

Collaborating Center for Questionnaire Design and Evaluation Research

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Cognitive Interview Evaluation of Questions on Attention Deficit/Hyperactivity Disorder

By: Ann MacFadyen, PhD, Amanda Wilmot, PhD

INTRODUCTION

This report summarizes findings from a cognitive interview evaluation of questions on Attention Deficit/Hyperactivity Disorder (ADHD) for the National Health Interview Survey (NHIS). The study was conducted by staff at the National Center for Health Statistics' (NCHS) Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) using interpretive cognitive interview methodology. It was carried out in collaboration with the Child Development and Disability Branch in the Division of Human Development and Disability at the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention.

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ADHD is a common neurodevelopmental condition affecting many children and adults (1). While symptoms develop during childhood, they often continue into adulthood. In 2023, data from the NCHS Rapid Surveys System-2 indicated that an estimated 15.5 million adults in the U.S. had a current ADHD diagnosis, half of whom were diagnosed as adults (2). This prevalence rate highlights the magnitude of ADHD as a public health concern. As part of an effort to improve national-level data for adults with ADHD, CCQDER evaluated questions on adult ADHD for use on national surveys, particularly the NHIS. New insights into ADHD treatment and diagnosis in adults, as well as how ADHD may affect daily functioning, may improve understanding of potential gaps or delays in diagnosis and the scale of treatment needs across the U.S.

The term Attention Deficit Disorder (ADD) falls under the broader category of ADHD and is no longer used as a medical diagnosis. This report uses “ADHD” unless “ADD” is indicated directly by a survey question or a respondent’s statement.

The NHIS is an interviewer-administered nationally representative household survey with the main objective of monitoring the health of the U.S population through the collection and analysis of data on a range of health topics (3). The evaluation of new or modified questions for the NHIS can help to reduce the potential for measurement error and evaluates whether the questions accurately capture the intended constructs.

This evaluation study is based on 34 cognitive interviews with English-speaking adult respondents, conducted remotely using Zoom for Government from mid-2024 to early 2025. This report includes a description of the



methodology used in the study as well as results. A detailed summary of findings on a question-by-question basis is included in Appendix 1. The full set of tested questions is included in Appendices 2-4.

METHODOLOGY

Cognitive interviewing

This question evaluation study utilized one-on-one cognitive interviews. CCQDER uses cognitive interviewing methodology to gain an understanding of the mental processes that respondents go through when answering the survey questions, within the context of their individual life circumstances (4). This method allows researchers to explore construct validity, identify any difficulties respondents encounter in understanding and answering survey questions, and uncover potential sources of response error (5). Ultimately, the findings from the cognitive interviews help in determining whether questions may be prone to measurement error when administered in a survey. This study received both Office of Management and Budget (OMB) and NCHS/CDC Human Subjects approval.

Study sample and respondent recruitment

In total, 34 cognitive interviews were conducted in English with adult respondents, aged 18 or over. A purposive sample was recruited by CCQDER Operations staff from advertisements emailed to members of CCQDER's respondent database, placed on websites such as Reddit and Craig's list, or recruited by word-of-mouth. With a purposive sample, the aim is not to produce a statistically representative sample or draw statistical inference. Rather, the characteristics of the individual are used as the basis for sample selection, most often chosen to reflect the population under investigation.

Respondents represented those who both did and did not have a medical diagnosis of ADHD, as well as a range of ages at diagnosis and treatment approaches. The focus of the sample was primarily on people with medically diagnosed ADHD, meaning that a doctor or other health professional had told them they had ADHD at some point in their life, and they considered that diagnosis current. In addition, some respondents were recruited because they suspected that they had ADHD, even though they have not been formally diagnosed. People who suspected they had ADHD felt they displayed symptoms of ADHD and considered themselves to have the condition, even without medical confirmation. Finally, a small number of respondents were recruited who did not have or suspect they had ADHD.

Respondents who took part were located in different states across the United States, including Arizona, California, Florida, Georgia, Kansas, Maryland, Minnesota, New Jersey, New York, North Carolina, Ohio, South Dakota, Texas, West Virginia and in the District of Columbia.

Care was taken to recruit a sample with a wide variety of demographic characteristics, to the extent possible. The table below shows the overall achieved sample distribution by key characteristics.

Table 1. Sample Characteristics

Demographics	Number (N=34)
Age group in years	
18-29	5
30-49	17
50-64	10
65 and older	2
Sex	
Female	14
Male	19
No response	1
Education	
Less than high school (HS) Diploma/GED	0
HS Diploma/GED	12
2- or 4-year college degree	15
Graduate degree	7
Race/Ethnicity	
Non-Hispanic	32
Asian	3
Black or African-American	15
White	12
Middle East and North African	1
Multiple race groups	1
Hispanic	2
Self-reported ADHD	
Has ADHD	21
Suspects ADHD	9
Does not have ADHD	4

Source: National Center for Health Statistics, Collaborating Center for Questionnaire Design and Evaluation Research, 2025

Data collection

Interviews were no longer than one hour, and they were conducted remotely using Zoom for Government. All respondents completed confidentiality paperwork before the interview began, and respondents received a \$50 remuneration.

The questions were first read aloud to respondents by the interviewer as written. ‘Don’t know’ and ‘Refusal’ codes were available to interviews to use if respondents spontaneously answered in that way, but these responses were not read out to respondents, consistent with the way questions are asked by NHIS interviewers.

CCQDER utilizes an interpretivist approach to cognitive interviewing which focuses on how respondents’ life experiences inform their answers to survey questions. Therefore, staff relied on unscripted, emergent verbal probing to fill in gaps in the respondents’ narratives and to ascertain respondents’ circumstances that inform how and why they answered a question the way they did (6). A mix of retrospective and concurrent probing was used – depending on which was most appropriate for the individual respondent.

The questions were tested iteratively across three rounds of interviewing, allowing for evaluation of any

changes made to questions between rounds. Each round of interviewing was comprised of a separate sample of respondents. Round 1, 2, and 3 were comprised of seven, 17, and ten interviews, respectively. The questionnaires for each round are included in the appendices of this report. Where relevant to question performance, discussion of the question changes is included in the question-by-question summaries in Appendix 1.

Data analysis and reporting

Analysis of cognitive interview data followed a systematic approach of data reduction and synthesis. The approach aims to identify patterns in the way respondents interpret the questions, based on empirical data. With consent, all interviews were video- and audio-recorded. Interviewers created summary notes about the way in which respondents interpreted and responded to the survey questions from the recordings, evidenced by verbatim statements made by respondents during the interview and observation of non-verbal behaviors. The summary notes were organized by question and entered into CCQDER's Q-Notes software (7). Respondent confidentiality was maintained throughout the analytical process. Where this report refers to verbatim statements, the respondent's accounts are italicized.

Results

Findings and themes that emerged and are applicable across multiple questions are presented in this section. A detailed question-by-question analysis of findings can be found in Appendix 1.

Age when Diagnosed

Respondents who were diagnosed as children had a different diagnosis process than those who were diagnosed as adults. They explained that parents or teachers initially noticed symptoms of inattention, hyperactivity, or impulsivity, and a diagnosis process was then started on their behalf. Therefore, respondents who had been diagnosed as children sometimes had a difficult time remembering the exact sequence of events, how old they were at the time (Question 4), or even who initially told them they had ADHD (Question 5), as it was many years prior. Also, some respondents did not understand or were not privy to the full extent of their diagnoses until later in life, when it was revealed to them by their parents, further complicating recall. For instance, one respondent explained that his parents hid his diagnosis of combined genetic disorder and ADHD from him until he accidentally found out when he was in high school.

Respondents who had been diagnosed as adults, tended to have greater agency in their diagnosis processes, and thus more accurate recall of the event, even when their diagnosis process was complex. Some respondents were diagnosed with ADHD by chance, while being treated for another condition. In other cases, respondents diagnosed as adults reported having a period of stress or difficulty in their lives that led them to speak about their difficulties with their primary care doctor, who then referred them to a specialist. Additionally, some also went through a period of suspecting they had ADHD before actively seeking out treatment, sometimes seeking multiple opinions.

Many respondents who were diagnosed in adulthood also noted that prior childhood struggles suddenly made sense to them in hindsight. As one respondent explained, *"Looking back on it it's obvious [...] I was always good at school – so if you get good grades and everything – but I guess it started being more of a struggle especially as I got older, especially with college, to keep up with everything."* However, that hindsight, and the changes in accepted terminology over time, sometimes made it difficult for respondents to clearly

identify who had first told them they had ADHD (Question 5). As one respondent, who said “Don’t know” to Question 5 explained,

Do you mean the symptoms or that they said the words ‘ADHD’? [...] I’ll push back on that question because the whole neurodiverse world is out there for discussion now. And, I’m going to be 65. This was not acceptable [before]. Even until my daughter being able to get accommodations. People were still viewing people with ADHD or anyone with ADD in a negative vein. There was caution. People didn’t want to put it in your record because it was seen as a negative.

In this respondent’s case, despite knowing her diagnosis story clearly, she was unable to ascertain the meaning of Question 5, “Who first told you that you had ADHD or ADD?” within the context of her age and her diagnosis experience.

Attribution of Difficulties to ADHD

When answering questions related to day-to-day difficulties (Question series 13 and 14), respondents needed to assess two things at once: 1) whether they had difficulty with the task asked in the question and 2) whether they attributed that difficulty to their ADHD. Some respondents were not able to determine clearly if their difficulty was due to their ADHD, their general personality, or some other condition. For example, one respondent who said that she did have difficulty with seeking medical treatment for other conditions (Question 13a) explained, “*Pretty much [...] and also anxiety about it – I don’t like making phone calls, like talking on the phone and just putting it off.*” In other cases, however, respondents were more confident separating their active decisions from ADHD symptoms. For example, when asked if they had difficulty eating healthy foods due to their ADHD (Question 14a), respondents considered their day-to-day diet and whether they felt control over their decisions or if they felt their impulsivity tended to take over. As one respondent who said “No” to Question 14a said, “*I ate a key lime pie yesterday. That was all me.*” Whereas, another respondent answered, “*I don’t know if that is part of my ADHD, but maybe, because sometimes I’ll just eat a donut because it’s easier.*”

Respondents who suspected they had ADHD through self-diagnosis tended to have gone through a realization about themselves in adulthood. Some were told by a family member or friend that they might have ADHD, and some had concluded that they must have ADHD after completing online self-assessments or researching online. The degree of confidence that this group of respondents had in their suspicions was an important factor in the way they considered and responded to questions about having ADHD (Question 2) and attributing functional difficulties to their ADHD (Question series 13 and 14). While this group is screened out of the NHIS series of questions, if they are screened into other surveys, their range of considerations and responses may affect the resulting data.

Perspectives on Medical Intervention

While most respondents answered symptoms questions based on their “*medicated self*,” some felt that the improvement in their overall severity when taking medications was so notable, that it was, at times, difficult for them to answer questions about their symptom frequency and severity. When asked to rank the severity of her current ADHD (Question 2a) one respondent, who ultimately answered “Don’t know,” explained her thought process in the following way: “*Uh, with or without medication? [...] with medication – mild. And without medication – severe [...] If it was multiple select, I would try to circle both. But if there was a neutral or ‘not sure’ I would put it in the middle as neutral.*”

Other respondents specifically avoided seeking out medical treatments or professional help of any kind for their ADHD due to various medical-related fears. Some were afraid or embarrassed to have a diagnosis permanently on their medical file. Some feared being put on medication. This phenomenon of medical avoidance occurred in both respondents with and without an official diagnosis. This fear impacted the way respondents understood and answered certain questions, such as those about speaking with medical professionals (Question 1, Question 3) or taking medications of any kind (Question 7, Question 13c). For example, one self-diagnosed respondent explained that she had no interest in taking pills or being labeled with a “disease,” and so she avoided talking with her doctor about ADHD at all, thus limiting herself from other types of treatments. She said,

I think I can manage it myself somehow, and I don't want to take drugs. Like, I don't want to take pills for it. Plus, I don't want it to be on my file – you know another ‘diagnosis.’ I don't want to put names down next to it – you know – names of diseases next to me.

