

# **Cognitive Interview Evaluation of Questions for Inclusion on the 2023 National Health Interview Survey**

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# 1. Introduction

This report summarizes findings from an evaluation of survey questions intended for inclusion on the 2023 National Health Interview Survey (NHIS).<sup>1</sup> NHIS is an interviewer-administered<sup>2</sup> nationally representative household survey, providing information on the health of the civilian non-institutionalized population of the United States. NHIS is one of the major data collection programs of the National Center for Health Statistics (NCHS), which is part of the Centers for Disease Control and Prevention (CDC). The main objective of the NHIS is to monitor the health of the United States population through the collection and analysis of data on a broad range of health topics.<sup>3</sup>

When survey questions are modified or new are questions added to the NHIS it is standard practice for these questions to be evaluated in advance. This helps ensure that questions accurately collect data consistently across respondent groups, in accordance with the objectives of the research. An evaluation of proposed questions was conducted by NCHS' Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) using cognitive interviewing methods. The study was conducted in collaboration with the Division of Health Interview Statistics at NCHS. The questions evaluated covered topics for inclusion on both sponsored questionnaire content and the annual NHIS core questionnaire. Questions were included on the topics of:

## *Sponsored content*

- Hearing
  - Hearing ability
  - Exposure to chemicals
  - Exposure to loud sounds or noise
- Vision
- Family history of cancer

## *Annual core content*

- Difficulty paying for health care
- Prescription medication
- Health care utilization
- Schooling

During the summer of 2022, 30 English-speaking adult respondents took part in one-on-one cognitive interviews, conducted remotely using video conferencing software, over two rounds. Respondents answered questions about themselves and other family members. This report includes a high-level description of key themes that were apparent across questions sets, as well a summary of the findings related to the performance of each question evaluated.

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<sup>1</sup> [NHIS - National Health Interview Survey \(cdc.gov\)](https://www.cdc.gov/nchs/nhis/)

<sup>2</sup> Face-to-face interviewing is the primary mode of administration for NHIS. The telephone may be used for follow-ups or at the request of the respondent.

<sup>3</sup> [NHIS - About the National Health Interview Survey \(cdc.gov\)](https://www.cdc.gov/nhis/about-nhis/)

## 2. Background

In compliance with standards and guidance for conducting cognitive interviewing studies recommended by the Office of Management and Budget (OMB, 2016)<sup>4</sup> and outlined by Miller (2017),<sup>5</sup> the National Center for Health Statistics manages an on-going program of question evaluation and testing of survey questions included on the NHIS. The NHIS makes provision for a core set of questions that are asked on a continuous basis, annually, as well as content that is sponsored separately from agencies external to NCHS. Questions from both were evaluated by this study.

NHIS sponsored content for this study included questions on hearing, vision, and family history of cancer. The 2023 NHIS includes hearing content from the National Institute of Health's (NIH) National Institute on Deafness and Other Communication Disorders (NIDCD) and from the CDC's National Institute on Occupation Safety and Health (NIOSH). Sponsored content from NIDCD includes a question on respondents' ability to hear. Sponsored content from NIOSH includes questions on ototoxicity and exposure to loud sounds in the workplace. Ototoxicity is ear poisoning that comes from exposure to drugs or chemicals that damage the inner ear, often impairing hearing and balance. The purpose of these questions is to understand the typical exposure to ototoxicity across industries and occupations. Regular exposure to secondhand smoke can also be ototoxic. Vision content is sponsored by the NIH National Eye Institute (NEI) and includes questions to address Healthy People 2030 objectives on increasing the use of vision rehabilitation services, as well as assistive and adaptive devices, for people with vision loss. A question also attempts to ascertain whether respondents with vision loss are being advised on these services and devices as part of the health care that they receive. The NIH National Cancer Institute and the CDC National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) sponsored content is on family history of cancer which has been modified since its last inclusion on the 2015 NHIS. A content of care question was also included about whether a health professional talked with the respondent about what a family history of cancer might mean for their own health and cancer risk. The goal of this question is to understand if a conversation about family history occurred among those with a family history of cancer, beyond filling out a form in the waiting room.

NHIS annual core content for this study included questions on difficulty paying for health care, prescription medication, health care utilization, and schooling. These questions have been included on the NHIS previously but there have either been modifications in the wording since they were last evaluated, or the questions have not been evaluated in recent years. These questions are also considered

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<sup>4</sup> U.S. Office of Management and Budget (OMB). (2016) Statistical policy directive no. 2 addendum: Standards and guidance for cognitive interviews. Washington DC. Retrieved from:

[https://obamawhitehouse.archives.gov/sites/default/files/omb/inforeg/directive2/final\\_addendum\\_to\\_stat\\_policy\\_dir\\_2.pdf](https://obamawhitehouse.archives.gov/sites/default/files/omb/inforeg/directive2/final_addendum_to_stat_policy_dir_2.pdf)

<sup>5</sup> Miller K. (2017). Standards and Guidelines for Conducting Cognitive Interviews. Presentation to Questionnaire Evaluation Standards workshop. Rome, Italy. Retrieved from: [Q-Bank: Question Evaluation for Surveys \(cdc.gov\)](https://www.cdc.gov/questionnaire/questionnaire-evaluation-workshop/)

priority due to their relevance to the Department of Health and Human Services' health equity-related goals.

### 3. Methods

#### 3.1 Cognitive interviewing

This survey question evaluation utilized a one-on-one cognitive interviewing methodology. During the interviews, the survey questions under investigation were administered and cognitive interviewing techniques applied in order to make an assessment of the mental processes that respondents went through when answering the survey questions, within the context of their individual life circumstances (Miller, 2011).<sup>6</sup> Using this method, researchers are able to explore construct validity and identify any difficulties respondents encounter in understanding and answering the survey questions (Miller, 2016).<sup>7</sup> Ultimately, the findings from the cognitive interviews help in determining whether questions may be prone to measurement error when administered in a survey. Two rounds of testing were completed. Cognitive interviews were conducted remotely using the Zoom for Government video conferencing platform to comply with the CDC's requirements to use an authorized and secure video conferencing platform through which to conduct the interviews.

#### 3.2 Study sample and respondent recruitment

A small-scale, purposive sample of respondents was selected for interview. With a purposive non-random sample, the characteristics of the individual are used as the basis for sample selection, most often chosen to reflect the population under investigation. Indeed, the number of people interviewed is less important than the criteria used to select them (Wilmot, 2005).<sup>8</sup>

CCQDER's Operations staff recruited and screened respondents. Respondents were recruited from advertisements emailed to members of CCQDER's respondent database, placed on websites such as Reddit, or posted on targeted listservs or on social media. Respondents were also recruited by word-of-mouth. CCQDER Operations staff reached out to people who expressed an interest in taking part, administered a set of screening questions, and scheduled appointments with those who fulfilled the screening criteria.

Screening criteria for this study included age, gender, race/ethnicity, number of adults in the household, educational attainment, current education status, as well as household income and health insurance

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<sup>6</sup> Miller, K. (2011). Cognitive interviewing. In J. Madans, K. Miller, A. Maitland & G. Willis (Eds.), *Question evaluation methods*. (1<sup>st</sup> ed.) Hoboken, NJ: Wiley.

<sup>7</sup> Miller, K. (2014). Introduction. In K. Miller, S. Willson, V. Chepp & J.L. Padilla (Eds.), *Cognitive interviewing methodology*. Hoboken, NJ: Wiley.

<sup>8</sup> Wilmot, A. (2005). Designing sampling strategies for qualitative social research: With particular reference to the Office for National Statistics Qualitative Respondent Register. *ONS Survey Methodology Bulletin No. 56*, pp. 53-65. Retrieved from: <https://webarchive.nationalarchives.gov.uk/20160108193821/http://www.ons.gov.uk/ons/guide-method/method-quality/survey-methodology-bulletin/smb-56/index.html>

status (as indicators of socio-economic group). Key topic related screening criteria included, self-rated hearing and vision difficulty, previous exposure to chemicals or loud sounds or noise at work, a family history of cancer, and whether prescription medication had been taken in the past 12 months.

Respondents who took part in the study were located in different states across the United States including Alabama, Florida, Maryland, Massachusetts, Nevada, New York, and Pennsylvania, as well as the District of Columbia. An attempt was made to obtain a mix of respondent demographic characteristics, though priority was given to those respondents fulfilling key criteria related to the question topics.

It was important for the testing of questions on exposure to have a good mix of respondents with differing employment statuses and who worked, or who had worked, in a variety of industries. Twenty-five respondents recruited to take part in the study were currently in employment, either full-time or part-time; five were not, including one not currently employed, two full-time students not currently working in a job, and two who were fully retired. Respondents worked in a variety of industries and positions, including construction workers, train, truck and bus drivers, lawn care specialists, farm workers, cleaners, school technicians, cooks, sales assistants, and respondents in remote teleworking administrative and IT positions. In past employment, respondents had worked in factories and warehouses, bars and restaurants, the music industry, a flower shop, a sewage plant and served in the military. One respondent did not consider farm work on his small holding as a job, and the youngest respondent had never had a job.

Respondents were also selected for interview who lived with other adults in their household, in order that the questions pertaining to paying for health care, which ask about all family members' experiences, could be tested adequately. In total, eight respondents did not live with other adults in the household; twenty-two lived with at least one other adult in the household to a maximum of three other adults.

Table 1 shows the demographic breakdown for achieved interviews across both rounds of testing. The sample skews towards those in the older age groups and lower socio-economic groups because these respondents were more likely to fulfil the key topic related screening criteria.

**Table 1: Respondent Demographics**

<b>Demographics</b>	<b>Number of respondents (N=30)</b>
<b>Age group in years</b>	
18-29	6
30-49	7
50-64	12
65 or over	5
<b>Gender</b>	
Female	14
Male	16
<b>Education</b>	
High School Diploma/GED or less	14
2- or 4-year college degree	14
Graduate degree	2
<b>Race/Ethnicity</b>	
<i>Non-Hispanic</i>	27
Asian	1
Black or African American	16
White	9
Multiple Race Groups	1
<i>Hispanic</i>	3
<b>Employment status</b>	
Employed	25
Economically inactive	5
<b>Number of adult household members*</b>	
One	8
More than one	22

\*Includes respondent

### 3.3 Data collection

This study received OMB and CDC Human Subjects review and approval. Each respondent took part in an interview lasting at most one hour and received \$50 cash for participating. All interviews were conducted on a voluntary basis. Because the interviews were conducted remotely, consent forms were emailed in advance and verbal consent was sought prior to taking part in the interview. The approach to cognitive interviewing used by CCQDER staff is interpretivist. It focuses on how respondents' own life experiences inform their answers to survey questions. As such, staff rely on non-scripted, verbal probing to illuminate the respondent's circumstances and inform how and why they answered the

question the way they did (Cibelli Hibben & de Jong, 2020).<sup>9</sup> Probing was conducted either retrospectively, after first administering the survey questions, or on occasion, concurrently - whichever was most appropriate for the person being interviewed.

The questions were tested iteratively with 30 English-speaking respondents over two rounds. Round 1 comprised of 13 interviews, Round 2 comprised of 17 interviews. During a brief pause following Round 1 interviewing, a few amendments were made to the wording of section introductions and questions to help respondents better understand and interpret the questions, as intended.

With respect of the question administration, ‘don’t know’ and ‘refusal’ codes were available for interviewers to use if respondents answered spontaneously in this way. Consistent with the way the questions are asked by survey interviewers in the field, these response choices were not read to the cognitive interview respondent as part of the question administration. Furthermore, for the purposes of this study, any interviewer ‘read if necessary’<sup>10</sup> instructions were not administered before ascertaining respondent understanding of the question, to help determine if the instructions were required or indeed added clarity.

