

Question Specifications for the Cognitive Test Protocol

Core Questions

These are the 6 disability questions to be tested in the interview. All of the other questions in the cognitive test protocol are designed to examine how well these core questions perform. Therefore, it is imperative that you ask the core question and the response categories exactly as they are written. **You may repeat the question and/or the answer categories, but do not try to help or assist the respondent if they are experiencing difficulty.** That is, do not attempt to explain the question or help them figure out what their answer should be. It is important to learn how respondents are interpreting the question, regardless of whether or not their interpretation is correct. Additionally, it is important to discover the degree of difficulty that they experience without the help of an interviewer. If the respondent is unable to answer the question, this is important information to know.

Introduction: The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

A. Objective

The purpose of the introduction is to get the respondent to focus on difficulties they may have that result from a physical or mental health problem. Since persons living in developing countries may not have access to Western medicine which would provide a diagnosed 'condition', the term problem was substituted. However, condition can be used interchangeably with the term problem if that facilitates the respondent understanding the context. We are interested in establishing difficulties that occur within a health context rather than those caused by a lack of resources.

B. Definitions

Health refers to the general condition of the body or mind with reference to soundness, vitality, freedom from disease

Problem refers to the respondent's perception of a departure from physical, mental or emotional well-being. This includes specific health problems such as a disease or chronic condition, a missing limb or organ or any type of impairment. It also includes more vague disorders not always thought of as health-related such as senility, depression, retardation, drug dependency, accidental injuries, etc.

Questions

1. **Do you have difficulty seeing, even if wearing glasses?**
 - a. **No - no difficulty**
 - b. **Yes – some difficulty**
 - c. **Yes – a lot of difficulty**
 - d. **Cannot do at all**

A. Objective

The purpose of this item is to identify persons who have some serious vision limitation problems of any kind that contribute to difficulty in doing their daily activities. They can have a problem doing close handwork or reading, or the problem can be that they can't read road signs when driving. They may not be able to see out of one eye or they may be only able to see directly in front of them, but not to the sides. Any problem with vision that they consider serious should be captured.

B. Definition/s

Seeing refers to an individual using his/her eyes and vision capacity in order to perceive or observe what is happening around them.

C. Instructions

These questions are designed to be asked of the individual respondent. Note if the person is wearing glasses and make sure that they understand that the question refers to difficulties they may have while they are wearing their glasses.

The answer categories are set up so that the respondent can indicate 'yes', 'no' or that they cannot do it easily. However people aren't always sure how much difficulty is considered to be enough for a 'yes' answer. So they usually qualify their 'yes' with comments about their experience such as 'yes', I have a little problem or 'yes sometimes', or, when the problem is very serious, they indicate 'Oh, yes, a lot'. These answer categories try to capture that process. They may have to be repeated for the first one or two questions in order for the respondent to get familiar with the choices.

2. Do you have difficulty hearing, *even if using a hearing aid?*

- a. No- no difficulty**
- b. Yes – some difficulty**
- c. Yes – a lot of difficulty**
- d. Cannot do at all**

A. Objective

The purpose of this item is to identify persons who have some serious hearing limitation or problems of any kind with their hearing that contribute to difficulty in doing any aspect of their daily activities. They can have a problem hearing someone talk when in a crowded or noisy space or the problem can be that they can't hear when someone talks to them directly in a quiet space. They may not be able to hear in one ear or both. Any problem with hearing that they consider serious or important should be captured.

B. Definition/s

Hearing refers to an individual using his/her ears and auditory (or hearing) capacity in order to know what is being said to them or the sounds of activity, including danger that is happening around them.

C. Instructions

These questions are designed to be asked of the individual respondent. Note if the person is wearing hearing aids, make sure that they understand that the question refers to difficulties they may have even while they are wearing their hearing aids.

Instructions relative to the answer categories are the same as for question 1.

3. Do you have difficulty walking or climbing steps?

- a. No- no difficulty**
- b. Yes – some difficulty**
- c. Yes – a lot of difficulty**
- d. Can not do at all**

A. Objective

The purpose of this item is to identify persons who have some serious limitation or problems of any kind getting around on foot. It may or may not contribute to difficulty in doing their daily activities. They can have a problem walking more than a block or some short distance, or the problem can be that they can't walk up or down steps without difficulty. They may not be able to walk any distance without stopping to rest or they may not be able to walk without using some type of device such as a cane, a walker or crutches. In some instances they may be totally unable to stand for more than a minute or two and need a wheelchair to get from place to place.

Any difficulty with walking (whether it is on flat land or up or down steps) that they consider a problem should be captured.

B. Definition/s

Walking refers to an individual using his/her legs in such a way as to propel themselves over the ground to get from point A to point B. The capacity to walk should be without assistance of any device or human. If such assistance is needed, the person has difficulty walking.

