

Analysis of Cognitive Interview Testing of Questions on Cognitive Functioning

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1. Introduction

This report summarizes findings from cognitive testing of two questions on cognitive functioning intended for inclusion on the National Health Interview Survey (NHIS): an initial question on cognitive difficulties and a follow-up question on the main cause of cognitive difficulties.

The initial question is one of the six questions to identify disability that is being used with increasing frequency in Department of Health and Human Services health surveys and was developed by the Washington Group on Disability Statistics. While this question identifies difficulty with cognitive functioning, it does not provide information as to the underlying cause of the disability (i.e., intellectual disability, mental illness, etc.). Therefore, a follow-up was developed to identify the condition underlying the cognitive limitation among self and proxy-respondents who report some level of cognitive difficulty. The two questions are:

COG1: [Do you/Does she/he] have serious difficulty remembering or concentrating?

COG2: What is the main reason for [his/her/your] difficulty remembering or concentrating?

Cognitive testing of these two questions was conducted to ascertain how the cognitive functioning follow-up question (COG2) performs overall and its relationship to the full short set of Washington Group disability questions (Appendix 1). These questions were tested as part of a larger project that also included testing of questions on general health, sleep and health care providers. The evaluation of the cognitive difficulty questions is based on 40 cognitive interviews that were conducted by the Center for Question Design and Evaluation Research (CCQDER) at the National Center for Health Statistics (NCHS), in April and May of 2016. Cognitive interviewing is a qualitative question evaluation method used to assess the construct validity of survey questions (Willis, 2015; Miller, Willson, Chepp, & Padilla, 2014). The following sections of this report include an overview of cognitive interviewing methodology, a summary of key findings, and a question-by-question analysis.

2. Methods

Cognitive Interviewing. Cognitive interviewing is a qualitative method whose purpose is to evaluate survey questionnaires, and determine which constructs the questionnaires' items capture. As an investigation into question validity, a cognitive interviewing study allows researchers and survey designers to understand whether or not a question is capturing the intended constructs and gives insight into design changes that may advance the survey's overall goals.

Cognitive interviewing provides rich, contextual data into how respondents interpret questions, apply their lived experiences to their responses, and formulate responses to survey items based on those interpretations and experiences (Miller et al 2014). Thus, the documented findings of cognitive interviews provide data end users the context needed to more fully understand the quantitative trends that emerge from survey data.

Cognitive interview methods are founded on the underlying theory of the question response process. Individuals typically interpret survey questions through a four-step process: comprehension of the underlying construct, recall of relevant information, judgement of an appropriate response, and finally selection from available response options (Tourangeau, Rips and Rasinski 2000). Ideally, cognitive interviewing can provide insight into respondents’ performance through each of these four steps.

Traditionally, cognitive interviewing studies are performed by conducting in-depth, semi-structured interviews with a small sample of approximately twenty to forty respondents. The typical interview structure consists of respondents first answering the evaluated question and then answering a series of follow-up probe questions that reveal what respondents were thinking and their rationale for that specific response. Through this semi-structured design, various types of question-response problems, such as interpretive errors or recall accuracy, are uncovered—problems that often go unnoticed in traditional survey interviews. By asking respondents to provide both textual verification and the process by which they formulated their answer, elusive errors are revealed.

Sampling and Respondent Characteristics. As a qualitative method, the sample selection for a cognitive testing project is purposive. Respondents are not selected through a random process, but rather are selected for specific characteristics such as gender or race or some other attribute, such as diabetes diagnosis, that is relevant to the type of questions being examined. The goal of a purposive sample is not to obtain a statistically representative sample. Instead, emphasis is on coverage of the survey questions and topics, not the survey population. As a result, recruitment for this project included individuals who have cognitive difficulties or have a household member with cognitive difficulties.

Forty respondents were included in this study and were recruited through newspaper advertisements, flyers and word-of-mouth. Twenty self-responders and twenty proxy-responders were recruited and interviewed in April and May 2016. The demographic breakdown of respondents appears in table 1.