### 3.4 Data analysis and reporting

Analysis of cognitive interviewing data follows a systematic process of synthesis and reduction from interview to report (Miller et al., 2014).<sup>11</sup> Firstly, all interviews were video and audio recorded to allow the interviewer the freedom to concentrate on the discussion and enable a more thorough analysis than could be achieved by simply taking notes during the interview. Interviewers created summary notes about the way in which respondents interpreted and responded to the survey questions from the recordings, evidenced by verbatim statements made by respondents during the interview and observation of non-verbal behaviors. Where this report refers to verbatim statements, the respondent’s accounts are italicized. The summary notes were organized by question and entered into CCQDER’s Q-Notes software,<sup>12</sup> a freely available application designed to facilitate the management and analysis of cognitive interview data. All notes were anonymized. That is, they did not contain any personal information that could identify those respondents who took part in the interviews. Respondent confidentiality was maintained throughout the analytical process.

As mentioned previously, an interpretivist approach to cognitive interviewing assumes that respondents understand and process survey questions based on their own personal experience. Findings reported incorporate information elicited through probing the respondent narrative, which helps the analyst to

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<sup>9</sup> Cibelli Hibben, K.L. & de Jong, J. (2020). Cognitive Interviewing. *Guidelines for Best Practice in Cross-Cultural Surveys*. Ann Arbor, MI: Survey Research Center, Institute for Social Research, University of Michigan. Retrieved from <https://ccsg.isr.umich.edu/chapters/pretesting/cognitive-interviewing/>

<sup>10</sup> The NHIS provides additional information for field interviewers to relay to respondents who ask for clarification or appear to be struggling with comprehension after the initial question reading.

<sup>11</sup> Miller, K., Willson, S., Chepp, V. & Ryan, J.M. (2014). Analysis. In K. Miller, S. Willson, V. Chepp & J.L. Padilla (Eds.), *Cognitive interviewing methodology*. Hoboken, NJ: Wiley.

<sup>12</sup> More information about Q-Notes is available at: <https://www.cdc.gov/nchs/ccqder/products/qnotes.htm>



identify the basis on which the survey question is answered, and the construct captured (Chepp & Gray, 2014).<sup>13</sup> Furthermore, recognizing that respondents with different backgrounds and life experiences may interpret the questions differently, this study's approach to analysis is consistent with the socio-cultural approach to question evaluation as described by Miller and Willis (2016),<sup>14</sup> which is specifically focused on addressing comparability across sub-groups throughout the analysis process.

## 4. Findings

### 4.1 Key themes

Each question is reported on individually as part of a question-by-question review in section 4.2. However, three cross-question themes stood out.

#### 1. Comprehension of technical terms

Respondents were sometimes unfamiliar with technical terminology used in the question stem, or included as additional information for interviewers to read out if necessary, which could lead to response error when questions are administered in a quantitative survey. In particular:

- In Question 2, respondents were often unclear of the meaning of the technical terms used to describe certain types of chemicals, such as 'solvents' or 'heavy metals.' Although the more detailed description for interviewers to read out if necessary helped some to formulate an accurate response, this was not always the case.
- In Question 9, respondents were often unfamiliar with the term 'vision rehabilitation services,' which led to response error.
- In Question 10, the examples provided were not always known to respondents. On hearing the term 'prescriptive lenses' many thought about their use of prescription lenses (glasses and contact lenses) and answered on that basis alone. Some understood the acronym CCTV to mean Closed-Caption rather than Closed-Circuit Television.

#### 2. Potential question order effects

Question order effects can be more impactful during administration of omnibus style survey questionnaires<sup>15</sup> such as that used by the NHIS, because of changing topics and definitions. Definitions provided in the questionnaire were sometimes carried over, across question sets, influencing the way in which some respondents understood or responded to subsequent questions. An example, which emerged during the cognitive interviews, involved how the definition of 'family' influenced later items. When answering Question 13 about discussions with a health care provider about their family history of cancer, respondents sometimes applied the definition of 'family' provided in the previous Question

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<sup>13</sup> Chepp, V. & Gray, C. (2014). Foundations and New Directions. In K. Miller, S. Willson, V. Chepp & J.L. Padilla (Eds.), *Cognitive interviewing methodology*. Hoboken, NJ: Wiley.

<sup>14</sup> Miller, K., & Willis, G. (2016). Cognitive models of answering processes. In C. Wolf D. Joye, & T. W. Smith *The SAGE Handbook of survey Methodology* (pp. 210-217). SAGE Publications Ltd, <https://dx.doi.org/10.4135/9781473957893.n15>

<sup>15</sup> Meaning that the survey questionnaire covers a variety of different topics.

12. That is, respondents answered in relation to a close family member (parents, siblings, or children) rather than thinking more broadly. When asked about their family's ability to pay medical bills (Questions 16 and 17), rather than answering about their household family members, some respondents answered about biological relatives who were not household members - a definition carried over from the previous section on family history of cancer.

### 3. Lack of knowledge

Lack of knowledge impacted data quality leading to a less confident or 'Don't know' response. Some respondents did not know, for example, the type of chemical to which they had been exposed, when answering questions on exposure risk. Lack of knowledge about other family members' medical history made it difficult for some respondents to provide accurate responses to the set of questions about family history of cancer. This lack of knowledge was due to the fact that more intimate health issues were not always discussed, even among family members, and particularly if the family member had been a child at the time of diagnosis.

## **4.2. Question by question review**

This section describes the findings for each of the 28 questions evaluated as part of this study. All of the questions were administered during both rounds of interviewing, albeit in Round 2 a few were asked in a different order or with minor amendment. The question wording as shown in this report is that administered during Round 2 interviewing. This report notes any changes that were made to the questions prior to Round 2 and describes any impact on the response task or respondents' interpretation of the question. A frequency distribution table is also shown indicating how respondents answered each question immediately after hearing it, across both rounds. These tables may give some indication of scale in relation to the qualitative sample of cognitive interview respondents; however, they do not reflect any distributions that might be apparent from a quantitative probability sample of the general population (see also section 3.2). Where a question was on route but not administered by the interviewer because of time constraints during the interview, these cases are also shown in the frequency table as 'Not asked.'

As with other omnibus style survey data collections, where the topic under investigation changes throughout the questionnaire, transitional statements or specific section introductions are provided in order to help orientate survey respondents. Where the wording to these statements was changed between rounds this is noted. Where probed sufficiently during the cognitive interviews, findings are also reported on how these statements impacted the survey response process.

As mentioned earlier, respondents with different backgrounds and life experiences may interpret questions differently and this understanding underpins the methodological approach to evaluation applied and reported on throughout this report. In general, there were very few differences in interpretation across specific demographic subgroups of respondents taking part in this study (to include gender, age and race/ethnicity). Any differences worthy of note are reported on within the question-by-

question review below.

## 4.2.1 Hearing

### Hearing ability

#### Question 1

**This first question asks about your hearing.**

**Without the use of hearing aids or other listening devices, is your hearing excellent, good, a little trouble hearing, moderate trouble, a lot of trouble, or are you deaf?**

- 1 Excellent
- 2 Good
- 3 A little trouble hearing
- 4 Moderate trouble
- 5 A lot of trouble
- 6 Deaf
  
- 7 Refused
- 9 Don't know

*Frequency distribution (N=30)*

Response option	Count
Excellent	9
Good	12
A little trouble hearing	1
Moderate trouble	8
A lot of trouble	0
Deaf	0
Refused	0
Don't know	0

#### **Findings**

All 30 cognitive interview respondents were asked this question. Respondents understood this question as asking for an assessment of their ability to hear sounds, without the use of a hearing aid or other listening devices, except in one instance where a respondent answered on the basis of her ability to comprehend what she heard. Apart from this one case, any hearing loss, either perceived or actual, influenced the response selection. It may be useful to note that the way in which the question was phrased made it a little awkward for interviewers to read out.

Similar to findings discussed by Miller et al (2021)<sup>16</sup> respondents generally considered their self-perceived ability to hear when doing various activities, such as watching television, or in specific contexts, such as having conversations with people in a noisy bar, alongside their

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<sup>16</sup> Miller, K., Vickers, J.B., Scanlon, P. (2021). Comparison of American Community Survey and Washington Group Disability Questions. National Center for Health Statistics - QDRL. Hyattsville, MD <https://wwwn.cdc.gov/QBank/Report.aspx?1216>

need to make accommodations, such as increasing the volume on their television or asking people to repeat themselves during conversation. Some respondents compared their hearing ability to that of other people, or in a few cases compared their ability to hear with their own ability over time. Due to the subjective nature of the questioning, the degree to which respondents rated their hearing ability, based on the effect of similar events or experiences, varied somewhat. However, a couple of respondents referred to the results of hearing tests that they had undertaken which, for them, provided a more concrete basis on which they could make an assessment of their hearing capability, and select an appropriate response option.

#### Response option selection

Those who rated their hearing as ‘Excellent’ explained that they had done so because they could hear things that other people could not hear, *“I can hear things that other people can’t hear. I mean I hear light rain drops,”* or simply that they had not experienced any problems with their hearing ability: *“I have no problem hearing.”*

Those who rated their hearing as ‘Good’ said that their hearing had been impaired somewhat because of past exposure to loud sounds, such as loud music (attending music concerts) or ammunition explosions (serving in the military), which meant that they found it more difficult to hear what other people were saying if there was a lot of background noise. Some older respondents cited their age and a lifetime of exposure to loud sounds as the reason why they had rated their hearing as ‘Good’ rather than ‘Excellent:’

*“I say good because sometimes I cannot hear people like I used to be able to, you know when I was younger, my hearing was great. And I just find it’s not as good. Maybe it’s from listening to loud music over the years, going to these concerts and things like that, I don’t know...Maybe just aging. I’m in my 50’s...it catches up to you.”*

Indeed, one respondent in his 60s said that he did not select ‘Excellent’ purely because of his age, and although he didn’t know for sure that his hearing had been affected, he was certain that it must have been as he used to play in a band. A few said that their hearing was impaired due to past ear or sinus infections and that subsequently they had noticed that they needed to ask people to repeat themselves. A couple of respondents made an assessment of their hearing as ‘Good’ based on workplace testing. One respondent said, *“So I’m around trains every day, but you know, they have us take the hearing test every year and I just took one some months ago and they’re saying that from when I started until now it’s not too much of a change, so that’s why I didn’t say excellent, so I said good.”* The other based his answer on the language that had been used during workplace testing: *“At different places where I’ve worked, once a year they come around with a mobile hearing thing, and they test your ears. They’ve always said it was good – they’ve never said it was excellent.”*

Also based on the effect that old age has on one's ability to hear, one respondent answered, 'A little trouble hearing,' explaining that sometimes she had to ask people to repeat themselves, while another respondent, on the same basis, answered 'Moderate trouble.' Some reported moderate trouble hearing because of damage to their hearing from long term exposure to loud sounds or ear infections that meant they suffered from tinnitus, which interfered with the clarity of sound, or they had trouble hearing high or low frequencies. One respondent who answered 'Moderate trouble' wore hearing aids (assessing his hearing ability without the use of his hearing aids). No one answered that they had 'A lot of trouble hearing', or that they were 'Deaf.'

It should be noted that one respondent gave a 'Good' rather than 'Excellent' rating on the basis of her medical condition which meant that she was not always able to make sense of what other people were saying, rather than her inability to hear sounds:

*"I do have some issues because I have [name of medical condition] where I have issues interpreting what someone is saying. So, it's not necessarily that I can't hear what someone is saying, it's that I can't understand."*

## Exposure to chemicals

### Section introduction

**The next set of questions ask about your exposure to chemicals and tobacco smoke in your job.**

#### **Changes to the wording between rounds**

Between rounds the wording of this introduction was changed to better reflect the topics covered by the specific question set. Hence, the wording was changed from, 'The next set of questions ask about your exposure to chemicals and loud noises in your job' to 'The next set of questions ask about your exposure to chemicals and tobacco smoke in your job.'

#### **Findings**

Although most respondents understood that they were to be asked about exposure to chemicals and, respectively, loud noises or tobacco smoke in their current job, a recency effect<sup>17</sup> was apparent in respect of a few Round 1 respondents who only heard that the questions were to be about exposure to loud noises – although there was no evidence that this impacted on their responses to the subsequent questioning.

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<sup>17</sup> Respondents focus on the last thing that they heard when questions are presented orally.

