



INSTRUCTIONS FOR THE AD8 DEMENTIA SCREENING INTERVIEW (10/22/2015) (ADS, VERSION 1, 4/29/2015)

I. General Instructions

The AD8 Dementia Screening Interview (ADS) is a measure used to detect dementia. The ADS is designed to be administered to a knowledgeable proxy/informant, such as a spouse, other family member or close friend. When speaking with such an individual, it is permissible to refer to the participant as "your mother" or "your father" etc., rather than including the participant's full name for the AD8 dementia surveillance interview. The full question should be presented to the proxy which includes the portion in parentheses.

If the interview is partially completed due to the fact that the proxy/informant/other contacted refuses to complete the interview, or becomes frustrated with the questions due to the participant's known dementia, and therefore the interview cannot be fully administered, please click the arrows to the right of the missing field, select 'Refused' as the reason for the missing data in the drop down menu and then click on the save button to save the selected reason. If the participant has (or had) known dementia, verify and update when necessary item 0d in the Contact Information Update form.

Dementia refers to a loss (a change) in cognitive abilities severe enough to interfere with one's day-to-day functioning. Common cognitive symptoms of dementia include: memory loss, lack of orientation to time (confusion about month, day, year), problems with thinking, reasoning and judgment. The ADS seeks to determine whether the participant has (or had, if deceased) problems with any of these common dementia symptoms.

Cognitive changes associated with dementia may come about rapidly (e.g., following a stroke) or may come about gradually, developing slowly over many years (e.g., in the case of Alzheimer's disease). In order to determine whether the symptoms captured by the ADS are due to dementia, we need to know: 1) that the symptom represents a change from previous functioning (e.g., not being able to tell time using a watch would not be considered a symptom of dementia, if the participant had never been able to tell time), and 2) the symptom, even if it represents a change in functioning, must be due to a cognitive/mental decline, not due solely to a physical impairment (e.g., not being able to tell time because the participant lost his/her vision would not be considered a change due to dementia).

ADS items related to dementia symptoms have two parts. The first part of the question asks whether a symptom/problem is present. Note that a response of "somewhat" or "sometimes" is counted as "yes". If yes, the second part of the question attempts to establish whether the symptom/problem represents a change for the participant "compared to several years ago." or "compared to several years ago (before his/her death)" if the participant is deceased. As noted above, change in the participant's thinking skills could have come about recently or developed over many (5-15) years. If a proxy informant expresses uncertainty about what defines "several years ago", the interviewer may add: "compared to 5 to 15 years ago (or 5 to 15 years before his/her death)." In rare cases, symptoms may come about even earlier in life. Any problem, other than a lifelong problem, would be considered a change.

Questions 4 and 6 require an additional prompt to determine if a change in functioning is due to a cognitive/mental decline versus a physical limitation. The ADS includes present tense (for living participants) and past tense language (for deceased participants). In the case of a deceased

participant, we would not consider a symptom to be positive for change if the problem only appeared acutely in the immediate days or weeks just prior to death. Likewise, for living participants, we would not consider a symptom to be positive for change if the problem has only appeared recently in the days or few weeks immediately following major surgery.

A stroke or other brain injury (or brain tumor) would *not* be considered a physical limitation (these will always be considered as a cognitive problem). If an informant describes problems ever since a participant had a stroke (that persisted, even if then didn't worsen further), you should consider a symptom to be positive. If an informant believes that a participant has had problems only since initiation of a new medication, we would consider this a physical reason unless details are not clear about if it was clearly related to medications (for instance, if symptoms started ever since a patient was placed in a nursing home when a number of new medications were started, it isn't clear that this was caused by a medication, so would still be positive; if someone was fine and a new medication was started and ever since that medication was started they had problems with their memory, we would count that as a physical reason).

The ADS questions may prompt the proxy to relate concerns about the participant's cognitive functioning and inquire about the need for further evaluation. The interviewer may reassure the participant that there are several treatable conditions that may affect memory and thinking, and recommend that the proxy discuss their concerns with the participant's primary care provider. Should the proxy request assistance with a physician referral, the interviewer should follow the field centers' local protocol for this situation.

Example ADS question and response with scoring:

Example A:

Question 6: Does Mr. Smith have trouble using or learning how to use a tool, household appliance, etc.?