Similarly, another respondent, who had been diagnosed by her doctor, feared being labeled with a condition on her medical record. She explained herself in terms of being a black woman in her 70s:

I would say I've been formally diagnosed. But I've never been...it's never been put in writing, and I've never been told that I need to be on medication for it. And let me just say this: For my generation, that's really not the words they would use back then in the black community, when you were diagnosed with anything – still to this day in many cases – you were given a stigma which meant something was wrong with you.

Another respondent, who had been overly medicated as a child diagnosed with ADHD, said, he had not spoken to a doctor about his ADHD since he was in high school. He explained, “*I didn't feel like talking about it after that, because I didn't want to risk them putting me on medication.*” Therefore, when asked if he had ever spoken with a doctor or other health professional about ADHD (Question 3), he took the question as referring to his adult life, when he had the agency and choice to avoid doctors. He answered, “*Not recently, no.*”

Questions selected for inclusion in the 2025 NHIS

Following the first two rounds of interviewing, the collaborating study partners finalized content and wording for five questions that were included on the 2025 NHIS. That wording was then evaluated in Round 3. NHIS variable names are shown below and in Appendix 1 in brackets following the questionnaire number. These evaluated NHIS questions included the following:

- **Question 1 [ADHDEV_A]** (Has a doctor or other health professional ever told you that you had Attention Deficit/Hyperactivity Disorder or ADHD or Attention-Deficit Disorder or ADD?)
- **Question 2 [ADHDNW_A]** (Do you currently have Attention-Deficit/Hyperactivity Disorder or ADHD or Attention Deficit Disorder or ADD?)
- **Question 4 [ADHDAGE_A]** (How old were you when a doctor or other health professional FIRST told you that you had Attention-Deficit/Hyperactivity Disorder or ADHD or Attention Deficit Disorder or ADD?)
- **Question 7 [ADHDMED_A]** (Do you currently take prescription medication for your ADHD or ADD?)
- **Question 8 [ADHDTHRPY_A]** (During the past 12 months, did you receive counseling, therapy, or behavioral treatment for your ADHD or ADD?)

Overall, these questions captured the intended constructs, particularly for respondents who answered “Yes” to Question 1 [ADHDEV_A], indicating that they had received a medical diagnosis during their life. These respondents generally had a clear understanding of their condition and the medications and other treatments they had received for their condition, and they answered the following four questions with consistent considerations and without response error.

One notable case was a respondent who had been diagnosed as a child but felt he that his diagnosis was no longer current. His symptoms had improved since the age of 15 when he stopped taking prescription medication for his ADHD, and he answered “Don’t know” to Question 2 [ADHDNW_A] (about whether he currently had ADHD), as an accurate reflection of feelings about his ADHD. He explained that his home environment had improved greatly since childhood and, *“now I am more able to focus on my own accord.”* Additionally, he was able to provide answers to Questions 4 [ADHDAGE_A], 7 [ADHDMED_A], and 8 [ADHDTHRPY_A], based on his experience with medical care for his ADHD as a child.

Furthermore, respondents who had never received a diagnosis for ADHD, but suspected they had ADHD through self-diagnosis, consistently answered “No” to Question 1 [ADHDEV_A], as well as those respondents who did not suspect they had ADHD and had not been diagnosed previously.

In the 2025 NHIS, only those answering “Yes” to Question 1 [ADHDEV_A] received the remaining ADHD questions. Those answering “No,” “Don’t know,” or “Refused” all skipped to the next section. For the purposes of this evaluation study, all respondents were asked Question 2 [ADHDNW_A], including those without a diagnosis who suspected they may have ADHD based on their experience with common symptoms. Respondents without a medical diagnosis for their suspected ADHD answered questions inconsistently, and if they were included in a large-scale sample, those inconsistencies would likely affect the resulting data. For a detailed summary of question considerations for people who suspected they had ADHD, refer to Appendix 1.

Conclusion

This cognitive interview study serves as a validity study of the proposed ADHD survey questions, including the five questions that were included on the NHIS. This evaluation updated the wording of some questions utilized in the NCHS Rapid Survey System-2 for inclusion on the 2025 NHIS, including questions on diagnosis, age at diagnosis, treatment through counseling or therapy, and treatment through prescription medications. The study explored the constructs captured by the survey questions and highlighted how respondents interpreted and responded to them. Using interpretive cognitive interviewing methodology, this study identified patterns in responses, the effects of respondent personal and social context, and sources of potential response error. For respondents who had received a medical diagnosis of ADHD, the proposed NHIS questions performed well, in that respondents had consistent interpretations of the questions and answered without response error. For questions which address difficulties in day-to-day life, differences in the age at which respondents were diagnosed, if they were in fact diagnosed, affected whether they attributed those difficulties to their ADHD. And, respondent perspectives on the relative risks and benefits of medical interventions contributed in part to how they considered and responded to questions about diagnosis and treatment.

The study provides information about occurrences of out-of-scope, unintended interpretations, which is key for understanding the extent to which questions capture the intended constructs. These findings are valuable to data users, who can use the information in this report to better understand and interpret survey results by understanding how different groups of respondents process and answer survey questions.

Works Cited

1. National Center for Birth Defects and Developmental Disabilities. About Attention-Deficit/Hyperactivity Disorder (ADHD): Centers for Disease Control and Prevention; 2024 [Available from: <https://www.cdc.gov/adhd/about/index.html>.]
2. Staley BS. Attention-Deficit/Hyperactivity disorder diagnosis, treatment, and telehealth use in adults—national center for health statistics rapid surveys system, United States, October–November 2023. MMWR Morbidity and Mortality Weekly Report. 2024;73.
3. National Center for Health Statistics. About NHIS: Centers for Disease Control and Prevention; 2024 [Available from: <https://www.cdc.gov/nchs/nhis/about/index.html>.]
4. Miller K. Cognitive Interviewing. In: Madans J, Miller K, Maitland A, Willis G, editors. Question Evaluation Methods. Hoboken, NJ: Wiley; 2011. p. 49-75.
5. Miller K. Introduction. In: Miller K, Willson S, Chepp V, Padilla J-L, editors. Cognitive Interviewing Methodology Hoboken, NJ: Wiley; 2014. p. 1-5.
6. Cibelli K, de Jong J. Cognitive Interviewing. Guidelines for Best Practice in Cross-Cultural Surveys. Ann Arbor, MI: Survey Research Center, Institute for Social Research, University of Michigan; 2020 [Available from: <https://ccsg.isr.umich.edu/chapters/pretesting/cognitive-interviewing/>]
7. National Center for Health Statistics. CCQDER Products; 2024 [Available from: <https://www.cdc.gov/nchs/ccqder/technology-products/index.html>.]

Appendix 1: Question-by-Question Summaries

This Appendix provides a summary of findings for each evaluated question. The data collection for this study occurred over three rounds of interviewing. The question-by-question summaries show the final tested questions from Round 3, and they are presented in the order in which they were administered in Round 3. The findings are reported across all rounds of interviewing, except where the changes to the questions impacted the respondents' interpretations and response. Where relevant, the report explains the changes to the questions and the effects of those changes. Where respondents are quoted directly, their verbatim statements are italicized.

Question 1 [ADHDEV_A]

Has a doctor or other health professional ever told you that you had Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?

1. Yes
2. No

This question was evaluated for inclusion on the NHIS. All respondents received this question, and they considered whether they had been told by a health professional that they had either ADHD or ADD. No one answered “Don’t know” or said that they were unsure how to answer. The health professionals that respondents considered included the following: psychiatrists, psychologists, primary care physicians, behavioral health therapists, and, in one case, a school nurse.

All respondents who considered themselves to have a diagnosis of ADHD answered “Yes” to this question. Additionally, respondents who had been diagnosed as children, answered ‘Yes’ to this question, even if their parents or guardians had spoken with the health professional. As one respondent explained, *“Yes...but it wasn’t necessarily directly me. I was 5 or 6 at the time. It was my mom and dad that told me. I was a minor – and my guardian was told at the time.”*

Respondents who answered “Yes” included those who had gone through formal “tests” for ADHD as well as others who were told by their doctor or psychiatrist that they had ADHD but were not tested further. Respondents who had not undergone the additional testing did not consistently consider themselves to have official diagnoses of ADHD.

Those who answered “No” had never been told by a health professional that they had ADHD. Although in a few cases, they suspected they might have ADHD or had been told by family members, friends or coworkers. As one person said, *“No, just my neighbor.”* Another person who answered “No” explained, *“Nobody told me. I’m just following social media. People started coming out with their experiences their life. And I was like, oh this is me.”*

Question 1a

Since the time you were first diagnosed, has your diagnosis of ADHD or ADD changed?

1. Yes
2. No

Respondents received this question if they answered “Yes” to Question 1 (“Has a doctor or other health professional ever told you that you have Attention Deficit/Hyperactivity Disorder, or ADHD or Attention Deficit Disorder or ADD?”). Respondents interpreted the question in one of two ways, which affected their answers. First, some respondents chose answers based on whether their medical diagnosis had been updated or altered since they were initially told they had ADHD. Second, other respondents chose their answers based on whether their experience of their diagnosis – their symptom severity – had changed since they were first told they had ADHD.

All respondents who did have an update to their diagnosis answered “Yes.” For example, one respondent, who was diagnosed with a genetic disorder as a comorbidity with his ADHD about nine years after his initial diagnosis of ADHD, said, *“It’s not just the ADHD anymore. It’s this because of this – it’s this with this.”*

However, there were also cases where respondents answered “Yes” or “No” because their symptoms had either changed or stayed the same over time, though their diagnoses of record had not changed. A respondent who answered “Yes” explained the improvement of his symptoms in the following way: *“Yes I think it has changed a lot, because before even I was diagnosed [...] it was very difficult to stay focused and now I can do one thing until the end.”*

Changes to the Question Wording

Respondents in Rounds 1 and 2 received a different version of the question: “Since the time you were first diagnosed, have you always had ADHD?” Except for one respondent who answered “Don’t know,” those with ADHD answered “Yes.” However, several respondents were unsure of the purpose of the question. Some respondents wondered if the question implied there was a cure for ADHD. Others interpreted the question as asking if they always had ADHD, even before they were diagnosed. For example, one respondent noted, *“Yes, I would imagine...I mean there was no such thing as ADHD when I was young...knowing what I know now I would say ‘Yes’.”* Also considering her time prior to a medical diagnosis as an adult, a respondent who answered “Don’t know” explained, *“I don’t know. I don’t know if I had already had it or if it was diagnosed with it after everything had gone down. That’s tough question I don’t remember my childhood that clearly.”*

The question change for Round 3 clarified the question intent for most respondents, however as noted above, some respondents in Round 3 answered based on symptom severity, an out-of-scope interpretation.

Question 1b

When your symptoms were at their worst, how would you describe your ADHD?

1. Mild
2. Moderate
3. Severe

Respondents were asked this question if they answered “Yes” to Question 1 (“Has a doctor or other health professional ever told you that you have Attention Deficit/Hyperactivity Disorder, or ADHD or Attention Deficit Disorder or ADD?”). Respondents consistently considered the time in their life with the most severe symptoms to determine their answers.