C. Instructions

These questions are designed to be asked of the individual respondent. Note if the person is using an assistive device or has a person to help them with this function, it is highly likely they have difficulty with walking.

Instructions relative to the answer categories are the same as for question 1.

4. Do you have difficulty remembering or concentrating?

- a. **No – no difficulty**
- b. **Yes – some difficulty**
- c. **Yes – a lot of difficulty**
- d. **Cannot do at all**

A. Objective

The purpose of this item is to identify persons who have some serious problems with remembering or thinking that contribute to difficulty in doing their daily activities. They can have a problem finding their way around, or the problem can be that they can't concentrate on what they are doing, or they may forget where they are or what month it is. They may not remember what someone just said to them or they may seem confused or frightened about most things. Any problem with remembering, concentrating or understanding what is going on around them that they or family members (if the family member is the respondent) consider serious should be captured.

B. Definition/s

Remembering refers to an individual using his/her memory capacity in order to recall what has happened around them. It means the individual can bring to mind or think again about something that has taken place in the past (either the recent past or further back). In connection with younger people, remembering is often associated with storing facts learned in school and being able to retrieve them when needed.

Concentrating refers to an individual using his mental ability to accomplish some task such as reading, calculating numbers, learning something. It is associated with focusing on the task at hand in order to complete the task. It is the act of directing ones full attention to one subject or to focus without distraction on one thing.

C. Instructions

These questions are designed to be asked of the individual respondent, but occasionally require that a close family member respond. This is particularly true if the respondent has severe problems with remembering or concentrating.

Instructions relative to the answer categories are the same as for question 1.

Additional Questions:

5. Do you have difficulty (with self-care such as) washing all over or dressing?

- a. **No – no difficulty**
- b. **Yes – some difficulty**
- c. **Yes – a lot of difficulty**

d. Cannot do at all

A. Objective

The purpose of this item is to identify persons who have some serious problems with taking care of themselves independently. Washing and dressing represent tasks that occur on a daily basis and are very basic activities.

B. Definition/s

Remembering refers to an individual using his/her memory capacity in order to recall what has happened around them. It means the individual can bring to mind or think again about something that has taken place in the past (either the recent past or further back). In connection with younger people, remembering is often associated with storing facts learned in school and being able to retrieve them when needed.

Concentrating refers to an individual using his mental ability to accomplish some task such as reading, calculating numbers, learning something. It is associated with focusing on the task at hand in order to complete the task. It is the act of directing ones full attention to one subject or to focus without distraction on one thing.

C. Instructions

These questions are designed to be asked of the individual respondent, but occasionally require that a close family member respond. This is particularly true if the respondent has severe health problems.

Instructions relative to the answer categories are the same as for question 1.

- 6. Because of a physical, mental or emotional health condition, do you have difficulty communicating, (for example understanding others or others understanding you)?**
- a. No – no difficulty**
 - b. Yes – some difficulty**
 - c. Yes – a lot of difficulty**
 - d. Cannot do at all**

A. Objective

The purpose of this item is to identify persons who have some serious problems with talking, listening or understanding speech such that it contributes to difficulty in doing their daily activities. They can have a problem making themselves understood, or the problem may be that they can't understand people who talk to them or try to communicate with them in other ways

B. Definition/s

Communicating refers to an individual exchanging information or ideas with other people through the use of language. They may use their voices for their exchange or make signs or write the information they want to exchange. Communication can be interrupted at numerous places in the exchange process. It may involve mechanical problems such as hearing impairment or speech impairment, or it may be related to the ability of the mind to interpret the sounds that the auditory system is gathering and to recognize the words that are being used.

C. Instructions

These questions are designed to be asked of the individual respondent, but occasionally require that a close family member respond. This is particularly true if the respondent has severe problems with remembering or concentrating.

Instructions relative to the answer categories are the same as for question 1.



Interviewer Coding Questions

These 3 questions appear in the shaded box immediately after the core question. They are to be answered by the interviewer and should not be read out loud to the respondent. These Interviewer Coding Questions are designed to capture basic information about the ease of administration for the core question, specifically, whether the question (or any part of the question) needed to be repeated, if the response categories worked appropriately, and if the respondent needed to clarify their answer. To ensure accuracy, these questions must be answered immediately, when they appear in the questionnaire. Do not wait until the end of the interview.

Did the respondent....

1. need you to repeat any part of the question? Yes (1) No (2)

Instruction: For this first interviewer-coded question, check the box marked "Yes" if the respondent asked to have any part of the question repeated—the question portion, the response options or the entire question. Also, check the box marked "Yes," if (when administering the question) you saw that the respondent did not hear or understand the question so repeated it for their benefit. Otherwise, check the box marked "No."

