

Participants who were not concerned about the effects of the genetic test on their ability to get or keep health insurance expressed that insurance companies could not raise their rates or drop their coverage if they were at higher risk, and that insurance companies could not access test results such as these.

- “I know that my health insurance is something like ‘condition blind.’”
- “I don’t think a health insurance company can legally drop you if you’re at a higher risk.”
- “It’s not supposed to be shared with companies. Unless you do it through your health insurance company I suppose, but I don’t even know if they offer that.”

GEN_LIFEINS	How concerned are you that the results of genetic testing for cancer risk would impact your ability to get or keep...life insurance?
--------------------	---

GEN_DISAINS	How concerned are you that the results of genetic testing for cancer risk would impact your ability to get or keep...long-term care or disability insurance?
--------------------	---

Participants expressed slightly higher levels of concern for how the results of the genetic test would impact their ability to get or keep life insurance and long-term care or disability insurance. Those who expressed concern felt that life insurance companies require access to a lot of medical information or are likely to not provide coverage to a person if the company feels they are high risk.

- “I think life insurance sometimes decides not to take you on if they feel you’re a potentially risky case to take on.”
- “When you sign things for life insurance you have to like sign away your life. I feel like they want access to every little thing.”

Similar to GEN_HLTHINS, participants who did not express concern felt that life insurance companies would not have access to these medical records and test results.

- “How would they even know you’d had the test done? You don’t have to disclose that.”

GEN_JOB	How concerned are you that the results of genetic testing for cancer risk would impact your ability to get or keep...employment at a job?
----------------	--

Participants were the least concerned with the genetic test’s results impact on their ability to get or keep employment at a job. Participants noted that they were not concerned with this because employers could not have access to their health information, or because they had a high level of confidence in their ability to get a job.

- “I don’t think most jobs are even allowed to view your health information. It depends on the position because for some jobs there is a physical required, but in general, I’m not concerned.”
- “Your job shouldn’t have any access to that kind of information...That’s protected health information and you shouldn’t have to sign a waiver for them to get that information.”
- “There will always be a need for a workforce.”

Nearly all participants indicated that they were thinking about their level of concern for each of the above questions individually as opposed to in relation to each other; however, one participant did note that they began to rank their concern level in their mind as they answered the questions.

GEN_TESTEV	Have you <u>ever had</u> a genetic test to determine if you are at greater risk of developing cancer in the <u>future</u>?
-------------------	---

The three participants who indicated that they had done a genetic test to determine whether they were at greater risk for developing cancer in the future answered in line with the question intent. These participants named 23andMe, the BCRA test, and blood tests.

- “It’s been several years now...when you sign up they send you a little thing to do a swab of your cheeks. So, I did that. Then, they have a whole list of health screens along with your potential relative matches.”

Two participants expressed that they had considered doing a genetic test for cancer risk but had not done the test because it was either cost prohibitive or they were concerned that the test itself would cause them to develop cancer. Based on their responses during probing, none of the participants who answered “No” responded incorrectly—that is, none had done genetic testing for cancer risk.

- “Knowing that cancer...I mean you hear about it everywhere so it’s like it makes you think should I get tested now? Sometimes they claim that if you get tested you can develop it because the machine they’re using, like, it can cause certain rays to enter your body.”
- “I considered 23andMe, but it was too expensive.”

Cancer Risks From Alcohol Questions

The cancer risk from alcohol question asked about the perceived level of risk of getting cancer associated with drinking alcoholic beverages.

CRI_ALCOHOL	How do you think drinking alcoholic beverages affects the risk of getting cancer?
--------------------	--

Among the participants who answered “Increases risk,” eight were very confident in their responses. These participants based their response on information they had read or seen about the effects of alcohol on one’s health, or they thought about people in their lives who were “drinkers” and developed cancer.

- “I know for a fact that alcohol increases risk. I actually read somewhere that alcohol is considered a carcinogen.”
- “I know the impacts of alcohol have a negative impact on your body and a positive impact on your likelihood of developing cancer.”
- “I know people who were drinkers and ended up with cancer and passing, but people who just drink water and exercise are fine.”