Age	
18 - 29	2
30 - 49	10
50 - 64	24
65 and Over	4
Gender	
Male	24
Female	16
Race	
Black	31
White	6
Multiple	2
Refused	1

Education	
Less than High School	7
HS diploma /GED	14
Some college	12
College Degree	4
Graduate Degree	3

Interviewing Procedures: All interviews were conducted face-to-face in the Questionnaire Design Research Laboratory within the CCQDER. Twenty respondents (referred to throughout this report as “self-respondents”) answered questions about themselves, while an additional twenty respondents (referred to as “proxy respondents”) were only asked questions about a member of their household (i.e. the “reference person”). All respondents were asked the initial question on cognitive difficulty (COG1). Two versions of COG2 were asked—one with set response categories and one that was open ended:

COG2 v.1 What is the main reason for [your/his/her] difficulty concentrating, remembering or making decisions?

1. Intellectual or learning disability
2. Dementia or Alzheimer’s disease
3. Mental illness
4. Traumatic brain injury
5. Stroke
6. Other (_____, please specify)
7. I’m not sure

COG2 v.2 What is the main reason for [your/his/her] difficulty concentrating, remembering or making decisions? _____

Two-thirds of respondents were randomly assigned to COG2 v.1 (with set response categories) while one-third were randomly assigned the open-ended version (COG2 v.2).

Prior to the interviews, respondents filled out several forms, including a consent form to allow video-recording of the interview. Once paperwork was completed, the interviewer described the mission of NCHS, the purpose of the current study, and how the interview would take place. During the interviews, retrospective, intensive verbal probing was used to collect response process data. First, respondents were administered all of the survey questions, and then interviewers returned to each question and probed retrospectively. Probes included such things as: “Why did you answer the way that you did?” “How did you arrive at your response?” “Can you tell me more about that?” “Can you clarify what you mean?” Video and/or audio recordings and written notes of interview summaries were made of each interview. Interviews typically lasted 60 minutes, and a \$40 token of appreciation was given to each respondent

Data analysis. As is normally the case for analyses of qualitative data, the general process for analyzing cognitive interview data involves synthesis and reduction—beginning with a large amount of textual data and ending with conclusions that are meaningful and serve the ultimate purpose of the study. With each incremental step, a data reduction product is created (Miller, Willson, Chepp, & Padilla, 2014).

The steps consist of: 1) Conducting interviews to produce interview text; 2) Synthesizing interview text into summaries to produce detailed summaries; 3) Comparing summaries across respondents; 4) Comparing identified themes across subgroups; and 5) Making conclusions. Although these steps are described separately and in a linear fashion, in practice they are iterative; varying levels of analysis typically occur throughout the qualitative research process. As each step is completed, data are reduced such that meaningful content is systematically extracted to produce a summary that details a question's performance. In detailing a question's performance, it is possible to understand the ways in which a question is interpreted by various groups of respondents, the processes that respondents utilize to formulate a response as well as any difficulties that respondents might experience when attempting to answer the question. It is the ultimate goal of a cognitive interviewing study to produce this conceptual understanding, and it is through data reduction that this type of understanding is possible.

A data entry and analysis software application (Q-Notes¹) was used to conduct analysis. Q-Notes, developed by CCQDER, ensures systematic and transparent analysis across all cognitive interviews as well as provides an audit trail depicting the way in which findings are generated from the raw interview data.

3. Overall findings

Uncertainty: In general, respondents were not always sure of the causes of their or the reference people's cognitive difficulty. This uncertainty occurred for several reasons:

1. The cognitive difficulty may not be worrisome enough to warrant a medical consultation, so there has been no official medical diagnosis;
2. Some cognitive difficulties are so vague that medical professionals are also not certain of their causes;
3. Proxy respondents don't always have access to information about the causes of their reference people's cognitive difficulties;
4. Cognitive difficulty is a symptom that could be caused by many conditions that are more prevalent in old age.

Therefore, many respondents rely on the pervasive stereotype that old age is a primary cause of cognitive difficulty. Additionally, the question asks respondents to indicate the main cause of the cognitive difficulty, but in cases where there may be multiple causes, respondents aren't sure which one is the main cause and which others are contributing causes.