No respondents selected “Mild” to this version of the question. Those who answered “Moderate” considered their most severe symptoms to be challenging, but overall tolerable. For example, one respondent explained their answer of “Moderate” in the following way: *“Because it’s like before I didn’t realize I had ADHD. So the things I was doing, I just viewed them as normal – being forgetful and things like that. So, it’s moderate.”* Whereas respondents who answered ‘Severe’ spoke about more extreme experiences. They spoke about feeling *“in total disarray”* or like they were *“drowning.”*

One respondent had difficulty rating herself because she did not want to blame her ADHD when she was late for work or faced other repercussions in her life. She answered, “Don’t know,” and said, *“How would you classify it to be when it’s actually an interference in your life or your job? [...] Like, how would you classify that, because I don’t know.”*

Across all rounds, respondents appeared to differentiate between symptoms that were considered “Mild,” “Moderate,” or “Severe.” Those who answered “Mild” to a prior version (in Round 1, see below) described symptoms of irritability, tiredness, poor attention, fidgeting and task prioritization. Across all rounds, those who selected “Moderate” mentioned memory issues, hyperactive and being *“scatterbrained,”* and those who described their symptoms as “Severe” talked about feeling that they were unable to control them.

Changes to the question wording

Following Round 1 interviewing, the question stem was changed to specify all respondents to answer on the same basis, by rating the severity of their symptoms when they were at their worst. Round 1 wording was the following: “How would you describe your ADHD?” Round 1 respondents responded based on their current symptoms, though they noted variability overall, with some days better than others. As one respondent described, *“Um, it varies on the day... I guess mild.”* The question update was successful as evidenced by respondents’ consistent anchoring of

their responses to the time when their symptoms were at their worst in Rounds 2 and 3. No respondents selected “Mild” in Rounds 2 or 3.

Question 1c

Has the severity of your ADHD or ADD changed a lot over the years, such as getting better and/or worse over time?

1. Yes
2. No

Respondents were asked this question if they answered “Yes” to Question 1 (“Has a doctor or other health professional ever told you that you have Attention Deficit/Hyperactivity Disorder, or ADHD or Attention Deficit Disorder or ADD?”). Respondents viewed this question as asking if there was variation in the severity of their symptoms over long periods of time. When describing their answers, respondents either referred to the time of their diagnosis or they thought as far back as they could remember their symptoms bothering them. Then, they considered their symptom severity since that time.

All respondents with diagnosed ADHD in Round 3 answered “Yes” to this question. However, in some cases, respondents initially answered ‘better’ or ‘worse’ before being prompted to answer either “Yes” or “No.” As one respondent said, *“I would say it got worse over time until I went to see the doctor.”* Another said, *“A little bit of both,”* before being responding “Yes.”

Changes to the question wording

The wording of this question was changed between Rounds 1 and 2 and also between Rounds 2 and 3. Respondents in both Rounds 1 and 2 interpreted the question in one of two ways: either as asking 1) if their symptoms fluctuate (with ups and downs) in the present day or, 2) if their symptoms have gotten better or worse over time. For instance, one respondent, who interpreted the question in the first way, explained, *“No not really...So because I’m currently medicated so with that I say that my ADHD is pretty steady while my meds are in my system and working.”* Whereas another respondent, considering the question in the second way, explained his answer ‘Yes’ in the following way: *“Um. I would say as I’m getting older it’s getting better.”*

Following changes for Round 3, respondents consistently understood the question to be asking about changes over the course of their lives.

Question 2 [ADHDNW_A]

Do you currently have Attention-Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?

1. Yes
2. No

This question was evaluated for inclusion on the NHIS. On the 2025 NHIS, only respondents who had been told by a doctor or other health professional that they had ADHD, by answering “Yes” to Question 1 (Has a doctor or other health professional ever told you that you had Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?), received this question. For the purposes of this evaluation project, all respondents received this question irrespective of whether they had been told by a health professional that they had ADHD. In so doing, the evaluation included people who suspected or thought they had ADHD, despite not having a formal diagnosis. Across all rounds of interviewing, respondents answered based on whether they considered themselves to currently have ADHD or ADD. Factors that respondents considered when determining if they currently had ADHD or ADD included the following: whether they had a medical diagnosis, how long ago that diagnosis occurred, and whether they were experiencing day-to-day symptoms that they attributed to ADHD.

Two groups of respondents answered this question consistently. First, respondents with current, up-to-date medical diagnoses answered “Yes.” Second, respondents who were confident that they did not have ADHD symptoms, or any medical diagnoses, answered “No.”

There was inconsistency, however, in the way two other groups of respondents answered the question. People who felt they were experiencing symptoms related to ADHD, but who did not have the confirmation of a medical diagnosis answered inconsistently – either “Yes,” “No,” or “Don’t know.” For instance, one respondent who answered “Yes” said, *“I would say ‘yes’. But that is not diagnosis. I mean look. I’m just fidgeting like doing this.”* Another group of people who answered inconsistently, either “Yes” or “Don’t know,” were those who received a medical diagnosis in the past, but they did not feel confident that the diagnosis was still current. For example, one respondent in this group who answered “Yes” did feel day-to-day symptoms that he attributed to ADHD. Whereas, the other two in this group who answered, “Don’t know,” felt that their past diagnoses were out of date due to changes in their personal context or medical care. As one respondent explained, her current psychiatrist, *“...kinda put me in a different category with mental disorders and now I’m diagnosed with something else, so I don’t know if I currently have it or not.”*

Figure 1 below shows the four groups of people and their associated answers they selected.

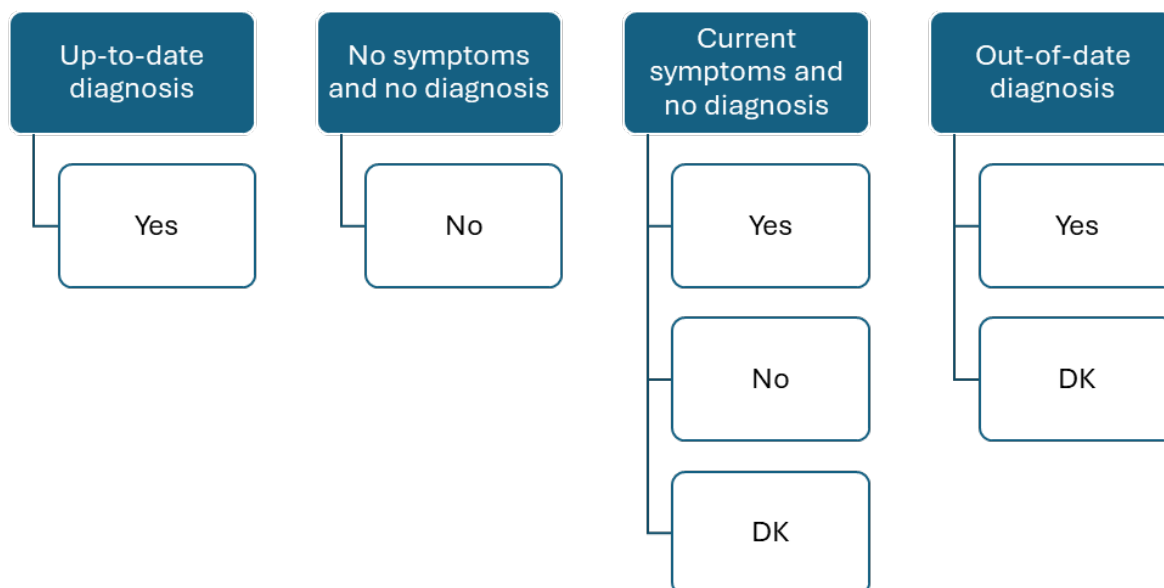


Figure 1. Answers by respondent group for Question 2

Changes to the question wording

The prior version of the question, used for Rounds 1 and 2, did not include the acronym ADD, and some respondents were confused how to answer. As one respondent said, *“I do not know, I always thought it was ADD. I was never hyperactive as a child and I’m not hyper now.”* Following the wording updates, there were no occurrences of such confusion in Round 3.

Question 2a

Would you describe your current ADHD or ADD as mild, moderate, or severe?

1. Mild
2. Moderate
3. Severe

Respondents were asked this question if they answered “Yes” to Question 2 (“Do you currently have Attention-Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”). Respondents generally understood the question to be asking them to rate the symptoms they generally experience nowadays, averaging their experiences across a given day. The classification from respondents was subjective to their experience and self-rated. In fact, one respondent noted, *“I don’t think anyone [any doctor] has put it in terms like that...If anything you might hear ‘mild depression’ but not ‘mild ADD or mild ADHD’ you kind of just have it.”*

The self-classifications of “Mild,” “Moderate,” or “Severe” was not always clearly delineated or mutually exclusive. This differs from the clear delineation of symptom severity represented in Question 1b (When your symptoms were at their worst, how would you describe your ADHD?). However, there were overarching patterns in the way respondents classified themselves.

Respondents who selected “Mild” explained that they had learned to control their symptoms, or their symptoms were controlled with medication most of the time:

“I’m doing my tasks with very little effort or little distraction pulling me away from it. I think I’m doing pretty good, so I guess that would make it mild.”

“Yeah medicated and while the medicine is in my system [it is mild]. But when it wears off or days I forget to take it, it is moderate to severe.”

Respondents selected “Moderate” on a similar basis as those who selected “Mild,” though they often compared themselves to their own prior or unmedicated “Severe” state or the idea of a “Severe” state. As one respondent explained, *“Well it’s not mild by any means. ‘Moderate’ in that it impacts me daily, and if I do not keep my habits and structures around me built up and supported and they start to tumble, then it becomes severe.”* Another respondent explained, *“Well, the higher moderate side, I guess. I don’t want to use the word ‘severe’ because I’m sure there are people who have worse symptoms than me. And I don’t like to think that I’m the worst.”*

Just one respondent selected the category “Severe” when responding to this question, explaining that her ADHD symptoms impacted all aspects of her life: *“Even when I’m watching a movie I want to watch...”* This respondent had not been told by a health professional that she had ADHD, but rather she had been told by a trusted friend, and the respondent suspected that she had ADHD. This respondent talked about how even simple tasks such as *“...brushing my teeth, taking a shower, the laundry”*, could turn into *“...this big imposing thing.”*

A few respondents were not able to select a classification of “Mild,” “Moderate,” or “Severe” because their symptoms varied in severity throughout the day. For example, one respondent explained, *“I don’t know! [...] It means I have to interpret who I am at any moment.”* Likewise, another respondent explained that her symptoms vary throughout the day, because she used medication to mediate them. She wondered, *“Uh, with or without medication?”*

Question 2b

What are the reasons why you do not currently have ADHD or ADD? [select all that apply]

1. Condition seemed to go away on its own
2. Treatment helped the condition to go away.
3. Coping strategies helped the condition go away

4. A doctor or health care provider changed the diagnosis
5. Other reason [free response]

This question was not evaluated. This question was intended for respondents who answered “Yes” to Question 1 (“Has a doctor or other health professional ever told you that you had Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”) and “No” to Question 2 (“Do you currently have Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”). No respondents fit those parameters across the three rounds of data collection.

Question 3

Have you ever talked with a doctor or other health professional about whether you have ADHD or ADD?

1. Yes
2. No
3. I wanted to, but was not able to do so

All respondents were asked this question. Across all rounds, respondents answered based on whether they had spoken at least once with a health professional about the possibility of having ADHD, including their symptoms, their concerns, or, for some, their diagnosis. The health professionals that respondents thought of included primary care physicians, nurse practitioners, psychiatrists, and psychologists.