The other two participants who answered “Increases risk” were not as confident in their response. One of these participants noted that the effect of alcohol on one’s cancer risk would depend on how much alcohol they drank. For the purposes of this question, the participant assumed that it was asking about heavy drinking.

- “It kind of depends. If you are an extreme drinker, it definitely increases the risk. But if you have a glass of wine, it could potentially decrease the risk. I’m going to assume that they’re not just talking about a glass of wine.”

Among the participants who answered “No effect,” one participant had never heard of someone getting cancer from drinking alcohol. Another stated that they were unsure but that they wanted to “look on the

bright side.” The final participant who answered “No effect” struggled to select a response because they were unsure of any correlation between alcohol consumption and cancer risk. This participant noted that they would have preferred to select a “Don’t know” option if it had been available.

- “I just have no idea how the two correlate at all. I know alcohol affects the liver and other systems. But, I have no idea how it correlates to cancer. I based it on the fact that I know of no correlation between the two. I would have preferred to answer ‘Don’t know.’”

Participants had mixed opinions about whether specifying a number of alcoholic beverages consumed per day in the question would make it easier to answer. One participant felt including this information would make the question more difficult because the question was already in its simplest form. Others felt it would have no effect on the question because they would still be uncertain of the relationship between alcohol consumption and cancer risk, or because they felt any alcohol consumption would increase one’s cancer risk, so specifying a number of alcoholic beverages consumed per day would be irrelevant.

- “I still wouldn’t know if there was any correlation between the two, so I would still have to answer ‘Don’t know’ if that was an option.”
- “It would need to tell me more. Like, some sort of proof that someone has developed cancer from drinking.”
- “I don’t think a number should be added because any alcohol consumption increases cancer risk.”

Lastly, some participants felt that if a number of alcoholic beverages consumed per day were included, the question would also need to include information about the type of alcohol consumed and how often that number of drinks is consumed.

- “I don’t consider [3-4 drinks] in a single day being an extreme drinker, but if you’re having 3-4 drinks a day on multiple days of the week, it’s probably going to start to affect your health and increase your risk of getting cancer...It would be easier to answer if it specified the number of drinks per day as well as how often that number of drinks was consumed.”
- “It would be easier if the types of alcohol were included. Breaking down the types of alcohol would help because wine is good for you, supposedly.”

Sunscreen Questions

The sunscreen questions asked about the frequency of sunscreen use on one’s face and other exposed skin when outdoors in warm weather, the importance of various features of sunscreen, and the level of agreement/disagreement with opinions about sunscreen and sun exposure.

SUN_USEFACE	When you are outdoors in the sun, in warm weather, how often do you use sunscreen on your face?
--------------------	--

SUN_USESKIN	When you are outdoors in the sun, in warm weather, how often do you use sunscreen on other exposed skin?
--------------------	---

Participants decided on their responses to SUN_USEFACE and SUN_USESKIN by reflecting on how often they use sunscreen in their day-to-day life. Participants seemed to provide honest and accurate responses based on their descriptions of their sunscreen use habits.

- “The only time I use sunscreen is if I’m using a bronzer to try to get a tan. I don’t really use sunscreen. I don’t get sunburned.”
- “I wear sunscreen every day even if it is not warm weather, and even if I am staying inside all day because I am fair skinned. It’s important to do that at a young age to prevent signs of aging.”

Some participants explicitly mentioned that they were answering based on the assumption that they were outside, in the sun, in warm weather. Further, a few participants specified that their use of sunscreen also depended on the amount of time they would be outdoors in the sun.

- “I know that you always should do it, but whenever I do it is if I’m going to be at a pool all day. For me, it’s more about the length of time – if I’m going to the beach or water park then I definitely do. If I’m just taking my daughters to the park for an hour, then I don’t. It’s not just length of time, but time of year. If it’s sunny but it’s January, then I wouldn’t wear it. So, time of year, temperature, and how long I’m going to be in the sun.”

When asked if their answer to the questions would change if they did not specify warm weather, some participants indicated their answer would change and others indicated it would stay the same. Those who said their answer would change noted that they either only use sunscreen when it is warm outside, or would only change their answer to SUN_USESKIN because they would have less exposed skin in colder months.

