



DEMENTIA RATING INTERVIEW DECEASED PARTICIPANT

ID NUMBER:

FORM CODE: DRD

DATE: 8/27/2013
Version 1.0

ADMINISTRATIVE INFORMATION

0a. Completion Date: / /
Month Day Year

0b. Staff ID:

Instructions: This form is administered to the informant. {S} refers to subject, please state subject's name where {S} is found below.

0c. Are you able to answer questions about {S's} memory and daily functioning before his/her death?

Y = Yes → **Go to Item 1**
N = No

0d. Is there someone else who could answer these questions?

Y = Yes
N = No → **Save and close**

If yes, Informant contact information:

0d1. Name and phone number:

BACKGROUND

1. What was your relationship to {S}? _____

- 1 = Spouse
- 2 = Sibling
- 3 = Child
- 4 = Other Relative
- 5 = Friend

2. For how many years had you known {S} (before his/her death)?

3. How often did you see {S}? _____

- 0 = Every day or every other day
- 1 = Between one and three times a month
- 2 = Once a month
- 3 = A few times a year or less often

MEMORY

Instructions: *The questions in this section are based upon changes that occurred before {s} death.*

4. Had you noticed any changes in {S} memory over the 12 months before his/her death? ____
- 0 = No (or no evidence of) → **Go to Item 5**
0.5 = Slight or possible
1 = Definite
- 4a. Did these memory changes start slowly, or more quickly? ____
- 0 = Slow, gradual start
1 = They started very quickly, and stayed about the same
2 = They started quickly, but continued to worsen
3 = Don't know
5. Before he/she died, did {S} repeat the same questions or stories more than once in a short period of time? ____
- 0 = No (or no evidence of)
0.5 = Rarely (once a week or less)
1 = Between rarely and frequently
2 = Frequently (every day or more often)
6. Before he/she died, did {S} forget conversations? ____
- 0 = No (or no evidence of)
0.5 = Rarely (once a week or less)
1 = Between rarely and frequently
2 = Frequently (every day or more often)
7. Before he/she died, did {S} spend more time looking for belongings (papers, glasses, keys, wallet, jewelry, etc.) (e.g., misplacing things)? ____
- 0 = No (or no evidence of)
0.5 = Rarely (once a week or less)
1 = Between rarely and frequently
2 = Frequently (every day or more often)
8. **[FAQ9]** Before he/she died, did {S} forget appointments? ____
- | | |
|--|-----------|
| 0 = Remembered without written or verbal reminders | CDR = 0 |
| 1 = Remembered but with aid of notes, calendar | CDR = 0.5 |
| 2 = Remembered with verbal reminders on day | CDR = 1 |
| 3 = Usually forgot appointments | CDR = 2 |
| Not Applicable | CDR = N/A |
9. **[FAQ7]** Before he/she died, did {S} have trouble keeping track of current events? ____
- | | |
|--|-----------|
| 0 = No (or no evidence of) | CDR = 0 |
| 1 = Rarely (once a week or less) | CDR = 0.5 |
| 2 = Between rarely and frequently | CDR = 1 |
| 3 = Frequently (every day or more often) | CDR = 2 |
| Not Applicable | CDR = N/A |
10. Before he/she died, did {S} forget names of close friends or relative? ____
- 0 = No (or no evidence of)
0.5 = Rarely (once a week or less)
1 = Between rarely and frequently
2 = Frequently (every day or more often)

ORIENTATION

Instructions: *The questions in this section are based upon changes that occurred before {S} died.*

11. Before he/she died, do you think that {S} had more trouble knowing the exact day of the week and date (time orientation)? _____

- 0 = No (or no evidence of)
- 0.5 = Rarely (once a week or less)
- 1 = Between rarely and frequently
- 2 = Frequently (every day or more often)

12. **[FAQ10]** Before he/she died, did {S} have trouble with directions in familiar areas such as {S}'s specific neighborhood? _____