Proxy response: I'm not sure if this is what you mean, but he doesn't seem to know how to work the microwave.

Coding: Record "Yes" to question X.

Subquestion 6a: Would you say this is (was) a change for Mr. Smith compared to several years ago (before his/her death)?

Proxy response 1: Definitely.

Interviewer prompt 1: Can you tell me what you think caused this change for Mr. Smith: Would you say it was because of problems with memory or thinking or was it due to physical problems (for example, hearing loss or loss of mobility)?

Proxy response 1: It's hard to say exactly, but I first noticed it about 2-3 years ago. I first thought it may be that he needed new glasses, but we had his eyes checked and he still can't work the microwave. It seems like he just doesn't know to work it any more.

Coding: Yes, change.

Rationale: The proxy has ruled out an obvious physical problem (vision), therefore the item would be positive for a change due to cognitive function.

Example B: (same answer to question 6 above)

Subquestion 6a: Would you say this is (was) a change for Mr. Smith compared to several years ago (before his/her death)?

Proxy response 2: Definitely.

Interviewer prompt 2: Can you tell me what you think caused this change for Mr. Smith: Would you say it was because of problems with memory or thinking or was it due to physical problems (for example, hearing loss or loss of mobility)?

Proxy response 2: It started last year, when he lost his vision due to macular degeneration.

Coding: No change.

Rationale: The participant's inability to work the microwave is due to a physical reason, therefore coded as no change.

Section B: Personal Neurologic History

This section includes 4 items related to dementia-related medical diagnoses that are asked of the proxy/informant for deceased participants. (Note: For living participants, these questions are collected as part of the Medical Conditions Update form).

Section C: Proxy/informant/other person interview assessment

This section includes 3 questions seeking the interviewer's impressions about the accuracy of the information obtained. For example, accuracy may be questionable in cases where the proxy/informant has some degree of cognitive impairment or in cases where the informant (perhaps a friend or family member who does not live with the participant) does not have a good sense of the participants daily functioning.

II. Detailed Instructions for each Item.

- 0a. Enter the date on which the ADS was administered.
- 0b. Enter the staff ID for the person administered the ADS.

Read the script introducing the ADS:

If the participant is alive: **“The next few questions have to do with [name’s] memory, thinking and day-to-day functioning. These are similar to questions that [name] has answered in the ARIC clinic.”**

If the participant is deceased: **“The next few questions have to do with [name’s] memory, thinking and day-to-day functioning before [name’s] death. These are similar to questions that [name] answered in past visits to the ARIC clinic.”**

If the proxy/informant requests additional information before answering the ADS questions, the interviewer should reply: **“Thanks to information shared by ARIC study participants like [name] over the years, we have learned many important things about prevention of heart disease and stroke. We are asking about memory and daily functioning to identify the causes of difficulties with memory and day-to-day functioning in older people. This may show us ways to prevent**

memory loss and to better maintain independence in older age”.

Additional information for specific items:

1. Indicate whether AD8 was administered. If question is recorded as “Yes”, the form skips to question 2.

1a.-1a1. If the AD8 is not administered, record the reason in question 1a. If ‘other’ is recorded in question 1a, specify the reason in question 1a1.

If administration of the ADS is interrupted for some reason and not completed, the interviewer should attempt to recontact the proxy at a convenient time.

2. Indicate whether the participant is alive or deceased. If the participant is alive, ask questions 3-10a, skip questions 12-15 and continue with questions 16-18.

3. Does/Did [name] have any problems with judgment (e.g., problems making decisions, make bad financial decisions, or have problems with thinking?)

Issues related to problems with judgment or thinking may be quite varied, but involve making clearly inappropriate decisions. For example, a person may go outside to garden in a thunderstorm or reach into a hot oven to remove a dish with bare hands. Often, problems with judgment become most obvious when it comes to handling money or finances. For example, a person may give large sums of money to complete strangers (telemarketers) or spend large sums on sweepstakes. If the proxy/informant is still unclear about what is being asked, the interviewer can provide the examples above.

3a. Indicate whether this is (was) a change for [name] compared to several years ago (before his/her death)?

