

Cognitive Testing Evaluation of Survey Questions on COVID-19

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Introduction

This report documents findings from a cognitive interview evaluation of survey questions on the topic of coronavirus disease 2019 (COVID-19). The Collaborating Center for Question Design and Evaluation Research (CCQDER) at the National Center for Health Statistics (NCHS) conducted this study in support of federal surveys that have incorporated (or intend to incorporate) COVID-19 measurements into their questionnaires. The questions evaluated include items on the RANDS during COVID-19 survey (a methodological survey housed at NCHS) and other federal surveys, such as the NHIS (National Health Interview Survey) and the ECHO (Environmental Influences on Child Health Outcomes) adult primary questionnaire, a project supported by the National Institutes of Health.

The findings of this study serve two purposes. First, the results serve as a validity study for COVID-19 questions, so that survey data analysts can understand what constructs the questions capture. As a validity study, the cognitive interviews provide information about the patterns of interpretation associated with these survey questions.

Second, this study explored the question-response process which identified problems respondents had in answering the questions and, by extension, possible sources of response error. Information from these findings may be used to improve question design for future surveys.

The next section describes the methodology of the study and is followed by an overview of key findings. The last section documents findings for each individual question.

Method

Cognitive Interviewing: The aim of this cognitive interview study was to explore the ways in which respondents interpreted each question and how they formulated a response based on that interpretation. As a qualitative method, data produced from the cognitive interviews provide in-depth understandings of the ways in which the questions operate and the kind of phenomena they capture.

A total of 50 cognitive interviews were conducted in English between September and November of 2020. Interviews were not longer than one hour in length and were conducted by trained qualitative interviewers. Due to social distancing requirements of the pandemic, all interviews were conducted virtually, via the Zoom internet meeting platform. Respondents completed confidentiality paperwork before the interview began and were given a forty-dollar remuneration after it ended. The data collection portion of the interview began with interviewers administering the survey questions as designed. Interviewers read the questions aloud and recorded respondents' answers. This was followed by probing that included follow-up questions designed to elicit information about both the question-response process and patterns of interpretation.

Recruitment and Sample Composition: Cognitive interviewing employs purposive sampling, a technique where sample composition is defined by the questions under evaluation. Because the questions in this study included topics on COVID-19 testing and experiences with the virus (such as symptoms and

quarantining), the main goal of recruitment was to obtain respondents who 1) had never been tested for COVID-19, 2) had been tested for COVID-19 and were negative, or 3) were tested for COVID-19 and had tested positive. Beyond these criteria, demographic diversity was also a goal of recruitment. This included geographic diversity, as experiences with the pandemic have varied by state. Table 1 summarizes the demographic sample composition.

Table 1: Sample Composition, n = 50

	Number	Percent
Gender		
Women	30	60%
Men	18	36%
Non-identified	2	4%
Race/Ethnicity		
Hispanic	3	6%
Non-Hispanic (NH)	47	94%
NH-black	21	42%
NH-white	24	48%
Asian	2	4%
Native American/Alaska Native	1	2%
Missing	2	4%
Education		
High school diploma or less	8	16%
Some college, no degree	11	22%
2- or 4-year college degree	18	36%
Post graduate degree	13	26%
Geographic Region		
Mid-Atlantic: DC/MD/VA	32	64%
South: NC/GA	6	12%
Northeast: PA/NJ/NY	6	12%
Mid-West: MI/OH	2	4%
Southwest: AZ/TX	2	4%
Pacific Northwest: WA	1	2%
New England: ME	1	2%

Data Analysis: Analysis of the interview data included a three-stage process similar to the constant comparative method first developed by Glaser and Strauss (1967)¹ and adapted to cognitive interviews by Miller et al. (2014).² Systematic comparisons were made within each interview and across interviews by question. Themes were then developed by sorting out differences and similarities among individual patterns of question interpretation. Data analysis was assisted by the use of Q-Notes, a software application specifically designed by CCQDER for cognitive interview studies.

¹ Glaser, B. and Strauss, A. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Hawthorne, NY: Aldine de Gruyter.

² Miller, K., Willson, S., Chepp, V., & Padilla, J.-L. (2014) *Cognitive Interviewing Methodology: A Sociological Approach for Survey Question Evaluation*. Hoboken, NJ: Wiley.

Key Findings

Several themes emerged among the questions and are summarized next. Specific examples of each theme may be found in the question-by-question analysis in the final section of the report.

1. The importance of context on question interpretation

The COVID-19 pandemic created a contextual backdrop that influenced respondents' interpretations of the questions, sometimes in unexpected ways.

Pandemic frames question intent: The COVID-19 pandemic framed the intent of most questions, even for those that were not meant to be related to COVID-19. For example, one question (see #26 in the question-by-question analysis) offers a list of symptoms and asks respondents to identify those they experienced since March 1, 2020. The intent of the question was to capture any and all symptoms respondents experienced irrespective of cause. However, many respondents understood the question as asking about symptoms specifically associated with the virus. For example, if they experienced 'red/itchy eyes' (a symptom on the list) but did not understand that as a COVID-19 symptom they did not report it. Other respondents saw an even stronger connection between this question and COVID-19. They understood it as asking whether they ever had the virus and, if so, which symptoms they personally experienced, since symptoms can vary by individual. In other words, some respondents thought the question might be indirectly asking about prevalence. Those who never had COVID-19 sometimes failed to report any symptoms that corresponded to the virus because reporting those symptoms might be misconstrued as having had COVID-19.

Similarly, one question (#5) asks if respondents were unable to work because they were sick with COVID-19. While this question is intended to measure the impact of COVID-19 illness on the ability to work, some respondents applied a broader interpretation and thought of *any* impact (not just illness) that COVID-19 had on their ability to work. For example, some respondents defined inability to work as job loss due to businesses closing or contracting because of COVID-19. Put simply, the question was interpreted as asking if they were unable to work for any reason related to COVID-19.

Finally, several questions (#7, #30) ask respondents if they needed medical care but did not get it due to the pandemic. Like the previous examples, COVID-19 was embedded in respondents' interpretation of these questions. Specifically, 'need' proved to be an elastic concept that was influenced by the events at hand. For example, medical care that respondents judged as essential prior to the pandemic was often seen as non-essential during the pandemic. Routine visits, check-ups, dental care, and preventative care and screenings were often defined as non-essential. This interpretation was particularly prominent among respondents who were sensitive to the risk of contracting COVID-19. As a result, they understood 'needing' medical care as critical situations which could not be postponed, such as acute illness or injury.

Fitting new phenomena into existing frameworks: Sometimes respondents took into account new phenomena that emerged from the pandemic when answering a question. Specifically, new organizational structures for healthcare delivery and new types of healthcare workers have arisen during the pandemic. Respondents had to decide first how to categorize these new experiences and then how to incorporate them into their answers. For example, one question (#15) asks respondents if a doctor or other health professional ever told them they had or likely had COVID-19. Some respondents

were unsure whether ‘health professional’ included the contact tracer who notified them that they may have been exposed to the virus. Similarly, some respondents who received results at drive-up testing centers were unsure whether these workers counted as ‘doctors or other health professionals.’ Inconsistent interpretations were observed regarding these terms.

Further, telemedicine has greatly increased during the pandemic, but respondents were not yet sure how to categorize or define this method of healthcare delivery because many were not familiar with the term and had no prior experience with it. For example, one question (#21) asks if respondents sought out medical care for COVID-19. Some respondents consulted with a doctor via phone or video about their COVID-19 status, yet not all defined this type of consultation as receiving medical care.

In sum, the new reality that has emerged over the course of the pandemic means that respondents took new factors into account when answering survey questions. As a result, questions that incorporate these new realities may not be interpreted in the intended manner and may give rise to confusion and response error.

2. Evolving timeline of the pandemic:

As of this writing, the COVID-19 pandemic has affected life in the US for almost a year, yet its impact has not been consistent or even linear. Knowledge and experiences have undergone changes over the course of the pandemic as society and individuals struggle to adjust to this unprecedented phenomenon. This created challenges for answering some of the questions – respondents had to decide which phase of their experience in the pandemic to consider. For example, Question 20 asked respondents if they ‘suspected they ever had COVID-19.’ Respondents who suspected they had the virus, got tested, and were negative, had to decide whether to answer based on their beliefs prior to or after obtaining their test results. In other words, prior to testing they did suspect they had COVID-19, but a negative test result changed their mind so that presently they do *not* suspect they had COVID-19. Some respondents answered on the basis of their original belief while others were thinking of their current assessment.

Another question (#21) asks respondents if they sought ‘medical care for COVID-19.’ Some respondents who sought medical care had not been thinking of COVID-19 at the time they became ill, especially when this occurred early in the pandemic when they were less aware of the virus and its symptoms. They may have sought medical care, but at the time they did not think it was for COVID-19. Some respondents decided retrospectively that they might have had COVID-19 early on and just not realized it. As a result, this question produced different interpretations. Some respondents focused on what they believed about their illness at the time they sought care, while others thought about what they believed later in the pandemic. Difficulties arose for this group of respondents in Question 22 as well.

As a follow-up to those who answered ‘no’ in Question 21, Question 22 asks respondents why they did not seek medical care. It was difficult to choose a category that was exactly right for this group of respondents because their understandings were tied to their evolving experiences in the pandemic. Many respondents did not seek medical care when they felt symptoms because the thought of having COVID-19 did not occur to them at the time – they thought their symptoms were the result of more common maladies, such as allergies, colds, or the flu. It was only in hindsight – and increasing knowledge of the virus – that they suspected COVID-19. (None of the response options allowed for this experience.)

Question 31, while not necessarily problematic for respondents to answer, also demonstrates the fluid nature of respondent experiences during the pandemic. It asks whether respondents have felt more/less sad or lonely since the pandemic began. The wording of the question implicitly assumes a consistent level of emotion that was often not experienced by respondents. Instead they mentioned that their feelings of sadness ebb and flow over the course of the pandemic.

Similarly, Question 32 asks if respondents have felt more/less socially connected since the pandemic. This was also a fluid experience that the question assumes to be static. For example, while technology (e.g., phone calls and Zoom) may have been an adequate substitution for in-person interaction initially, it has become less so over time for some – and perhaps more so for others who were initially slow to adopt it. Respondents' answers to the question were contingent on what phase of the pandemic they thought of.

Taken together these patterns reveal the challenge in crafting cross-sectional survey questions in the context of a societal phenomenon that is on-going and unprecedented in nature.