Respondents who answered “Yes” said that they had spoken at least once, sometimes multiple times, with a health professional about having ADHD. Some, but not all, of the respondents who spoke with a doctor or other health professional were eventually diagnosed with ADHD. As one respondent explained, *“I have talked to a doctor and my therapist about it, but I was never diagnosed.”* Whereas, another person said, *“I was 12 years old when the first time my doctor told me I had ADHD.”*

Respondents who answered “No” included people who never suspected they had ADHD at all, as well as respondents who suspected they had symptoms of ADHD, but they did not speak with a health professional about those suspicions. For example, one respondent who suspected she had ADHD said, *“I haven’t gotten there yet. I think I can manage it myself somehow, and I don’t want to take drugs.”* One respondent answered “No” despite describing her symptoms to her doctor. But she did not feel comfortable enough to bring up ADHD by name with her doctor, so she selected “No.”

Additionally, in one case, a Round 3 respondent who had been diagnosed as a child and had not spoken recently to a doctor as an adult also answered ‘No.’ He said, *“Not recently, no.”* In Round 3 only, this question was placed after respondents already answered about whether a doctor or other

health professional told them they had ADHD or ADD (Question 1), and the order may have affected this respondent's consideration, along with the respondent's strong aversion to medical doctors. This type of error can be avoided by not asking this question of people who were told by a doctor that they had ADHD, as it would be redundant. Indeed, this question was not included in the 2025 NHIS series of adult ADHD questions.

One respondent answered, "I wanted to but was not able to do so." The respondent had taken an online screening test provided by their health provider which determined anxiety and depression rather than ADHD: *"I've attempted to but from what I can remember instead of being screened for ADHD I got screened for anxiety and depression instead."*

Question 3a

Why did you not talk with a doctor or other health professional about whether you have ADHD or ADD?

1. I did not suspect I had ADHD or was not concerned
2. I did not have health insurance, or enough insurance coverage
3. My doctor does not provide care or referrals for ADHD
4. I did not know what doctor to ask
5. I managed my symptoms myself
6. I was worried about being labeled "ADHD"
7. Other reasons (Please specify: _____)

This question was asked of respondents who answered either "No" or "I wanted to, but was not able to do so" to Question 3 ("Have you ever talked with a doctor or other health professional about whether you have ADHD or ADD?"). The response categories were reworded and reordered after both Round 1 and Round 2 to make the response options more mutually exclusive, to best capture relevant reasons that respondents had not spoken with a health professional about ADHD, and to reduce instances of respondents selecting "Other (Please Specify)."

The response option "I did not suspect I had ADHD or was not concerned" was added between Rounds 1 and 2. Following that update, all respondents who did not suspect they had ADHD, and therefore had never spoken to a health professional about it, selected that response option. Additionally, that response option was moved to the top of the list, as it was the most common reason respondents did not seek out medical consultation for ADHD.

Respondents who suspected they had ADHD but had not spoken with a doctor selected a variety of responses relevant to their experience. For example, a few respondents selected "I was worried about being labeled ADHD" based on feelings of stigma they had previously experienced for other conditions. One respondent explained, *"I don't want to take pills for it. Plus, I don't want it to be on my file – you know another 'diagnosis.' I don't want to put names down next to it – you know –*

names of diseases next to me.”

One Round 2 respondent, who selected “Did not have a doctor to ask,” explained, *“I’ll go with ‘did not have a doctor’ at the time, to be honest. I’m the kind of person that would not go a doctor until I was dying.”* Not only did the respondent not have a doctor, they also did not have insurance and did not intend to seek out treatment. In response, the options were edited following Round 2 to reduce redundancies and specifically ascertain whether lack of insurance coverage was the primary limitation for speaking to a doctor.

Feelings of dismissal by the medical community, and resentment towards it, were captured by respondent answers in a few ways. One respondent selected “I managed my symptoms without getting a formal diagnosis” (Round 2) while another selected “Other reasons (Please Specify)” (Round 3). The Round 2 respondent said, *“I was dismissed then I was not interested in getting it checked out again.”* The Round 3 respondent noted, *“I wasn’t able to put it across because I wasn’t comfortable.”*

Question 4 [ADHDAGE_A]

How old were you when a doctor or other health professional FIRST told you that you had Attention-Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?

_____ Age in years

INTERVIEWER: PROMPT IF NECESSARY

- When you were 6 years old or younger
- When you were 7-12 years old
- When you were 13-17 years old
- When you were 18 years old or older

This question was evaluated for inclusion on the NHIS. The question is intended for people who answered “Yes” to Question 1 (“Have you ever been told by a doctor or other health professional that you had Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”).

Respondent considered their age at diagnosis when answering this question in Round 3¹. This was the case for respondents who had been diagnosed as children or as adults. One respondent who had been diagnosed as a child first answered *“third grade”* rather than an age, as that was most memorable to him. Some other respondents gave a narrow range of ages: *“five or six”* and *“30 or 31,”* for example.

¹ Respondents in Rounds 1 and 2 received a different version of the question which was not specifically linked to health professionals: ‘How old were you when you were first told you had ADHD?’

Changes to the question wording

In Rounds 1 and 2, the question universe was broader than in Round 3, as it included people who suspected they had ADHD or ADD, but who did not necessarily have a medical diagnosis. The wording was the following: “How old were you when you were first told you had ADHD?”

Respondents who both did and did not have a medical diagnosis considered the first time they were told by anyone that they had, or might have, ADHD. One respondent answered based on the age at which she was told by a coworker. The respondent explained, *“I too was just all over the place. I never sat still to do anything but eat. And she said, ‘I really think you are suffering from ADHD.’”*

The question was hard for some respondents to answer because they had been told about their symptoms or told they were *‘hyper,’* but they had not been told they had ADHD in those exact terms until much later in life. The updates for Round 3 narrowed the scope of the question and clarified the intent for respondents.

Question 5

Who first told you that you had ADHD or ADD?

- Pediatrician
- Primary care doctor (family medicine, internal medicine)
- Psychiatrist
- Nurse practitioner
- School psychologist or counselor
- Psychologist outside of school
- Teacher
- I was told by a parent/caregiver
- I was told by another family member or friend
- A social media group or online screening tool
- None – self-diagnosed

This question was asked of any respondent who answered “Yes” to either Question 1 (“Has a doctor or other health professional ever told you that you had Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”) or Question 2 (“Do you currently have Attention-Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”). When answering, respondents gave open responses. Then, following confirmation by the respondents, interviewers coded the answers.

Respondents thought about the first time they could remember being told they had ADHD. For some respondents with medical diagnoses, the first time they were told they had ADHD was during the medical diagnosis process, whether as a child or as an adult. These respondents reported being told by medical doctors, psychiatrists, and psychologists. In some cases, respondents had been told

they were “*hyper*” or “*crazy*” by family members before their diagnosis – but they did not answer based on that earlier interaction, as they were not told they had ADHD, literally.

For other respondents, the first time they were told was in a non-medical setting, wherein another person suspected they had ADHD or ADD and voiced their suspicions. As one respondent, who answered “I was told by another family member or friend,” said, “*It was probably one of my friends, honestly. They were like, ‘I think you have ADHD’ and I was like, ‘this isn’t normal?’ [laugh].*”

One respondent answered “Don’t know” because she was unsure if the question intent referred to being told the “*words ‘ADHD’*” or being told she was “*hyper*” or had symptoms of ADHD generally.

Respondents who, over the course of the cognitive interview, described their ADHD as “*self-diagnosed*” did not spontaneously report at this question that they were self-diagnosed or that no one had told them. In those cases, respondents reported that family members, friends, or co-workers had spoken with them about their symptoms.

Question 6 Series

Question 6a (“How often have you been bothered by your ADHD symptoms?”) was asked of respondents who answered “Yes” to either Question 1 (“Has a doctor or other health professional ever told you that you have Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”) or Question 2 (“Do you currently have Attention Deficit/Hyperactivity Disorder or ADHD?”). Therefore, respondents to this question were both people who had been diagnosed by a health professional with ADHD, and knew they had the condition, and respondents who thought they had ADHD for other reasons, such as an informal self-diagnosis or having been told by someone else. If respondents answered “Not at all” to Question 6a, they were routed forward to Question 7, skipping 6b and 6c. Any response to 6a other than “Not at all” routed respondents to both 6b and 6c, which ask about hyperactivity/ restlessness or impulsivity and poor attention respectively.

Question 6a

Over the last two weeks, how often have you been bothered by...

Your ADHD symptoms?

1. Not at all
2. Several days
3. More than half the days
4. Every day or nearly every day

When considering this question, respondents thought about how they felt overall about their ADHD symptoms. Without specific symptoms named in this first question in the series, respondents

considered the symptoms most relevant to their experience when answering. They considered being “bothered” to refer to times when managing their symptoms was a “*struggle*.” One respondent noted that on certain days her restlessness bothers her, she feels like her “*brain starts panicking*.”

No respondent selected “More than half the days.” However respondents who selected “Several days” included those who reported being bothered by their symptoms from “*one or two*” to “*Nine*” days in the past two weeks. One respondent noted that she was unsure by the response options. She said, “*You said over the past two weeks, right? I would say ‘several’ but those are kind of confusing. Because ‘several’ sounds like ‘a lot.’ But, based on the scale several sounds like it should be the second to least.*” Giving a specific number, she said she was bothered between two to three days in the prior two weeks.

Respondents who selected “Not at all” said that they managed their symptoms well, and that they had strong coping strategies. As one respondent explained, “*I have certain coping skills, I don’t notice it. So, if it flares up, its’ like muscle memory.*”

Question 6b-6c

Read if respondent received Q6a and answered anything other than “Not at all.” **Specifically, how often have you been bothered by...**

Read if respondent did not receive 6a. **Over the last two weeks, how often have you been bothered by...**

Hyperactivity/restlessness or impulsivity

1. Not at all
2. Several days
3. More than half the days
4. Every day or nearly every day

Poor attention

1. Not at all
2. Several days
3. More than half the days
4. Every day or nearly every day

When forming answers to Questions 6b and 6c, respondents thought either about how often these specific symptoms occurred or how often the symptoms bothered them. Because some respondents focused on simple occurrence, rather than how often they were specifically “bothered” by symptoms, respondent answers to these specific symptom questions did not always align clearly with their answers to Question 6a (“... your ADHD symptoms”). For example, one respondent, who selected “Several days” to Question 6a, answered “Every day or nearly every day” to Question 6b. She explained her answer in terms of her day-to-day impulsivity: “*Because it’s usually things I*

do during the course of the day impulse wise – I’ll just do because I feel like I should do something.”

Respondents differentiated Questions 6b and 6c clearly – speaking about different experiences of their condition, and also sometimes selecting different answers. For example, one respondent, who selected “Every day or nearly every day” to Question 6b, answered “Not at all” for Question 6c. He explained, *“I tend to – not a lack of attention but over attention. I’m paying attention to everything everywhere all at once.”*

Changes to the question wording

In Rounds 1 and 2, Question 6a, 6b, and 6c were a single question: “Over the last two weeks, how often have you been bothered by any of the following problems: poor attention or hyperactivity or impulsivity?” Respondents in these rounds noted that the question asked them to rate disparate symptoms that did not always occur at the same frequency. Because of that, they selected one answer for all symptoms in one of two ways: averaging their symptom frequency or answering based on the most frequent symptom. Dividing the question into parts, including adding a general “ADHD symptoms” question, reduced the double-barreled nature of the question. And respondents in Round 3 did not express difficulties answering Questions 6b (“hyperactivity/restlessness or impulsivity”) and 6c (“poor attention”) based on conflicting symptom frequencies.

Question 7 [ADHDMED_A]

Do you currently take prescription medication for your ADHD or ADD?