2. have any difficulty using the response options? Yes (1) No (2)

Instruction: For the second interviewer-coded question, check the box marked "Yes" if the respondent did not answer using one of the provided response categories (for example, if they made up their own category or used other words) or if they experienced any other kind of difficulty with the response options. Otherwise, check the box marked "No."

3. ask for clarification or qualify their answer? Yes (1) No (2)

Instruction: For the third interviewer-coded question, check the box marked "Yes" if the respondent needed to provide additional information along with their answer **or** if they asked you to clarify some aspect of the question. Otherwise, check the box marked "No."

Open-ended Follow-up Probes

This is the first question asked of the respondent after they have answered the core question. It is designed to elicit what the respondent was thinking when answering the core question. As much as possible, record exactly what the respondent states in the provided space. More than any other probe-question, this qualitative information will provide detailed insight into how the respondent interpreted the core question and how their response was formulated.

1. Why did you answer that way?
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Functioning Follow-up Probes

These functioning probe-questions appear at the end of each section. They are designed to provide an objective assessment of the respondent's physical abilities—information that will help to assess the validity of the core question. However, in our testing of this questionnaire, we found these questions to be the most difficult questions in the questionnaire—especially for respondents who have little education or experience taking surveys. Therefore, some respondents may misunderstand the intention of the question or may not be able to apply the question to their personal circumstances. In these cases, please do your best to get the most accurate answer—by asking the question in different ways, explaining the purpose, or by observation.

Vision

Do you have difficulty seeing and recognizing a person you know about 7 meters (20 feet) away?

The respondent should answer this question taking into account any assistive device (glasses or contact lenses) she may be using. "Seeing and recognizing a person" under normal circumstances. One would not be expected to recognize a person on a foggy or stormy day for example.

Do you have difficulty seeing and recognizing an object at arm's length or in reading?

The respondent should answer this question taking into account any assistive device (glasses or contact lenses) he/she may be using. The kinds of vision problems associated with seeing and recognizing an object is different than reading from a newspaper or a book. We are looking for whether a person is experiencing either of the two problems - a positive response to either problem should result in a positive answer.

Hearing

Do you have difficulty hearing someone talking on the other side of the room in a normal voice?

By "normal" voice we mean not speaking loudly or shouting. Any hearing aid should be taken into account. This assumes a normal size room such as a livingroom or kitchen and it also assumes that the person is not shouting or whispering but speaking in a conversational tone.

Do you have difficulty hearing what is said in a conversation with one other person in a quiet room?

This refers to hearing in a quiet room with no background noise. Any hearing aid should be taken into account.

Cognitive Follow-up Probes

The cognitive probe-questions are designed to capture how the respondent came up with their answer, specifically, what the respondent considered when formulating a response. These questions are based on analysis of previous open-ended cognitive interviews and represent all of the various considerations used by respondents to construct answers to the core questions. The cognitive probe-questions are subjective; there is no right or wrong answer. Additionally, because they are subjective and based solely on the respondents' perceptions, these probe-questions should be relatively easy for respondents to answer. However, if a respondent is unable to answer (for whatever reason), check box marked "*No Answer/Don't Know*" which appears below the list of response options. This *No Answer* option (appearing in italics) is not to

be read to the respondent and is only to be used in rare occasions-- if the respondent, in all sincerity, cannot answer the question.

3. How often do you have difficulty remembering or concentrating well?

- Never (0)**
- Somewhat often (1)**
- Very often (2)**

No Answer/Don't Know (9)

The question is designed to understand how frequently the respondent believes he or she experiences difficulty. The question is not intended to measure the actual amount of time (e.g. daily, weekly, monthly), but rather the extent to which the respondent believes he or she has difficulty.

4. When you are having difficulty, how much effort do you have to put into remembering or concentrating?

- No effort (0)**
- Some effort (1)**
- A lot of effort (2)**

No Answer/Don't Know (9)

The question is designed to measure the degree of exertion or work that the respondent feels that he or she experiences because of the difficulty.

5. Do you believe that your memory or concentration difficulties are...

- [MARK ALL THAT APPLY]**
- because you have too many things to do? (1)**
- because you getting older? (2)**
- Or, because of something else? (3)**

No Answer/Don't Know (9)

The question is designed to uncover false positive reports of the cognitive functioning core question. Some respondents may answer yes to the core question, not because they have a disability, but because they are very busy or are aging.

6. Are there any activities that you cannot do because of a problem with your memory or concentration?

- No (1)**
- Yes (2) Go to 6a**
- No Answer/Don't Know (9)***

6a. What activity are you thinking about?

The two questions together are designed to capture any activities that a respondent cannot do because of a disability. For question 6a, please write down all activities that the respondent states.