3. Vocabulary: new terms and old words with new meanings

New terms have emerged during the pandemic and, while they are becoming more commonplace, they still do not enjoy widespread common understandings. Alternatively, the coronavirus pandemic has cast a new light on the meaning of existing words. When these words are used in survey questions, they produce different interpretations. Two examples are 'telemedicine' and 'isolation/quarantine.'

Telemedicine: The word 'telemedicine' was used in Question 10 but is a term that is not yet widely used or consistently understood. Respondents unfamiliar with the term pieced together their own understandings. Some respondents had a reasonably accurate understanding and thought of video appointments, email, and phone calls. However, others arrived at less accurate definitions. Having never heard the specific term, they cobbled together a definition of their own. The most common incorrect strategy was to break down the two components into 'tele' and 'medicine.' In these cases, the question was seen as asking about phone calls made by doctors ('tele') to pharmacies to fill drug prescriptions ('medicine'). On the other hand, several questions (#9, #11, and #12) omitted the word 'telemedicine' in favor of asking whether a respondent had an appointment 'by phone or video.' The focus on specific examples yielded more consistent interpretations of the questions.

Isolation or quarantine: Unlike 'telemedicine' which is a relatively new word, 'isolation' and 'quarantine' are more common vocabulary words. As a result, respondents generally understood what they mean. However, in the context of the pandemic, the words took on different shades of meaning and this was reflected in respondents' answers to Question 24. The question asked, 'Have you isolated or quarantined yourself because of the coronavirus?' The intent of this question was understood in two different ways. One understanding was based on 'isolation/quarantine' as a medical directive to isolate a sick person (or potentially sick person) from the rest of society (including cohabiting family) in order to prevent the spread of COVID-19.

However, this question was also understood more broadly as asking about new standards of interaction that help prevent the spread of COVID-19. Respondents thought of emergent norms regarding pandemic-appropriate social interaction for *all* individuals, not just those who are infected with COVID-19. These new norms included mask wearing, hand washing, staying home when possible, and maximizing distance between people in public (i.e., social distancing). Respondents thought of one or

both of these meanings – traditional medical quarantine or pandemic-appropriate behavior – when answering, and some even asked for clarification.

The emergence of new terminology or new meanings associated with familiar words has implications for question design. Such language should be avoided; questions should instead ask about specific behaviors.

Question-By-Question Analysis

COVID_NOWK.

5. [Last week] Were you unable to work because you or a family member was sick with the Coronavirus?

- Yes
- No

This question was not especially problematic. Most respondents demonstrated no confusion and answered correctly with ease. However, one case does suggest a potential problem. The only respondent who answered ‘yes’ to this question did so in error. The respondent did not miss work because anyone was ill with COVID-19, he lost his job because the employer cut back on hours due to the pandemic. The question was interpreted as asking whether work was missed due to *any* reason related to the pandemic.

On the other hand, all respondents who answered ‘no’ did so correctly. For example, some respondents had missed work due to COVID-19 illness, but not within the past week. Other respondents missed work due to illness in the past week, but not COVID-19.

COVID_INS.

6. Did you lose health insurance coverage at any point because of the Coronavirus pandemic?

- Yes
- No

Most respondents answered ‘no’ to this question because they had health insurance and experienced no interruption in their coverage. Only two respondents answered ‘yes’. Both were response error. These false positive cases are discussed next.

The question asks respondents to consider two things before answering. First, they must answer whether or not they lost health insurance – which all respondents could do without difficulty – and second, they must assess whether this loss, if it occurred, was due to the pandemic. However, all respondents did not take the last clause into account. For example, one respondent who answered ‘yes’ lost health insurance, but only due to a clerical error that caused her Medicaid benefits to temporarily expire. Her loss of insurance had nothing to do with the pandemic.

Additionally, without prior establishment of whether respondents ever had health insurance, the question falsely assumes that they did. This makes the question double-barreled for respondents who never had health insurance and draws into question the meaning of a ‘no’ response. For example, the second respondent who answered ‘yes’ in error never had health insurance because she is not a US citizen. Her assessment of the question was that it was simply asking whether she lacks health insurance – to which she said yes. A filter question prior to this one would eliminate this type of error.

COVID_CARE.

7. At any time in the last 4 weeks, did you need medical care for something other than Coronavirus, but not get it because of the Coronavirus pandemic?

- Yes
- No

This was a problematic question due to its conceptual complexity and corresponding judgment tasks.

Two assessments in one question: There are two essential components incorporated into a single question. The first component asks respondents to assess whether they needed care. If they did, the second component asks them to assess whether receipt of care was affected by the pandemic, creating an effectively double-barreled question that also requires respondents to assess causality.

The double-barreled nature of the question makes it difficult to interpret respondent answers. In particular, an answer of ‘no’ does not have a consistent meaning. One meaning is that respondents did not need care in the last four weeks. One respondent (who specifically commented that the question was difficult to follow) decided to answer ‘no’ and explained, “I haven’t been sick with anything else that I should be going to the doctor for that I am skipping because of the pandemic.” Others also answered ‘no’ when care was unnecessary (“I haven’t needed anything during the pandemic at all.”).

However, an answer of ‘no’ meant something different to other respondents. Some answered ‘no’ when they needed care and did receive it. For example, one respondent said, “It was a back problem. I have a lot of other back problems. But I needed to get an MRI and then to talk to my GP about it. And it was no problem [to get appointments or procedures].” Note, however, the potential for confusion due to the cognitive demands of the question. A respondent who, yes, needed care and, yes, received that care must answer ‘no’ in order to provide a correct response.

Conceptual complexity of the word ‘need’: A second difficulty was created by the conceptual complexity of, and judgment calls required by, the phrase ‘needing’ medical care. The assessment of ‘need’ was often made specifically in the context of the pandemic, as opposed to some independent state of health and well-being. As a result, it was unclear whether medical care such as routine check-ups, dental cleanings, or preventative care and screenings should be included. Does one truly need a yearly check-up when such a visit might mean exposure to COVID-19? When answering the question, some respondents thought to include only urgent care, such as an illness or injury, including dental problems, knee injuries, surgeries, and back problems.

However, other respondents did think of routine visits and based their answers on their own personal assessment of risk associated with visiting a doctor during a pandemic. For example, one respondent answered ‘no’ and said, “I had an annual physical. So, I had preventative care that I still went for [despite the pandemic].” Others who thought of routine visits answered differently because their assessment of the pandemic was more cautious. One respondent answered ‘yes’ because, “I am due for a cleaning, and I am afraid to go and get my teeth cleaned.” Another respondent who answered ‘yes’ said, “I didn’t want to go to a doctor’s office and expose myself if I didn’t absolutely need to.”

Understandings of ‘not getting’ medical care and assessment of ‘because of the pandemic’: The last part of the question asks if those who needed medical care did not get it because of the pandemic. Since a pandemic has no agency, a respondent must link the causal agent’s (either the healthcare provider or

the respondent themselves) action and decision-making directly to the pandemic in order to answer 'yes.' Additionally, the phrase 'not get it' is an ambiguous timeframe that can cause confusion. Respondents' experiences and difficulties with these aspects of the question are discussed next.

Many respondents reported postponing medical care in the context of the pandemic. When postponement was part of respondents' experiences, it was difficult to decide the responsible agent. Was it due to the pandemic or due to their personal decision making? It was also difficult to decide whether postponement was equivalent to 'not getting' medical care, particularly if they planned to eventually seek out such care.

Many respondents answered 'no' thinking of medical care which they could technically get but decided on their own to postpone. While made in the context of the pandemic, it was ultimately their decision-making that was the cause of delayed care. For example, one respondent answered 'no', not because she could not see her doctor, but because she was wary of going out. She said, "I mean, just going to regular doctor's appointments...it's just like 'hmm, can you just hold off a little longer.'" Another respondent answered 'no' for the same reason. She said, "I just had a tooth ache, and I was holding off on going to the dentist." Another respondent postponed visiting the doctor for five months, weighing fear over exposure to COVID-19 against the amount of pain he was experiencing. He said, "And then I felt I had to go to the podiatrist because I had this thing on my foot." He'd been trying to tolerate the pain for as long as possible. "And finally, I reached my limit and I said I gotta go." He answered 'no,' not because the doctor would not see him, but because he personally chose to delay the visit until he could no longer tolerate the pain. Had this been prior to the coronavirus pandemic, he would have visited the doctor much sooner. His assessment of needing to see the doctor was clearly shaped by the pandemic; but in the end, it was his choice not to seek care as soon as was needed. Another respondent highlights this dilemma in assessing the causal agent. She said, "I kind of waffled on that [question] a little bit. I was thinking that I haven't gone to back to the doctor. I'm waiting for a few more weeks to see if [my knee] gets better." She answered 'no' because she saw this as her decision based on the progress of her knee in the context of the pandemic. She admits that COVID-19 played a role in obtaining medical attention. "It's just harder to see people in person...Even when I had a fever and I was sick, I couldn't get a doctor's appointment." But she answered 'no' because it was ultimately her choice based on her assessment of need. In sum, respondents who felt they needed to see a doctor, but who decided on their own to postpone a visit because of fears over the pandemic, often answered 'no' to this question when the answer likely should have been 'yes.'

Others answered 'yes' not out of personal apprehension but rather because healthcare providers were temporarily shuttered or cutting back on visits. Because these actions were clearly due to the pandemic and outside of the respondent's control, the assessment to answer 'yes' was easier to make. For example, one respondent said, "I would say yes, meaning I tried to get a regular appointment and they were so backed up because of COVID-19 that I can't go in until December. Their office was closed for a period of time and now they're really back-logged." Another said, "I had been going to in-person physical therapy, and I haven't been able to do that [because the provider has suspended visits]." Another who answered 'yes' also noted, "some doctors were not open for a period of time." For some this also affected their ability to obtain prescriptions. "I'm unable to get some of the medication that the doctor normally prescribes because of COVID-19 and they can't see me. They don't want to fill the script again because they haven't seen me. They need blood work." In these cases, the causal agent/reason for not obtaining medical care was more clearly linked to the pandemic, which made the question easier to answer.

TELMED.

9. In the last two months, has [this/any] provider offered you an appointment with a doctor, nurse, or other health professional by video or by phone?

[READ IF NECESSARY] If you are unsure or don't know, you may say "Don't know".