1. Yes
2. No

Read if necessary: Prescription medications for ADHD or ADD include stimulant medications such as Adderall, Ritalin, and Concerta, as well as non-stimulant medications such as Strattera, Qelbree, and Intuniv.

This question was evaluated for inclusion on the NHIS. Respondents were asked this question if they answered “Yes” to Question 1 (“Has a doctor or other health professional ever told you that you have Attention Deficit/Hyperactivity Disorder, or ADHD or Attention Deficit Disorder or ADD?”). Respondents considered whether they were taking prescription medications to treat their ADHD or ADD condition.

There was no evidence of response error or confusion, and respondents to this question answered according to their current use of ADHD medication, regardless of whether they had taken prescriptions in the past or whether they were taking prescriptions for other conditions. For example, one respondent who answered “No” said, *“No, I’ve taken Adderall I’ve taken Ritalin, and they didn’t do anything. So, I figure why take it?”* As another example, a respondent who answered

“Yes” said, “*So I take Adderall, it’s the only thing I do take. I take it in the morning and the afternoon.*” One respondent answered “Yes” because she takes Zoloft and Wellbutrin. While these medications are traditionally used to treat depression, the respondent explained that her doctor prescribed them to help with her ADHD symptoms.

Changes to the question wording

In Rounds 1 and 2, a prompt was included before the question to explain ADHD and ADD medications. The removal of the prompt improved interview brevity and did not adversely affect respondent understanding of the question. However, since the respondents in Round 3 did not need to hear the new “read if necessary” text to understand the question or provide an answer, the potential role of the “read if necessary” text to improve understanding was not evaluated.

Question 7a

What type of prescription medication do you take for your ADHD or ADD?

1. A stimulant (*read if necessary*: Adderall, Ritalin, and Concerta)
2. A non-stimulant (*read if necessary*: Strattera, Qelbree, Intuniv)
3. A combination of stimulants and non-stimulants

This question was intended for respondents who selected “Yes” to Question 7 (“Do you currently take prescription medication for your ADHD or ADD?”). Respondents considered only the medications they were currently taking when answering the question, regardless of whether they had taken different kinds of ADHD medication in the past. Indeed, many respondents reported changes to their medications over the years, due to effectiveness or medication shortages. For example, one respondent, who answered “A non-stimulant” said that he was currently taking Strattera, but that he had previously taken Adderall, a stimulant.

Respondents knew the name of their medications and tended to know whether it was a stimulant or non-stimulant. Though, in one case, the “read if necessary” text was helpful for a respondent to confirm that their Adderall medication was a stimulant.

One respondent selected “Don’t know.” She was taking Zoloft and Wellbutrin, traditionally used to treat depression, to treat her ADHD symptoms.

Question 8 [ADHDTHRPY_A]

During the past 12 months, did you receive counseling, therapy, or behavioral treatment for your ADHD or ADD?

1. Yes
2. No

Read if necessary: Include counseling, therapy, or behavioral treatments for your ADHD or ADD, received from a mental health professional such as a psychiatrist, psychologist, psychiatric nurse, ADHD coach, or clinical social worker.

This question was evaluated for inclusion on the NHIS. In this evaluation, respondents were asked this question if they answered “Yes” to either Question 1 (“Have you ever been told by a doctor or other health professional that you had Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”) or Question 2 (“Do you currently have Attention Deficit/Hyperactivity Disorder or ADHD?”). However, for the NHIS, only respondents who answer “Yes” to Question 1 would receive this question.

When answering this question, respondents considered whether they had participated in one or more counseling, therapy or treatment sessions specifically for their ADHD symptoms in the prior 12 months. The type of treatments respondents considered included behavioral therapy, “*regular*” therapy sessions, psychotherapy, group sessions, and, in one case, therapeutic conversations with a medical concierge. Respondents who answered “Yes” included people who were in regular behavioral treatment and therapy for their ADHD, respondents who had participated in therapy/therapeutic treatments for a separate condition, but their therapy had, at last once in the prior 12 months, addressed their ADHD or had been helpful to their ADHD symptoms. As one respondent explained, “*I did speak with my therapist – we did touch on it – but it wasn’t the sole focus of it [...] I would say ‘Yes’ because it still helped.*” Another respondent explained his answer of “Yes” in the following way: “*Initially it started last year as grief therapy. But there was a quick realization that – you’ve got grief – but this is being amplified by your ADHD.*” One respondent who did not have an official medical diagnosis explained, “*My concierge does talk to me, console me, and that makes a lot of difference.*”

By contrast, respondents who were in therapy for other conditions, and felt that their therapy did not address their ADHD symptoms, answered “No.” As one respondent said, “*I have been in group sessions, but it was not specific to that subject, it was more for anxiety and stress.*”

Question 9

Which of the following treatments have you ever received for your ADHD symptoms?

(Select all that apply)

1. Prescription medication for ADHD
2. Counseling, therapy, or behavioral treatment from a mental health professional such as a psychiatrist, psychologist, psychiatric nurse, or clinical social worker
3. A coach specifically trained to help individuals with ADHD
4. Another type of treatment
5. Self-help resources like websites, social media, or peer support
6. None/ I have not received any treatment for my ADHD symptoms

Respondents were asked this question if they answered “Yes” to either Question 1 (“Have you ever been told by a doctor or other health professional that you had Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”) or Question 2 (“Do you currently have Attention Deficit/Hyperactivity Disorder or ADHD?”). Respondents to the question considered treatments or supports that they had ever received for their ADHD symptoms.

Respondents considered “Prescription medication for ADHD” consistently and answered according to whether they had ever used medications to treat their specific ADHD symptoms.

“Counseling, therapy, or behavioral treatment from a mental health professional such as a psychiatrist, psychologist, psychiatric nurse, or clinical social worker” was selected by respondents who had received formal counseling or therapy, and not for simple medication checks or updates. However, for those who received counseling or therapy that was not specifically focused on treating ADHD symptoms, they did select it if they felt the treatment helped with their ADHD in some way. For example, one respondent selected this response because, even though his psychiatrist was focused on treating his depression, the respondent felt that the therapy sessions addressed symptoms he associated with ADHD.

The two respondents who selected “A coach specifically trained to help individuals with ADHD” considered people such as life coaches and school psychologists who provided emotional support. One respondent explained why he considered his school counselor in the following way: *“After my diagnosis was confirmed, he took it upon himself to help me with that journey.”*

“Another type of treatment” was used to report the practice of mindfulness in one case, and the use of caffeine as a non-drug stimulant in another case, and finally, lifestyle change such as exercise and a good sleep routine in another.

Respondents selected “Self-help resources like websites, social media, or peer support” to report the use of ADHD-specific social media groups or receiving help by speaking to people in-person (friends, roommates, acquaintances, and physicians) with known ADHD diagnoses or expertise. As one respondent explained her use of social media resources, *“I’m always researching. And when I come across something interesting, I file it away.”*

Changes to the question wording

Following Round 1, “Prescription medication” was removed and replaced by “Prescription medication for ADHD” and “Prescription medication for another condition.” Additionally, “Self-help resources like websites, social media, or peer support” was added to help capture use of those resources and reduce instances of respondents choosing “Another type of treatment.” Following Round 2, “Prescription Medication for another condition” was removed because the considerations for that response item remained inconsistent, including respondents erroneously answering based on any prescription medication they took, regardless of its benefit to their ADHD symptoms.

Question 10

During your life, how many times have you allowed someone else to use your prescription ADHD stimulant medication?

1. 0 times
2. 1 or 2 times
3. 3 to 9 times
4. 10 to 19 times
5. 20 to 39 times
6. 40 or more times

This question was intended for respondents who answered indicating that they had taken prescription medication for ADHD at some point in their lives by selecting “Prescription medication for ADHD” to Question 9 (“Which of the following treatments have you ever received for your ADHD symptoms?”).

All respondents except for one answered, “0 times.” Respondents noted the legal, safety, financial, and ethical considerations around “sharing” or selling medications. As one respondent said, *“I got diagnosed as an adult, I have a clearance [for work]. I’m not dumb [laugh]. I’m not going to jail for anybody.”*

One respondent selected “1 or 2 times,” thinking of a specific person she knew during graduate school who asked for her Vyvanse. She explained, *“She was asking me for it, and I don’t like it. She was asking me for it, and I think I gave it to her once or twice. Like, ‘oh I need to write this paper!’”*

No one refused to answer the question, though some were surprised by the question. As one respondent said,

“Yeah so I think this is an ethics question, but it is kind of out of place for someone with ADHD. Like, you’re asking them ethically ‘would you sell your meds, because you know they are worth a lot of money.’ Is that the purpose of the study? Do you really want someone to answer that question? I don’t know.”

Question 11

During your life, how many times have you taken ADHD stimulant medications without a doctor's prescription or more frequently than how a doctor told you to use it?

1. 0 times
2. 1 or 2 times
3. 3 to 9 times

4. 10 to 19 times
5. 20 to 39 times
6. 40 or more times

This question was asked of respondents who either had ADHD or who thought they had ADHD, indicated by an answer of “Yes” to either Question 1 (“Have you ever been told by a doctor or other health professional that you had Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”) or Question 2 (“Do you currently have Attention Deficit/Hyperactivity Disorder or ADHD?”).

Respondents considered whether they had sought out stimulant medication without a prescription, if they had misused their own prescription, particularly taking it more often than recommended, for instance, or if they had used stimulant medication for off-label, non-recommended reasons.

All respondent answered, “0 times.” However, respondents still recognized scenarios where someone could misuse medications as described in this question. As one respondent said, *“I know that’s a medicine that helps you focus. I know that college students take it around exams to help them focus more.”* Similarly, another respondent noted that her answer did not take into account any use of ‘party drugs’ which shared certain characteristics to modern-day prescription medications. She explained, *“I think it’s one of these drugs we’re taking, an early version of it, as part of a party scene [in the 1980s], yes, but it’s not ADHD medicine at the time. It’s what grew up to be ADHD medicine.”*

One respondent noted that he had taken his medications less often than prescribed, to help stretch his medications when he was running low. However, he never had taken it more often than prescribed, so he selected “0 times.” He explained, *“I’m not a perfect goody too shoes but I just can’t think of a moment.”*

Question 12

During the past 30 days, how many times have you taken ADHD stimulant medications without a doctor's prescription or more frequently than how a doctor told you to use it?

1. 0 times
2. 1 or 2 times
3. 3 to 9 times
4. 10 to 19 times
5. 20 to 39 times
6. 40 or more times

This question was intended for respondents who answered anything other than “0 times” to Question 11 (“During your life, how many times have you taken ADHD stimulant medications without a doctor's prescription or more frequently than how a doctor told you to use it?”) No respondents were routed to this question since all respondents to Question 11 answered “0 times.”

Question 13 Series

This series of questions was asked of anyone who had a medical diagnosis of ADHD or thought they had ADHD, indicated by answering “Yes” to either Question 1 (“Have you ever been told by a doctor or other health professional that you had Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”) or Question 2 (“Do you currently have Attention Deficit/Hyperactivity Disorder or ADHD?”).

Respondents to this series of questions clearly differentiated the tasks in each question, and they primarily considered whether they had difficulty with that task. However, the series of questions asks respondents two considerations simultaneously: 1) whether the respondent had difficulty and 2) if the respondent’s difficulty was caused by ADHD. Some respondents, however, were unsure whether their ADHD symptoms caused their difficulties, particularly if they also had other factors that could cause the same difficulties, such as anxiety or “*old age*.”