An example of the complexities in knowing the main cause of a cognitive difficulty can be seen with a respondent who described forgetfulness that significantly impacted his life when answering Version 1 of COG2. When asked the main cause of his forgetfulness, he answered "other, please specify." He went on to detail several possible reasons for his forgetfulness. He had been shot in the head and also hit in the head with a baseball bat. He had also been in several comas due to drug overdoses and was on high levels of pain medication. According to the respondent, at the time of these incidents, "The doctor said I ain't got no brain damage," but then he wondered if the doctor might have been withholding details because the respondent is a Medicaid patient. "I might have brain damage or dementia or Alzheimer's and not even know I got it." Ultimately, the respondent answered "other" because he could attribute his difficulty to old age. He said, "That's the only thing it could be because as a child and a teenager, I didn't have these issues." These and other difficulties are explored in further detail below.

¹ <https://www.cdc.gov/qnotes>

Proxy: Half the sample was comprised of proxy-respondents who answered on behalf of a relative or household member (the “reference person”). The proxy-respondents in this sample were willing and able to answer on behalf of their household members. Most of the proxy-respondents in this sample answered based on cognitive difficulties that had a significant impact on their reference people’s functioning or for which their reference people had sought medical treatment. In contrast, the self-responders were more likely to indicate that they have “some difficulty” to indicate minor issues with memory and concentration that they consider to be “normal.” Therefore, self-responders are more likely to consider a wider range of difficulties than proxy responders, who tend to limit their responses to severe difficulties.

4. Question-by-question Review

COG1. [Do/does] [you/he/she] have serious difficulty remembering or concentrating? Would you say... [<i>Read response categories</i>]	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all / Unable to do
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Respondents were screened in on the basis of answering “yes” to the screener question, “Do you or someone in your household have difficulty concentrating, remembering, or making decisions?” Therefore, all respondents, except one, answered either “some difficulty” or “a lot of difficulty” to this question. Although a few respondents indicated some level of difficulty for what they considered “normal,” most respondents thought about significant difficulties.

Although there was some overlap between the concepts of remembering and concentrating, almost all focused primarily on either one or the other rather than both together. A single proxy-respondent had difficulty choosing a response category because the reference person’s level of difficulty remembering was different than her level of difficulty concentrating. This respondent reported that the reference person had no difficulty concentrating but a lot of difficulty remembering. Thus, she responded “some difficulty” as a compromise between the two. Overall patterns of interpretation for this question are depicted in Figure 1.