4. Does/Did [name] have less interest in hobbies or activities?

If this question is recorded as “Yes”, it will be important to ensure that the observed change in activities is not solely due to a physical impairment (e.g., vision loss, hearing loss, or loss of mobility). If the cause of the change is unclear from the proxy’s response, say: **“Can you tell me what you think caused this change for [name]: Would you say it was because of problems with memory or thinking or was it due to physical problems (for example, hearing loss or loss of mobility)?”** If due to physical impairment, record question 4a as “No”. If the proxy states that it was due to both mental and physical impairment, record question 4a as “Yes.”

4a. Indicate whether this is (was) a change for [name] compared to several years ago (before his/her death)?

5. Does/Did [name] repeat the same things over and over (such as repeating the same questions, stories, or statements)?

5a. Indicate whether this is (was) a change for [name] compared to several years ago (before his/her death)?

6. Does/Did [name] have trouble using or learning how to use a tool, household appliance, or gadget (e.g., VCR, computer, microwave, remote control)?

This can refer to any tool or other household items not listed in the example (e.g., dishwasher, etc.).

If this question is recorded as “Yes”, it will be important to ensure that the observed change is not solely due to a physical impairment (e.g., vision loss, hearing loss, or loss of mobility). If the cause of the change is unclear from the proxy’s response, say: **“Can you tell me what you think caused this change for [name]: Would you say it was because of problems with memory or thinking or was it due to physical problems (for example, hearing loss or loss of mobility)?”** If due to physical impairment, record question 6a as “No”. If the proxy states that it was due to both mental and physical impairment, record question 6a as “Yes.”

6a. Indicate whether this is (was) a change for [name] compared to several years ago (before his/her death)?

7. Does/Did [name] have trouble remembering what the correct month or year is?

7a. Indicate whether this is (was) a change for [name] compared to several years ago (before his/her death)?

8. Does/Did [name] have trouble handling complicated financial affairs (e.g., balancing the checkbook, doing income taxes, or paying bills)?

If the individual has never handled the bills, then the answer to question 8 should be ‘NA’.

8a. Indicate whether this is (was) a change for [name] compared to several years ago (before his/her death)?

9. Does/Did [name] have trouble remembering appointments?

This would most commonly be doctor’s appointments but could include any meetings (church, clubs, etc.).

9a. Indicate whether this is (was) a change for [name] compared to several years ago (before his/her death)?

10. Does/Did [name] have daily problems with thinking or memory?

Problems with memory represent the most common cognitive symptom of dementia. Memory issues may be varied but commonly include: forgetting names (acquaintances or things), forgetting where you’re going, getting lost while driving, and misplacing things around the house. Anyone may forget a name or occasionally misplace something, but in dementia memory loss has become so severe that it happens on a daily basis. If the proxy/informant has difficulty understanding the question or requests further clarification, the interviewer may help by saying, **“We are not asking about [name] only occasionally forgetting a person’s name, or misplacing something only every now and then, but instead if she/he experiences memory loss on a daily basis.”**

10a. Indicate whether this is (was) a change for [name] compared to several years ago (before his/her death)?

11. When Q3 through Q10a are completed or updated, click on the 'Save' button. Once the form is saved, click on the arrows in the entry field for Q11 to populate the score. Continue with data collection on the remainder of the form. [NOTE: The 'Save and Reload' button will also update the score in Q11. Be sure to save the form before closing, any time an update is made.]

12-15. These questions are asked only of the proxy/informant for deceased participants. These questions refer to conditions and diagnoses mentioned by the participant's physician or other health professional. Do not define or describe these conditions. If the participant has not heard the term or does not know the meaning of the condition, enter as "No". Other health professional can include nursing home health care staff familiar with the participant's medical history.

16. How would you rate the proxy/informant/other person's knowledge about the participant?

This is based on the interviewer's impressions of the proxy/informants knowledge about the participants day-to-day functioning. In some cases the only informant available may be a friend or perhaps a family member who lives far away from the participant, and thus, may not have a good sense of the participant's abilities and functioning.

17. How reliable of an informant was this person? Did he/she seem to understand the questions and answer appropriately?

This is based on the interviewer's impressions of the proxy/informants ability to understand the questions being asked. In some cases, the proxy/informant may also have some degree of cognitive impairment.

18. Indicate whether there were extenuating circumstances, such as poor phone reception, that might have interfered with the quality of the response?