- Yes**
- No**
- Don't know**

This question is likely to invoke a disproportionate number of false negative responses. There are several reasons for this. First, the word 'offered' was the most problematic aspect of this question. Some respondents took the word quite literally to mean that their provider proactively and directly offered them this type of appointment. As a result, some respondents were confused, even if they correctly answered 'yes.' For example, one respondent said, "Umm...I know that option is available. [But] they have not given it to me specifically because I have not had to go in the last few months." After considering the question again she said, "I would say yes. They offered the ability to get appointments." Even though this respondent arrived at the correct answer, other respondents answered 'no' to this question in error due to this type of confusion. For example, one explained that she answered 'no' because her provider does not "verbally say it to you unless you - per se - ask or something...that's my experience." However, her provider's practice does offer telemedicine appointments. Another also answered 'no' even though her provider does offer these appointments. She said, "They have one of those dashboard things, those interfaces. I think they put a message in there that you could get a telehealth appointment. It wasn't just directed at me."

A second problem with the word 'offer' is that it suggests a telemedicine visit actually occurred. And, in fact, some respondents did interpret the word in this manner. This was an additional source of false negative responses. One respondent answered 'no' because, even though his provider offers these types of appointments, he chooses to go in person. Another respondent mistakenly answered 'no' for the same reason. She said, "They offered it, but [I] didn't do it." Another respondent had a similar error. Even though her provider offers telemedicine appointments, she answered 'no' because she went in person. She said, "I needed my annual physical, which I did go in to get, but she told me that I had to go in because it was a physical."

Finally, one respondent interpreted this as a question about referrals. She answered 'no' even though she had had telemedicine appointments. When asked why, she said, "Oh. Because I understood that question to mean, did my doctor *refer* me to an appointment through telemedicine. Not: did they provide it as an option, but did somebody actively tell me 'go make an appointment with this doctor and it will be telemedicine.'" The question was interpreted as 'has this provider offered you an appointment with *another* doctor.'

PROBE_TELMED.

10. How do you know whether your provider offers telemedicine or not? [CHECK ALL THAT APPLY]

- The provider told you in an email, phone call, or mailing.**
- Had a previous telemedicine appointment**
- Checked provider's website or social media pages**
- Told by a family member**
- Do not know whether the provider offers this**

Some other place, please specify:

Two words created some interpretation difficulties in this question. First, telemedicine is a term that is not yet widely used or consistently understood. Respondents unfamiliar with the term pieced together their own understandings. Some respondents unfamiliar with the term were able to arrive at a reasonably accurate understanding. For example, one respondent said, “When I think what telemedicine is, if it, you know, we’re now in this world that everything’s, you know, now digital, so I was thinking, telemedicine, it would be something online?...Instead of being in person, now it has to be done online.” However, others arrived at a less accurate definition.

The most common misinterpretation was to think ‘telemedicine’ referred to doctors calling in prescriptions. In other words, the question was seen as asking about phone calls (‘tele’) being made to pharmacies to fill prescriptions (‘medicine’). When asked how they understood the term, they gave similar answers:

“Another way to provide someone with, not the receipt, the slip, like how you go get your medicine - to let you know it’s time for you to go get your medicine, the prescription.”

“They gave me, when I got to the doctor, when they pull out the phone, they tell you how you can get your prescriptions over the phone.”

“It means calling in a prescription over the phone, or I call in my medicine by the phone?”

‘Provider’ was another term that could be misinterpreted. For example, one respondent thought about her insurance company. She said, “My insurance...I don’t remember. My insurance, they emailed me and they mailed me, ‘snail mail,’ and I have an app that shows I have teledoc as an option.” But when she heard the response option, ‘provider told you in an email’ she questioned her initial thought and said, “My provider? My insurance is the one who told me in an email...I would say ‘no’ then. Not the doctor.”

Finally, the response category, ‘do not know whether the provider offers this,’ was often confusing. Some respondents were unsure what to make of the option. For example, one respondent heard the option, looked confused, and answered, “Not applicable? Because I *do* know.” Similarly, another respondent heard it and said, “That is incorrect. I *do* know.” Another respondent was quiet after hearing the response option. When asked why, she said, “I do [know]. So, how do you answer that, yes or no? That’s a tricky one. It’s badly worded.” If a respondent answered ‘yes’ (or even ‘no’) in the previous question, offering ‘don’t know’ in this question is illogical from a respondents’ perspective because it has already been established that they *do* know.

TELMEDUSE.

11. In the last two months, have you had an appointment with a doctor, nurse, or other health professional by video or by phone?

[READ IF NECESSARY] If you are unsure or don’t know, you may say “Don’t know”.

- Yes**
- No**
- Don’t know**

This was largely a straightforward question for respondents. Those who answered ‘no’ either had appointments in person or had no healthcare appointments at all (“All of my appointments have been in person for the last two months.”). No false negative cases were found.

Most respondents who answered ‘yes’ to this question were thinking about telephone consultations, but some also had video appointments. There were two respondents who were unsure what kind of appointments to include. For example, one respondent asked, “Does therapy count too?” She decided that it did and answered ‘yes.’ Another respondent answered ‘yes’ because he was thinking about talking with his doctor about needing to refill his pharmacy prescriptions. There was no further consultation about the respondent’s condition because this was a maintenance drug he’s been taking for years. This pattern suggests that respondents might be more likely to include unintended examples than they are to exclude intended ones.

TELMEDNEW.

12. Did this provider offer you an appointment with a doctor, nurse, or other health professional by video or by phone before the Coronavirus pandemic?

[READ IF NECESSARY] If you are unsure or don’t know, you may say “Don’t know”.

- Yes**
- No**
- Don’t know**

Respondents who answered ‘no’ to this question talked about how telemedicine was not a common practice prior to the pandemic. One respondent commented, “No, it never even occurred to any of us that that would be something to do.” Another said, “I’ve never done this before. I didn’t know that you could.”

Some respondents who were not certain answered ‘no’ instead of ‘don’t know.’ For example, one respondent answered ‘no’ because the provider did not offer a telemedicine appointment to him specifically, but he does not know whether the provider offered it to other patients. The ‘don’t know’ option was essential for this question, especially for those who first saw their provider after the pandemic began. For example, one respondent said, “I didn’t deal with it before. This is a new provider, new since the pandemic.” Another said, “I can’t say because I just started with them.”

Even though the question specifies ‘by video or by phone,’ some respondents were unsure whether to include other types of correspondence or communication that were perhaps more perfunctory in nature but potentially still in line with the intent of the question. For example, one respondent weighed whether to include email communication and ultimately decided not to. She said, “I’m trying to think. I know I had, like, email...like I could ask some questions on email. But this is different. You’re talking about just video. So, I would say [thinking] ‘no.’” Another respondent thought of prior-to-pandemic phone calls that were only brief check-ins from her doctor (“just checking on me to make sure everything was going okay with me.”). At first, she excluded those in her answer but then decided to include them. Another respondent included phone calls that involved requests for prescription refills. These examples suggest that a ‘video/phone appointment’ with a provider can be broadly interpreted to include potentially unintended experiences, especially when the intent of the question is understood as any interaction that occurs via technology and not in person.

NOCARTYP.

13. In the last two months, were you unable to get any of the following types of care for any reason?

- Urgent Care for an Accident or Illness**
- A Surgical Procedure**
- Diagnostic or Medical Screening Test**
- Treatment for Ongoing Condition**
- A Regular Check-up**
- Prescription drugs or medications**
- Dental Care**
- Vision Care**
- Hearing Care**

There are three factors that often made this question difficult to answer. First, the question makes the false assumption that medical care was needed in the last two months. Second, the question is posed as a double-negative, which increases both cognitive burden and chances for response error. Third, much like Question 7 (COVID_CARE), respondents had to decide whether personal decisions to postpone care constituted an inability to obtain care.

False assumption: Some respondents who did not need any medical care in the past two months had a difficult time choosing an answer because they saw the question as not applicable. One respondent specifically said, “No...I didn’t need it. Not applicable.” Others expressed the same difficulty, often in their first reaction to the question:

“I didn’t try to.”

“I haven’t tried to get any medical care.”

“I’ve had no reason to have that.”

“So if that hasn’t come up so that I need it...if I don’t need it, then I’m not unable.”

“Uh, no, I didn’t need it, so I wasn’t unable to get it.”

“Everything that I answered ‘no’ to, I didn’t need.”

Most respondents in this category chose to answer ‘no’ since ‘not applicable’ was not available. However, because an answer of ‘no’ can imply that they needed care and were able to get it (which is very different from not needing care to begin with), a ‘not applicable’ option should be provided.

Double-negative: Respondents who were unable to get medical care could answer ‘yes’ without much difficulty. However, if a respondent was *able* to get medical care, the structure of the question required them to answer ‘no,’ which was cognitively confusing for some. As a result, some respondents transposed the wording in their mind and incorrectly answered ‘yes.’ For example, one respondent said, “Yes, I have been able.” Another respondent also chose ‘yes’ for several of the options. The interviewer later probed, “You said you were unable to get that?” It was at this point that the respondent revealed, “Oh no, I said I was *able* to get that.”

Other respondents were more cognizant of their confusion. One said, “Yeah, I think it was about two months ago that they reopened. So I went and saw him. So yes. No. Wait...what’s the question again?” She eventually worked through the double-negative and answered no, not unable to get care. Others also reasoned out loud in order to arrive at the correct answer. “I’ve done all these things, I did the oral surgery, so no, I’ve not been unable.” Some directly asked the interviewer, “Is ‘no’ saying that everything’s okay, right?” Another asked, “Was I denied, or was I...what was the question?”

Because of these difficulties, interviewers routinely clarified answers. For example, one respondent initially answered ‘yes’ without hesitation. The interviewer confirmed, “Unable?” To which the respondent said, “I was *able* to get it.” Another interviewer attempted to confirm a ‘yes’ response, but the respondent said, “Yes, I was able to get it.”

Other respondents did not answer with a simple ‘yes’ or ‘no,’ but instead provided a clarification in order to have the interviewer choose the correct answer for them. For instance, one respondent replied, “I’ve been able to get the care each time.” Without interviewer intervention, response error would have occurred more frequently in this question.

Defining ‘unable’: Finally, it was unclear what constituted the inability to get medical care. Some respondents included personal decisions to postpone care even when it was available. For example, one respondent heard the question and asked, “It all depends what you mean by unable. I don’t feel comfortable getting my teeth cleaned at this point.” He decided to answer ‘yes.’ Another respondent also answered ‘yes’ because she decided to put off a visit to the dentist. Another respondent included her personal decision to postpone routine check-ups. She explained, “That was out of an abundance of caution. To not go and expose myself, potentially.” One respondent answered ‘yes’ and explained how getting medical care is an ongoing problem for her due to personal decisions (not because her provider is inaccessible). She said, “I [struggle] to get medical care because of my own problems, mentally. PTSD around medical issues. That’s why.” Another respondent was unsure of the question’s intent in this regard and explained his rationale for including his personal decision to delay getting care:

“I’m pausing...for one, for a while I didn’t actually know if dentists were open during COVID-19, and two, it has not been refused to me, but I have not chosen to do anything that’s not, like, that’s self-imposed. Like, I’m scared to go. I’m scared to do anything that I don’t have to do outside of my house. And so the dentist office might be open, and so they have not refused me care, but I have not gone despite needing to because it is like an added extra exposure.”