In the past 12 months, because of your ADHD have you had a lot of difficulty with any of the following:

Question 13a

Seeking medical treatment for other health conditions

1. Yes
2. No

Most respondents considered “seeking medical treatment” to refer to calling a doctor’s office and setting up an appointment. The conditions respondents thought of included seeking treatment for chronic conditions, acute ailments, and appointments for their annual physical. Respondents who considered themselves to have difficulty with seeking medical treatment noted that they felt the task was complex or burdensome, they preferred to do other things, or they just “*keep putting it off*.”

Respondents who did have difficulties seeking medical treatment for other conditions, and answered “Yes” to this question, were inconsistent as to whether they attributed that difficulty to their ADHD. Some were confident their ADHD played a role in putting off medical appointments. Others were unsure. As one respondent said, “*I take my time going to the doctor. I tell myself it will get better. I put it off until the situation is worse.*” When the interviewer asked if the respondent’s difficulty was due to her ADHD, she said, “*I can’t say it doesn’t.*” Likewise, another respondent

said she had just recently canceled a medical appointment due to “*irresponsibility*” since she had not slept well and was too tired to go. When asked if this had to do with her ADHD, she said, “*I don’t know.*”

In one case, a respondent considered “seeking medical treatment” to include taking his medications for other health conditions. He explained, “*Yes. I’ll forget to take the other medications.*”

Respondents who answered “No” either had no difficulty with the task of setting up appointments or, due to lack of insurance or interest, they did not seek any treatments at all.

Question 13b

Keeping medical appointments

1. Yes
2. No

Respondents considered “keeping medical appointments” to refer to remembering their appointment and also being on time. Respondents who chronically had difficulty managing their daily tasks and calendar of events also had difficulty remembering non-routine appointments, including medical appointments. One respondent summed up her difficulty in the following way: “*I’ll either make the appointment and forget the appointment, forget to put the appointment in the calendar, get the notification from the calendar and still forget to go, or just snooze alarms and just start doing other stuff. Just forgetting.*”

Respondents who answered “Yes” were inconsistent as to whether they attributed their difficulty to their ADHD. One respondent said that these difficulties are “*a big concern*” for her psychiatrist and primary care physician, and they are the reason she is on a waiting list for an ADHD therapist. Whereas other respondents were not sure why they “forget” to go to their appointments. For example, one respondent was not sure if it was due to his ADHD or his old age.

Respondents without difficulties either had no difficulty with the task generally or they had coping strategies in place to support them, such as calendars and reminders.

Question 13c

Taking medication the way the doctor prescribed

1. Yes
2. No

When answering this question, respondents considered whether they take medications and if they could consistently remember to take them at the correct time.

Whether respondents had consistent and successful strategies in place to help them remember medications was an important response factor. As one respondent, who answered “Yes” said, *“And trust me I have the little pill counter and the countertop thing, but that doesn’t mean it necessarily happens. I’ll be halfway down the road and be like, ‘oh did I take my pills?’”* Whereas, by contrast, another respondent who answered “No” said he always keeps his pill minder by his earbuds and keys, making his management strategy effective. Some respondents had no difficulty with their routine medications, but she answered “Yes” due to difficulties with unusual medications, such as short-course antibiotics. She said, *“Yeah and recently I had one where I couldn’t eat dairy four hours before and four hours after, and I got three doses in and just couldn’t process it.”*

Some respondents who answered “Yes” had indicated that forgetfulness and distractions were key symptoms of their ADHD, and taking medications routinely was a challenge. However, others who answered “Yes” were not sure whether to attribute their difficulty to ADHD.

Respondents without difficulties either had no difficulty with the task generally, did not take medications at all, or they had coping strategies in place to support them, such as calendars and reminders.

Changes to the question wording

In Rounds 1 and 2, the question series was formatted as a one question with a single “Yes” or “No” response for all three items. This prompted some respondents to select one of the three. Also, providing a “Yes” or “No” to each item differentiates the type of difficulties respondents attribute to their ADHD more clearly.

Question 14 Series

Respondents were asked this series of questions if they answered “Yes” to either Question 1 (“Have you ever been told by a doctor or other health professional that you had Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”) or Question 2 (“Do you currently have Attention Deficit/Hyperactivity Disorder or ADHD?”), indicating that they had a medical diagnosis of ADHD or thought they had ADHD for other reasons.

Respondents to this series of questions clearly differentiated the daily health tasks in each question, and they considered whether they had difficulty with that task and, additionally, if that difficulty was due to their ADHD.

In the past 12 months, because of your ADHD have you had difficulty with any of the following:

Question 14a

Eating the kinds of foods you should eat for your health

1. Yes
2. No

When answering this question, respondents considered if they had difficulty making healthy food choices, including remembering to eat, and if so, whether they attributed that to their ADHD. Most respondents who answered “Yes” described their ADHD causing them to have difficulty with meal planning and preparation or dealing with cravings. One respondent described how the impulsivity aspect of his ADHD affected his diet. He said, *“Yes, that’s the impulsivity. You can be an overeater really easily with ADHD and impulsivity. You have to do an intervention on yourself. You have to be very mindful and intervene.”*

A few respondents were unsure if their difficulties were related to their ADHD, some other condition, or simply a human attribute. As one respondent, who selected “Yes,” explained, *“I don’t know if that is part of my ADHD, but maybe, because sometimes I’ll just eat a donut because it’s easier. So, I don’t eat what I should probably but I don’t think any of us do.”* And, not all poor food choices were attributed to respondents’ ADHD. As one respondent who answered “No” explained, *“I don’t think so – I think that’s just me. I ate a key lime pie yesterday. That was all me.”*

Question 14b

Getting enough exercise for your health

1. Yes
2. No

Respondents considered whether they had difficulty getting enough exercise, and if so, whether they attributed that difficulty to their ADHD. Respondents who felt that their ADHD affected their exercise habits considered their difficulty with consistent routines, lacking energy due to their poor sleep, or having difficulty with distraction and lack of motivation.

However, some respondents recognized that lack of motivation to exercise extends beyond people with ADHD. One respondent who answered “Yes” said, *“I don’t know if that is because of ADHD. But maybe! I’ll start a regimen and then not keep up with it, so I don’t know. Am I lazy or is it the ADHD?”*

Respondents who answered “No” either had no difficulty with their exercise routines or they did not attribute their difficulty to ADHD. Indeed, some respondents used exercise as part of their ADHD symptom management.

Question 14c

Getting enough sleep for your health

1. Yes
2. No

This question was added for Round 3. When answering this question, respondents thought about having difficulties settling down for sleep, having racing thoughts, having trouble scheduling their sleep appropriately, and struggling with anxiety or insomnia. All but one Round 3 respondent answered “Yes” and reporting having difficulty with getting enough sleep in some capacity due to their ADHD. As one respondent said, *“Yeah sometimes staying up too late and not realizing what time it is, or scrolling, or sometimes binge watching something. Like, I could watch it tomorrow, but I want to watch the next episode now.”*

The respondent who said “No” to this question recognized he was unusual among people with ADHD. He said he will have difficulty sleeping, however, if he is going through emotional turmoil, such as a breakup.

Question 14d

Avoiding injuries

1. Yes
2. No

When answering this question, respondents considered whether they were particularly accident-prone, clumsy, distracted, or careless in ways that resulted in (typically minor) injury due to falls and bumps. Respondents who answered “Yes” tended to bump into things while distracted. As one respondent said, *“Oh good question. Maybe I get injured, and I don’t pay attention when I walk and things like that. Yeah.”*

Respondents who answered “No” considered their general bumps and bruises within a typical range not related to ADHD, or their bumps and bruises were not serious-enough injuries to bother them or require any special treatment. As one respondent, who answered “No” explained, *“I mean sometimes I’ll random bump, maybe it’s depth perception. Not injured enough to go to the hospital, so no.”*

One respondent answered, “Don’t know,” and expressed surprise with the question. She explained, *“Woah – have I had difficulty avoiding injuries? I don’t know what that means [...] Am I like – avoiding bumping into objects? Like, I’m not going to self-harm if that’s what that means.”*

Changes to the question wording

Like the Question 13 series, In Rounds 1 and 2, this question series was formatted as a one question with a single “Yes” or “No” response for all three items. This prompted some respondents to focus on one difficulty or their most significant difficulty. Asking the question items as a series differentiates the type of difficulties respondents attribute to their ADHD.

Question 15

Have you ever received any telehealth services for ADHD? That is, have you ever talked about your ADHD with a doctor, nurse, or other health professional by video or by phone?

1. Yes
2. No

Respondents were asked this series of questions if they answered “Yes” to either Question 1 (“Have you ever been told by a doctor or other health professional that you had Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”) or Question 2 (“Do you currently have Attention Deficit/Hyperactivity Disorder or ADHD?”), indicating that they had a medical diagnosis of ADHD or thought they had ADHD for other reasons.

In general, respondents understood the question to be asking if they received any medical care for their ADHD by video or phone. Respondents thought about medication check-ins, therapy appointments, and behavioral health appointments. For example, one respondent, who answered “Yes” based on her monthly medication check-ins with her psychiatrist, said, *“Yeah normally I’ll check in every month. She’ll just see how it’s going. We’ll talk about increasing or just generally how I’m doing.”*

Respondents answered based on telehealth calls or video appointments that specifically addressed the management of their ADHD symptoms. For instance, one respondent, who answered “No,” explained that her therapist calls focus on her anxiety and depression, not her ADHD.

Value of the ‘Telehealth Services’ Definition

For the purposes of cognitive testing the explanation of “telehealth services” included in the question was not always read to the respondent (“That is, have you ever talked about your ADHD with a doctor, nurse, or other health professional by video or by phone”). This approach meant that interviewers could verify the need to define the term “telehealth services” in the question. Without the definition provided, most respondents understood that telehealth services would include a phone or video conversation with a health professional. However, it was apparent that the definition of

“telehealth services” was important for respondent understanding in a few cases. For example, without the definition, one respondent thought that the interviewer was referring to some kind of helpline: *“Is it like 1800-Suicide?”* Another respondent said, *“Tele what? Say that again... Yeh I’m not sure what that is.”*

Instance of response error

One respondent answered “No” despite having had *“one or two teledoc check-ins”* to renew his prescription and refill medications in the past. He considered these calls *“maintenance”* for his ADHD rather than his regular care. Other respondents did include those types of calls when considering their answer.

Question 15a

During the past 12 months, have you had a telehealth visit regarding your ADHD with a doctor, nurse, or other health professional by video or by phone?

1. Yes
2. No

Respondents were asked this question if they answered “Yes” to Question 15 (“Have you ever received any telehealth services for ADHD? That is, have you ever talked about your ADHD from a doctor, nurse, or other health professional by video or by phone?”). When forming their answer, respondents considered whether they had any telehealth services specifically for the management of their ADHD within the past 12 months.

The types of services they considered were the same as those from the prior question: medication check-ins, therapy appointments, and behavioral health appointments. Respondents with routine medical appointments, no matter the frequency (every three months, monthly, or weekly) readily answered “Yes.” And, those who formerly used telehealth appointments in prior years past readily answered “No.” One respondent who had a single telehealth appointment *“about a year ago,”* had a harder time remembering whether the appointment occurred within the prior 12 months. Though, he ultimately answered, “Yes.”

Question 16

Did the process of getting your ADHD diagnosis involve telehealth visits, in-person visits, or a combination of both?

1. Telehealth
2. In person
3. Combination of telehealth and in person

Respondents were asked this question if they answered “Yes” to either Question 1 (“Have you ever been told by a doctor or other health professional that you had Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?”) or Question 2 (“Do you currently have Attention Deficit/Hyperactivity Disorder or ADHD?”) and “Yes” to Question 15 (“Have you ever received any telehealth services for ADHD? That is, have you ever talked about your ADHD from a doctor, nurse, or other health professional by video or by phone?”).