## **Question 2**

**During the past 12 months, did you work in a job where you were exposed to any of the following: solvents, industrial glues, heavy metals, pesticides, or motor engine exhaust?**

*Read if necessary:* Solvents are liquids, not including water, used for dissolving other substances, such as dry-cleaning fluids, thinners, components of paints, industrial cleaners and paint removers. Industrial glues are adhesives that include acrylic, epoxy, hot melt, polyurethane, silicone, thermoset and industrial sealants. Heavy metals include lead, nickel, mercury, cadmium, arsenic, chromium, zinc and copper.

1 Yes

2 No

7 Refused

9 Don't know

*Frequency distribution (N=30)*

Response option	Count
Yes	11
No	18
Refused	0
Don't know	1

### **Changes to the wording between rounds**

Between rounds the example of 'cancer fighting drugs' was dropped from the list used in the question stem to shorten the list and aid administration, but also because of potential misunderstanding of its use in the context of the question. For example, a Round 1 respondent heard 'cancer causing:' "...just a sealer kind of a glue. I don't know if it's cancer causing or anything." Another talked about receiving cancer fighting drugs himself in the past to treat his cancer.

### **Findings**

This question applied to everyone taking part in the study. In general, respondents understood this question to be asking about their exposure to chemicals that could cause them harm. 'Exposure to chemicals' meant physically handling them or inhaling the fumes: "*Things you can smell that you can't see;*" "*Basically if I'm around a bunch of fumes.*" The frequency of exposure or length of time respondents were exposed to chemicals in the past 12 months, along with the intensity of that chemical exposure, varied. Some respondents did not understand all of the terms used in the question stem, or whether or not a particular chemical to which they had been exposed should be included. When respondents were unsure, they first referenced the term 'chemicals,' used in the section introduction, to glean meaning.

## Exposure

Generally, exposure in their job was determined on the basis of whether respondents themselves used the chemicals, or that the chemicals were used by others in their vicinity or stored close to their work location, such that they could smell them in the air: *“It’s not really a strong odor, but it’s a different odor than regular.”*

All 11 respondents who answered ‘Yes’ to this question were currently employed. All said that they had been exposed to chemicals (including motor engine exhaust) while working in their job, during the past 12 months (from date of interview year prior). A few also mentioned exposure to herbicides, such as ‘Round Up,’ and one mentioned welding gas. Some had worked in their jobs where they had been exposed to chemicals for the entire 12-month reference period; others had been exposed for less time due to the part-time, or short-term nature of their employment. For example, one respondent said that during the past 12 months she had been exposed daily to crop sprayed pesticides in the area in which she had been deployed for a two-month period. Another had been exposed to a cleaning agent, which burned her skin, in a job lasting one week.

The intensity of the exposure described also varied. For example, a few people described exposure to motor exhaust fumes while working in a confined space, indoors *“...with no windows;”* while others included exposure to exhaust fumes outdoors: *“Motor exhaust, I’m around school buses. Some of them do be running when I’m walking around or getting ready to drive off.”* A farm worker changed his answer to ‘Yes’ during probing because he said he was exposed to motor engine exhaust fumes from a nearby road:

*“Probably the most toxic exposure I get is from the roadway overhead because we are under a bridge, a busy road, an overpass. A lot of people don’t really understand how motor vehicle emissions are a major risk driver for most of us in this region.”*

A few respondents described a lingering odor from chemicals, while others talked about an *“occasional”* smell. Furthermore, some talked about being exposed to more than one type of chemical in their job. For example, an underground railway worker described smelling the fumes from solvents, pesticides and exhaust fumes, *“...there’s a ton, like 24 of them.”* Another respondent said that she was exposed to a variety of different chemicals in her job as a school technician, including paint, industrial cleaners and welding gas, as well as motor-engine exhaust fumes.

Of those who said that they had not been exposed to chemicals in the past 12 months, 10 had been exposed in previous jobs such that their understanding of the question intent could be explored as it applied over their working lifetime. These respondents understood the question in a similar way to that described for those in current employment and answered ‘Yes’ when asked about exposure during past employment. They described being exposed to *“harsh”* chemicals every day in their previous jobs, including solvents, pesticides, and vehicle exhaust, and a few, who had served in the military, described exposure to *“carcinogenic paint,”* glues, diesel exhaust from tanks and ships, and smoke from burning

latrine waste. One respondent explained that he had worked in a factory as a young man where a lot of chemicals were used but he had no idea what they were.

Eight respondents, across the age spectrum, said that they had never been exposed to chemicals in any job. The youngest respondent had never had a job. A few of these respondents said that they might have been exposed to chemicals in past employment but for the fact that they wore protective clothing. One respondent answered 'Don't know' due to a comprehension issue.

#### Comprehension of terms used in the question stem

Cognitive interviewers were instructed not to read out the 'read if necessary' text before asking respondents for their interpretation of the examples of chemicals used in the question stem. This approach helped to understand that the terms used in this question stem were not always terms respondents were familiar with and the more detailed list provided was important for respondent comprehension. One respondent, who answered 'Yes' to this question, asked the cognitive interviewer to provide examples, and said that the list of different types of solvents had helped clarify what to include. However, it was only during probing that it became apparent that the terms were not universally understood. For example, one respondent, who said he had been exposed to chemicals in his previous maintenance job, described dry eyes and running nose when using floor wax and cleaning agents, but was unclear as to the meaning of the term 'solvents:' *"To be honest I don't know what that is, solvents."* Another respondent initially answered 'No' because she had not understood, nor queried, the meaning of the term 'solvents' prior to the interviewer administering the additional 'read if necessary' text provided during probing. She changed her answer to 'Yes' because of the carpet cleaning agents stored near her office: *"What is solvents?... But you would have to put in parenthesis like solvents (cleaners) something like that."* One respondent answered 'Don't know' to the question because she was not sure if her use of acid as a cleaning agent would count:

*"No, but I actually worked with like acid. So, um, I don't know if that fits into one of those categories, but I worked with acid where I had to pour acid into my tanks where I was doing. And that was in the past 12 months..."*

Those who answered 'No' to this question appeared less clear on the meaning of the terms used in the question stem than those who said that they had been exposed to chemicals. For example, those who said they had been exposed to industrial glues described glues used in manufacturing and construction, whereas some who answered 'No' described 'Gorilla Glue' as being a type of industrial glue or said they had not heard the term before. Indeed, some conflated the terms used hearing 'industrial solvents' or 'heavy glues:' *"I'm not really sure what a heavy glue is."* In particular, the term 'heavy metals' was confusing for many who described heavy machinery or simply said that they could only think about pieces of metal that were physically heavy: *"Like aluminum would be light, tin would be light, steel would be*



heavy, uh, ...gold I guess would be heavy... a big quantity of it would be heavy.” Only one respondent actually said that he was exposed to heavy metals in his current job describing exposure to debris and dust from metal railway tracks. One other respondent said that he had been exposed to heavy metals in a previous job as a welder, describing metal spatter that would fly off onto his clothes and possibly into his food.

### **Question 3**

*(Ask if Q2 = Yes)*

**Were you exposed for 4 or more hours a week?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*Frequency distribution (N=11)*

Response option	Count
Yes	9
No	2
Refused	0
Don't know	0

### **Findings**

Eleven respondents were routed to this question because they said that they had been exposed to chemicals in the past 12 months while working in their job.

Those who answered that they had been exposed for four or more hours per week thought about the amount of time they were exposed each day in their jobs and aggregated across their working week. Some said they were exposed all day, every day, and therefore the question was easy for them to answer: *“I was exposed because I had to do the job every day, so it was something that I had to do every day, so yes.”* As mentioned previously, a few respondents worked part-time, intermittently. These respondents answered about their exposure hours per week during the time they worked.

Two respondents answered ‘No’ to this question. One because he was exposed to industrial glue for only a short amount of time each day (10-15 minutes per day). The other calculated only the time he was exposed to chemicals when he himself was using them and did not include his exposure to chemicals when other people were using them around him, which may have led to response error. During probing he said,

*“The first thing I think about is me actually using those products, but then I guess I am in there with the trades which are working but if someone has been in there using those products...the framer may have just been in there laying down a bunch of glue or... we spray insulate homes with foam which is a chemical and nobody can be in the home when it is off gassing.”*

When asked by the interviewer for an estimate of his total exposure time each week, including that from chemicals being used by other people, this respondent found it difficult to quantify because the nature of his work meant that, *“I’m not exposed to any one thing, but I might be exposed to a variety of things...I think that probably 4 hours a week is accurate.”*

#### **Question 4**

**During the past 12 months, did you work in a job where you were exposed for 4 or more hours a week to tobacco smoke from other people?**

*Read if necessary:* Tobacco smoke includes from cigarettes, cigars, pipes, cigarillos, and hookahs. Do not include e-cigarettes or vaping devices that do not contain tobacco.

- 1 Yes
- 2 No
- 7 Refused
- 9 Don’t know

*Frequency distribution (N=30)*

Response option	Count
Yes	6
No	24
Refused	0
Don’t know	0

#### **Changes to the wording between rounds**

To more clearly define ‘tobacco smoke,’ between rounds the ‘read if necessary’ text associated with this question was revised from, ‘Tobacco smoke includes cigarette and cigar smoke’ to ‘Tobacco smoke includes from cigarettes, cigars, pipes, cigarillos, and hookahs. Do not include e-cigarettes or vaping devices that do not contain tobacco.’

#### **Findings**

Respondents generally understood this question as asking about the amount of time they spent actually breathing in secondhand cigarette smoke when at work, and included passive smoking in designated smoking areas.

### Type of tobacco smoke

When thinking about exposure to tobacco smoke from other people in the workplace, respondents tended to think about being exposed to other people's cigarette smoke. Only a few thought about tobacco smoke from cigars or vaping devices: *"Cigars, Cigarettes and ... Vaping... Oh yes, it was nasty."* The expanded 'read if necessary' text was therefore helpful in clarifying the type of tobacco smoke to include. As one respondent commented, *"...but a vape, for some reason it evaporates just like right in their little spot, ...that's why I didn't even count that. If I don't smell it, I don't count it."* Possibly due to the double negative construction, one respondent understood the 'Do not include...' instruction to mean that she should not include any e-cigarettes or vaping devices, rather than only excluding those that do not contain tobacco.

### Type of exposure

Six respondents said that they had worked in a job during the past 12 months where they had been exposed to tobacco smoke from other people. Five reported being exposed to other people's tobacco smoke when passing through, or choosing to stop and talk to, colleagues smoking in designated smoking areas outside of the building where they worked. All five estimated that their exposure time amounted to four or more hours per week. As one respondent explained:

*"The area where people are allowed to smoke is actually behind the kitchen. So, of course if I'm working in the kitchen, I'm going back and forth off the deck to get some supplies or whatever. That's where the exposure comes from. Because the majority of employees that smoke are back there."*

One respondent reported working in an environment where other people were allowed to smoke, over the course of a few months, while she was deployed: *"There would be 8-hour days, 3 or 4 days in a row, where we were exposed to this smoke."*

Everyone else answered 'No' to this question and probing confirmed that they had not been exposed to other people's smoke from cigarettes, cigars, pipes, cigarillos, hookahs etc. in the workplace within the past 12 months. Indeed, a few commented that they worked from home and had complete control over their environment. However, one respondent answered 'No' even though other people were allowed to smoke inside of the warehouse where he worked, explaining that he wore a face mask and therefore was not exposed. One respondent answered 'No' because she smoked cigarettes at work: *"I smoke myself, so I'm exposing myself. And I do smoke in the office"* No one else in her office smoked therefore she determined that she was not exposed to anyone else's tobacco smoke.

## Exposure to loud sounds or noise

### Section introduction

**These next questions ask about exposure to loud sounds or noise while working. Loud means so loud that you must speak in a raised voice to be heard.**

### **Findings**

All 30 respondents were routed to this section. After hearing the section introduction respondents understood that they would be asked questions about loud sounds or noise in places where they had worked (both current and past employment).