However, other respondents excluded personal decisions to temporarily abstain from seeking care. To these respondents, the inability to obtain medical care is linked to whether or not their provider is open for business. For example, one respondent postponed getting dental care for five months but answered ‘no’ because his dentist has been open and accepting appointments. Another answered ‘no’ for similar reasons. She said, “I know that if I needed to get an appointment, all my health care professionals had appointments available.” Another respondent also defined ‘unable’ as not being able to make an appointment if she wanted to and answered on that basis. One respondent described the difficulties he has faced from his provider who is limiting the number of appointments available. He said, “I just have to plead with my doctor, explain things to him. Then if he’s ok, if he’s available, he can just take me in. But apart from that, it was very difficult.” Other respondents included both personal decisions to delay care and lack of access to providers. One respondent explained, “Yes. By my choice for the dental care. For others, early on they were closed.”

COVIDNOCAR.

14. For the following, were you unable to get this because of the Coronavirus pandemic? [READ ONLY CARE TYPES MENTIONED IN PREVIOUS QUESTION, NOCARTYP., AND CHECK IF 'YES']

- Urgent Care for an Accident or Illness
- A Surgical Procedure
- Diagnostic or Medical Screening Test
- Treatment for Ongoing Condition
- A Regular Check-up
- Prescription drugs or medications
- Dental Care
- Vision Care
- Hearing Care

Similar to Question 7 (COVID_CARE), the word 'unable' requires judgments that varied among respondents. Some respondents included personal decisions to refrain from in-person visits or delay care due to their assessment of risk, even though such care was available to them. One respondent who needed physical therapy cancelled her appointments even though they were available to her. She said, "I was avoiding going in [to the in-person appointment], and I was weighing my pain versus my comfort of going into the therapist's office." Several other respondents included postponement of dental care for the same reason.

However, other respondents did not include personal decisions to delay medical care. They interpreted 'unable' more literally as the inability to visit a provider who closed an office or reduced appointments. For example, one respondent included 'dental care' in her answer but excluded 'surgical procedure' even though she needed one. This is because it was her choice to delay surgery on her wrist. Her dentist, on the other hand was unavailable. She explained, "That's because of corona. They postponed everything." Another respondent also thought of her dentist closing down. She said, "Yes. They just weren't taking patients. Were completely closed." Another respondent included 'regular check-up' because she has been unable to visit her doctor for diabetes monitoring. Others included types of medical care that were literally unavailable, such as regular check-ups, urgent care, and diagnostic tests. Examples include:

"At the beginning, everybody pretty much cancelled out."

"The government shut down those entities because of COVID-19, so they were not even open for me to make appointments."

"Because a lot of the ICUs are packed with COVID-19 victims, and they didn't have any beds."

"Because for the screening test, it's like, because of the coronavirus. The hospital changed their working hours, so we were not able to get help for this kind of attention."

COVIDDEV.

15. Has a doctor or other health professional ever told you that you had or likely had Coronavirus or COVID-19?

- Yes
- No

This question was easy to answer for some respondents. However, the context of the pandemic created some ambiguous experiences that made the question more difficult for other respondents. Specifically, the pandemic created new patterns in the healthcare industry, such as contact tracing and drive-up testing sites. This required respondents to make judgements about who to include as an 'other health professional.' Second, learning about one's COVID-19 status has not always been consistent or simple. This made it difficult for some respondents to decide how to answer whether they were told they had or likely had COVID-19.

Defining 'other health professional': The term 'other health professional' is ambiguous and open to multiple interpretations and judgment calls, particularly in the context of the COVID-19 pandemic. For example, some respondents were told by a contact tracer that they likely had COVID-19 but were uncertain whether to count this person as a health professional. One respondent answered 'no' (even though she was told by a contact tracer that she likely had COVID-19) because she assumed the question was asking about "doctors and nurses" specifically.

Personnel at drive-up testing sites were also an ambiguous group. One respondent had to think about whether to include these workers. He said, "It was just the testing site I went to. I am not sure if they are doctors or not." When the interviewer repeated the question, he answered 'yes.' "They are health professionals, yeah." Another respondent included an ambulance driver. The EMT who first arrived at her home after her emergency call suggested that the respondent might have "double pneumonia." However, while in the ambulance the drive told her it might be COVID-19. She included this person and answered 'yes.'

Defining 'told that you had': Some respondents were thinking about being told their test results when they answered this question. For some this was a straightforward answer. For example, one respondent said, "Yes, when I took the test and when they found out I had it, they called me and told me." Another also thought about her test results when answering 'no'. When asked what she was thinking when answering she said, "That I haven't had it. I have been tested and I am negative."

However, respondent experiences were not always straightforward. For example, some were aware that test results are not necessarily conclusive. For example, one respondent with symptoms tested negative but answered 'yes' because the doctor said, "Don't worry about what the tests say or don't say. They're not 100% accurate. We know that. If you are having the symptoms, we are assuming you have it. We're going to say you're a presumed positive."

Another respondent was not directly told she likely had the virus but was told to get tested because her husband (who spent some time in the ICU from a stroke) likely had it. Does that count as being told she likely had COVID-19? She was not certain. She said, "The neurologist was pretty certain that my husband had COVID-19, and therefore you [Respondent] should get tested. So I don't know if that's a yes or no." She went on to explain that both she and her husband ultimately tested negative. When pressed for an answer she said, "I'd probably say yes." Another respondent also was not directly told he likely had it because he lost consciousness in the ER. However, the staff initially did suspect he had COVID-19 and informed his wife of the possibility. The respondent answered 'no' because he was not told directly.

Finally, one respondent had symptoms and called the doctor for advice. The doctor told her neither to get tested nor that she likely had it, so the respondent answered 'no' to this question. However, there

was enough suspicion on the part of the doctor that he advised her to quarantine at home. The respondent explained, “The doctor said, ‘We don’t know, but let’s assume that you do have it, just stay in your home. If you feel worse, then come see me, but if not, just stay in your home.’” The respondent answered ‘no’ because in her mind even though the doctor said, ‘Let’s assume that you do have it,’ this was different from being told that she likely had it. When asked why she did not answer ‘yes’ she explained, “I guess I was thinking that he didn’t recommend a test. That’s why I said ‘maybe he thinks I don’t really have it, just stay home.’...If he had said ‘go take a test’ then I’d say, oh maybe he does think I do have it.” The doctor’s advice to stay home but not bother with testing was interpreted as cautionary, not as suggesting that she likely had COVID-19.

NHIS_TEST.

16a. Have you ever been tested for Coronavirus or COVID-19?

- Yes
- No [GO TO #20, SUSPECT.]

Half the respondents received this version. (The other half received 16b.) For many respondents this was an easy question to answer because getting tested for COVID-19 is such a memorable event. When probed after the question one respondent laughed and said, “I’m gonna remember that, oh my God.” Some respondents experienced symptoms and sought out testing. Others had been tested multiple times due to various factors such as the need to have other medical procedures or because initial COVID-19 tests were inconclusive.

However, there were some respondents for whom the answer to this question was not straightforward. Typically, this was because respondents had other medical conditions to contend with during the pandemic. For example, one respondent’s description of his hospital experience illustrates the difficulty. He said, “They did a lot of tests on me when I was admitted after I fell and broke my ribs. And that’s how they found my arteries were clogged. Because they did so many different tests on me...The honest answer is ‘I don’t know.’” He made the assumption that they did test him for COVID-19, but said, “They don’t tell you about each one.” Another respondent with hospital experience also was not certain but answered ‘yes.’ In explaining her answer, she said, “I think I was tested when I went into the hospital.” She discussed how they checked her temperature – which she associated with COVID-19 procedures. But she did not have a clear notion of other tests. She said, “I think they did a swab too, I just can’t quite remember.” She also described having blood tests. When the interviewer asked whether those were for COVID-19 the respondent said, “I don’t know, but I know they check everything on there. They check everything that’s wrong with me, every four to six months.” These experiences suggest that respondents with extensive experience with the healthcare system might not have full knowledge of their medical history, making it difficult to answer this question definitively or accurately.

PROBE_TESTTYP2.

17a. What kind of Coronavirus test did you receive? [CHECK ALL THAT APPLY]

- A cotton swab up the nose
- A cotton swab through the mouth and into the throat
- Saliva spit into a vial
- A blood test to check for antibodies
- A temperature check for a fever
- Assessment of physical symptoms, for example, cough, chills, and aches
- Something else, please specify:

Respondents who answered 'yes' to question 16a received this question. Those who answered could generally report the type of tests that they had and for some it was very straightforward. For example, one respondent said, "It was drive-up, hang-out-the car test." Another respondent proactively stated, "Nasal swab, both times." Others described their experiences more fully. One respondent described her test: "It was a cotton swab up the nose but a new version where they did not have to go up into my sinuses. They tried to do it down my throat, but I was gagging so they switched to the nose. But it's not the old test all the way up." Another respondent had testing done in association with travel. He explained, "Both times that I flew in August I took the test...That was just pre-flight so I wouldn't have to self-quarantine at the time...[the state] was saying you have to have one within 72 hours or something like that."

On the other hand, a few respondents did express uncertainty with their answers. These cases are described next.

Memory: Sometimes respondents' uncertainty was due to memory. "I don't remember [the type of test]. I just know that there was a cotton swab. And it was uncomfortable but nothing uncomfortable for a very long time." Although she expressed uncertainty, she did choose 'a cotton swab up the nose' which is likely a correct response.

Multiple tests/health conditions: Respondents with various medical conditions and related hospital stays tended to report having a variety of tests done. The problem was that sometimes the purpose of each test was unclear or unknown. For example, one respondent knew he tested negative for COVID-19 but was unaware – literally – of all the tests that might have been done because he was unconscious when he arrived at the hospital by ambulance. Another respondent also had a hospital stay that involved many tests, not just for COVID-19. She said, "And I've had several of them. Especially when I was in the hospital. In fact, I had one last week. And it seems like I should remember, but I don't." This was especially confusing when respondents had blood tests done. For example, one respondent said 'yes' to 'blood test to check for antibodies' because, "When they check my blood they check for any and everything." However, it is unclear whether these blood tests actually did check for coronavirus antibodies.