- | | |
|--|-----------|
| 0 = No (or no evidence of) | CDR = 0 |
| 1 = Rarely (once a week or less) | CDR = 0.5 |
| 2 = Between rarely and frequently | CDR = 1 |
| 3 = Frequently (every day or more often) | CDR = 2 |
| Not Applicable | CDR=N/A |

JUDGMENT AND PROBLEM-SOLVING

Instructions: *The questions in this section are based upon changes over the 12 months before he/she died.*

13. In the 12 months before he/she died, how would you have rated {S} ability to handle unexpected problems such as household emergencies such as plumbing leaks or tripped fuses or circuit breakers? _____

- 0 = As good as they had ever been
- 0.5 = Good, but not as good as before
- 1 = Fair, may be unable in some circumstances
- 2 = Poor

14. **[FAQ1]** In the 12 months before he/she died, had you noticed any changes in {S} ability to write checks, pay routine bills, cope with small sums of money e.g., make change, leave a small tip, handle cash in the past year? _____

- | | |
|---|-----------|
| 0 = No (or no evidence of), as good as they had ever been | CDR = 0 |
| 1 = Yes, minimal difficulty | CDR = 0.5 |
| 2 = Yes, considerable changes (requires assistance) | CDR = 1 |
| 3 = Yes, unable to do these things at all | CDR = 2 |
| Not Applicable | CDR=N/A |

15. **[FAQ2]** In the 12 months before he/she died, had you noticed any changes in {S} ability to handle more complicated financial or business transactions (e.g., pay taxes, make decisions about investments and savings)? _____

- | | |
|---|-----------|
| 0 = No (or no evidence of), as good as they had ever been | CDR = 0 |
| 1 = Yes, minimal difficulty | CDR = 0.5 |
| 2 = Yes, considerable changes (requires assistance) | CDR = 1 |
| 3 = Yes, unable to do these things at all | CDR = 2 |
| Not Applicable | CDR=N/A |

16. In the 12 months before he/she died, had you noticed that {S} had less initiative or desire to carry out necessary chores or activities? _____

- 0 = No (or no evidence of)
- 0.5 = Yes, minimal change
- 1 = Yes, considerable changes

COMMUNITY AFFAIRS

Instructions: *The questions in this section are based upon changes over the 12 months before he/she died.*

17. In the 12 months before he/she died, had {S} been less involved in activities outside the home than previously? _____

- 0 = No (or no evidence of)
- 0.5 = Yes, slightly
- 1 = Yes, completely

18. **[FAQ3]** In the 12 months before he/she died had {S} had difficulty with shopping alone and making a purchase (at a grocery store, hardware store, department store) on her/his own? _____

- 0 = No (or no evidence of), as good as they had ever been CDR = 0
- 1 = Yes, minimal difficulty CDR = 0.5
- 2 = Yes, requires assistance CDR = 1
- 3 = Yes, unable to do these things at all CDR = 2
- Not Applicable CDR = N/A

19. In the 12 months before he/she died had {S} exhibited unsafe practices in operating a motor vehicle safely, such as having accidents or near misses, hesitating in intersections, running stop signs/lights, driving recklessly? _____

- 0 = No
- 0.5 = Some minor concerns
- 1 = Significant safety concerns
- 2 = Ceased driving because of safety
- NA = Never drove or ceased driving for physical or sensory reasons

HOME & HOBBIES

Instructions: *The questions in this section are based upon changes over the 12 months before he/she died.*

20. In the 12 months before he/she died, had you noticed changes in {S}'s ability to do household chores? _____

- 0 = No (or no evidence of), as good as they had ever been
- 0.5 = Yes, but not as good as before
- 1 = Yes, definitely decreased

21. In the 12 months before he/she died, did {S} have any trouble using any standard household appliances? _____

- 0 = No (or no evidence of)
- 0.5 = Yes, but only briefly
- 1 = Yes, more than briefly but eventually mastered
- 3 = Yes, never mastered
- N/A = Not Applicable

22. **[FAQ4]** In the 12 months before he/she died, had {S} shown decreased interest in previous hobbies or pastimes, such as reading, woodworking, knitting, sewing, gardening, etc.? _____