- “Yes [my answer would change], because in the winter, I’m only putting it on my face and neck because I’m completely covered up. I would change my answer [to SUN_USESKIN] to “Most of the time.””
- “I only use sunscreen in warm weather, so I would change my answer to “Never.””

SUN_AFFORD	How important are the following features to you when purchasing sunscreen? The sunscreen is affordable.
-------------------	--

SUN_INGRED	How important are the following features to you when purchasing sunscreen? The sunscreen’s ingredients.
-------------------	--

SUN_SPRAY	How important are the following features to you when purchasing sunscreen? The sunscreen can be sprayed on the skin.
------------------	---

SUN_FEEL	How important are the following features to you when purchasing sunscreen? How the sunscreen feels on my skin.
-----------------	---

When answering SUN_INGRED, some participants were thinking of specific ingredients that they avoid in a sunscreen, such as fragrance and benzene. Others participants generally thought about the list of ingredients on the back of a bottle of sunscreen and evaluated how important that list was in their decision to purchase sunscreen. Others gave examples of things that may be included in ingredients, but did not name specific ingredients, such as chemicals, hormone disrupters, and oils. Lastly, one participant noted that they assume that any product for sale in stores is required to be FDA approved, so they do not need to worry about the ingredients.

- “A lot of sunscreens and skincare products have fragrance in them and that will irritate the heck out of my skin. I go on those websites like Cause DNA and look up the ingredients and I see what the irritation factor is because I have really sensitive skin and I’ve had horrible reactions to products in the past. I’m very careful with what I put on my skin. It can’t have fragrance or essential oils in it.”
- “I think of it, if it’s going to be on the shelf, it has to be FDA approved, so it’s most likely not a big deal.”

Participants were asked if there were any other features that were important to them when purchasing sunscreen that were included in the survey questions. Other features participants found important

included whether the sunscreen was cruelty-free and used “clean” ingredients, the sunscreen’s scent, the SPF level, and whether the sunscreen was waterproof.

- “The smell. The typical sunscreen when I was growing up had a very specific smell that could be really strong. I’ve appreciated sunscreens that don’t have to have that odor.”
- “The SPF level. The SPFs that are 10 or 15, you’re aren’t doing very much good. I would want, ideally, at least 30 or higher. But I try to go with a 50.”

SUN_NOHARM	Do you strongly disagree, somewhat disagree, somewhat agree, or strongly agree with the following statements? Sunburn is not really harmful in the long run.
-------------------	---

When deciding on their response to SUN_NOHARM, participants thought about their own experiences with painful or severe sunburns or the information they had heard or read about the connection between sunburns and skin cancer and melanoma. Participants understood “in the long run” to be referring to the long-term consequences of sunburn, for example, effects of sunburn that emerge several years later. Most participants discussed the fact that sunburns increase your risk for developing skin cancer or other skin conditions and thought about the effect of sunburns over time.

- “I definitely feel like that’s what leads to skin cancer. The more sunburns you have, the more likely you are to get skin cancer.”
- “I mean, it can lead to skin cancer, premature aging. It’s bad. It’s serious and it’s harmful in the long run.”
- “I’ve seen people get really bad sunburn so it does hurt the skin and stuff if you do get that.”

One participant reflected on their personal experience with sunburns that led to melanoma:

- “I did have a malignant melanoma. I had a mole taken off and it was a melanoma. I do know it’s harmful no matter what. I have a history of a lot of sunburns when I was a kid.”

Skin cancer was the most common type of “harm” participants thought of when answering this question. Other types of harm that participants mentioned included wrinkles, premature aging, blistering burns, and peeling skin.

Based on their responses to the probes, two participants seemed to overlook the word “not” in the question (i.e., “Sunburn is not really harmful in the long run.”), and thus, misinterpreted the question. One of these participants answered “Strongly agree” and then explained their answer during probing by stating, “I’ve heard you can get skin cancer from sunburn so that’s why I said strongly agree.” The participant’s focus on and discussion of skin cancer during probing made it evident that had they read the question correctly, they would have answered “Strongly disagree.”