The definition of ‘loud’ provided was useful in helping respondents to focus on particularly loud work environments, where a normal-volume voice could not be understood due to the environmental noise, and to discount environments that they initially considered loud but where they did not have to raise their voice to be heard (see also discussion to Question 5). For example, one respondent cited *“Construction. And I have had to raise my voice loud because of that,”* while another thought about her current manufacturing job where it was so loud that she had to use a walkie-talkie to communicate with colleagues. Another answered ‘No’ explaining, *“Oh well, I was going to say yes, but then when you said I had to raise my voice, no.”* However, for one respondent the definition steered her back to thinking about hearing issues (Q1) and she thought about her need to raise her voice when talking to one of her clients at work who was hearing impaired.

Generally, respondents understood ‘exposure’ to mean being around constant loud noise at work, rather than occasional or intermittent loud noise. Indeed, one respondent provided his own very precise definition of exposure as over 108 dB for at least a 20-minute period. A few mentioned that pain or ringing in ears was an indication of exposure.

Respondents carried these interpretations through when answering Questions 5 to 8.

### Question 5

**Have you ever had a job, or combination of jobs, where you were exposed to loud sounds or noise for 4 or more hours a day, several days a week?**

*Read if necessary:* Loud means so loud that you must speak in a raised voice to be heard.

1 Yes

2 No - [Go to Q9](#)

7 Refused - [Go to Q9](#)

9 Don’t know - [Go to Q9](#)

*Frequency distribution (N=30)*

Response option	Count
Yes	16
No	14
Refused	0
Don't know	0

**Findings**

Respondents considered all elements of this question, first determining if they had been exposed to loud sounds or noise at work, currently or in the past, what exposure looks like in terms of volume level according to the definition provided, and length of exposure time.

Many respondents considered any loud job, loud being so loud they had to speak in a raised voice to be heard, in which they had worked over their lifetime as qualification for a 'Yes' response, some spanning as far back as the 1970s. Some answered about loud jobs they had held over decades; others had had short-term periods of employment which had exposed them to loud sounds or noise over a few months.

Respondents answered this question considering the length of exposure defined in the question stem, that being '4 or more hours a day, several days a week.' For example, many described the noise at their job as all day and constant: *"It was loud basically all day every day."* One respondent, who worked in construction and was exposed to loud noise from machines, answered 'No' because the exposure did not accumulate to 4 or more hours a day.

Those who answered 'Yes' framed their response by providing examples of the types of industry in which they had worked and in which they had needed to raise their voice to be heard. These included factories, warehouses, construction sites, the fire service, collision repair shops, post offices, casinos, restaurants, farms, data centers, the music industry, truck driving, and the military. The loud sounds or noise described were mostly due to machinery or engine noise. However, one respondent interpreted the definition provided in the question stem quite literally, including the need to raise her voice to communicate with a client who was hearing impaired: *"I'm a CNA, so my client is just about deaf, can't hear, so I have to yell and he's yelling, we're all just yelling because he doesn't want to put his hearing aids on."*

For the most part, respondents who answered 'No' had never worked in a job that exposed them to constant, prolonged loud sounds or noise. Short, intermittent, bursts of noise were discounted. For example, respondents discounted intermittent engine or kitchen noise:

*"The only thing that is ever loud is if someone drops a pot or you're handling the big pots or equipment. It's not a constant banging or drilling. Just changing out the pots and the utensils and all that kind of stuff."*

Those who answered ‘No’ described their work environments as office, retail, and restaurant. One respondent had never had a job. However, three respondents may have provided an incorrect negative response. One understood the question as asking if his hearing loss was the result of exposure to loud sounds or noise, explaining that his hearing loss was congenital and not caused from such exposure. Another considered only her current quiet office job when answering and not her entire work history which included work in a sorting office where the machines were so loud that she and her coworkers had to raise their voices to be heard. Another counted only the most severe, but not all, loud noise or sounds that led to him raise his voice at work which amounted to less than the four-hour specified cut-off-period.

### **Question 6**

*(Ask if Q5 = Yes)*

**In your lifetime, how many years have you had a job, or combination of jobs, where you were exposed to loud sounds or noise for 4 or more hours a day, several days a week?**

*Read if necessary:* Loud means so loud that you must speak in a raised voice to be heard.

- 1 Less than 1 year
- 2 1 to 2 years
- 3 3 to 4 years
- 4 5 to 9 years
- 5 10 years or longer
- 7 Refused
- 9 Don't know

*Frequency distribution (N=16)*

Response option	Count
Less than 1 year	3
1 to 2 years	2
3 to 4 years	3
5 to 9 years	3
10 years or longer	5
Refused	0
Don't know	0

### **Findings**

Respondents who answered ‘Yes’ to ever having had a job where they were exposed to loud sounds or noise for the prerequisite amount of time (Question 5), were routed to this question. When answering, respondents considered all of their loud jobs over their working lifetime. In fact, some thought back decades to report on loud jobs that they had undertaken in their youth.

Most understood this question as asking for the total number of years they had worked in all of their loud jobs. For some, the calculation was easy to perform since their entire career had comprised of loud jobs: *“That would be all my life. [laugh]. That would be 27 altogether”* or they had only been in the job for a short time (a few months) which was easy for them to remember. For others the calculation was more complicated where they had had many loud jobs. Still, these respondents took the time to make the calculation over their working lifetime, thinking of each loud job they had worked and summing the number of years. For example, one respondent who answered ‘10 years or longer’ explained,

*“Three years in high school working in restaurants, six years in the army, another 3 years working in restaurants in college and a little time after college fighting fires and things. So, that adds up to a little more than 10 years.”*

One respondent avoided the cognitive burden involved in making the calculation providing an estimate of 8 years. However, probing established that the actual amount of time was ‘10 years’ which would have placed her in a different response category.

A few calculated the length of time that they had been exposed while in their loud jobs, rather than the length of time they had worked in those jobs. For example, one respondent answered ‘3 to 4 years’ estimating the total length of time he was actually exposed to loud sounds or noise while working in a band, working in a factory, and serving in the military. If he had answered about the length of time he held these jobs it would have added up to 8 years in total (5 to 9 years).

A few answered only about their current job. For example, a respondent answered, *“About four years”* (3 to 4 years) thinking only of his current job at a data center. If he had also included his loud warehouse job, he would have answered six years (5 to 9 years).

A couple of respondents initially understood this question as asking for the number of loud jobs they had worked over their lifetime: *“Uh, I’d say two of my jobs.”*; *“In my lifetime? One, two, three. I want to say three jobs... Yeah, those are the only three that I can think of that I worked at that had a lot of loud noise.”*

### **Question 7**

*(Ask if Q5 = Yes)*

**During the past 12 months, have you had a job, or combination of jobs, where you were exposed to loud sounds or noise for 4 or more hours a day, several days a week?**

*Read if necessary:* Loud means so loud that you must speak in a raised voice to be heard.

1 Yes

2 No – *Go to Q9*

7 Refused - *Go to Q9*

9 Don’t know - *Go to Q9*



*Frequency distribution (N=16)*

Response option	Count
Yes	7
No	9
Refused	0
Don't know	0

Those who answered 'Yes' to Question 5 were also asked this question.

Most understood that this question was only focused on loud jobs they had had in the past 12 months. For example, one respondent answered 'No' because, although his entire career involved working in loud environments, such as warehouses and military service, he had been retired for over a year. Another said, *"Yes, the job I have now."*

Respondents also made an assessment based on the number of hours and days of exposure. For example, one respondent, who wore ear protection while using his tractor, answered 'No' because he said he did not spend four hours a day, several days a week on his tractor. However, a couple of respondents included just once or twice a week in their definition of 'several days a week' and answered 'Yes' to this question. One had worked at a local ball park twice a week for three or four weeks. The roar of the crowd and the loud speakers were such that: *"No-one could speak at all. So you waited for the roar and the announcements to end before you spoke to anybody."* This respondent estimated that the noise reached this volume for at least four hours during any one event at the ball park. The other respondent was a sound engineer working at loud concerts for four or more hours once or twice a week.

One respondent, who operated loud machinery as part of his job in lawn maintenance, answered 'No' explaining: *"Well, when we, if one of my partners and I need to, we just turn our machines off and talk. We don't try to talk over them."* This respondent also considered that: *"Loudness outside is not the same as loudness in a building."*

One respondent was initially confused by the changing reference periods across questions and queried, *"During my lifetime?"*

The one respondent, mentioned previously, who raised her voice to communicate with her client who was hearing impaired, continued to answer 'Yes' to this question set.



## **Question 8**

*(Ask if Q7 = Yes)*

**During the past 12 months, how often did you wear hearing protection, such as ear plugs or ear muffs when exposed to loud sounds or noise at work? Would you say...**

- 1 Always
- 2 Usually
- 3 About half the time
- 4 Seldom
- 5 Never
  
- 7 Refused
- 9 Don't know

*Frequency distribution (N=7)*

Response option	Count
Always	3
Usually	1
About half the time	0
Seldom	0
Never	3
Refused	0
Don't know	0

## **Findings**

Seven respondents were routed to this question having answered 'Yes' to Question 7. They understood the question to be asking if, during the past 12 months from date of interview, they had used hearing protection of any kind while at work, due to loud sounds or noise. Respondents defined 'hearing protection' to include noise canceling headphones, in-ear hearing protection alone, and in-ear hearing protection in combination with over-the-ear hearing protection.

Respondents who answered 'Always' included those who described ear protection as a mandatory part of their personal protective equipment at work, as well as others who mentioned that hearing protection is not provided by their job and it is their personal choice to wear it. For example, the person who worked at a data center and had answered 'Yes' to Question 7 said that he always wore noise cancelling headphones when at work. The one respondent who answered 'Usually' explained that he wore hearing protection most, but not all, of the time: *"I said usually because I wear it and sometimes I don't because sometimes it be irritating."* No respondents selected 'About half the time' nor 'Seldom.' Those who answered 'Never' had not used hearing protection at work in the past 12 months. Some thought that their job was not loud enough to warrant hearing protection. One respondent explained that her job did not supply hearing protection and, therefore, she assumed the noise was not loud enough to require it. The respondent who was considering times when she

raised her voice to communicate with a client who was hearing impaired was perhaps not surprisingly, confused by this question, but nevertheless answered ‘Never.’

## **4.2.2 Vision**

### **Section introduction**

**The next set of questions are about services or devices that you may have used to help with your vision.**

### **Changes to the wording between rounds**

Following Round 1 administration the section introduction was changed from ‘The next set of questions are about your vision’ to a more detailed description that better reflected the measurement concepts - ‘The next set of questions are about services or devices that you may have used to help with your vision.’

### **Findings**

During Round 1 administration the introduction to this section simply stated, ‘The next set of questions are about your vision.’ After hearing this, respondents said that they were expecting to be asked to rate their ability to see, as they had been similarly asked to do at the start of the hearing module (Question 1): *“Like how would you rate your vision?”* Between rounds the introduction was changed to better reflect the measurement concept. The revised introduction read, ‘The next set of questions are about services or devices that you may have used to help with your vision.’ Although a few respondents still thought that the questions would be about their ability to see, most focused on the terms ‘services’ and ‘devices’ to help with vision and applied a definition that conformed to their experiences in life, understanding ‘services’ to include restorative eye surgery, such as retina repair or Lasik eye surgery and ‘devices’ to include eye glasses and contact lenses: *“I’m thinking do you wear regular prescription glasses, maybe are you going to get Lasik surgery?”* Possibly influenced by the previous question sets on exposure, a few Round 2 respondents also thought about eye protection, for example, safety glasses.