- | | |
|-----------------------------------|-----------|
| 0 = No (or no evidence of) | CDR = 0 |
| 1 = Yes, slightly | CDR = 0.5 |
| 2 = Yes, requires assistance | CDR = 1 |
| 3 = Yes, unable to do this at all | CDR = 2 |
| Not Applicable | CDR=N/A |

23. **[FAQ5]** In the 12 months before he/she died, did {S} have trouble heating up water, making coffee, turning off stove? _____

- | | |
|-----------------------------------|-----------|
| 0 = No (or no evidence of) | CDR = 0 |
| 1 = Yes, slightly | CDR = 0.5 |
| 2 = Yes, requires assistance | CDR = 1 |
| 3 = Yes, unable to do this at all | CDR = 2 |
| Not Applicable | CDR=N/A |

24. **[FAQ6]** In the 12 months before he/she died, did {S} have trouble preparing a balanced meal for him/herself? _____

- | | |
|-----------------------------------|-----------|
| 0 = No (or no evidence of) | CDR = 0 |
| 1 = Yes, slightly | CDR = 0.5 |
| 2 = Yes, requires assistance | CDR = 1 |
| 3 = Yes, unable to do this at all | CDR = 2 |
| Not Applicable | CDR=N/A |

PERSONAL CARE

Instructions: *The questions in this section are based upon changes over the 12 months before he/she died.*

25. In the 12 months before he/she died, did you think that {S} had any difficulty managing his/her own bathing, dressing or toileting? _____

- 0 = Completely independent without supervision or concerns
- 1 = Somewhat dependent on others for non-physical reasons
- 2 = Anything worse

26. In the 12 months before he/she died, did you think that {S} had any difficulty controlling his bladder or bowels? _____

- 1 = Yes
- 0 = No → **Go to Item 27**

26a. In the 12 months before he/she died, had {S} had any incontinence, or accidents with {S}'s bladder or bowels? _____

- 0 = No
- 1 = Yes, urinary incontinence
- 2 = Yes, bowel incontinence
- 3 = Yes, both urinary and bowel incontinence

OTHER NEUROLOGIC HISTORY

27. Did he/she ever take medications for memory problems? _____

- Y = Yes
- N = No

28. Did he/she ever have a stroke? _____

Y = Yes

N = No → **Go to Item 29**

28a. Did he/she have problems with his/her memory BEFORE the stroke (Clarify if there were any cognitive or memory problems before [meaning months or years] the stroke even occurred-not just immediately before it was diagnosed)? _____

Y = Yes

N = No

28b. Did he/she have problems with memory AFTER the stroke (was a change in memory noticed soon after the stroke)? _____

Y = Yes

N = No

Was he/she ever told by a doctor or health professional that he/she had any of the following neurologic disorders; these would be conditions that affect the brain?:

29a. Dementia? _____

Y = Yes

N = No

29b. Alzheimer's disease?

Y = Yes

N = No

29c. Vascular dementia or hardening of the arteries of the brain? _____

Y = Yes

N = No

29d. Mild Cognitive Impairment (or MCI)?

Y = Yes

N = No

29e. Parkinson's Disease? _____

Y = Yes

N = No

29f. Brain Tumor? _____

Y = Yes

N = No

29g. Any others? _____

Y = Yes

N = No → **Go to Item 30**

29g1. If Yes, please list: _____

FOR INTERVIEWER

30. How would you have rated the proxy's knowledge about the participant? _____

- 1 = Good
- 2 = Fair
- 3 = Poor

31. How reliable of an informant was the proxy? Did he/ she seem to understand the questions and answer appropriately? _____

- 1 = Good
- 2 = Fair
- 3 = Poor

32. Were there extenuating circumstances, such as poor phone reception, that might have interfered with the quality of the responses? _____

- 0 = No
- 1 = Yes, mild extenuating circumstances
- 2 = Yes, significant extenuating circumstances

33. In your opinion based on your interview of the informant, what is your overall impression of the subject's level of function in daily affairs in the year prior to his/ her death? _____