On the other hand, the other participant answered “Strongly disagree” and explained their answer by stating, “I was thinking in the long run if it was harmful but I don’t think so because once you get out of the sun and let it heal, I don’t think it should be harmful to your skin in the long run.” This participant’s responses to the probes made it clear that, had they read the question correctly, they would have answered “Strongly agree.”

SUN_REAPPLY	Do you strongly disagree, somewhat disagree, somewhat agree, or strongly agree with the following statements? It is a hassle to reapply sunscreen.
--------------------	---

SUN_SAFETY	Do you strongly disagree, somewhat disagree, somewhat agree, or strongly agree with the following statements? I’m concerned about the safety of ingredients in sunscreen.
-------------------	--

SUN_CLOUDY	Do you strongly disagree, somewhat disagree, somewhat agree, or strongly agree with the following statements? On cloudy days, I don't need to worry about the sun.
-------------------	---

Responses to these questions were not systematically probed, and no interpretive findings are available.

Chemical Hair Products Questions

The Chemical Hair Products questions asked about use of chemical straighteners, relaxers, or pressing products in the past 12 months, and how use of these products has changed, if at all, over the past 12 months.

CAR_USE	In the past 12 months, have you or someone else used <u>chemical straighteners, relaxers, or pressing products on your hair?</u>
----------------	---

Participants had no difficulty selecting a response to this question, and no participants expressed any uncertainty in their response. When the participants who answered “Yes” were asked to provide some examples of the products they had used on their hair in the past 12 months, they included products such as chemical straighteners, perm/relaxer products, serums, and hair dyes. Two of the participants who answered “Yes” indicated that they applied these products to their hair on their own and the other two participants indicated that a hair stylist had applied these products to their hair at a salon.

One of the participants answered “Yes” and reported using products that aligned with the question intent, but felt the question could be improved by including a list of example products.

Two participants misinterpreted the phrase “or someone else.” These participants thought this phrase was referring to someone else they knew using these types of products on their own hair rather than someone else applying these types of products to the participant’s hair. However, this misinterpretation did not result in misreporting for either of these participants.

CAR_FREQUSE	In the past 12 months, how often have you or someone else used <u>chemical straighteners, relaxers, or pressing products on your hair?</u>
--------------------	---

Three of the four participants who answered CAR_FREQUSE indicated that it was easy for them to remember how often they had used these products on their hair. For these participants, their use of these products occurred on a somewhat regular schedule, making it easy to select their response.

- “It was easy because I have a 3-month cycle.”

One participant, however, found it moderately difficult to remember how often they used these products on their hair because they used these products frequently. It can be difficult for respondents to determine the frequency with which an event or behavior occurs when it occurs often.

Air Cleaners and Purifiers Questions

The Air Cleaners and Purifiers questions asked about use (and reasons for use or non-use) of portable air cleaners or air purifiers, and use (and reasons for non-use) of portable high-efficiency particulate air (HEPA) filter units.

VEN_USE	A portable air cleaner or air purifier can remove particles like dust, pollen, viruses, bacteria, and mold from the air. Portable air cleaners or air purifiers are free-standing and can be moved around the home. How often do you use a portable air cleaner or purifier in your home?
----------------	--

Participants knew whether they had a portable air cleaner or air purifier in their home and were able to easily select a response after reflecting on their routines and use patterns. Although some participants used their air cleaners or air purifiers daily, others only used it in certain situations, such as when cleaning their home or to combat allergies.

- “I have a desktop air purifier for my allergies and I always run it.”
- “I use it often. I cook a lot. I like to have people over. I usually put it on when I do my weekly cleaning or deep cleaning. I’m just in the practice of turning it on.”
- “I do have one and whenever my allergies really start to act up, I get it out, but in general, I don’t use it.”
- “I just don’t have one. I don’t have any portable anything for doing anything in the house.”

When asked to provide an example of what they thought of when they read “portable air cleaner or air purifier,” participants mostly thought of smaller machines that could be picked up and moved to different locations.

- “I think of those tall, column-like ones with the grate on the front. I also think of the short ones that kind of look like a box. Those are the ones I’ve had.”
- “A little, small air purifier machine that cleans the air, gets all the dust and pollen out of your room.”