### **Question 9**

**Do you use any vision rehabilitation services, such as job training, counseling, or training in daily living skills and mobility?**

1 Yes

2 No

7 Refused

9 Don’t know

*Frequency distribution (N=30)*

Response option	Count
Yes	2
No	26
Refused	0
Don't know	2

## **Findings**

None of the sampled respondents had used vision rehabilitation services such as those described in the question stem (even though two indicated to the contrary). Most said that they had not heard the term 'vision rehabilitation services' before taking part in the cognitive interview, and even with the examples provided were not always clear as to what the term meant or how it applied to them. This included one respondent who described herself as legally blind: *"I don't know what it is."*

### Comprehension of terms used in the question stem

Often a 'No' response was provided because respondents did not understand the term 'vision rehabilitation services' or how the question applied to them: *"I can't say I've ever heard of anything like that before, vision rehabilitation or training. So, I would say No..."* However, understanding that some survey respondents will try to find resonance in order to provide a response, some wondered if the question was asking about their use of assistive or adaptive devices *"...do I need assistance in any kind of way like a darker screen, a lighter screen, the distance of the computer...the lighting maybe, something like that"* and included their use of glasses or contact lenses: *"I would say it would be glasses, contacts. That's the only thing I can come up with...That's what it sounds like to me."* Indeed, one respondent, who said that he used to be an eye technician, considered treatment of an eye injury as a rehabilitation service, giving the example of removing a splinter from someone's eye or having an ingrown eyelash removed, stating, *"I don't know if that's what you're getting at?"* Another wondered if the use of transportation services would be included as a rehabilitation service for those with vision difficulties because in her job, *"Sometimes we would have to help patients call to get their rides because they couldn't see. Would that be rehabilitation services?"*

Consequently, two respondents answered 'Yes' to this question, but in error. One changed his response from 'No' to 'Yes' during probing and two answered 'Don't know.'

Of the two respondents who answered 'Yes' initially, one heard the term rehabilitation services and answered about rehabilitation services he had received following his discharge from the military, which were not related to his vision. The other answered on the basis that she had used rehabilitation training in her job, but which was not related to vision training: *"I train in daily living skills and mobility with my clients, yeah that's what we do. We train in daily living skills."* One respondent initially answered 'No' but after further consideration changed his answer to include the medication he took and his regular follow-up appointments following retinal surgery. Two respondents answered 'Don't know' because they said they

were confused by the question and unsure as to what it was asking. One did not hear the term ‘vision’ used in the question stem and could only think of examples of rehabilitation services, such as Alcoholics Anonymous or physical therapy. The other explained “...I wear contacts and glasses. I’m not too sure about the question.” During probing this respondent queried whether a vision check-up with her eye doctor could be included as a vision rehabilitation service: “If it’s the eye doctor than yeah. My vision is not perfect. I need glasses to see far.”

### **Question 10**

**Do you use any assistive or adaptive devices such as telescopic or other prescriptive lenses, magnifiers, large print or talking materials, CCTV, white cane, or guide dog?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don’t know

*Frequency distribution (N=30)*

Response option	Count
Yes	15
No	13
Refused	0
Don’t know	2

All 30 respondents were routed to this question. Most based their answer on their use of prescription lenses (glasses and contact lenses), although there was some inconsistency. Respondents did not always understand the meaning of the terms ‘assistive’ or ‘adaptive’ devices used in the question stem: “Honestly I don’t even know what those are;” “...I really don’t know what the difference would be. Maybe I’m confused on what assistive and what adaptive is.” As a result, respondents attempted to draw meaning from the examples provided, although comprehension of the question intent was compounded by the fact that they were not always familiar with all of the examples provided.

### **Understanding the question intent**

On hearing the term ‘prescriptive lenses’ used in the question stem, many thought about their use of prescription lenses (glasses and contact lenses). Indeed, eight respondents answered ‘Yes’ to this question on the basis that they used prescription lenses and no other type of assistive or adaptive device. However, whether or not respondents included prescription lenses when considering their answer was not consistent. Eleven respondents answered ‘No’ and one other answered ‘Don’t know’ to this question who wore glasses or contact lenses that required a prescription: “No, but I do use contacts and glasses;” “I don’t know if to say ‘Yes’ or ‘No’ because I do wear glasses and they are prescription. So, I don’t know with that question.” One respondent changed his answer from ‘No’ to ‘Yes’ because during probing he realized that he used larger text on his phone and also wore prescription lenses:

*“So, for my phone, I got big print on my phone. Big print letters so that I can text somebody. Something bigger than what it would normally be. And I have my magnifying bifocals at the bottom of my glasses...I would say ‘Yes’ as far as the bifocals and, you know, my glasses and everything, big print cell phone. I would say ‘Yes.’”*

However, many gave a ‘No’ response because they understood that the question was intended for those with more serious vision problems:

*“Uh, No. That doesn’t include normal glasses, right?...I don’t feel like it counts those because you said magnifying and that’s the ones that makes your eyes go like boom, big. And then you said cane, and I said nah, I just have normal glasses.”*

One respondent, who answered ‘Yes’ to this question, did so based on his use of an eye loop at his job as a toolmaker and not because he had any vision difficulties.

#### Comprehension of terms used in the question stem

When asked to clarify their understanding of the examples used in the question stem, irrespective of how they answered the question, some respondents did not understand what was meant by ‘telescopic lenses.’ Some thought about ‘large print’ only in terms of physical books or newspapers: *“Yes, if I buy books I try to buy large print books;”* others thought about the use of larger font on smart phones or other electronic devices. Some considered talking books or text to speech when they thought about ‘talking materials,’ while one respondent considered the head set he used for work to hear better on conference calls. One respondent said that she didn’t know what ‘talking materials’ was referring to. Although one respondent understood the meaning of the acronym ‘CCTV’ as Closed-Circuit Television or Video Magnifier for use by the visually impaired, and a few recognized the generic term used for Closed-Circuit Television in a surveillance setting, most believed that the acronym CCTV stood for Closed-Caption Television, *“Closed caption, where you read it,”* or did not know what the acronym stood for.

#### Question 11

**Has a doctor or other health professional ever told you that rehabilitation services and assistive, adaptive, or accessibility devices are available to help with your vision difficulties?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don’t know

#### Frequency distribution (N=30)

Response option	Count
Yes	5
No	25
Refused	0
Don't know	0

As previously discussed, respondents were not always clear on the meaning of ‘rehabilitation services,’ ‘assistive,’ ‘adaptive’ or in this question the additional use of the term ‘accessibility’ devices. As a result of this lack of understanding they found it more difficult to determine the extent or severity of vision difficulties to consider when answering. Indeed, the wording of this question assumes that the respondent has vision difficulties. This assumption, along with the lack of clarity of meaning and a potential question order effect from Question 10, may have influenced a positive response from a few respondents who wore prescription lenses. In the context of the question, most considered an ophthalmologist or optometrist when they thought about a doctor or other health professional.

When formulating their response, respondents first assessed the severity of vision difficulties being asked about and then assessed if their own vision difficulties corresponded. Some determined that the question asked about more severe vision difficulties: *“When I consider vision difficulties I think if it can't be corrected”* and answered ‘No.’ Others determined the question as asking about less severe or potential vision difficulties. As a result, all of those who answered ‘Yes’ to this question did so on the basis that they had regular eye exams with an optometrist or ophthalmologist and had been told they needed prescription lenses or that their vision was being monitored more closely than is usual because of a health condition, such as diabetes. One respondent who answered ‘Yes’ explained that her ophthalmologist had told her to use *“blue lenses”* to protect her eyes when using a computer screen and to use *“special drops for dry-eye.”* A few respondents answered ‘No’ because they could not assign meaning at all: *“I don't know. I don't have slightest clue what they might be talking about.”*

### 4.2.3 Family history of cancer

#### Section introduction

**The next few questions are about your family history of cancer. When answering these questions, only think about relatives who you are related to biologically or by blood but do not include those who you are related to you by marriage.**

#### **Findings**

On first hearing the introduction to this set of questions respondents thought about members of their family to whom they were biologically related and who had had different forms of cancer. One respondent thought about his own cancer diagnosis. Respondents did not include family members to whom they were not biologically related, mostly excluding a spouse, but in one case, a grandparent: *“Just pertaining to only by genetics or biologically related to me pertaining to cancer.”* After hearing



the section introduction, in addition to thinking about parents, siblings, and children, respondents also considered more distant biologically related family members such as grandparents, aunts, uncles, cousins, and in one case great grandparents: “*My parents, my grandparents, my great grandparents, my siblings, my kids, my aunts and uncles, and cousins who are related by blood rather than by marriage. So my mother’s brother, not his wife.*” Some respondents of course did not have children or siblings.

### **Question 12**

**Have any of your biological parents, brothers, sisters, or children ever been diagnosed with cancer, other than skin cancer?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don’t know

*Frequency distribution (N=30)*

Response option	Count
Yes	12
No	17
Refused	0
Don’t know	1

### **Findings**

All 30 respondents were routed to this question. In general respondents considered whether close family members (biological parents, siblings, or children) had ever been diagnosed with cancer, other than skin cancer, when responding ‘Yes’ or ‘No.’ For example, on reaching this question one respondent had wanted to report her aunt’s ovarian cancer because she believed it put her (the respondent) at a higher risk of developing this type of cancer, but did not because of the instructions contained in the question stem. Another respondent answered ‘No’ because his father had been diagnosed with skin cancer and that type of cancer was excluded from the questioning.

### **Relationship to respondent**

Respondents who answered ‘Yes’ reported different types of cancers including breast, lung, ovarian, prostate, stomach, and throat cancer. However, a few answered affirmatively on the basis that more distant family members had been diagnosed with these types of cancers. For example, one respondent answered about a biologically related grandparent and an aunt. It is possible that this broader focus could be, in part, due to the more open nature of the section introduction, such that some respondents were still thinking about more distant family members and were not focused on the additional information now provided in the question stem.

### Knowledge of family members' history with cancer

Many of those who answered 'No' to this question were confident in their response because they explained that cancer did not run in their family: "*No. Me or my family, we have never been diagnosed with cancer.*"; "*Nobody in my family has been diagnosed with that.*"

However, one respondent, who answered 'Yes,' said that she knew that more distant relatives (aunts and uncles) had been diagnosed with cancer but was less sure about her father's lung cancer diagnosis: "*That's the question because my father had a piece of his lung taken for a biopsy for cancer, he never told me if he did or didn't have cancer...so I can't, you know, say.*" Indeed, lack of knowledge as to whether or not close family members had been diagnosed with cancer meant that a few respondents were unsure how to answer. For example, a respondent who answered 'No' said, "*As far as my knowledge I would say No.*" Another answered, "*I think so, I'm not sure*" selecting a 'Don't know' response because he said he knew that his mother had had breast lumps removed but did not know if she had been diagnosed with breast cancer or if the lumps were benign: "*She didn't really discuss it that much, so I don't really know the whole detail.*"

Similar to findings reported by Willson & Schoua-Glusberg (2016),<sup>18</sup> the main reason for lack of knowledge was that intimate health issues were not always discussed in detail among family members. Willson & Schoua-Glusberg also identified lack of knowledge resulting from not knowing all family members, for example, because a respondent was adopted or raised by only one parent not knowing about the other parent's history. Among respondents in this study, one mentioned that he was estranged from siblings and therefore lacked knowledge. This study also highlighted lack of knowledge related to the age of the respondent when a family member was diagnosed. That is, as a child, the respondent was not fully informed. One respondent changed his answer from 'No' to 'Yes' because he had forgotten that his sister had cancer which was now in remission: "*Oh wait! I take that back. I did have a sister who had ovarian cancer. And she got over it I think. She got over it as far as I know – she's fine now.*"

### Question 13

**Have you ever talked with your doctor or health care provider about what your family history of cancer might mean for your own health and cancer risk?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

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<sup>18</sup> Willson, S., Schoua-Glusberg, A. (2016). Cognitive Interviewing Evaluation of the Pregnancy Risk Assessment Monitoring System (PRAMS) Phase 8 Supplemental Questions. National Center for Health Statistics. Hyattsville, MD. <https://www.cdc.gov/qbank/report.aspx?1161>



*Frequency distribution (N=30)*

Response option	Count
Yes	12
No	17
Refused	0
Don't know	1

**Changes to the question order between rounds**

Following Round 1 this question was moved from after Question 14 to be asked after question 12. Although there was no direct evidence that respondents were influenced by Question 14 during Round 1 testing, there was some concern from sponsors that a potential order effect could mean that respondents might only answer in relation to breast cancer, which is the focus of Question 14, rather than more broadly about all types of cancer, other than skin cancer.