- 0 = Normal level
- 1 = Daily functioning was questionably impaired on cognitive grounds
- 2 = Daily functioning was mildly but definitely impaired on cognitive grounds
- 3 = Daily functioning was at least moderately impaired on cognitive grounds

STANDARD CDR

Instructions: *This form is to be completed by the clinician or other trained health professional based on informant report. Score only as decline from previous level due to cognitive loss, not impairment due to other factors, based on approximately the 12 month period prior to the participant's death.*

34. MEMORY: _____

- 0 = None - No memory loss, or slight inconsistent forgetfulness
- 0.5 = Questionable - Consistent slight forgetfulness; partial recollection of events; "benign" forgetfulness
- 1 = Mild - Moderate memory loss, more marked for recent events; defect interferes with everyday activities
- 2 = Moderate - Severe memory loss; only highly learned material retained; new material rapidly lost
- 3 = Severe - Severe memory loss; only fragments remain

35. ORIENTATION: _____

- 0 = None - Fully oriented
- 0.5 = Questionable - Fully oriented except for slight difficulty with time relationships
- 1 = Mild - Moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere
- 2 = Moderate - Severe difficulty with time relationships; usually disoriented to time, often to place
- 3 = Severe - Oriented to person only.

36. JUDGMENT AND PROBLEM SOLVING _____

- 0 = None - Solves everyday problems, handles business and financial affairs well; judgment good in relation to past performance
- 0.5 = Questionable - Slight impairment in these activities
- 1 = Mild - Moderate difficulty in handling problems, similarities and differences; social judgment usually maintained
- 2 = Moderate - Severely impaired in handling problems, similarities and differences; social judgment usually impaired
- 3 = Severe - Unable to make judgments or solve problems.

37. COMMUNITY AFFAIRS _____

- 0 = None - Independent function at usual level in job, shopping, volunteer and social groups
- 0.5 = Questionable - Life at home, hobbies and intellectual interests slightly impaired
- 1 = Mild - Unable to function independently at these activities, although may still be engaged in some; appears normal to casual inspection
- 2 = Moderate - No pretense of independent function outside the home; appears well enough to be taken to functions outside the family home
- 3 = Severe - No pretense of independent function outside the home; appears too ill to be taken to functions outside the family home

38. HOME AND HOBBIES _____

- 0 = None - Life at home, hobbies and intellectual interests well maintained
- 0.5 = Questionable - Life at home, hobbies, and intellectual interests slightly impaired
- 1 = Mild - Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned
- 2 = Moderate - Only simple chores preserved; very restricted interests; poorly maintained
- 3 = Severe - No significant function in the home.

39. PERSONAL CARE: _____

0 = None - Fully capable of self-care

1 = Mild - Needs prompting

2 = Moderate - Requires assistance in dressing, hygiene, keeping of personal effects

3 = Severe - Requires much help with personal care; frequent incontinence.

40. STANDARD CDR SUM OF BOXES: _____

41. STANDARD GLOBAL CDR: _____ (<http://www.biostat.wustl.edu/~adrc/cdrpgm/index.html>)



INSTRUCTIONS FOR THE DEMENTIA RATING INTERVIEW - LIVING PARTICIPANT (DRL) AND DEMENTIA RATING INTERVIEW - DECEASED PARTICIPANT (DRD) FORMS

The DRL/ DRD has two formats: one, for living participants, and two, for deceased participants. In both circumstances, an informant is being interviewed to obtain information about the participant's current/ recent cognitive status (for living participants) or cognitive status prior to death (for deceased participants).

Each field center will be provided with lists of participants to call, which will include information on 1) whether participant permission is required (yes/no); if yes, start with Script A; 2) if the participant is living or deceased (see table below); and 3) known versus new informant (see table below).

Script A should be used only for participants for whom we do not have a name of an informant/ proxy or for whom permission is required before contacting an informant/ proxy.