Most said that they were first diagnosed with ADHD during an in-person visit with a health professional. Answering this question was straightforward for people who had been diagnosed as children or as adults in a pre-Covid-19 pandemic medical setting. Some respondents commented that telehealth services were not available at the time of their diagnosis: “...*wasn't really available back then*”; “*Yeah, telehealth wasn't really there.*”

No respondents selected “Combination of telehealth and in person.” However, respondents who were diagnosed either during or shortly after the Covid-19 pandemic answered “Telehealth.” For example, one respondent who answered, “Telehealth,” had first been diagnosed with ADHD during a telehealth visit, which allowed her to receive prescription medication as part of her management. At a later point, she had followed up her initial diagnosis with an in-person visit which is when she had been formally tested for ADHD. Another respondent, who selected “Telehealth,” explained that she initially went to her primary care doctor in-person for an annual check-up. That doctor then referred her to a therapist and psychiatrist who diagnosed her via telehealth calls.

Appendix 2: Round 1 Questionnaire

1. Have you ever talked with a doctor or other health professional about whether you have Attention Deficit/Hyperactivity Disorder or ADHD, sometimes also called Attention Deficit Disorder or ADD?

Yes (Go to Q2)

No (Go to Q1a)

I wanted to, but was not able to do so (Go to Q1a)

Don't know / Not sure (probe for more info)

Refused

1a. Why did you not talk with a doctor or other health professional about whether you have Attention Deficit/Hyperactivity Disorder or ADHD?

[free response]

Prompts (if respondent is having trouble answering)

Did not know what doctor to ask

Did not have a doctor to ask

Too expensive to see a doctor/ the doctor I wanted to ask is not covered by my insurance

I managed my symptoms without getting a formal diagnosis

I was worried about being labeled "ADHD"

(Any response above: Go to Q2)

2. Have you ever been told by a doctor or other health professional that you had Attention Deficit/Hyperactivity Disorder or ADHD?

Yes (Go to Q2a)

No (Go to Q3)

Don't know / Not sure (probe for more info)

Refused

2a. Since the time you were first diagnosed, have you always had ADHD?

Yes (Go to Q2b)

No (Go to Q2b)

Don't know / Not sure (probe for more info)

Refused

2b. How would you describe your ADHD?

Mild

Moderate

Severe

Don't know / Not sure (probe for more info)

Refused

(Any response above: Go to Q2c)

2c. Do you have ADHD symptoms that get better and worse?

1 Yes

2 No

7 Don't know/Not sure (probe for more info)

9 Refused

(Any response above: Go to Q3)

3. Do you currently have Attention Deficit/Hyperactivity Disorder or ADHD?

Yes (Go to Q3a)

No (Go to Q4)

Don't know / Not sure (probe for more info)

Refused

(If no to Q1, Q2, and Q3, END HERE)

3a. Would you describe your current ADHD as mild, moderate, or severe?

Mild

Moderate

Severe

Don't know / Not sure (probe for more info)

Refused

(Any response above - Go to Q4)

4. Over the last two weeks, how often have you been bothered by the following problems: poor attention or hyperactivity/impulsivity?

Not at all

Several days

More than half the days

Every day or nearly every day

Don't Know (probe for more info)

(Any response above - Go to Q5 or Q6: If Q2=Yes and Q3=No, go to Q5; otherwise, go to Q6)

5. What are the reasons why you do not currently have ADHD? [select all that apply]

Condition seemed to go away on its own

Treatment helped the condition to go away.

Coping strategies helped the condition go away

A doctor or health care provider changed the diagnosis

Other reason [free response]

(Any response above - Go to Q6)

6. How old were you when you were first told you had ADHD?

___ Code age in years (Go to Q6a)

Don't know / Not sure (probe for more info)

Refused

Prompts (if respondent is having trouble providing a specific age)

When you were 6 years old or younger

When you were 7-12 years old

When you were 13-17 years old

When you were 18 years old or older

6a. Who FIRST told you that you had ADHD?

Pediatrician

Primary care doctor (family medicine, internal medicine)

Psychiatrist

Nurse practitioner

School psychologist or counselor

Psychologist outside of school

Teacher

I was told by a parent/caregiver

None – self-diagnosed

Don't know

(Any response above - Go to Q7)

7. Which of the following treatments have you ever received for your ADHD symptoms? (Respondent can choose all that apply)

Prescription medication (Go to Q8)

Counseling, therapy, or behavioral treatment from a mental health professional such as a psychiatrist, psychologist, psychiatric nurse, or clinical social worker (Go to Q8)

A coach specifically trained to help individuals with ADHD (Go to Q8)

Another type of treatment (Go to Q8)

None/ I have not received any treatment for my ADHD symptoms (Go to Q11)

PROMPT: "The next questions ask about the use of stimulant and non-stimulant ADHD medications prescribed by a doctor. For this question, count stimulant medications such as Adderall, Vyvanse, Ritalin, Concerta, generic methylphenidate, generic amphetamines or mixed amphetamine salts, or other ADHD medications."

8. Do you currently take prescription medication for ADHD?

Yes (Go to Q8a)

No (Go to Q9)

Don't know/not sure (probe for more info)

Refused

8a. What type of prescription medication do you take for ADHD?

A stimulant (read if necessary: Adderall, Focalin, Vyvanse, Concerta, Mydayis, Jornay)

A non-stimulant (read if necessary: Strattera, Qelbree, Intuniv)

A combination of stimulants and non-stimulants

Don't know/not sure (probe for more info)

Refused

(Any response above - Go to Q9)

PROMPT: The next questions ask about the use of stimulant medications without a doctor's prescription or differently than how a doctor told you to use it.

9. During your life, how many times have you allowed someone else to use your prescription stimulant medication?

0 times

1 or 2 times

3 to 9 times

10 to 19 times

20 to 39 times

40 or more times

(Any response above - Go to Q10)

10. During your life, how many times have you taken stimulant medications without a doctor's prescription or more frequently than how a doctor told you to use it?

0 times

1 or 2 times

3 to 9 times

10 to 19 times

20 to 39 times

40 or more times

(Any response above - Go to Q11)

11. During the past 30 days, how many times have you taken stimulant medications without a doctor's prescription or more frequently than how a doctor told you to use it?

0 times

1 or 2 times

3 to 9 times

10 to 19 times

20 to 39 times

40 or more times

(Any response above - Go to Q12)

12. In the past 12 months, because of your ADHD have you had difficulty with any of the following:

-Seeking medical treatment for other health conditions

-Keeping medical appointments

-Taking medication the way the doctor prescribed

Yes

No

Don't know/Not sure (probe for more info)

Refused

(Any response above - Go to Q13)

13. In the past 12 months, because of your ADHD have you had difficulty with any of the following:

-Eating the kinds of foods you should eat for your health

- Getting enough exercise for your health
- Avoiding injuries

Yes

No

Don't know/Not sure (probe for more info)

Refused

14. Have you ever received any telehealth services for ADHD? That is, have you ever talked about your ADHD with a doctor, nurse, or other health professional by video or by phone?

Yes (Go to Q14a)

No (Go to Q15)

Don't know / Not sure (probe for more info)

Refused

14a. During the past 12 months, have you had a telehealth visit regarding your ADHD with a doctor, nurse, or other health professional by video or by phone?

Yes

No

Don't know / Not sure (probe for more info)

Refused

15. Were you first diagnosed with ADHD during telehealth visits, in-person visits, or a combination of both?

Telehealth

In person

Combination of telehealth and in person

Don't know / Not sure (probe for more info)

Refused

END

Appendix 3: Round 2 Questionnaire

1. Have you ever talked with a doctor or other health professional about whether you have Attention Deficit/Hyperactivity Disorder or ADHD, sometimes also called Attention Deficit Disorder or ADD?

Yes (Go to Q2)

No (Go to Q1a)

I wanted to, but was not able to do so (Go to Q1a)

Don't know / Not sure

Refused

1.a. Why did you not talk with a doctor or other health professional about whether you have Attention Deficit/Hyperactivity Disorder or ADHD?

[free response]

Prompts (if respondent is having trouble answering)

Did not know what doctor to ask

Did not have a doctor to ask

Too expensive to see a doctor/ the doctor I wanted to ask is not covered by my insurance

I managed my symptoms without getting a formal diagnosis

I was worried about being labeled "ADHD"

Did not suspect I had ADHD or was not concerned

2. Have you ever been told by a doctor or other health professional that you had Attention Deficit/Hyperactivity Disorder or ADHD?

Yes (Go to Q2a)

No (Go to Q3)

Don't know / Not sure

Refused

2a. Since the time you were first diagnosed, have you always had ADHD?

Yes

No

Don't know / Not sure

Refused

2b. When your symptoms were at their worst, how would you describe your ADHD?

Mild

Moderate

Severe

Don't know / Not sure

Refused

2c. Does the severity of your ADHD change a lot over time, such as getting better or worse?

Yes

No

Don't know/Not sure

Refused

3. Do you currently have Attention Deficit/Hyperactivity Disorder or ADHD?

Yes (Go to Q3a)

No (Go to Q4)

Don't know / Not sure

Refused

(If no to Q1, Q2, and Q3, END HERE)

3a. Would you describe your current ADHD as mild, moderate, or severe?

Mild

Moderate

Severe

Don't know / Not sure

Refused

4. Over the last two weeks, how often have you been bothered by any of the following problems: poor attention or hyperactivity or impulsivity?

Read out response options

Not at all

Several days

More than half the days

Every day or nearly every day

Don't Know

Refused

(If Q2=Yes AND Q3=No, go to Q5; otherwise, go to Q6)

5. What are the reasons why you do not currently have ADHD? [select all that apply]

Condition seemed to go away on its own

Treatment helped the condition to go away

Coping strategies helped the condition go away

A doctor or health care provider changed the diagnosis

Other reason [free response]

6. How old were you when you were first told you had ADHD?

___ Code age in years

Don't know / Not sure

Refused

Prompts (if respondent is having trouble providing a specific age)

When you were 6 years old or younger

When you were 7-12 years old

When you were 13-17 years old

When you were 18 years old or older

6a. Who FIRST told you that you had ADHD?

Pediatrician

Primary care doctor (family medicine, internal medicine)

Psychiatrist

Nurse practitioner

School psychologist or counselor

Psychologist outside of school

Teacher

I was told by a parent/caregiver

I was told by another family member or friend

A social media group or online screening tool

None – self-diagnosed

Don't know

7. Which of the following treatments have you ever received for your ADHD symptoms? (Respondent can choose all that apply)

Prescription medication for ADHD (Go to Q8)

Prescription medication for another condition (Go to Q10)

Counseling, therapy, or behavioral treatment from a mental health professional such as a psychiatrist, psychologist, psychiatric nurse, or clinical social worker (Go to Q10)

A coach specifically trained to help individuals with ADHD (Go to Q10)

Another type of treatment (Go to Q10)

Self-help resources like website, social media, or peer support (Go to Q10)

None/ I have not received any treatment for my ADHD symptoms (and Go to Q10)

If skipping to Q10: READ PROMPT 2 FIRST

PROMPT1: “The next questions ask about the use of stimulant and non-stimulant ADHD medications prescribed by a doctor. For these questions, count stimulant medications such as Adderall, Vyvanse, Ritalin, Concerta, generic methylphenidate, generic amphetamines or mixed amphetamine salts, or other ADHD medications.”

8. Do you currently take prescription medication for ADHD?

Yes (Go to Q8a)

No (Go to Q9)

Don't know/not sure

Refused

8a. What type of prescription medication do you take for ADHD?