**Findings**

Potential question order effect

The definition of ‘family’ applied by respondents when answering this question differed. Some applied the definition provided previously in Question 12. That is, they understood that they should only answer ‘Yes’ to this question if their conversations with a medical practitioner related to a close family member i.e., parents, siblings, or children. A few therefore excluded discussion with their doctor that came about because of a more distant family member’s experience with cancer, such as a grandparent. Others answered more broadly and included conversations in relation to more distant relatives, including grandparents, aunts, or cousins:

*“...when the doctor see’s you the first time, they’ll ask your family history and I always bring up my aunt. It started with cancer. I think it was ovaries and then her whole body was ravished by the end of it.”*

Respondents did not appear to carry over the instruction from Question 12 to exclude skin cancer. Two respondents answered ‘Yes’ to this question in relation to a family member who had had skin cancer. Both referred to receiving regular skin checks from a dermatologist.

Family history of cancer

It should be noted that the question text assumes that the respondent has a family history of cancer. Of those who said that they had ever talked with their doctor or health care provider about their family history of cancer, some reported a family history of cancer to the interviewer, while others had no family history of cancer. For example, some female respondents reported talking to their doctor about the importance of their annual mammograms because of a family history of breast cancer (including more distant family members) and in a few cases respondents had started receiving their mammograms earlier

than is usual because of it. However, one respondent answered ‘Yes’ since her OB-GYN conducted routine cancer screening as part of her well-woman visits. This respondent did not report a family history of cancer when asked by the interviewer:

*“Have I? I think when I went to my...feminine doctor. I talked to her and I asked her if she is taking cultures and samples for cancer and she says yes. So by the grace of god, so far, I’m good. So I have talked to my doctor about the cancer, yes.”*

One respondent answered ‘Yes’ because he had been concerned about his own health following a friend’s cancer diagnosis, even though he himself had no family history of cancer:

*“My best friend was diagnosed with cancer, so that’s what made me have the conversation with my doctor. The doctor was like, my family don’t have a history of it, usually people that have cancer, have a history of cancer in their family.”*

Most who answered ‘No’ to this question reported no family history of cancer. *“No I’ve never talked to my doctor anything about any cancer. It’s not really relatable to me, so we don’t really talk about that.”*

#### Lack of knowledge of family members’ history with cancer

Lack of knowledge about other family members’ history with cancer, both close and distant members, played an important role in some respondents selecting a ‘No’ response (see also discussion at Question 12). For example, one respondent said that he had “*probably*” been asked by his doctor, but the discussion did not go further because he, the respondent, didn’t know of anyone. One respondent answered ‘Don’t know’ because he understood that the question was asking about his knowledge of his family history of cancer as it related to all his family members. He could only answer about his father who had had prostate cancer: *“I could give no answer about that one because I can only speak for myself and my father.”*

#### Type of encounter with doctor

All of those who answered ‘Yes’ to this question reported having talked to their doctor face-to-face. Some of those who answered ‘No’ mentioned completing an intake form when visiting their doctor which asked about their family history of cancer, *“So I’ve filled out those forms”* but since they had no family history of cancer the topic had not been discussed in-person with the doctor. A few male respondents had reported a family history of breast cancer on their intake form which had not been followed up by their doctor during any discussions.

## **Question 14**

**Have your biological parents, brothers, sisters, or children, ever been diagnosed with breast cancer?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*Frequency distribution (N=30)*

Response option	Count
Yes	4
No	25
Refused	0
Don't know	1

### **Changes to the question order between rounds**

The order in which this question was asked changed between rounds. This was due to sponsor concerns about the influence this question might have on answers to Question 13, if asked prior (although there was no direct evidence of this type of order effect from Round 1 data).

### **Findings**

All four respondents who answered 'Yes' to this question answered about a close blood relative i.e., mother or sister.

Most of those who answered 'No' also answered on the basis that they: i) had no family history of cancer of any type, "*Cancer doesn't run in our family. Thank god we never had any one to be diagnosed with cancer;*" ii) there was no family history of breast cancer specifically, "*No my father had prostate cancer, that's it*"; or, iii) that those family members who had been diagnosed with breast cancer were more distant relatives or not biologically related and therefore would not be counted according to the question definition, "*No, a grandparent, yes;*" "*My...wife did, but that didn't count.*" However, as discussed previously, respondents answered as best they could, given their knowledge of a family history of cancer. For example, as mentioned at Question 12, one respondent was "*...not sure*" if his mother had been diagnosed with breast cancer. Another respondent who answered 'No' was also not sure whether a close relative had breast cancer, although he knew she had breast surgery. One other respondent who answered 'No' did so to the best of his knowledge explaining that he was estranged from his siblings: "*Not that I know of...I'm not likely to be the first one to hear.*"

## **Question 15**

*(Ask if Q14 = Yes)*

**How many of your biological parents, brothers, sisters, or children have been diagnosed with breast cancer?**

\_\_\_\_\_ number diagnosed

*Frequency distribution (N=4)*

Response option	Count
One family member	2
Two family members	2
Refused	0
Don't know	0

### **Findings**

Of the four respondents who reported that a close family member had been diagnosed with breast cancer, all four were able to easily provide a number: *“Just one, my mom”*; *“Two of my sisters had breast cancer.”*

## **4.2.4 Difficulty paying for health care**

There was no evidence from this evaluation that respondents did not know if other members of their family unit had difficulty paying medical bills. Indeed, some said they were very confident in their responses because their family were open about these types of issues and would help each other in financial difficulty. Those who were unsure were those who referred to the medical bills of family members who did not live with them.

All respondents had some form of health cover coverage to include coverage through an employer as well as government or state funded (to include Medicare, military coverage, or Medicaid). No one was without health coverage at the time of interview.

### **Section Introduction**

**Now I am going to ask you about your medical bills. Include bills for doctors, dentists, hospitals, therapists, medication, equipment, and nursing home or home care.**

### **Findings**

On hearing this introduction respondents said that they understood that the next set of questions would be about any medical expenses they had incurred, to include any *“out-of-pocket expenses”* not covered by health insurance, including co-pays. Consistent with the instruction, different respondents said they thought of doctor and hospital bills, dental bills, the cost of laboratory tests, X-Rays, MRIs and prescription medication, along with in-home care. One respondent mentioned allergy testing. When

prompted “*mental health or rehabilitation therapists after any surgery*” were also mentioned. The list of examples provided was therefore important in prompting respondents to consider ongoing treatments or outstanding bills across a variety of medical providers or procedures.

Respondents framed their responses to Question 16 to 18 by providing examples of what their health insurance covered and did not cover. One respondent reacted to the introduction unprompted by the interviewer, “*I have Medicaid. My Medicaid pretty much takes care of my doctor expenses.*”

### **Question 16**

**In the past 12 months, did (you/anyone in your family) have problems paying or were unable to pay any medical bill?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*Frequency distribution (N=30)*

Response option	Count
Yes	5
No	25
Refused	0
Don't know	0

### **Findings**

Consistent with findings described by Scanlon (2014),<sup>19</sup> core to the way in which respondents answered this question was their interpretation of the phrase ‘problems paying.’

#### Problems paying

Those who answered ‘Yes’ reported different reasons for having problems paying medical bills, including not having the money to pay at all or in full, such that a few respondents reported making payments, or that they were in dispute over a bill they had received.

Most of those who answered ‘No’ cited having health insurance as the reason why they did not have problems paying medical bills: “*No, I have insurance;*” “*No, because the plan that I’m in...they pay;*” “*No because I didn’t have no problem because Medicaid is taking care of my bills. So I didn’t have no problems.*” Some cited familial financial support, as the reason for not having problems paying medical bills: “*...my sister pays them.*” A few had overcome their difficulties. As one respondent explained, *I had some trouble, but I got it paid... Oh well it got paid. It wasn’t easy. That’s kind of a trick question*

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<sup>19</sup> Scanlon, P. (2014). The National Health Interview Survey’s Family Health Insurance Section and Proposed Affordable Care Act-Related Questions: 2014 Cognitive Interviewing Results. National Center for Health Statistics. Hyattsville, MD. <https://www.cdc.gov/QBank/Report.aspx?1140>

there.” One respondent, who received a large medical bill that was not covered by his insurance, simply had the resources to pay it.

Respondents thought only of medical bills they had actually incurred and not about expenses they had avoided. For example, a couple of respondents answered ‘No’ to this question but explained later during the interview that they could not afford to pay for prescription medication and had skipped medication doses, or avoided filling a prescription to save money.

### Definition of ‘family’

Where more than one adult lived in the household respondents were asked this question about all family members ‘anyone in your family.’ A definition of ‘family’ was not provided for respondents taking part in the cognitive interviews. As a result, some respondents thought of their biological family members rather than the family members with whom they lived. This may likely be a question order effect from the previous set of questions about a family medical history of cancer where a definition of ‘family’ as ‘biological parents, brothers, sisters or children,’ was provided. Some respondents thought about their immediate family members as described, even where they did not live in the same household; others also considered more distant family members such as aunts, uncles, and cousins. Respondents did not always know whether family members who did not live with them had problems paying any medical bills. Other respondents thought about household members who lived with them. These respondents had greater confidence in their answers stating knowledge of other household members’ health insurance coverage or that there was open communication about financial matters between household members who were related. In one case a respondent included her adult child who did not live with her because this child was still on the respondent’s health insurance plan.

### **Question 17**

**(Do you/Does anyone in your family) currently have any medical bills that you are unable to pay at all?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don’t know

*Frequency distribution (N=30)*

Response option	Count
Yes	6
No	24
Refused	0
Don’t know	0



## Findings

### Comprehension of the phrase ‘unable to pay at all’

Most respondents interpreted ‘unable to pay at all’ to mean not having the financial means, nor insurance, nor familial support to make a single payment on their medical bills. This was not the case where respondents were making payments. Of the two respondents who answered ‘Yes’ to the previous Question 16 and said that they were making payments on outstanding medical bills, one answered ‘No’ to this question, because although he was having problems it wasn’t that he was unable to pay at all: *“I would have to say ‘No’ because I am paying them. It’s rough, but it’s manageable, I am paying them.”* The other answered ‘Yes’ to this question currently but he was *“Starting to nip away at it...Right now the answer would be a ‘Yes.’”* One respondent, who answered ‘Yes’ to this question, counted a waived bill as a medical bill she was unable to pay.

### Focus of question

Similar to Question 16, some respondents considered their other household members when answering this question, while others thought about their biological family, irrespective of whether they lived with them in the same household (a possible question order effect from the previous questions set where a definition of ‘family’ was provided as ‘biological parents, brothers, sisters or children’).

Interestingly, more than one respondent, who also considered other people in their ‘family’ when answering the previous Question 16, answered only about themselves in response to this question. This may be because of the way in which the question is phrased, ‘Does anyone in your family currently have any medical bills that you are unable to pay at all?’ For example, one respondent who lived with a housemate and received the question with ‘anyone in your family’ thought of his estranged family when answering Question 16 (‘No’) but thought about only himself when answering Question 17 (‘No’).

## Question 18

**If you get sick or have an accident, how worried are you that you will be able to pay your medical bills? Are you very worried, somewhat worried, or not at all worried?**

- 1 Very worried
- 2 Somewhat worried
- 3 No at all worried
  
- 7 Refused
- 9 Don’t know

### *Frequency distribution (N=30)*

Response option	Count
Very worried	3
Somewhat worried	12
Not at all worried	15
Refused	0
Don’t know	0

## Findings

### Question comprehension

When respondents thought about getting sick or having an accident, they tended to think about more serious, or even “*catastrophic*,” situations involving hospitalization, such as catching COVID-19, being diagnosed with cancer, or being injured in accident, that would cause prolonged loss of work and income.

### Question response

The basis on which respondents answered this question varied.