For participants for whom there is already a known informant/ proxy, or for deceased participants, the appropriate script and form from those below should be selected for the interview:

	Script	Interview form
Known informant (previously provided information or consent): Living participant	B	DRL
New informant: Living participant	C	DRL
New <i>or</i> known informant: Deceased participant	D	DRD

Instructions for the telephone scripts:

The telephone scripts should be read after establishing a connection with the individual answering the phone. For Script A, if the participant gives permission, please obtain the name and contact number for an informant, and this person's relationship. Otherwise, thank the participant for his/ her involvement and time.

For the other scripts, please read through the script and ask if the informant can speak today; if not, arrange another convenient time (if willing) to speak. Record the informant's name and contact information in a notelog on the DMS form, under question 1.

At all points in the interview, wherever he/she is listed should be replaced with the appropriate pronoun. In addition, the subject's name should be inserted wherever {S} is listed.

DRL

General instructions: The Dementia Rating Interview for Living Participants is a modified/ shortened version of the CDR-Informant interview for participants unwilling/ unable to come in for a clinic visit or to be interviewed by phone or at home. The primary difference between this interview and the CDR is that there is no participant component; there is only an informant interview, so the ratings need to be made only based on the informant reports. The DRL will always be done by telephone, and efforts should be made to conduct the interview in a quiet place so responses can be well understood and heard (for instance, if the informant is driving or in a noisy place, arrangements should be made to call back during a safer/ quieter time).

Scoring/ interview technique:

Please remind the informant that questions are based upon changes as compared to the past. When the item states i.e. “changes in memory over the preceding 12 months”, this does not mean that the change had to happen during the last 12 months but that change was observed at some point over the 12 months prior to the call (or prior to death, in the case of the DRD). In other words, if a participant had begun to decline 10 years prior to the call, and remained impaired, but there weren’t new changes observed in the year prior to the call, this would still count as an affirmative response to these items about change in memory occurring in the 12 months prior to the call/ death (DRL/ DRD).

In some instances, the informant may need to be reminded this at several points throughout the examination, or may need to be asked a follow-up question not specifically listed on the form in order to clarify a response. (to clarify that a problem is new and not a life-long problem, such as forgetting names).

If the informant states that the participant is doing certain activities less because of physical, but not mental limitations, the reason for this limitation should be clarified, and if it is purely for physical reasons, should not be marked as a change.

At the end of the interview, the interviewer should rate how well the informant knows the participant, based on how comfortable he or she seemed answering the questions in the interview.

See the CDR-Summary QxQ for details about scoring the CDR box items at the bottom of the form, combined with the online training module that all individuals certified will have completed.

DRD

General instructions: The Dementia Rating Interview for Deceased Participants is a modified/ shortened version of the CDR-Informant interview for participants deceased prior to an in-clinic visit. The primary difference between this interview and the CDR is that there is no participant component; there is only an informant interview, so the ratings need to be made only based on the informant reports. The DRD will always be done by telephone, and efforts should be made to conduct the interview in a quiet place so responses can be well understood and heard (for instance, if the informant is driving or in a noisy place, arrangements should be made to call back during a safer/ quieter time).

Scoring/ interview technique:

Please remind the informant that questions are based upon changes in the time period prior to the participant’s death, as compared to the past. In some instances, the informant may need to be reminded this at several points throughout the examination, or may need to be asked a follow-up question not specifically listed on the form in order to clarify a response. (to clarify that a problem was new in the months/ year prior to death and not a life-long problem, such as forgetting names).

If the informant states that the participant was doing certain activities less because of physical, but not mental limitations, the reason for this limitation should be clarified, and if it was purely for physical reasons, should not be marked as a change.

At the end of the interview, the interviewer should rate how well the informant knew the participant, based on how comfortable he or she seemed answering the questions in the interview.

See the CDR-Summary QxQ for details about scoring the CDR box items at the bottom of the form, combined with the online training module that all individuals certified will have completed.

At the end of the interview, thank the informant for his/ her time and assistance in the ARIC study.

Other circumstances:

The DRL/DRD were designed to be shorter than their equivalent CDI forms, so certain items have been excluded. If a circumstance comes up in discussion such as severe mental illness, mental retardation, or other conditions that might interfere with long-term daily function, this can be recorded in a notes file in item 29g, even though these diagnoses are not only neurologic in nature.