7. How concerned or worried are you about your ability to remember or concentrate?

Not at all (0)

Somewhat concerned (1)

Very concerned (2)

No Answer/Don't Know (9)

The question is designed to measure the degree of uneasiness (including fear, concern, worry, irritation or frustration) that the respondent feels about the difficulty

Remembering and Concentrating

Do you have difficulty concentrating on doing something for ten minutes?

This question is intended to determine the respondent's rating of difficulty with concentration for a short period, defined as 10 minutes. Generally, respondents have no problem understanding this item. If clarification is requested, however, respondents should be encouraged to think about their concentration in usual circumstances, not when they are preoccupied by a problem or in an unusually distracting environment. They may be cued to think about concentration while doing work tasks, reading, writing, drawing, playing a musical instrument, assembling a piece of equipment etc.

Do you have difficulty remembering to do important things?

This is a question about memory for matters of day to day importance. It does not refer to memory for irrelevant content nor to memory for detailed information from the past. Respondents should consider how well they remember to do things that are important to them or to their family. If note taking, electronic reminder systems or verbal cueing from personal assistants is *usually* in place as a memory aid, performance should be rated with this help taken into consideration.

Communicating

Do you have difficulty generally understanding what people say?

The respondent should consider his/her usual mode of communication (i.e. spoken language, sign language, with an assistive device such as a hearing aid) and overall, rate the degree of difficulty in understanding the messages of others.

All situations encountered in the past 30 days by the individual should be considered, such as:

- when others speak quickly
- with background noise
- with distractions

Difficulties due to the fact that the language spoken is not one's mother tongue should be excluded when rating this question.

Do you have difficulty starting and maintaining a conversation?

Both starting and maintaining conversation should be rated. If a respondent states that they have more trouble with starting than maintaining a conversation (or vice versa), they should indicate what is their overall experience or in general their experience on a regular basis. Conversation includes use of whatever is the usual

mode of communication (spoken, written, sign language, gestural). If assistive devices are used by the respondent for communication, the difficulty rating provided should take into account conversation while using those devices, assuming they are usually present. The respondent should consider any and all other factors of relevance to them in starting and maintaining a conversation such as hearing loss, language problems as after a stroke, stuttering, anxiety or any other factor *related to a health condition*.

Mobility

Do you have difficulty moving around inside your home?

This item refers to moving from room to room, and within rooms, using assistive devices or personal help that is usually in place. If the respondent lives in a house with multiple floors, this question also includes getting from one floor to another as needed. This will give a good idea of a person's mobility. A person who has problems moving inside the house is likely to have problems outside as well.

Do you have difficulty going outside of your home?

This question seeks information about:

- mobility aspects of getting out of the home
- emotional or mental aspects of leaving the home (depression, anxiety, etc.)

For this question, "home" means the respondent's current dwelling, which might be a house, apartment, or nursing home.

Do you have difficulty walking a long distance such as a kilometer [or equivalent]?

Distances should be converted into local measurement where necessary.

Do you have difficulty using your hands and fingers, such as picking up small objects or opening or closing containers?

This includes using hand, fingers and thumb to handle objects, picking up, manipulating and releasing them, such as required to lift coins off a table or turn a dial or knob.

Self Care

Do you have difficulty feeding yourself?

This item refers to both feeding oneself (i.e. cutting food, getting food or drink from plate or glass to mouth) and swallowing (both food *and* drink). It also includes mental/emotional factors contributing to difficulty eating such as anorexia, bulimia, or depression. This question does not refer to meal preparation. If the respondent uses non-oral feeding (e.g.. tube feedings), this question refers to any difficulties experienced in self administering the non-oral feeding (e.g. feeding pump set up and cleaning).

Additional Questions

Learning

Do you have difficulty learning a new task, for example, learning how to get to a new place?

Learning a new route to the store or learning how to cook a new dish can be offered as *an example* in this question however, respondents should not limit themselves to only this situation. If further clarification is requested or if the interviewer feels the respondent has difficulty answering the interviewer may ask the respondent to think about a situation in the past month where learning something new was required, such as learning a task at work (such as a new procedure or assignment), or a new activity (cooking, learning a language, a new sport).

When making the rating, respondents should consider how easily new information was acquired, how much assistance or repetition they needed in order to learn and how well what was learned was retained.

Interpersonal Interactions

Do you have difficulty in making new friends?

This includes:

- seeking opportunities to meet new people
- following up on invitations to get together
- social and communication actions to make contact and to develop a friendship

On occasion, participants will report that they have not engaged in friendship-making activities in the past 30 days. In this case, interviewers should ask whether this is due to a health condition). If respondents report that it is due to a health condition, then the item should be coded "5" for extreme/cannot do. On the other hand, if respondents report that it is not due to a health condition, then the item should be coded "N/A" for not applicable.