Some respondents answered ‘Not at all worried’ based on the fact that they had good health insurance coverage: “*Not at all. That is one problem I don’t have to worry about.*”

Some based their response taking into account the high cost of healthcare in general. They answered ‘Somewhat worried’ because although they did not currently have problems paying medical bills, the future is unpredictable and medical expenses can become unmanageable even with health insurance. A respondent who answered ‘Somewhat worried’ explained, “*It adds up, you know, you never know if you have an emergency, something happens, you end up in the hospital, god forbid you get COVID or whatnot. It gets very expensive.*”

Some respondents’ answers were based on past experience with their health insurers. For example, one respondent answered ‘Not at all worried’ citing past experience where all his surgical costs and associated medical expenses had been paid by his health insurance. Another respondent had received an unexpectedly high medical bill following a routine procedure. The anesthetist used was out of network and he had not been informed of the additional charge. He was somewhat worried that something similar could happen again in the future: “*The fact that we had a big surprise that happened I guess that makes us nervous.*” One respondent answered ‘Very worried’ because he also had a negative past experience when his health insurance had not covered all of his medical bills.

A few answered the way that they did because they were not confident in their public health coverage due to lack of knowledge about what was covered:

*“I guess it’s mostly because I don’t know exactly what’s covered. We’re on Medicaid, and I know it covers what you need. But I know there are some [medical] areas when they [the insurance co] dispute, and you might have to pay out of pocket.”* [Somewhat worried]

*“Somewhat worried, I can’t guarantee I’ll get great treatment on Medicaid.”*

On the other hand, a few said they were not at all worried because they had Medicaid coverage: “*I’m not that worried because I know they taking care of my bills.*”



A few worried about losing their jobs and therefore losing their health insurance: *“Maybe somewhat worried. Basically I have health insurance, and so long as I’m working, I have health insurance.”*

A few respondent answers of ‘Not at all worried’ were influenced by their personal approach to life. For example, one respondent answered ‘Not at all worried’ because even if she were faced with medical bills that she could not pay, she would not *“go crazy”* because she couldn’t pay them. Similarly, another respondent answered, ‘Somewhat worried:’ *“To be honest with you, a person like me if I have a chronic illness, the last thing I’ll worry about is the bill.”*

One respondent misunderstood the question initially and answered ‘Very worried’ because he was worried about the increase in his car insurance premiums following a car accident in which he had not been injured.

#### Focus of question

Most answered about themselves, although on hearing the question one respondent queried, *“Myself? For me?”* However, a few answered about other members of their household for which they were responsible. For example, one respondent answered ‘Somewhat worried’ thinking about paying medical bills for his wife, children, and parent, all who lived with him:

*“I’m somewhat worried... You know smaller bills, a thousand here a thousand there, you know I can pay ‘em but once you add up 5 people if we all have thousand-dollar bills that really starts to eat into our basically into our savings you know and god forbid anything worse than that happens to any one of us, um you know...”*

## 4.2.5 Prescription medication

### Section Introduction

**The next set of questions are about prescription medication.**

#### **Findings**

Respondents understood ‘prescription medication’ to mean medication that is prescribed by a licensed medical professional that cannot be obtained over the counter (OTC):<sup>20</sup> *“Medication I can’t buy off the shelf for which I need a prescription from a doctor or maybe a nurse practitioner, somebody qualified to prescribe the medicine.”* Examples provided by respondents included prescription medication for high blood pressure, thyroid disease, prescription pain medication, antibiotics, and birth control. Respondents carried this definition through Questions 19 to 23.

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<sup>20</sup> [Over-the-Counter Medicines DrugFacts | National Institute on Drug Abuse \(NIDA\) \(nih.gov\)](#)

## **Question 19**

**At any time in the past 12 months, did you take prescription medication?**

1 Yes

2 No – Go to Q23

7 Refused - Go to Q23

9 Don't know - Go to Q23

*Frequency distribution (N=30)*

Response option	Count
Yes	23
No	7
Refused	0
Don't know	0

### **Findings**

Most respondents understood this question to be asking about all medication prescribed to them by a licensed medical professional within the past year. Similar to findings reported by Scanlon (2020),<sup>21</sup> a possible order effect may have led to a false negative response for one respondent.

Most considered the past 12-month reference period from date of interview to date of interview in the previous year. One respondent thought about an 18-month period to include the previous calendar year to date of interview.

Respondents who answered 'Yes' to this question included those who had taken prescription medication throughout the reference period, as well as those who had taken one-time prescription medication at some point during the reference period.

Respondents who answered 'No' to this question had not taken prescription medication during the reference period. They were confident in their answers because, for example, one respondent said that he never took any kind of medication, another because the last time he was prescribed medication was for a pulled muscle and he was certain that it was over a year ago. However, a couple of respondents answered 'No' because, although they had been prescribed medication, they could not afford the cost of filling the prescription; one respondent because she said she did not have health insurance. One respondent answered 'No' because she thought that the question was only asking about prescription medication for more serious health problems citing vision problems or cancer treatment asked about in previous questions. Although her prescription was for pain relief she took it as needed, for what she considered more minor issues:

*"It's a prescription. The doctor's will call it into the pharmacy and you pick it up from the pharmacy...it's a medication that the doctor will provide you for pain or a tooth ache and stuff like*

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<sup>21</sup> Scanlon, P. (2020). Cognitive Evaluation of the National Center for Health Statistics' 2018 Research and Development Survey. National Center for Health Statistics. Hyattsville, MD <https://wwwn.cdc.gov/QBank/Report.aspx?1203>

*that, it's just a medication like that. So it's not nothing that I have to take for cancer or eye vision and stuff, you know. It ain't nothing that can keep my vision that I have to take. It's nothing like that...So it is not as serious - Right."*

## **Question 20**

*(Ask if Q19 = Yes)*

**During the past 12 months, were any of the following true for you? ...You skipped medication doses to save money.**

1 Yes

2 No

7 Refused

9 Don't know

*Frequency distribution (N=23)*

Response option	Count
Yes	1
No	21
Refused	0
Don't know	0
Not asked	1

## **Findings**

Respondents understood this question to be asking if, in the past 12 months, they had stretched their prescription medication supply by taking fewer doses than prescribed due to cost:

*"Uh, it just means you're not going to take it a day or two because like you said, you want to save money. Maybe your tight budget, you figure oh I don't need to take these today, I'll just kind of skip so they'll stretch out a little bit until I get my next check."*

The term 'medication' used in the question stem was understood to be referring to 'prescription medication' (definition described in section introduction above.)

Most answered 'No' to this question citing their health insurance as the reason why they did not have an issue with paying for their medication and therefore, had not skipped medication doses.

One respondent answered 'Yes' to this question as well as to Question 21 (took less medication), Question 22 (delayed filling a prescription), and Question 23 (did not get medication) because she was only receiving half of her prescribed doses due to billing issues with her medical insurance.

## **Question 21**

*(Ask if Q19 = Yes)*

*Read if necessary:* During the past 12 months, were any of the following true for you?...

**You TOOK LESS medication to save money.**

1 Yes

2 No

7 Refused

9 Don't know

*Frequency distribution (N=23)*

Response option	Count
Yes	1
No	21
Refused	0
Don't know	0
Not asked	1

### **Findings**

Twenty-three respondents were routed to this question. In general, respondents understood this question to be asking if they had, in the past 12 months, taken a smaller dose or fewer doses of prescribed medication due to cost.

The term 'medication' used in the question stem was understood to be referring to 'prescription medication' (definition described in section introduction above.)

Although some noted a distinction between Question 20 and Question 21 whereby 'skipping' meant missing doses of a medication entirely and 'taking less' meant taking a smaller dose (e.g., cutting a pill in half), others considered the meaning the same:

*"Less medication? That would kind of be the same thing [as skipping medication], like maybe you have to take 2 of the pills and you take 1 a day instead of 2. Cutting back on your dosage."*

*"That's again, the same thing [as Question 20]."*

As with Question 20, almost all those who answered 'No' referenced their health insurance as the reason why they did not have difficulty paying for their prescription medication. For example, one respondent answered, *"No, I have insurance, so these things, I don't have an issue with."* Another explained, *"I've taken less supplements to save money, yeah, because those are all out of pocket. My medications are covered, so I haven't, I generally haven't skipped so much on those."*

There was one possible false negative response to this question. One respondent had to pay a portion of the cost for her prescription pain medication and the burden of this cost caused her to take less of the

pain medication. She answered ‘No’ and explained, *“If I could tolerate it I didn’t bother with it to save it because insurance didn’t pay for the whole thing.”*

One respondent answered ‘Yes’ to this question because she was only receiving half of her prescribed doses due to billing issues with her medical insurance.

## **Question 22**

*(Ask if Q19 = Yes)*

*Read if necessary:* During the past 12 months, were any of the following true for you?...

**You DELAYED filling a prescription to save money.**

1 Yes

2 No

7 Refused

9 Don’t know

*Frequency distribution (N=23)*

Response option	Count
Yes	2
No	20
Refused	0
Don’t know	0
Not asked	1

## **Findings**

Of the 23 respondents routed to this question, almost all understood this question to mean putting off or waiting to fill a prescription due to financial constraints. For example, one respondent explained, *“Maybe you’re supposed to pick up your prescription every month, but you wait a little bit, maybe a week or so until you get more money. Get your paycheck, your funds together.”*

Two respondents answered ‘Yes’ to this question. One, discussed earlier, because she was only receiving half of her prescribed doses due to billing issues with her medical insurance. The other because he had delayed buying over the counter supplements that were recommended by his doctor. *“The supplements, yup.”* However, this response may have been influenced by concurrent probing administered during the cognitive interview. This respondent previously did not include the over-the-counter supplements when answering ‘No’ to previous questions in this set.

Similar to the previous questions in this set, many respondents who answered ‘No’ credited their health insurance for covering medication costs: *“No I have pretty good insurance. The co-pay is pretty reasonable usually.”*

A few did not see a difference between this and previous questioning on the same topic: As one respondent explained, “*Same thing [as question 20 and question 21]. Maybe you’re supposed to pick up your prescription every month, but you wait a little bit, maybe a week or so until you get more money. Get your paycheck, your funds together.*”

**Question 23**

*Ask all*

**During the past 12 months, was there any time when you needed prescription medication, but DID NOT GET IT because of the cost?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don’t know

*Frequency distribution (N=30)*

Response option	Count
Yes	4
No	22
Refused	0
Don’t know	0
Not asked	4

**Findings**

Some respondents understood this question as having the same intent as Question 22 ‘delaying filling a prescription:’ “*To me no, it’s no difference. If you’re not gonna’ get the prescription that’s delaying the prescription;*” “*No, because they are covered. If they weren’t covered, then I could not afford them.*” Others interpreted these questions differently explaining that ‘did not get it’ means that you do not have the medication at all and ‘delayed filling a prescription’ means that you may get it in the future. Those who answered ‘No’ to this question cited their health insurance coverage as the reason why they had been able to afford their prescription medication: “*No, there hasn’t been no medication that I needed that I couldn’t get because I’m covered with Medicaid. And if I needed any medication, it would cover it.*” Others did not have a need to take prescription medication in the past 12 months.

Respondents who answered ‘Yes’ described situations where they could not afford to get their prescription medication. In one instance this was because the respondent had been without health insurance.

*“So, I didn’t have insurance for about a year and half because my dad lost his job and then got a new one. It was a little hectic. So, out of pocket, the medication I was on was just way too much money.”*



## 4.2.6 Health care utilization

The next set of questions are about health care

### Question 24

**During the past 12 months, did you receive care at home from a nurse or other health professional?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*Frequency distribution (N=30)*

Response option	Count
Yes	1
No	27
Refused	0
Don't know	0
Not asked	2

### **Findings**

Respondents understood this question as asking about home visits from a certified nurse or other type of health care professional, such as physical therapist or home help, occurring within the past 12 months.