In-person vs virtual: Uncertainty arose over the sixth option because assessments of physical symptoms can occur in telemedicine appointments. For example, one respondent was unsure whether a phone conversation should be included for 'assessment of physical symptoms.' She decided to include it but said, "I guess, because they already did a phone thing. They already did a phone assessment. I guess it would be 'yes.' It just gets weird between the phone and a physical meeting. They did the phone thing and then the doctor said, 'go get a COVID-19 test.'"

[ALT_NHISTEST1.](#)

16b. Have you ever had a test to determine if you were infected with Coronavirus or COVID-19 at the time of the test?

- Yes
- No

Half the respondents received this version. (The other half received 16a.) This question confused some respondents. The last clause ('at the time of the test') was the source of confusion. One respondent thought about it and then asked for the question to be repeated. She said, "Oh, I see. The 'at the time

of the test' confused me. Yes." One respondent heard the question and said, "I don't think I understand the question. I have been tested for COVID-19-coronavirus. I have not been told at the test. The results have all been sent to me." When asked by the interviewer how she might answer, the respondent said, "I guess yes. I wanted to find out if I had it. I guess that's what the question is asking. It's the end part of the question that makes it a little hard to understand." Another respondent expressed the same difficulty. He answered 'yes' but said, "I was a little confused with the last part of the question. The last part 'at the time of the test' is throwing me. It seems redundant. Is it trying to ask if I got the results immediately?" One respondent was confused enough to answer in error. He did have a COVID-19 test but answered 'no' initially. He said, "What is that? Is that like [an] instant test?...The question sounded like if I found out that I had it at the testing, like instant results. I'll say 'no' for that because I found out my results two days later."

This question may perform better in a self-administered format, where respondents can deduce the intent in relation to the next question, ALT_NHISTEST2 (17b). In fact, one respondent specifically said, "Maybe if I had read it, it would have been different?" The interviewer asked how so to which she replied, "The next question is asking about antibodies, so this one is asking about the, oh, now I understand."

ALT_NHISTEST2.

17b. Have you ever had an antibody test to determine if you had Coronavirus or COVID-19 in the past?

- Yes
- No

The half of respondents who received 16b also received this question. Most respondents answered with no difficulty. Only one person answered 'yes.' She had the test done as part of a university study. All others answered 'no.' Some who had COVID-19 expressed no need for the antibody test. A couple respondents had not had the test but expressed an interest in eventually getting it. One respondent said, "A while back they put out a notice that you could get free antibody testing. And I kept calling the number to do it because I'd had mild symptoms – my husband and I both say maybe we had it. So I wanted to get that test. And then it turns out I wasn't eligible by certain criteria. So I haven't done it. But I'd like to." Another respondent was also curious about it but had been dissuaded by her doctors. She said, "Not yet at least, only because the ICU doctor explained – the strength, I guess? – of the test, and just like the false positive, false negatives. Basically, just saying it's not so definitive." Most respondents easily answered because they had no test of any kind.

However, some respondents were unsure about this question, especially if their experience involved other tests. For example, one respondent who "I don't think so. I just had a COVID-19 test." One respondent answered 'no' but said, "I don't think that I've done the antibody test, so I am going to say 'no.'" Her confusion was because she gets tested for COVID-19 monthly at a free clinic but did not know whether antibody tests are included. Another respondent has had many tests during hospital visits but admitted he did not know what they were all for. He said, "So, I don't know if they did an antibody test or not. The honest answer is 'I don't know.'" These respondents who were unsure answered 'no' instead of 'don't know.'

NHIS_RSLT.

18. Did the test find that you had Coronavirus or COVID-19?

[READ IF NECESSARY] If you are unsure or don't know, you may say "Don't know".

- Yes [GO TO #21, COVIDSEEK.]**
- No [GO TO #20, SUSPECT.]**
- Did not receive results**
- Don't know**

Most respondents had no difficulty with this question and were able to accurately report their test results. Many respondents had multiple tests, most of which came back with consistent results. This made answering the question easy. However, possibility for confusion over how to answer occurred among respondents who received false positive or false negative results. Some were unclear of what message to take away from that – they did not know what the truth was about their COVID-19 status. For example, one respondent could not decipher her results. She said, “It just said [reaches for the test results paper and reads it]...it says ‘this test has not been FDA-cleared or approved.’ So what kind of test did I have? [laughs].” She decided to answer ‘don’t know’ because, “they can’t even tell me if I had it.” However, some might not choose the ‘don’t know’ option. One respondent answered ‘no’ but explained that he was tested several times with different results. Given both a false positive and a false negative reading he said, “It’s a head-scratching situation. You do or you don’t, I couldn’t get a plain yes or no.” This suggests that, unlike many survey questions, it is important to proffer the ‘don’t know’ option for this item.

PROBE_RSLT.

19. Were you not told the results, are you still waiting on the results, or do you not remember the results of the test?

- Not told results**
- Still waiting on results**
- Do not remember results**

Most respondents followed the skip pattern out of this question. It was administered to only 11 respondents and most had no difficulty. However, one respondent who answered ‘don’t know’ in the previous question had a difficult time answering this one because the choices did not easily match her experience. Even though she was told the results, they were presented to her in a confusing way. She said, “It’s saying here ‘results not detected.’ It tells me that the test is not cleared or approved by Drug Administration so what kind of test did I get?...We did this swab up your nose, but this test here ain’t even been approved yet...All I’m saying is I don’t feel like this is even an accurate test...I would say that I couldn’t tell you whether I actually have it or not.”

SUSPECT.

20. Do you suspect that you have ever had the Coronavirus or Covid-19?

[READ IF NECESSARY] If you are unsure or don’t know, you may say “Don’t know”.

- Yes**
- No [GO TO #24, QUARANTINE.]**
- Don't know**

Respondents generally know and can answer whether they suspected they ever had COVID-19. However, confusion was sown in relation to the question’s timeframe, which asks about the present time (‘do you suspect’). Because the pandemic has progressed and evolved, people’s experiences and thinking have also evolved. What they thought or suspected in the beginning of the pandemic (for

example, early Spring, 2020) might not be what they currently believe. Usually this was due to testing. Respondent beliefs often changed in response to being tested for COVID-19. One respondent answered ‘no’ even though there was a time she did suspect she might have had COVID-19. She said, “Now I don’t, because I tested negative for it. I mean I thought I did [have COVID-19], but I tested negative for it. So, obviously I didn’t.” Another respondent also believed she had COVID-19, which prompted her to get tested. Her results twice came back negative. However, she answered ‘no’ to this question. When asked why, she said, “Because I believe the results. I don’t think I did have it.” She answered on the basis of what she currently believes as a result of her test, not on what she believed prior to getting tested. Another respondent also answered ‘no’ but said, “I did [suspect] at one point.” However, it was determined that he had a heart attack, not COVID-19. If the intention is to capture whether a respondent *ever* thought they had COVID-19, more precise wording might ask ‘did you ever suspect that you had...’ instead of ‘do you suspect that you ever had....’

COVIDSEEK.

21. Did you seek medical care for Coronavirus or Covid-19?

- Yes [GO TO #23, SYMPTOMS.]
- No

Only about half the respondents were routed into this question. The rest skipped out. Most answered ‘no,’ but this may be error for some respondents.

Seeking medical care for COVID-19: The last part of the question ‘for Coronavirus or COVID-19’ may result in inconsistent reporting. The difficulty lies in respondents having different levels of knowledge about COVID-19 over the course of the pandemic. Some respondents who answered ‘no’ explained that they were not necessarily thinking of COVID-19 *at the time* they became ill – this was especially true early on in the pandemic, when people were generally less aware of the virus or its symptoms. For example, one respondent said, “I thought it was just like a cold, or a flu, or a stomach virus or something. I did not know about all the symptoms of coronavirus.” Another respondent fell ill but also did not think it was COVID-19. She said, “When I went to seek medical care, I wasn’t feeling well, but I assumed it was cold and sinus. I didn’t go thinking I had COVID-19.” This respondent eventually took a COVID-19 test at the urging of her doctor, but it came back negative.

On the other hand, not all respondents who were unsure of the cause of their symptoms reported ‘no’ to this question. For example, one respondent remembered having COVID-19 symptoms in February of 2020 and answered ‘yes’ to seeking medical care. However, because the pandemic was in its infancy, the doctor did not think it possible that she had COVID-19 and no test was ever recommended. The respondent answered ‘yes’ because she went to the doctor for symptoms that *could have been* COVID-19.

Definition of medical care: Some respondents included telemedicine in their definition of medical care. As one respondent said, “All I got was the teledoc appointment, but that is all I could get.” However, other respondents thought of ‘medical care’ as seeking care in person. This was another source of potential false negatives. One respondent excluded a phone consultation with the doctor, because it was determined the respondent should stay home and quarantine and not visit a doctor unless the symptoms worsened. Another respondent also answered ‘no’ even though she had a phone call with a nurse after testing positive. She said, “I did get information from the nurse about getting a humidifier and taking Ibuprofen and all that stuff. So I did get medical advice, but not from a visit.” Another

respondent also answered 'no' because even though he did consult a doctor in a virtual appointment, he did not visit a doctor in person for his symptoms.

COVIDCARNO.

22. Why did you not seek this medical care? [CHECK ALL THAT APPLY]

- Too expensive
- Not available
- Symptoms were not severe enough
- Something else, please specify:

Respondents who answered 'no' to question 21 were asked this question. The rest skipped out. For those on whom the question was tested, the response categories did not do an adequate job of capturing their experiences.

Burden associated with judgment and response stages: Direct and simple answers to this question were rarely elicited from respondents. As a result, respondents had difficulty assessing their experience and then choosing an adequate response option. There was sometimes an elevated level of burden associated with assessing why they did NOT seek out care and then mapping that reason onto the categories; so, in some instances respondents simply relayed their experience to the interviewer. For example, instead of choosing 'too expensive' as the reason he did not seek care, one respondent told the interviewer, "If you go somewhere, they need an insurance [card] or you might have to pay a lot." The interviewer chose the 'too expensive' category for him, but he would have answered 'something else' because lack of health insurance was different in nuance. Another respondent chose no response and instead relayed his experience to the interviewer. He explained that his parents (the entire family was sick at the same time) were told over the phone by the family doctor to stay home. This was not understood by the respondent as 'seeking care' because he had neither a direct conversation with nor an in-person visit to the doctor. (Though this did not come up for other respondents, this example, along with the previous question, suggests that interpretations of 'medical care' can include or exclude in-person visits to a healthcare provider.)