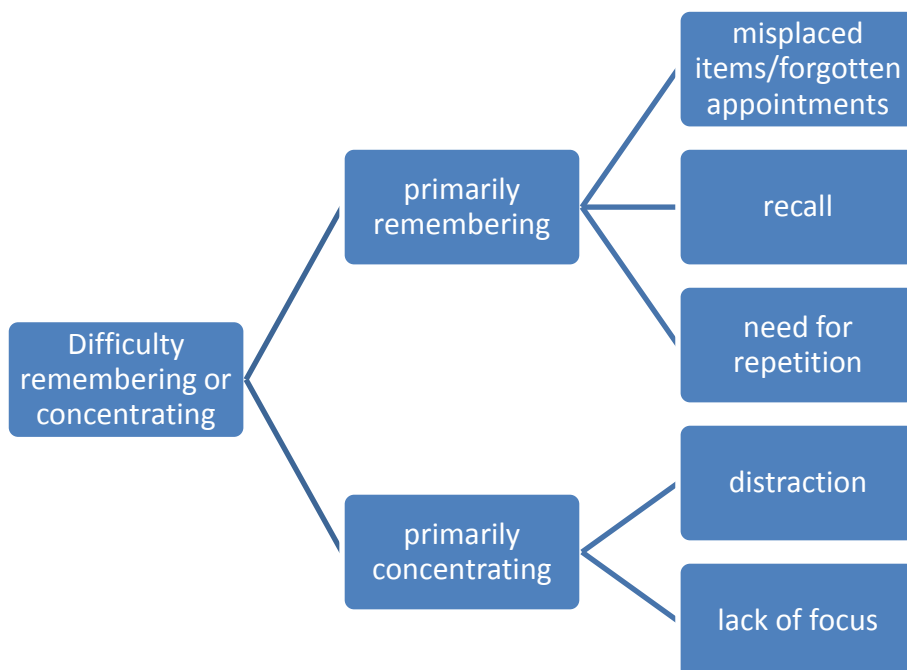


Figure 1. Difficulty concentrating or remembering

Remembering: Most respondents (both self and proxy) thought primarily about some aspect of remembering. Some focused on functional forgetfulness such as forgetting appointments and medication or misplacing everyday items like keys or papers. Other respondents thought about their ability to recall information when needed. Several respondents gave the example of not remembering names. Another respondent spoke of not being able to remember his address and phone number. Still others talked about how their family members have difficulty recalling past events. Finally, some respondents thought about their own or their reference person's repetitive statements or questions. One respondent said that he frequently starts to tell a story only to be told that he had already told that story. Another respondent described how her father asks the same questions (such as what day it is) over and over.

Two respondents, one proxy-respondent and one self-respondent noted that forgetting can be purposeful. The self-respondent reported that she had recently been raped and assaulted. She answered "some difficulty" because she intentionally tries to forget the incident.

Concentrating: A few respondents focused primarily on concentrating. Two proxy-respondents described how their reference people are frequently distracted or "tuned out" during conversation. One said, "He doesn't pay attention to nothing. He don't care. He just watch the TV." Self-responders described their own difficulty concentrating and staying focused. One respondent described how she has difficulty staying organized and focusing on tasks at work and home. A few noted how lack of focus impacts learning. One said, "My mind drifts off. I'm trying to get the details, but I just fade off. It's hard to explain....this may be why I didn't finish college."

Normal: A few respondents answered "some difficulty" for what they considered "normal" levels of difficulty remembering and concentrating. For example, one respondent described how her husband has difficulty concentrating on what she's saying when he's reading a book. She then commented, "I guess that's normal. I probably do that too." Another respondent said that he is sometimes forgetful and that "things slip my mind from time to time." He explained that he chose "some difficulty" because it's "not really a difficulty. I am human."

Disability: Respondents were recruited on the basis of having some cognitive difficulty, so it is not surprising that all respondents except one indicated that they had some level of cognitive difficulty in response to the initial question on cognitive functioning. Analysis of the rest of the Washington Group's short set of disability questions (on seeing, hearing, mobility, communication, self-care, anxiety and depression) reveals that respondents also had a high frequency of other disabilities as well. Only two out of the 40 respondents indicated that they (or their reference person) had no difficulties other than their cognitive difficulty.

In many cases, the person's cognitive difficulty was related to their other difficulties either as a cause of the other difficulties or because their cognitive and other difficulties all had the same cause. For example, one respondent indicated that her mother had "a lot of difficulty" in the cognitive domain. She described how her mother (her reference person) sometimes didn't recognize her and called her by the wrong name. This respondent also indicated that the reference person had "a lot of difficulty" communicating. The respondent said, "Sometimes she talks and I be like 'what she talking about?' She be calling me 'Louise' and mumbling and I don't know what all she going on about." In this case, the reference person's difficulty communicating was a result of her cognitive difficulty. In another instance,

a respondent indicated that his cognitive, vision, hearing, mobility and communication difficulties were all the result of a single automobile accident that occurred 20 years ago.

Daily anxiety was also related to cognitive difficulty. Half of the respondents, 7 self-respondents and 11 proxy-respondents, indicated they or their reference person had daily anxiety as well as some level of cognitive difficulty. Respondents often indicated that the anxiety was related to their trouble remembering or concentrating. For example, one respondent explained his reference person’s daily anxiety, saying, “She worries every day. She’s worried about losing her keys or whether she can take care of things at all.” Another respondent explained his own daily anxiety, saying, “I worry about my job. I really want to do a good job but because I have such a hard time remembering things, I’m afraid I’ll mess it up. It’s really all I’ve got.”

COG2v.1 What is the main reason for your [his/her] difficulty remembering or concentrating?	8. Intellectual or learning disability 9. Dementia or Alzheimer’s disease 10. Mental illness 11. Traumatic brain injury 12. Stroke 13. Other (_____, please specify) 14. I’m not sure
COG2v.2 What is the main reason for your [his/her] difficulty remembering or concentrating?	Open-ended _____

This follow-up question was asked to all respondents whose response to COG1 indicated some level of difficulty with remembering or concentrating. Frequencies for each response option are detailed in table 2.