Only one respondent said that in the past 12 months she had received one visit from a nurse at home to measure her weight and blood pressure. However, it should be noted that another respondent did not include a home health check he had received from a nurse when his health insurance provider changed because, *"It was more of an assessment."*

Everyone else who was asked this question answered 'No,' but demonstrated a good understanding of what 'receiving care at home from a nurse or other health care professional' could mean. Some had received home care themselves in the past, just not in the past 12 months. For example, a respondent described receiving home care for a few weeks after surgery. Some described relatives or friends who had received such care, again post-surgery (including wound dressing or physical therapy) on a short-term basis for a few weeks, or longer term to help with activities of daily living, such as bathing. Younger respondents in particular (under age 35) referenced grandparents who had received home help with bathing etc. or had received palliative care at home. Indeed, one respondent was herself a Certified Nursing Assistant who carried out such duties.

## **Question 25**

**During the past 12 months, how many times have you gone to a hospital emergency room about your health?**

*Read if necessary:* This includes emergency room visits that resulted in a hospital admission.

\_\_\_\_\_NUMBER OF TIMES

*Frequency distribution (N=30)*

Response option	Count
0 times	19
1 time	5
2 times	3
3 times	1
4 times	1
Refused	0
Don't know	0
Not asked	1

### **Findings**

Most respondents understood this question as asking if they had gone to an Emergency Room (ER) about their own health (not accompanying another person) within the past 12 months. However, a few included visits to an urgent care facility when responding. There was some evidence of a respondent thinking beyond the reference period (also referred to as ‘telescoping’). One of the ER visits made resulted in a hospital admission.

Most had not gone to an ER about their health within the past 12 months. They answered “Zero,” “None,” or “Never.” Ten respondents reported visits to the ER during the past 12 months because of: cuts; wrist, arm and knee injuries; eye, headache, stomach and arthritis pain; panic attack; heat stroke, and to get a COVID-19 test. A few respondents included visits to Urgent Care. Indeed, one respondent included her urgent care visit prior to being sent to the ER for the same medical emergency answering, “Um, twice.” Others did not include urgent care visits in their response even though they had been to Urgent Care within the 12-month reference period. One respondent asked the interviewer for clarification: “Not urgent care, but emergency room, right?”

Although the majority of those who had been to an ER outside of the 12-month reference period did not report these visits, one respondent reported an ER visit that occurred during 2020:

*“Yes, one time because during COVID I had a panic attack and that’s when it first came out and I was scared because they kept talking about it, so I had a panic attack....so I went to the hospital, she told me to just calm down.”*



### **Question 26**

**During the past 12 months, have you been hospitalized overnight? Do not include an overnight stay in the emergency room.**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*Frequency distribution (N=30)*

Response option	Count
Yes	1
No	28
Refused	0
Don't know	0
Not asked	1

### **Findings**

Respondents understood this question as asking if they had been admitted to hospital as an in-patient and stayed throughout the night for at least one night.

Only one respondent answered 'Yes' to this question. He had been admitted to hospital directly from an Emergency Room and had stayed as an inpatient for five subsequent nights. Everyone else who was asked this question answered 'No.' Correctly, those who had stayed overnight in the Emergency Room during the past 12 months did not count that stay when answering.

## **4.2.7 Schooling**

### **Question 27**

**Are you currently enrolled in or attending school?**

*Read if necessary:* School includes high school, college, trade school, and professional school. Students may be enrolled part-time or full-time.

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*Frequency distribution (N=30)*

Response option	Count
Yes	3
No	27
Refused	0
Don't know	0

**Findings**

Three respondents said that they were currently enrolled in or attending school, either in undergraduate or graduate studies at a university. All three were under the age of 30. One described attending part-time; the others attended full-time. All attended school virtually, online. However, one respondent in his 40s who answered 'No' to this question did not include his online college classes: "...but mine is just online."

The schooling questions were the last to be administered during the cognitive interview. Where time allowed, those who said that they were not currently enrolled in or attending school were also asked about their understanding of the question intent. Most understood the question to be asking about enrollment in formal academic studies at a university or college, either online or in-person, full-time or part-time. A few mentioned certified workforce training programs that they had undertaken in the past but were not sure if this type of training would be considered as 'attending school' because they had also been working full-time, albeit their employer allowed them to undertake the training during work hours.

**Question 28**

*(Ask if Q27 = Yes)*

**During the past 12 months, about how many days of school did you miss because you had an illness, injury, or disability?**

\_\_\_\_\_ NUMBER OF DAYS MISSED

*Frequency distribution (N=3)*

Response option	Count
0	0
1 day	2
>1 day	1
Refused	0
Don't know	0

**Findings**

All three respondents routed to this question were undertaking their studies virtually. All three answered that they had missed school days in the past 12 months due to illness, injury, or

disability. However, this did not necessarily correlate with missing a full day of study, or any learning at all.

Two respondents answered that in the past 12 months they had missed one day of school. One respondent had missed a class because she was unwell and had gone to Urgent Care. She remembered this clearly because, as she said, *“I was freaking out because I was like, ‘I need a doctor’s note.’”* The other respondent answered in error. He had missed a class because he had thought that it was optional and not because of ill health. The third respondent regularly missed school days because of a chronic medical condition. She estimated that she was unable to attend school for 2 or 3 days per week throughout the school year. However, she explained that because she studied online and was able to work at her own pace, there were no actual lectures or deadlines missed:

*“I’m thinking at least... because I have online school, so I didn’t technically miss attendance. But I didn’t technically do anything for school for a day. So, I did that like at least two or three days a week for the whole year. And a [name of school] year is like 8 months-ish.”*

One more respondent had likely answered the previous question incorrectly, saying ‘No’ when he was undertaking online study. The cognitive interviewer administered this question to that respondent who also described being able to do his work online at any time and therefore would not have technically missed any schooling if he had been sick.

## Appendix 1: Round 2 Questionnaire

This first question asks about your hearing.

*(Ask All)*

**Q1. Without the use of hearing aids or other listening devices, is your hearing excellent, good, a little trouble hearing, moderate trouble, a lot of trouble, or are you deaf?**

- 1 Excellent
- 2 Good
- 3 A little trouble hearing
- 4 Moderate trouble
- 5 A lot of trouble
- 6 Deaf
  
- 7 Refused
- 9 Don't know

The next set of questions ask about your exposure to chemicals and tobacco smoke in your job.

*(Ask All)*

**Q2. During the past 12 months, did you work in a job where you were exposed to any of the following: solvents, industrial glues, heavy metals, pesticides, or motor engine exhaust?**

*Read if necessary:* Solvents are liquids, not including water, used for dissolving other substances, such as dry-cleaning fluids, thinners, components of paints, industrial cleaners and paint removers. Industrial glues are adhesives that include acrylic, epoxy, hot melt, polyurethane, silicone, thermoset and industrial sealants. Heavy metals include lead, nickel, mercury, cadmium, arsenic, chromium, zinc and copper.

- 1 Yes
- 2 No
  
- 7 Refused
- 9 Don't know

*(Ask if Q2 = Yes)*

**Q3. Were you exposed for 4 or more hours a week?**

- 1 Yes
- 2 No
  
- 7 Refused
- 9 Don't know

*(Ask All)*

**Q4. During the past 12 months, did you work in a job where you were exposed for 4 or more hours a week to tobacco smoke from other people?**

*Read if necessary:* Tobacco smoke includes from cigarettes, cigars, pipes, cigarillos, and hookahs. Do not include e-cigarettes or vaping devices that do not contain tobacco.

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

**These next questions ask about exposure to loud sounds or noise while working. Loud means so loud that you must speak in a raised voice to be heard.**

*(Ask All)*

**Q5. Have you ever had a job, or combination of jobs, where you were exposed to loud sounds or noise for 4 or more hours a day, several days a week?**

*Read if necessary:* Loud means so loud that you must speak in a raised voice to be heard.

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask if Q5 = Yes)*

**Q6. In your lifetime, how many years have you had a job, or combination of jobs, where you were exposed to loud sounds or noise for 4 or more hours a day, several days a week?**

*Read if necessary:* Loud means so loud that you must speak in a raised voice to be heard.

- 1 Less than 1 year
- 2 1 to 2 years
- 3 3 to 4 years
- 4 5 to 9 years
- 5 10 years or longer
- 7 Refused
- 9 Don't know

*(Ask if Q5 = Yes)*

**Q7. During the past 12 months, have you had a job, or combination of jobs, where you were exposed to LOUD sounds or noise for 4 or more hours a day, several days a week?**

*Read if necessary:* Loud means so loud that you must speak in a raised voice to be heard.

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask if Q5 = Yes)*

**Q8. During the past 12 months, how often did you wear hearing protection, such as ear plugs or ear muffs when exposed to LOUD sounds or noise at work? Would you say...**

- 1 Always
- 2 Usually
- 3 About half the time
- 4 Seldom
- 5 Never
- 7 Refused
- 9 Don't know

**The next set of questions are about services or devices that you may have used to help with your vision.**

*(Ask All)*

**Q9. Do you use any vision rehabilitation services, such as job training, counseling, or training in daily living skills and mobility?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask All)*

**Q10. Do you use any assistive or adaptive devices such as telescopic or other prescriptive lenses, magnifiers, large print or talking materials, CCTV, white cane, or guide dog?**

- 1 Yes
- 2 No
- 7 Refused
- 7 Don't know

*(Ask All)*

**Q11. Has a doctor or other health professional ever told you that rehabilitation services and assistive, adaptive, or accessibility devices are available to help with your vision difficulties?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

**The next few questions are about your family history of cancer. When answering these questions, only think about relatives who you are related to biologically or by blood but do not include those who you are related to you by marriage.**

*(Ask All)*

**Q12. Have any of your biological parents, brothers, sisters, or children ever been diagnosed with cancer, other than skin cancer?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask All)*

**Q13. Have you ever talked with your doctor or health care provider about what your family history of cancer might mean for your own health and cancer risk?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask All)*

**Q14. Have your biological parents, brothers, sisters, or children, ever been diagnosed with breast cancer?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask if Q14 = Yes)*

**Q15. How many of your biological parents, brothers, sisters, or children have been diagnosed with breast cancer?**

\_\_\_\_\_ number diagnosed

**Now I am going to ask you about your medical bills. Include bills for doctors, dentists, hospitals, therapists, medication, equipment, and nursing home or home care.**

*(Ask All)*

**Q16. In the past 12 months, did (you/anyone in your family) have problems paying or were unable to pay any medical bill?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask All)*

**Q17. (Do you/Does anyone in your family) currently have any medical bills that you are unable to pay at all?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask All)*

**Q18. If you get sick or have an accident, how worried are you that you will be able to pay your medical bills? Are you very worried, somewhat worried, or not at all worried?**

- 1 Very worried
- 2 Somewhat worried
- 3 No at all worried
- 7 Refused
- 9 Don't know

**The next set of questions are about prescription medication.**

*(Ask All)*

**Q19. At any time in the past 12 months, did you take prescription medication?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know



*(Ask if Q19 = Yes)*

**Q20. During the past 12 months, were any of the following true for you? ...You skipped medication doses to save money.**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask if Q19 = Yes)*

**Q21. *Read if necessary:* During the past 12 months, were any of the following true for you?... You TOOK LESS medication to save money.**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask if Q19 = Yes)*

**Q22. *Read if necessary:* During the past 12 months, were any of the following true for you?... You DELAYED filling a prescription to save money.**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask All)*

**Q23. During the past 12 months, was there any time when you needed prescription medication, but DID NOT GET IT because of the cost?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

The next set of questions are about health care

*(Ask All)*

**Q24. During the past 12 months, did you receive care at home from a nurse or other health professional?**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask All)*

**Q25. During the past 12 months, how many times have you gone to a hospital emergency room about your health?**

*Read if necessary:* This includes emergency room visits that resulted in a hospital admission.

\_\_\_\_\_ NUMBER OF TIMES

*(Ask All)*

**Q26. During the past 12 months, have you been hospitalized overnight? Do not include an overnight stay in the emergency room.**

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask All)*

**Q27. Are you currently enrolled in or attending school?**

*Read if necessary:* School includes high school, college, trade school, and professional school. Students may be enrolled part-time or full-time.

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

*(Ask if Q27 = Yes)*

**Q28. During the past 12 months, about how many days of school did you miss because you had an illness, injury, or disability?**

\_\_\_\_\_ NUMBER OF DAYS MISSED