Insufficient response options: Adding to the difficulty of having to assess why an action was not taken and then choosing a response, the list of response options was not exhaustive. This contributed to higher numbers of the 'other-specify' category than would be ideal for most surveys. For example, one respondent chose 'other' because he did not want to go to the hospital and potentially expose himself if he did not actually have COVID-19. Another respondent who chose 'other' explained he did not seek medical care because he did not judge himself to have key symptoms of the virus. According to him, this included loss of taste and smell and trouble breathing. Even though he had many other COVID-19 symptoms, such as a cough, body aches, and a sore throat, he did not seek care because he lacked what he thought were the tell-tale symptoms. He concluded it might have been allergies and never sought out COVID-19 testing.

Another reason why the categories were insufficient is because they lacked an option that acknowledges there is no cure for COVID-19, so going to the doctor is perceived as pointless. For example, one respondent chose 'not available' because she believed that a medical cure for COVID-19 does not exist. However, the intended meaning of the response option 'not available' is unclear but is likely designed to capture lack of access to healthcare – not a lack of medical cures for COVID-19. Another respondent with similar rationale had difficulty answering. When asked by the interviewer why she did not seek out care she said, "Because I know COVID-19 is a new disease and doctors don't have a

clue on it. I can easily visit an ENT but what is he going to tell me other than prescribe me a medication that's not going to work or tell me to do smell training?" She chose to answer 'other.'

Evolving pandemic and states of respondent knowledge: It was also difficult to choose a category that was exactly right because respondent decision-making was tied to the evolving nature of the pandemic. For example, many respondents did not seek medical care at the time they felt symptoms because COVID-19 was not yet part of their repertoire of possible illnesses. They thought their symptoms were the result of something else, such as allergies, colds, or the flu. One respondent who chose 'other' said, "I didn't know about coronavirus at the time...I thought it was just like a cold, or a flu, or a stomach virus or something. I did not know about all the symptoms of coronavirus." Another respondent chose 'symptoms not severe enough' but this does not adequately reflect her story. She said, "But, it was early on, like early March, and there was just a lot of confusion and misinformation. And I'm in [state], where it was like really difficult to get a test in the beginning. So, I just didn't. I stayed in, I isolated. I didn't actually go to the doctor." Another person also initially thought she had the flu and did not seek medical care for that reason. However, as knowledge of the pandemic grew, she now thinks she might have had COVID-19 because a housemate had traveled to Asia prior to the respondent falling ill. This respondent did not know which response option to choose and answered 'don't know.'

SYMPTOMS.

23. How would you describe your coronavirus symptoms when they were at their worst? Would you say no symptoms, mild symptoms, moderate symptoms or severe symptoms?

- No symptoms**
- Mild symptoms**
- Moderate symptoms**
- Severe symptoms**

Respondents who answered 'yes' to question 21 received this question. All narratives that were elicited during probing aligned with survey responses in terms of having or not having symptoms. In other words, there were no errors among those who chose 'no symptoms' (which included only three respondents). Additionally, respondents who reported symptoms were retrospectively asked to describe their experiences. In answering this question, respondents made judgments on the basis of either the intensity of the symptoms or on the need for medical intervention, such as seeing a doctor or being hospitalized. These patterns are discussed next.

Medical intervention: The need for medical intervention was one criterion for deciding how to answer. The need for hospitalization was often the basis for 'severe.' One respondent said, "I assumed when they were at their worse that I was not going to make it – when they put me on the ventilator in the beginning." Another respondent answered 'moderate' because although his symptoms escalated, he never had to be hospitalized. He said, "When I think of severe, I think of like hospital level." Another respondent used the same rationale for her answer of 'moderate' and explained, "As a regular human, I would say moderate. And 'severe' meant being in the hospital." One respondent summed it up by saying, "Everyone knows what severe symptoms are. You had to go to the hospital because you weren't breathing." By extension, 'moderate' was often defined as needing to seek medical attention, if not hospitalization. One respondent had flu symptoms but described them as 'mild'. He said, "Had it been moderate, in my mind, I would've just gone to the doctor."

Intensity: Some respondents based their answer on the intensity of the symptoms they felt. For example, one respondent was never hospitalized but still answered 'severe' because, "The fatigue was

deep, really deep.” Another respondent answered ‘moderate’ because he believed his symptoms could have escalated beyond what they did. He said, “I’d say moderate, because I know they could be worse than this. I never got to the point of no breathing.” One respondent answered ‘severe’ because she believed her symptoms could not have gotten any worse. She said, “My symptoms was everything on the symptoms list: diarrhea, throwing up, hallucinating. I was weak, dry mouth, couldn’t walk. I had a respiratory issue where I couldn’t hardly breathe during night. During the day, you walk more than five steps, felt like I was about to pass out. My feet were all swollen, I couldn’t walk. It took about two weeks for me to get past that problem.” Another respondent shared a similar description, “It was severe. I suffered. I really suffered. I lost a lot of weight during this time, almost a month and two weeks I think...I couldn’t breathe very well, I couldn’t breathe properly. I have choked...It was severe...I thought I was going to die.”

Intensity was sometimes determined by comparing their symptoms to other illnesses (usually the flu). For example, one respondent said, “It was a matter of having had some type of flu, cold, sickness and juxtaposing that with what I went through with coronavirus. So in moderate and severe, it was definitely not moderate.” Another respondent reported, “Severe, chronic, beyond my imagination...way beyond somebody saying they had the flu.”

Some respondents made judgments by comparing their symptoms to others they knew who had COVID-19. One respondent was in a situation where he and his four roommates all contracted COVID-19. He judged his symptoms as more severe than his roommates’. His roommates were able to function, but the respondent said that, in comparison, his symptoms were much worse. He answered ‘severe’ because “For like two days, I couldn’t even get out of bed. I just couldn’t move around. My body was aching. My fever was still really high. I was like coughing a hard, dry cough. So I just laid in bed and watched Netflix all day.” Another respondent answered ‘mild’ for herself in relation to her husband. She said, “Because I had a loss of taste and smell and just headache. My husband, on the other hand, he had shortness of breath, he had fever, he had everything. He would be considered moderate. And I would be mild.” Another respondent also answered ‘mild’ thinking, “It might just be me being ‘well, it wasn’t that bad, surely there’s other people who had it worse.’”

QUARANTINE.

24. Have you isolated or quarantined yourself because of the Coronavirus?

- Yes
- No

Respondents made two different assessments of the intent of this question. Some understood it to be asking specifically about a medically imposed directive to contain COVID-19 by isolating a sick person (or potentially sick person) from the rest of society. Others saw it more broadly as asking about newly emerging standards of social interaction that include primarily minimizing time spent in public, but also include behaviors such as mask wearing, hand washing, and maximizing distance between individuals interacting in daily life. The details of these patterns are discussed next.

Medical understanding: Some respondents answered this question on the basis of defining quarantine behavior as that which is driven by potential exposure to the virus and the subsequent medical directives to remove oneself from the presence of others. Respondents who tested positive for COVID-19 often thought of this definition. One respondent explained, “Yes, they told me 14 days, and I did the 14 days.” Another respondent answered ‘yes’ and said, “When my husband tested positive, we all were in isolation and I had a daily...the health department would text me and ask me if I had any symptoms.”

One respondent answered 'no' because she could not follow the medical advice given to her. She said, "When I went for that first test [in May] they asked me, if you're positive can you quarantine? And I tried to wing it and say that I would, but that I would still go to work. And they're like, no! That's not quarantining! Quarantining is staying out of contact with any people." Another respondent answered 'no' because, "For me, isolating or quarantining I would stay in one room and avoid contact with my husband and my daughter so I don't infect them, to me that's truly isolating, and I didn't do that."

New norms for interaction during a pandemic: However, other respondents included quarantine-like precautionary behavior, even if it was not prompted by suspected exposure to the virus. These respondents seemed to understand the question as asking about new norms surrounding pandemic-appropriate social interaction. For example, one respondent answered 'yes' because he was thinking of these new norms. He described his quarantine behavior as, "Only leaving the house when necessary, consistently washing my hands and making sure I'm clean, and wearing a face mask when I do exit the house." Another respondent answered 'yes' and said, "Me and my husband, as things completely shut down, we stayed in our house. We didn't go out anywhere unless we unfortunately had to get some groceries or some important stuff. For the most part we wore face coverings and stayed inside." Another respondent answered 'yes' linking the concept of 'isolate or quarantine' to emergent norms of social interaction associated with the pandemic. She said, "Early on, I did do some distanced things with people in the community that I trust. Like visited in yards or larger porches." This respondent incorporated the concept of 'social distancing' into her understanding of the question. Another answered 'yes' and said, "I was already kind of quarantining" because she was spending most of her time in her house and leaving for essential purposes only, such as for work and groceries. Another respondent answered 'yes' and said, "We have been quarantining the whole time. We took my kid out of school in March. In that case yes. But I did not quarantine myself from others in the house."

Some respondents were aware that the question could have two meanings and explained their interpretation. One respondent answered 'no' because in her mind, her behavior to isolate at home was not due to personal exposure to the virus, it was due to everyone taking precautionary steps to avoid exposure, which she did not think this question was asking. She clarified, "I haven't quarantined because I was interacting with someone who had coronavirus or I thought had coronavirus. No, I didn't isolate or quarantine because of that. I was isolated or quarantined because of the fact that we asked everyone to not come into the office and work remotely as we figure this out." Another respondent with the same rationale answered 'no' and said, "Well, nobody wanted to be around us, so we were by ourselves. It was at the very beginning when everybody was paranoid. We were stuck here for about 10 days. We quarantined ourselves." He answered 'no' because this was not a medically imposed quarantine.

Other respondents were also aware of the difference between 'medical quarantine' behavior and new 'pandemic-appropriate' behavior and were not sure how to answer. One respondent clarified her response of 'yes' by explaining, "Because I have been isolating and self-removing in general; not because I had it [COVID-19]." Another respondent answered 'no' but sought clarification. He said, "Well...[thinks]. I would say no for the coronavirus. But if working from home counts, I would say 'yes'. But not because of it -- I don't have it [COVID-19]. I haven't isolated because of it. But at large, I would say 'yes.'" When asked if he would change his answer to yes, he could not provide a definitive response. He said, "The reason why I had to think about it is because where I work we call it "isolated" [to work from home]. It's isolating because of the coronavirus, but I'm not doing it because I have the virus." Another respondent who answered 'yes' also thought of both dimensions of the definition. She first described the medical nature of her quarantine behavior and said, "I got an email...they said you tested

positive and you need to quarantine for I think 10 days. And then if you go a day without fever-reducing medication or symptoms, you can go out in public.” However, she added that prior to contracting COVID-19 she also engaged in pandemic-appropriate behavior. She said, “I’ve also quarantined at the beginning of the pandemic. I tried to really not go anywhere. And I also in September went to visit my grandma who has a lot of health issues and I quarantined for 10 days before I went there. So I’ve done by-choice isolation. And that ranges from only going to the grocery store but not seeing anybody, to I left my house just to take my dog out [when she had COVID-19].” Another respondent also answered ‘yes’ because he quarantined for both reasons. He said, “Yes, because of me having it [COVID-19] and for other reasons before that...just kind of trying to not get the virus and stuff [general precautions].”