Two participants were unable to describe or provide examples of air cleaners or air purifiers. One of these participants selected “Never” as their response to VEN_USE and indicated that they did not know what an air cleaner or air purifier was. The other participant, however, answered “Rarely” but was unable to describe or give an example of an air cleaner or air purifier.

VEN_HEPAUSE	Portable high-efficiency particulate air or HEPA filter units trap particles in the air. Do any portable air cleaners or purifiers in your home use a HEPA filter?
--------------------	---

Participants who knew their response to this question decided on their answer by reflecting on the types of filters they purchase for their portable air cleaners or purifiers. Some participants noted that they knew their air cleaners or air purifiers used HEPA filters because the filters they purchased were labeled as “HEPA.” On the other hand, others knew their air cleaners or purifiers did *not* use HEPA filters because the filters they purchased were not “special” or labeled as “HEPA.”

- “I know that the filters I buy have the high-efficiency filters.”
- “I’ve had to buy replacements for the filters. I keep the cardboard box it comes with so I know which one I need to buy.”
- “I know mine doesn’t have a special filter.”

Those participants who were unsure of the type of filter their air cleaner or air purifier used selected “I don’t know if I have a portable air cleaner or purifier that uses a HEPA filter.”

Intimate Partner Violence Questions

The IPV questions asked about experience with physical forms of intimate partner violence. The introduction to this set of questions reminded participants that they did not have to answer any questions they did not want to answer and provided a link to resources they could access should the question content upset them. One participant refused to answer these questions and skipped to the next section of the survey.

IPV_PUSH	In your lifetime, has a current or ex-romantic or sexual partner ever done any of the following things to you on purpose? Slapped, pushed, or shoved you?
-----------------	--

IPV_HIT	In your lifetime, has a current or ex-romantic or sexual partner ever done any of the following things to you on purpose? Hit you with a fist or something hard?
IPV_KICK	In your lifetime, has a current or ex-romantic or sexual partner ever done any of the following things to you on purpose? Kicked or stomped on you?
IPV_HAIR	In your lifetime, has a current or ex-romantic or sexual partner ever done any of the following things to you on purpose? Hurt you by pulling your hair?
IPV_SLAM	In your lifetime, has a current or ex-romantic or sexual partner ever done any of the following things to you on purpose? Slammed you against something to hurt you?
IPV_CHOKE	In your lifetime, has a current or ex-romantic or sexual partner ever done any of the following things to you on purpose? Tried to hurt you by choking or suffocating you?
IPV_KNIFE	In your lifetime, has a current or ex-romantic or sexual partner ever done any of the following things to you on purpose? Used or threatened you with a knife?
IPV_GUN	In your lifetime, has a current or ex-romantic or sexual partner ever done any of the following things to you on purpose? Used or threatened you with a gun? Please include firearms such as pistols, revolvers, shotguns, and rifles (but not BB guns or paint ball guns).

Three participants expressed some level of discomfort with the IPV questions. After reading the introduction and the first question in the series, one participant requested to skip these questions and move to the next section of the survey. Another participant indicated they were uncomfortable with the IPV questions and were unsure if they wanted to answer. Ultimately, this participant decided to answer the questions. Lastly, another participant became visibly uncomfortable as they read the disclaimer leading into the IPV section and the introduction to the IPV questions. This participant was blushing, laughing (out of discomfort), and shifting in their seat. However, once the participant began answering the IPV questions, all signs of discomfort disappeared, and they were able to respond without issue.

Among those participants who responded to the IPV questions, most were thinking of multiple people as they answered the questions. Those participants who thought of only one person did so because they had only been in a relationship or been intimate with one person, or on questions for which they answered “Yes,” they thought of the one person with whom they had experienced that form of IPV.

- “I was mostly thinking about one person because I was with the same person for the majority [of time]. There were people before that but not that many. I did think of them, too, but the majority of my brain was the one person.”

Two participants indicated that they included a person they only went on one date with or only hooked up with one time when answering the IPV questions. These participants did not provide additional details to determine whether their answers to these questions would change if they had not included these people.