A stimulant (read if necessary: Adderall, Focalin, Vyvanse, Concerta, Mydayis, Jornay)

A non-stimulant (read if necessary: Strattera, Qelbree, Intuniv)

A combination of stimulants and non-stimulants

Don't know/not sure

Refused

PROMPT2: The next questions ask about the use of stimulant medications without a doctor's prescription or differently than how a doctor told you to use it.

9. During your life, how many times have you allowed someone else to use your prescription ADHD stimulant medication?

0 times

1 or 2 times

3 to 9 times

10 to 19 times

20 to 39 times

40 or more times

10. During your life, how many times have you taken ADHD stimulant medications without a doctor's prescription or more frequently than how a doctor told you to use it?

0 times

1 or 2 times

3 to 9 times

10 to 19 times

20 to 39 times

40 or more times

11. During the past 30 days, how many times have you taken ADHD stimulant medications without a doctor's prescription or more frequently than how a doctor told you to use it?

0 times

1 or 2 times

3 to 9 times

10 to 19 times

20 to 39 times

40 or more times

12. In the past 12 months, because of your ADHD have you had difficulty with any of the following:

- Seeking medical treatment for other health conditions
- Keeping medical appointments
- Taking medication the way the doctor prescribed

Yes

No

Don't know/Not sure

Refused

13. In the past 12 months, because of your ADHD have you had difficulty with any of the following:

- Eating the kinds of foods you should eat for your health
- Getting enough exercise for your health
- Avoiding injuries

Yes

No

Don't know/Not sure

Refused

14. Have you ever received any telehealth services for ADHD? That is, have you ever talked about your ADHD with a doctor, nurse, or other health professional by video or by phone?

Yes (Go to Q14a)

No (Go to Q15)

Don't know / Not sure

Refused

14a. During the past 12 months, have you had a telehealth visit regarding your ADHD with a doctor, nurse, or other health professional by video or by phone?

Yes

No

Don't know / Not sure

Refused

15. Were you first diagnosed with ADHD during telehealth visits, in-person visits, or a combination of both?

Telehealth

In person

Combination of telehealth and in person

Don't know / Not sure

Refused

END

Appendix 4: Round 3 Questionnaire

Note: Bracketed numbers represent the question number from the prior round.

(Ask all)

1. [Q2] Has a doctor or other health professional ever told you that you had Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?

Yes (Go to Q1a)

No (Go to Q2)

Don't know / Not sure (probe for more info) (Go to Q2)

Refused (Go to Q2)

(Ask if Q1= Yes)

1a. [2a] Since the time you were first diagnosed, has your diagnosis of ADHD or ADD changed?

Yes

No

Don't know / Not sure (probe for more info)

Refused

(Any response above: Go to Q1b)

(Ask if Q1= Yes)

1b. [2b] When your symptoms were at their worst, would you describe your ADHD or ADD as mild, moderate, or severe?

Mild

Moderate

Severe

Don't know / Not sure (probe for more info)

Refused

(Any response above: Go to Q1c)

(Ask if Q1= Yes)

1c. [2c] Has the severity of your ADHD or ADD changed a lot over the years, such as getting better and/or worse over time?

Yes

No

Don't know/Not sure (probe for more info)

Refused

(Any response above: Go to Q2)

(Ask all)

2. [3] Do you currently have Attention Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD ?

Yes (Go to Q2a)

No (Go to Q2b)

Don't know / Not sure (probe for more info) (Go to Q3)

Refused (Go to Q3)

(Ask if Q2=Yes)

2a. [3a] Would you describe your current ADHD or ADD as mild, moderate, or severe?

Mild

Moderate

Severe

Don't know / Not sure (probe for more info)

Refused

(Any response above - Go to Q3)

(Ask if Q2 = No)

2b. [5] What are the reasons why you do not currently have ADHD or ADD?

You may select more than one answer.

[Running prompt]

Condition seemed to go away on its own

Treatment helped the condition to go away

Coping strategies helped the condition go away

A doctor or health care provider changed the diagnosis

Other reason [Please specify]

(Any response above - Go to Q3)

(Ask all)

3. [1] Have you ever talked with a doctor or other health professional about whether you have ADHD or ADD?

Yes (Go to Q4)

No (Go to Q3a)

I wanted to, but was not able to do so (Go to Q3a)

Don't know / Not sure (probe for more info)

Refused

(Ask if Q3 = No or Q3 = I wanted to, but was not able to do so)

3a. [1a] Why did you not talk with a doctor or other health professional about whether you have ADHD or ADD?

I did not suspect I had ADHD or was not concerned

I did not have health insurance, or enough insurance coverage

My doctor does not provide care or referrals for ADHD

I did not know what doctor to ask

I managed my symptoms myself

I was worried about being labeled "ADHD"

Other reason (Please specify)_____

(For 1, Go to 6b, all others go to 6a)

4. [6] How old were you when a doctor or other health professional FIRST told you that you had Attention-Deficit/Hyperactivity Disorder or ADHD, or Attention Deficit Disorder or ADD?

___ Code age in years

Don't know / Not sure (probe for more info)

Refused

Prompts (if respondent is having trouble providing a specific age)

When you were 6 years old or younger

When you were 7-12 years old

When you were 13-17 years old

When you were 18 years old or older

(Any response above - Go to Q5)

5. [6a] Who FIRST told you that you had ADHD or ADD?

Pediatrician

Primary care doctor (family medicine, internal medicine)

Psychiatrist

Nurse practitioner

School psychologist or counselor

Psychologist outside of school

Teacher

I was told by a parent/caregiver

I was told by another family member or friend

A social media group or online screening tool

None – self-diagnosed

Don't know

(Any response above - Go to Q6)

6. [4] Over the last two weeks, how often have you been bothered by...

6a. Your ADHD symptoms?

Not at all

Several days

More than half the days

Every day or nearly every day

Don't know (probe for more info)

(Any response above: Go to Q6b)

(Ask if 6a was anything other than 'Not at all')

Read if respondent received **Q6a: Specifically, how often have you been bothered by...**

Read only if respondent did not receive **Q6a: Over the last two weeks, how often have you been bothered by...**

6b. [4] Hyperactivity/restlessness or impulsivity

Not at all

Several days

More than half the days

Every day or nearly every day

Don't know (probe for more info)

(Any response above: Go to Q6c)

6c. [4] Poor attention

Not at all

Several days

More than half the days

Every day or nearly every day

Don't know (probe for more info)

(Any response above: Go to Q7)

(If Q1 and Q2=no, Go to Q11)

(Ask if Q1 = Yes)

7.[8] Do you currently take prescription medication for your ADHD or ADD?

Yes

No

Don't know

Refused

Read if necessary: Prescription medications for ADHD or ADD include stimulant medications such as Adderall, Ritalin, and Concerta, as well as non-stimulant medications such as Strattera, Qelbree, and Intuniv.

(Ask if Q7 = Yes)

7.a. [8a] What type of prescription medication do you currently take for your ADHD or ADD?

A stimulant (read if necessary: Such as Adderall, Ritalin, and Concerta)

A non-stimulant (read if necessary: Such as Strattera, Qelbree, Intuniv)

A combination of stimulants and non-stimulants

Don't know/not sure (probe for more info)

Refused

(Ask if Q1 = Yes or Q2=Yes)

8. [7item3] During the past 12 months, did you receive counseling, therapy, or behavioral treatment for your ADHD or ADD?

Yes

No

Don't know / not sure (probe for more info)

Refused

(Any response above - Go to Q9)

Read if necessary: Include counseling, therapy, or behavioral treatments for your ADHD or ADD, received from a mental health professional such as a psychiatrist, psychologist, psychiatric nurse, ADHD coach, or clinical social worker.

9. [7] Which of the following treatments have you ever received for your ADHD symptoms?

You may select all that apply.

Prescription medication for ADHD (Go to Q10)

Counseling, therapy, or behavioral treatment from a mental health professional such as a psychiatrist, psychologist, psychiatric nurse, or clinical social worker (Go to Q11)

A coach specifically trained to help individuals with ADHD (Go to Q11)

Another type of treatment (Go to Q11)

Self-help resources like websites, social media, or peer support (Go to Q11)

None/ I have not received any treatment for my ADHD symptoms (Go to Q11)

(To all remaining in the module)

INTRO1: The next questions ask about the use of stimulant medications without a doctor's prescription or differently than how a doctor told you to use it.

(Ask if Q9 = Prescription medication for ADHD)

10. [9] During your life, how many times have you allowed someone else to use your prescription ADHD stimulant medication?

Read if necessary: Prescription medications for ADHD include stimulant medications such as Adderall, Ritalin, and Concerta

0 times

1 or 2 times

3 to 9 times

10 to 19 times

20 to 39 times

40 or more times

(Any response above - Go to Q11)

(Ask all remaining in the module)

11. [10] During your life, how many times have you taken ADHD stimulant medications without a doctor's prescription or more frequently than how a doctor told you to use it?

Read if necessary: Prescription medications for ADHD include stimulant medications such as Adderall, Ritalin, and Concerta

0 times (Go to Q13)

1 or 2 times (Go to Q12)

3 to 9 times (Go to Q12)

10 to 19 times (Go to Q12)

20 to 39 times (Go to Q12)

40 or more times (Go to Q12)

(Ask if Q11 NE 0)

12. [11] During the past 30 days, how many times have you taken ADHD stimulant medications without a doctor's prescription or more frequently than how a doctor told you to use it?

Read if necessary: Prescription medications for ADHD include stimulant medications such as Adderall, Ritalin, and Concerta.

0 times

1 or 2 times

3 to 9 times

10 to 19 times

20 to 39 times

40 or more times

(If Q1 or Q2 = Yes go to 13, all else EXIT)

(Ask all remaining in module)

13. [12] In the past 12 months, because of your ADHD have you had a lot of difficulty with any of the following:

13a. [12] Seeking medical treatment for other health conditions

Yes

No

Don't know/Not sure (probe for more info)

Refused

(Any response above - Go to Q13b)

13b. [12] Keeping medical appointments

Yes

No

Don't know/Not sure (probe for more info)

Refused

(Any response above - Go to Q13c)

13c. [12] Taking medication the way the doctor prescribed

Yes

No

Don't know/Not sure (probe for more info)

Refused

(Any response above - Go to Q14)

(Ask all remaining in module)

14. [13] In the past 12 months, because of your ADHD have you had a lot of difficulty with any of the following:**14a. [13] Eating the kinds of foods you should eat for your health**

Yes

No

Don't know/Not sure (probe for more info)

Refused

(Any response above - Go to Q14b)

14b. [13] Getting enough exercise for your health

Yes

No

Don't know/Not sure (probe for more info)

Refused

(Any response above - Go to Q14c)

14c. [13] Getting enough sleep for your health

Yes

No

Don't know/Not sure (probe for more info)

Refused

(Any response above - Go to Q14d)

14d. [13] Avoiding injuries

Yes

No

Don't know/Not sure (probe for more info)

Refused

(Any response above - Go to Q15)

(All remaining in the module)

15. [14] Have you ever received any telehealth services for ADHD? That is, have you received care for your ADHD from a doctor, nurse, or other health professional by video or by phone?

Yes (Go to Q15a)

No (END)

Don't know/Not sure (probe for more info)

Refused

(Ask if Q15 = Yes)

15.a. [14a] During the past 12 months, have you received telehealth services for your ADHD from a doctor, nurse, or other health professional by video or by phone?

Yes

No

Don't know/Not sure (probe for more info)

Refused

(Any response above - Go to Q16)

(All remaining in the module)

16. [15] Did the process of getting your ADHD diagnosis involve telehealth visits, in-person visits, or a combination of both?

Telehealth

In person

Combination of telehealth and in person

Don't know / Not sure (probe for more info)

Refused

END

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