In sum, this question captures two very different constructs and could benefit from a clarification of the intended measure by asking about specific behavior rather than using words (such as isolate and quarantine) that do not yet have shared meaning in the context of the pandemic.

PROBE_QUAR1.

25. When answering the previous question about isolating or quarantining because of the Coronavirus, which of the following, if any, were you thinking about? [CHECK ALL THAT APPLY]

- Staying inside your house and not leaving at all**
- Staying in one room in your house as much as possible**
- Limiting interactions with members of your household as much as possible**
- Limiting interactions with people outside your household as much as possible**
- Leaving your house for essential purposes only, such as grocery shopping, healthcare appointments, and exercise**
- Staying six feet away from other people as much as possible**
- Something else, please specify:**

There is not sufficient evidence to suggest that respondents kept in mind their rationale from the previous question when answering ‘yes’ or ‘no’ to this list of items. Instead, they tended to answer this question as a stand-alone item. For example, one respondent answered ‘no’ to these items indicating that he did not do those behaviors. It had nothing to do with what he was thinking in the previous question. Similarly, sometimes respondents would shift midstream. For example one respondent went from thinking about what he was thinking quarantine meant in the previous question to thinking about which of the practices on this list he thinks defines ‘isolating or quarantining’. When respondents lose track of the connection between these two questions, this question is not a good indicator of factors taken into account in the previous question.

ECHO_2

26. Which of the following symptoms have you had at any point in time since March 1, 2020? [CHECK ALL THAT APPLY]

- Fever or chills**
- Cough**
- Shortness of breath**
- Sore throat**
- Headache**
- Muscle or body aches**
- Runny nose**
- Fatigue or excessive sleepiness**

- Diarrhea, nausea, or vomiting**
- Loss of sense of smell or taste**
- Itchy/red eyes**
- None of the above**

Literal interpretation: Some respondents answered this question on the basis of symptoms they had irrespective of the cause. For example, one respondent included cough, fatigue, headache, itchy/red eyes, and runny nose and explained, “Lots of allergies. Especially, with my allergies it’s the red, puffy eyes. And, I do cough and sneeze a lot because of that.” She added, “When I get super-stressed I get headaches, migraines. That’s a constant thing unfortunately.” One respondent who had COVID-19 included both COVID-19 symptoms and non-COVID-19 symptoms, such as ‘itchy/red eyes.’ He said, “In general, even before I got the virus, my eyes were always getting red.” Another respondent who tested positive for COVID-19 also included all symptoms she felt, irrespective of cause. For example, she included symptoms that, “I know [are] pregnancy related.” However, she expressed doubt about the intent of the question. She said, “I would have thought that it was asking literally, have I felt those things. But maybe I also would have been self-conscious because, like, I know that [my symptoms are] not [all] COVID-19-related [some are pregnancy related]...I would have thought the question was trying to determine whether or not I might have had COVID-19 and just not known it?”

Other respondents included symptoms that were not necessarily related to illness per se, but were experienced nonetheless. One respondent thought of outcomes related to work and leisure activities. He explained, “My eyes are generally irritated and red because I work in a dusty environment. And the muscle soreness and aches could be from falling down because I do random sports.” Several respondents mentioned that certain symptoms are a normal reaction to physical exercise. One respondent said, “Well, I work out. If I didn’t have muscle and body aches there’d be something wrong.” An older respondent included body aches not because he was ill but because, “I’m [elderly].”

Contextual interpretations: Not all respondents interpreted this question literally. Some respondents interpreted it in the context of the pandemic and answered on the basis of symptoms they associated specifically with COVID-19. For example, one respondent listed many symptoms, all of which were linked to having COVID-19. Some symptoms, such as fatigue, muscle aches, and fever, “were pretty much the whole time.” But others came and went. She said, “[Nausea] was the day I had horrible cramps and all of my COVID-19 symptoms [at the same time].” Another respondent also checked off almost every symptom because she had COVID-19. “I still have the occasional sore throat, cough, and shortness of breath...I’m still feeling the residual effects of it.”

Some respondents who tested positive for COVID-19, but who had multiple symptoms for a variety of health conditions, chose only the COVID-19 symptoms when answering this question. For example, one respondent chose only the symptoms he associated with having COVID-19 (fever and chills) and excluded symptoms he deemed as unrelated, such as diarrhea. He said, “Before I had COVID-19, I had some diarrhea. But I wasn’t sure if that was related to COVID-19.” Another respondent did the same – listed only those symptoms associated with COVID-19. For example, ‘itchy/red eyes’ were excluded because, “My eyes are generally irritated and red because I work in a dusty environment.”

Oddly, one respondent who was recently diagnosed with COVID-19 answered ‘none of the above’ to this question even though he experienced many of the symptoms. He said when he answered the question he was thinking of the “the whole time I didn’t have COVID-19.” The respondent was thinking only of

COVID-19 symptoms for this question, but because he only recently tested positive, he thought the March 1 timeframe was asking about an earlier period – not ‘currently.’

ECHO_2a

27. Which of the following occurred as a result of your symptoms? [CHECK ALL THAT APPLY]

- I was kept overnight in a hospital because a healthcare provider thought I had COVID-19
- I saw a healthcare provider in person, such as in a clinic, doctor’s office, urgent care, or emergency room (ER)/emergency department (ED)
- I spoke to a healthcare provider over the phone, by email, or online
- I self-isolated or quarantined at home
- None of the above

Keeping track of the previous question: Some respondents lost sight of the connection between this question and the previous. For example, one respondent heard the second response option (saw a healthcare provider) and asked, “In what period of time?” The interviewer repeated the entire question and he asked, “For what symptoms?” Another respondent demonstrated similar difficulty. After the second response option she asked, “The question was because of these symptoms?” Another also asked for clarification, “And this is just due to those symptoms that you read off that I said ‘yes’ to?”

Definition of seeing a ‘healthcare provider’: Because of new types of pandemic-related healthcare, some respondents were uncertain who to include as a provider. This was especially true for COVID-19 testing sites. For example, one respondent was unsure whether to include staff at an outdoor testing site. Another respondent expressed similar confusion and said, “I guess I would say ‘yes.’ But, again, it was literally a tent outside where they did the COVID-19 test.” Another respondent did not speak with her primary care physician but did speak with a personal friend who is a physician and included this person in her answer.

Shifting definition of ‘quarantine’: Some respondents answered this question differently from Question 24 (on isolating or quarantining because of the coronavirus). This was due to the different context of this question, which attempts to link the list of behaviors here to symptoms identified in the previous question. This can lead to logically different answers between this question and Question 24. For example, one respondent answered ‘yes’ to Question 24 but ‘no’ to quarantine in this question. This was because she quarantined due to her husband’s illness, not because of her own symptoms. Another respondent answered ‘no’ to Question 24 and ‘yes’ to the quarantine option here. Because of the discrepancy, the interviewer asked how long she quarantined. The respondent said, “I gotta be honest, not that long. Because I [had symptoms] on Thursday and on Friday I woke up much worse. And I normally do not get headaches. So on Thursday I didn’t see my housemates. Then on Friday I made sure I didn’t touch anything. I cancelled everything, like work. And then I went and got the test as soon as I could.” Because she was thinking more specifically about her behavior and symptoms here, she gave a more literal answer than in Question 24. In Question 24 she thought more generically about quarantining and answered ‘no’ because her experience with it was not lengthy. These examples further illustrate how understandings can shift according to question context and different aspects of respondent experience in the pandemic.

ECHO_2b

28. In the two weeks before you had symptoms, did you: [MARK ALL THAT APPLY]

- Have contact with someone who tested positive for COVID-19

- Have contact with someone who likely had COVID-19 (e.g., was not tested but had symptoms; was told by a healthcare provider that he/she likely had it)**
- Travel to a different state or country (please specify)**
- None of the above**

Lack of knowledge: The first two categories can present some difficulty. They are worded as though respondents know and can report whether they came into contact with a person who had COVID-19. In reality respondents often do not have this information. As one respondent said, “The one thing about this virus, you can’t even recognize who got what – you can’t. It’s a very smart virus. You can’t tell by looking at someone if they have it.”

Several respondents who tested positive for COVID-19 admitted they had no idea where or how they got it. As a result, they did not choose either of the first two options. One respondent said, “No, not that I know of.” One person left the first two blank and said, “I have no idea.” Similarly, another left the first two items blank because “There was no way I could know if a person was positive or not.”

For others it was more difficult to answer. Several respondents chose the first option to begin with but then changed their mind to exclude it because they did not know specifically who might have had COVID-19. Other respondents expressed confusion. One respondent said, “No, not that I knew of at the time. They did – it turns out they did. So, I don’t know how to answer.” Another left those items blank and said, “I don’t know. I’m not sure. I went to the mall and then after I went to the restaurant. And then I felt like a complete loss of smell and taste at the restaurant. So, I’m not sure who had COVID-19.”

Other respondents acknowledged that assumptions must be made in order to choose either of those responses. One respondent said, “I assume so, but not to my knowledge...No one that I knew explicitly.” Another said, “My kid is a figure skater, and so many parents are professors in [university] and probably some of them are Chinese, and we go and sit in the rink lobby waiting for our kids. Many of them go back and forth all the time [to China], so that is where, I assume, I came into contact with it.” Another heard the first category and said, “If they did [test positive], they didn’t tell me. And I think that’s what it was.” She decided to answer ‘yes’ to the first option reasoning that she caught the virus from someone who did not disclose their COVID-19 status to her.

In some ways the first two categories are meaningless. A respondent with COVID-19 by definition contracted it from another person, so technically everyone (with COVID-19) could answer ‘yes’ to those first two categories. As one respondent commented, “Not that I know of, but I guess. I mean, obviously I did, since I got [COVID-19].” Given this logic, some respondents assumed that the question was asking whether they knew *specifically* who they got the virus from. But this is a question that was impossible for many respondents to answer.

Travel out of state: Finally, because some parts of the country are made up of multiple states that are considered one region, the third option may elicit different responses. The Washington DC metropolitan area is one example. During the pandemic, travel between Maryland, DC, and Virginia was not considered traveling across state lines and residents were not required to quarantine at any time when traveling in this area. As a result, residents of that area must decide whether to answer the question literally or not. One respondent decided to include these as different states. She said, “I travel between DC, Maryland and Virginia, but not very far. I consider the DMV one big area, but technically I crossed state lines.” However, another respondent did not include this in his answer because he considered this to be one area.