Table 2. Main causes of cognitive difficulties

	Proxy	Self
Intellectual or learning disability	3	1
Dementia or Alzheimer’s disease	4	0
Mental illness	3	2
Traumatic brain injury	2	4
Stroke	0	0
Other (_____, please specify)*	4	4
I’m not sure	1	4
Open ended**	3	4

*age, drugs, stress, trauma/PTSD, chronic condition, normal functioning

** age, trauma/PTSD, mental illness, Don’t know

Respondents were presented with either the predetermined response categories (22) or an open ended response (8). Most of the respondents who were given the open ended question, answered “I don’t know” or “old age.” Of the respondents who were asked to choose one of the response categories, all

were all able to select a response from among the categories presented. However, overall, the response categories did not function as intended and several potential problems emerged.

Uncertainty: cause. Five respondents who were presented with the response categories chose “I’m not sure.” The self-responders who answered “I’m not sure” wondered if their difficulties were due to advancing age or simply felt that there was no good reason for their difficulties. One respondent described significant ongoing trouble concentrating and remembering and then said, “That’s just the way I am. I don’t do drugs; I don’t drink much. I don’t think that’s the cause for it. I just don’t know.”

Several respondents who chose response options other than “I’m not sure” also expressed uncertainty. For example, one proxy-respondent answered “mental illness” but then explained that she wasn’t really sure if her mother’s cognitive difficulties were due to her diagnosis of mental illness or perhaps from her heart problems. “I don’t really know. She’s very private and doesn’t tell me that,” the respondent said. Another proxy-respondent answered “dementia or Alzheimer’s disease” but then explained that she wasn’t sure what the source of her mother’s difficulty was. “She’s getting older, but maybe it’s just a phase. I hope it doesn’t turn into Alzheimer’s.”

Uncertainty was not only a problem for proxy-respondents as self-responders weren’t always certain of their chosen responses either. One self-responder chose “mental illness” but then said, “I guess. I don’t know if it’s the bipolar or not. I don’t know if it’s because I’m hitting 50 or not.”

Uncertainty was more prevalent in responders who indicated that their or their relative’s difficulties concentrating or remembering were “normal.” That is, when the cognitive difficulties had a significant impact on life, respondents were more likely to feel more certain of the cause.

Uncertainty: category. A few respondents were more sure of the cause of their or their relative’s cognitive difficulties but weren’t sure which response category to choose. For example, one respondent’s difficulties were a result of epilepsy. She wasn’t sure which response option to choose because she wasn’t sure if epilepsy was a mental illness or a learning disability (since it had kept her out of school). She ultimately chose “mental illness” but explained that she would have chosen “health issue” if that had been an option.

More than one reason. Quite a few respondents wanted to select more than one response option. For example, after hearing the response categories several times, one respondent said, “I’d say a lot of head injuries and mental health.” When pushed to choose one, he chose “traumatic brain injury” but explained that his difficulties were really a result of both. “I’ve got some mental illness, but I was also hit by a bus, hit on the head with a hammer and stabbed in the head. It’s both.” Another respondent wanted to answer both mental illness and education level. She chose “mental illness” because it was an explicit category but explained that her difficulties were due in larger part to having “dropped out of the 9th grade, got in trouble with drugs and boys and never learned the basics.”

Some respondents chose “other, please specify” in order to indicate multiple causes for their difficulties. One respondent thought his cognitive difficulties might be due to having had several head injuries, but he also thought that it might be due to his Autism. He chose “other” to encompass both of these possibilities.

Age. Many respondents attributed their or their relative's cognitive difficulties at least in part to age. Since "age" in and of itself was not a response category, respondents generally chose another response category but then indicated that it could also be due to "just getting old." Several respondents who were given the open ended option chose "old age" as the main cause of their difficulties.

Open ended and other please specify: Respondents who were given the open ended option or who chose "other, please specify" offered other potential causes of cognitive difficulty. The most common, as mentioned, was age. Trauma, drugs and other health conditions were also mentioned multiple times.