DISR. MED.

29. Since the Coronavirus pandemic began, have you been able, unable, or have not needed to get medications?

- Able**
- Unable**
- Have not needed**

It was unclear whether this question refers only to prescription medication or is also meant to capture difficulty obtaining over-the-counter (OTC) medication.

Many respondents were thinking of prescription medication. In addition to traditional pharmacy pick-up, several respondents answered 'able' because they included services that mailed prescriptions to their door – a service that has increased greatly during the pandemic. One respondent said, "I do mail order pharmacy. I have received them with an active prescription." Another said, "I used to be picking them up, but now they mail them to me."

However, some respondents questioned whether to also include OTC medicine. One respondent asked, "You mean prescription medications? I have not had trouble with prescription medications, but I have not found NyQuil for a long time." Another answered on the basis of prescription medications but when probed, she wondered if she should also include OTC medications. She did not need prescription medication (and answered 'have not needed'), but back in March and April she tried to buy Tylenol and Mucinex and had difficulty finding them on the shelves.

Finally, the wording of question was awkward for some respondents. One respondent heard the question and said, "That covers every possibility. What's the question again?" The interviewer repeated the question and she said, "Oh! Able. The way that question was posed, I was totally uncertain that it was multiple choice." One respondent heard the question and answered 'no' rather than able/unable. The question was repeated and he chose 'have not needed.' Another respondent also did not use the categories and answered, "No. I've been able to get them." The inability to directly choose a category was not uncommon. One respondent who had trouble with the able/unable format heard the question, thought for a moment, and said, "I've been able to get my medication any time I needed it." In these cases it took guidance from the interviewer to choose the correct category.

DISR. DOC.

30. Since the Coronavirus pandemic began, have you been able, unable, or have not needed to get a doctor's appointment or some other kind of healthcare?

- Able**
- Unable**
- Have not needed**

As with Question 7, the concept of 'need' can be a difficult judgment call in the context of a pandemic. The assessment of 'need' can be made either in relation to access to care (e.g., offices being closed) or postponement of care that is accessible (i.e., a personal choice to minimize exposure to others). When offices were closed, respondents easily chose 'unable.' However, deciding how to answer was more complicated when offices were open and respondents chose to delay or avoid getting care.

Some respondents who delayed care chose 'able,' but did so with hesitancy. One respondent thought before answering. When asked why, she said, "I just kept postponing [visits to dentist and podiatrist]. I could [get an appointment] but I chose not to. I had to think about that." She chose 'able' because both offices have been open during the pandemic. Another respondent said, "I mean, I did put off the joint pain surgery." But because it was technically available to her, she answered 'able.' Another respondent chose 'able' for similar reasons. He said, "I feel like if we were really pushing and wanted to find somebody that could do it, I'm sure we could have. Although it didn't take much to go 'Oh, we're not doing routine cleanings.'" Another respondent answered 'able' but added, "There are so many [doctor visits] that are voluntary that I am putting off." One respondent summed up this rationale, "The word 'able' means you want to do it and you're not able. And when I think of the dentist it wasn't so much that I needed...it was just a matter of, oh, this is just a normal routine thing. Okay, we're going to put this off because of the pandemic." Postponements in receiving healthcare are not adequately captured by this question yet may be important to measure.

Some respondents, on the other hand, did include postponement as 'unable.' For example, one respondent needed an appointment with her gynecologist but had been delaying the visit. She included this as 'unable' but added, "I guess that's by choice." She said she could get an appointment if she chose to. Another respondent with a similar experience decided to answer 'have not needed.' He described his symptoms as severe, but because he did not seek an appointment with his provider, he defined this as 'not needed.'

Finally, one respondent illustrated another judgment challenge when experiences differ by provider. She saw her dermatologist without any problems. She was, however, not able to book a Well Woman's exam. The clinic was closed for a period of time due to the pandemic. She answered 'able' thinking specifically of the dermatologist.

FEEL_DEP.

31. Since the Coronavirus pandemic began, have you felt more lonely or sad, less lonely or sad, or about the same?

- More lonely or sad**
- Less lonely or sad**
- About the same**

Changes in feelings over time: Because feelings can change over the course of the pandemic, respondents had to decide how to answer. Some decided to answer on the basis of their lowest point. One respondent said, "Sometimes it's a high and sometimes it's a low." She decided to answer 'more lonely/sad' because she thought of her worst moments. She said, "Some days or some weeks, especially during the quarantining, it did get very difficult." Another respondent also thought about the worst times and answered 'more.' She said, "I was probably lonelier at the beginning than we are now. People are more willing to meet up now." One respondent answered 'more' and acknowledged how these feelings change. She said, "But I know for sure that emotions have been all up and down." Although she said she feels more stable now, she answered for when she was feeling 'down.'

Cause of feelings: Most people who answered 'more sad/lonely' linked the cause of these feelings directly to the pandemic. Examples of their rationales include:

"Because we're all cooped up inside and we can't resume social activities. For me social activities is a big thing...I've had moments where I've felt hopeless."

“I have two elderly parents. My mom is in a nursing home and went into it about a year ago. In March we were told we couldn't visit her anymore. That has just been horrible.”

“Quarantine had me feeling a little lonely or sad. Staying home, not being able to see friends for two weeks.”

“I miss physical proximity and touching others. Like hugging my sister or my mom. I can't do that.”

“I'm not out in the community. I am not out meeting new people in my community.”

“My birthday was the week after everything shut down. I haven't been able to hang out with friends. I'm not going to events to explore my new city.”

However, a few respondents who answered ‘more sad/lonely’ were thinking of reasons unrelated to the pandemic. “A lot of it's political. And I have severe clinical depression already. And politically I'm horrified.” Another respondent also referred to world events in addition to the pandemic. When asked why she answered ‘more,’ she said, “The state of the world...the resurgence of the Black Lives Matter movement and the [expletive] election...for whatever reason it was easier to handle when life was normal.” Similarly, another explained, “There's more isolation than ever before. There's a lot of uncertainty. The political climate on top of everything.”

False assumption: Finally, some respondents argued that the question implicitly assumes a certain level of sadness or loneliness preexisted. In this context, the category ‘about the same’ implies one's level of sadness has remained constant. However, some respondents felt no sadness or loneliness to begin with. They chose ‘about the same’ as the best option to convey the absence of sadness or simply feeling ‘normal,’ but expressed the inadequacy of that category. For example, one respondent said, “The premise is, are you more lonely, less lonely or about the same. It assumes that I am lonely in the first place, which I am not.” Another said, “I was my normal self. I didn't feel lonely. I didn't feel sad. I felt normal as I always feel.” One respondent chose ‘about the same’ but argued that there have always been times when she feels sad and other times she does not. She preferred to express this as feeling normal. Similarly, another respondent answered ‘same’ “because I am not lonely. I don't have a problem with that.”

FEEL_SOC.

32. Since the Coronavirus pandemic began, have you felt more socially connected to family and friends, less socially connected to family and friends, or about the same?

- More socially connected**
- Less socially connected**
- About the same**

Respondents gave a variety of answers to this question, depending on how they interpreted ‘socially connected.’ The two main dimensions framing social connections were technology and physical contact. In either case, respondents experienced both more and less social connection.

Technology: Even though staying connected via technology often requires more effort, respondents identified it as a means by which they remained connected to friends and loved ones. As a result, some

answered 'more' or 'about the same' even when their physical presence around others had become minimal during the pandemic. Examples of respondents' rationales often included phone calls and social media:

"We've made a greater effort to stay connected, to check-in. You know, to communicate via social media, via text, phone calls. We just make a greater effort to stay connected but also checking in, make sure people are okay."

"To some degree more...I made it a point to reconnect with a lot of old friends on Facebook and phone calls."

"Before, you would run into someone and say, 'let's get lunch next week,' but now you say 'I'll call you tonight.' And then you do."

"Because we talk on the phone every day, so we are still connected. We can't physically see each other, but we talk on the phone at the same time every day."

Virtual meetings such as Zoom also factored prominently into respondents' experiences with staying socially connected:

"With the online reality, it's great. Zoom is a wonderful thing."

"It ebbs and flows. In the beginning, everybody wanted to do Zoom, but...it takes a lot of work. Maybe it works out to be the same. But I think more, maybe more."

"Definitely family Zooms."

Physical contact: Other respondents defined social connections as being physically present with people. In these cases, they made their judgments based on any increase or decrease in the amount of time they spent with family or friends during the pandemic. Some reported an increase in connections as they spend more time at home with their family. One respondent said, "I've been connecting more with my close family and close friends. Girlfriend. Learning things that I didn't know. Now that I work from home, I'm engaging with them. We have frequent lunches together... I'm getting closer to relatives." Another respondent had the same experience and said, "There was more of a togetherness. We all went into quarantine together. Built strong relationships in the house." Another also answered 'more connected' because, "Among us as a family we've spent more time together. We've gotten closer, especially my husband and my daughter. So that has been nice."

Others, however, had the opposite experience and reported less physical connection. One respondent said, "It was months before I was even able to see my own grandson in person." Another respondent also answered 'less socially connected' because she "has been getting lots of cards, but no one is visiting because I had coronavirus." Other respondents reported similar situations:

"We can't meet up. We can do, you know, social media. Or you can see someone but you have to be far away [social distancing]. I went home to see my family and I couldn't hug my grandma. I get it, but it's still sad."

“I can't hang out with friends and can't socialize with my family. I have a sister who lives in the area and we've seen each other like twice, outside, at a distance. But my family, we would do dinners together and Passover and all that. And nothing. It's hard.”

“Going from seeing friends and family like three to five times a week to like...barely [seeing them at all]. Having to cancel trips...just made me like sad not to be able to be with people.”

In thinking about physical proximity to others, some respondents noted that proximity has increased for some and decreased for others in their life. In these cases, respondents had to decide the more salient experience when answering the question. One respondent said, “I ran a drone racing club and we would meet a couple times a month and have social gatherings inside and outside and in bars. That has been put on hold. Lost all that social interaction. But being indoors all day and both my kids being home and my wife, there is a lot more interaction between us. Usually, they would be at school and I would be at work.” He answered ‘less socially connected’ thinking more about friends than home life. Another person averaged it out and answered ‘about the same.’ He said, “I guess a mixture. In some ways I’m closer to my sons because I check in every week or two weeks, which I had not done as much before. But I’m less for all these people I can’t see, so I guess they balance each other.”