Question order: Half of the respondents were asked this question directly following COG1 while the other half was asked this question after the full set of Washington Group questions. Differing question placement resulted in no discernable differences in how respondents answered. Even when the question was placed after the full set of Washington Group questions, respondents understood that the question was a follow-up to COG1.

Works Cited

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- Tourangeau, R., L. J. Rips, and K. Rasinski. 2000. *The Psychology of Survey Response*. New York, NY: Cambridge University Press.
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Appendix One

Cognitive Functioning		
VIS_1	[Do you/does he/she] have difficulty seeing, even when wearing [your/his/her] glasses? Would you say... [<i>Read response categories</i>]	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all / Unable to do
HEAR_1	[Do you/does he/she] have difficulty hearing, even when using a hearing aid(s)? Would you say... [<i>Read response categories</i>]	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all / Unable to do
MOB_1	[Do you/does he/she] have difficulty walking or climbing steps? Would you say... [<i>Read response categories</i>]	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all / Unable to do
COM_1	Using [your/his/her] usual language, [Do you/does he/she] have difficulty communicating, for example understanding or being understood? Would you say... [<i>Read response categories</i>]	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all / Unable to do
COG_1	[Do you/does he/she] have serious difficulty remembering, concentrating or making decisions? Would you say... [<i>Read response categories</i>]	1. No difficulty [Go to SC_1] 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all / Unable to do
<p>Note: Half of respondents were asked either v.1 or v.2 of COG2 here, directly following COG1 while half of respondents were asked COG2 after the rest of the disability questions.</p>		
COG_2 v.1	What is the main reason for [your/his/her] difficulty remembering or concentrating?	1. Intellectual or learning disability 2. Dementia or Alzheimer's disease 3. Mental illness

		<ol style="list-style-type: none"> 4. Traumatic brain injury 5. Stroke 6. Other (_____, please specify) 7. I'm not sure
COG_2 v.2	What is the main reason for [your/his/her] difficulty remembering or concentrating?	Open-ended _____
SC_1	[Do you/does he/she] have difficulty with self-care, such as washing all over or dressing? Would you say...	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all / Unable to do
ANX_1	How often [Do you/does he/she] feel worried, nervous or anxious? Would you say... [<i>Read response categories</i>]	<ol style="list-style-type: none"> 1. Daily 2. Weekly 3. Monthly 4. A few times a year 5. Never [skip to DEP_1]
ANX_2	[Do you/does he/she] take medication for these feelings?	<ol style="list-style-type: none"> 1. Yes 2. No
ANX_3	Thinking about the last time [you/he/she] felt worried, nervous or anxious, how would [you/he/she] describe the level of these feelings? Would you say... [<i>Read response categories</i>]	<ol style="list-style-type: none"> 1. A little 2. A lot 3. Somewhere between a little and a lot
DEP_1	How often [Do you/does he/she] feel depressed? Would you say... [<i>Read response categories</i>]	<ol style="list-style-type: none"> 1. Daily 2. Weekly 3. Monthly 4. A few times a year 5. Never [skip to Gen_Q005]
DEP_2	[Do you/does he/she] take medication for depression?	<ol style="list-style-type: none"> 1. Yes 2. No

DEP_3	Thinking about the last time [you/he/she] felt depressed, how depressed did [you/he/she] feel? Would you say... [<i>Read response categories</i>]	<ol style="list-style-type: none"> 1. A little 2. A lot 3. Somewhere between a little and a lot
<p>Note: Half of respondents were asked either v.1 or v.2 of COG2 here, after all of the disability questions while half of respondents were asked COG2 directly after COG1.</p>		
COG_2 v.1	What is the main reason for [your/his/her] difficulty remembering or concentrating?	<ol style="list-style-type: none"> 8. Intellectual or learning disability 9. Dementia or Alzheimer's disease 10. Mental illness 11. Traumatic brain injury 12. Stroke 13. Other (_____, please specify) 14. I'm not sure
COG_2 v.2	What is the main reason for [your/his/her] difficulty remembering or concentrating?	Open-ended _____