



# PARKINSON'S DISEASE INTERVIEW

ID NUMBER: [ ][ ][ ][ ][ ][ ][ ][ ]

FORM CODE: [ P ] [ D ] [ I ]

DATE: 11/09/15  
Version 1.0

## ADMINISTRATIVE INFORMATION

0a. Completion Date: [ ][ ]/[ ][ ]/[ ][ ][ ][ ]  
Month Day Year

0b. Staff ID: [ ][ ][ ]

**Instructions:** This form is administered during a separate telephone interview from the annual or semi-annual follow-up contact OR following the annual or semi-annual follow-up interview. This form should be completed for participants who have provided information to the ARIC Study between Visit 1 and the last completed Follow-up interview indicating they may have Parkinson's disease. See the detailed QxQ instructions for completion of the PDI form. For proxy respondents, say the participant's name when [name] is in the prompt. Special missing values are allowed for cases where the response "Don't know", "Refused", "Unknown", or "N/A" is not listed as an option.

**INTRODUCTION SCRIPT:** "Hello, this is [your name] from the ARIC Study. May I please speak with [name of contact]?"

"Hello [name of respondent]. My name is [your name] and I am from the ARIC Study. Our records indicate that you [name] may have reported a possible diagnosis of Parkinson's disease or may have used medications for Parkinson's disease or a related disorder. May I ask you a few questions about this, which will take less than 10 minutes? It will be very important for us to confirm with you whether or not you have [name has] the disease. The information you provide will be kept strictly confidential to the extent possible by the law and will only be used for research. "

## A. CONTACT AND BACKGROUND

1. Result of contact for the interview (select one)

- Participant contacted, agreed to be interviewed .....  A → **GO TO QUESTION 4**
- Participant contacted, agreed to respond by mail .....  B → **GO TO QUESTION 1a**
- Proxy/Informant contacted, agreed to be interviewed .....  C → **GO TO QUESTION 3**
- Proxy/Informant contacted, agreed to respond by mail .....  D → **GO TO QUESTION 1a**
- Contacted and refused .....  E → **GO TO QUESTION 2**
- Contact pending; continue to attempt to contact .....  F → **SAVE AND CLOSE FORM**
- Contact not possible .....  G → **SAVE AND CLOSE FORM**

1a. What packet materials were returned to the field center?

- a. Consent only .....  A → **GO TO QUESTION 24**
- b. PDI only .....  B → **GO TO QUESTION 4**
- c. Consent and PDI .....  C → **GO TO QUESTION 4**
- d. None .....  D → **GO TO QUESTION 27**

2. Reason the respondent refused:

- Respondent indicates no Parkinson's disease..... A → **GO TO QUESTION 27**
- Respondent indicates PD but no interest in study..... B → **GO TO QUESTION 27**
- Respondent is not interested in study; PD status unknown ..... C → **GO TO QUESTION 27**
- Participant is too ill with PD to continue ..... D → **GO TO QUESTION 27**
- Other ..... E

2a. Specify other: \_\_\_\_\_ → **GO TO QUESTION 27**

3. Are you able to answer some questions related to the health of [name]?

- Yes ..... Y
- No..... N → **GO TO QUESTION 27**

4. Has a doctor ever diagnosed you [name] with Parkinson's disease?

- Yes ..... Y
- Maybe..... M
- No ..... N → **GO TO QUESTION 9a1**
- Don't know..... D → **GO TO QUESTION 9a1**

5. How old were you (was [name]) when a doctor first diagnosed Parkinson's disease?

→ **IF COMPLETE, GO TO QUESTION 8**

6. In what year did a doctor first diagnose you [name] with Parkinson's disease?

→ **IF COMPLETE, GO TO QUESTION 8**

7. About how long ago were you (was [name]) first diagnosed with Parkinson's disease? Would you say:

- a. Within 2 years..... A
- b. 3-5 years ago ..... B
- c. 6-10 years ago..... C
- d. 11-15 years ago ..... D
- e. More than 15 years ago ..... E

*[For the interviewer – select one of the following 2 prompts based on the vital status of the participant.]*

8. If speaking to the participant or to the proxy/informant and the participant is alive:

Do you (Does [name]) still have the diagnosis of Parkinson's disease?

If speaking to the proxy/informant and the participant is not alive:

Did [name] still have the diagnosis of Parkinson's disease when he/she passed away?

- Yes ..... Y → **GO TO QUESTION 10**
- No, diagnosis changed..... N
- Don't know..... D → **GO TO QUESTION 10**

**B. NEUROLOGIC DISORDERS**

	Did you [name] ever have any of the following neurological diagnoses?  Yes.....Y No.....N→ <b>NEXT ROW</b> Don't know...D→ <b>NEXT ROW</b>	Was the diagnosis made by:  a. Neurologist.....A b. Other doctor.....B c. Don't know.....C
Essential tremor	9a1 <input type="checkbox"/>	9a2 <input type="checkbox"/>
Restless leg syndrome or RLS	9b1 <input type="checkbox"/>	9b2 <input type="checkbox"/>
Alzheimer's disease or AD	9c1 <input type="checkbox"/>	9c2 <input type="checkbox"/>
Dementia with Lewy bodies or DLB	9d1 <input type="checkbox"/>	9d2 <input type="checkbox"/>
Other types of dementia	9e1 <input type="checkbox"/>	9e2 <input type="checkbox"/>
Progressive supranuclear palsy or PSP	9f1 <input type="checkbox"/>	9f2 <input type="checkbox"/>
Multiple system atrophy or MSA	9g1 <input type="checkbox"/>	9g2 <input type="checkbox"/>
Shy Drager syndrome	9h1 <input type="checkbox"/>	9h2 <input type="checkbox"/>
Nigrostriatal degeneration	9i1 <input type="checkbox"/>	9i2 <input type="checkbox"/>
Other neurologic disease	9j1 <input type="checkbox"/> If Y, specify in Q9k.	9j2 <input type="checkbox"/>
9k. Specify other neurologic disease: _____		

*[Note: When Q9a1 through Q9k are completed, GO TO QUESTION 27.]*

**C. PARKINSON'S DIAGNOSIS**

10. Did a movement disorder specialist make your [name's] Parkinson's diagnosis?

- Yes .....  Y → **GO TO QUESTION 13**
- No .....  N
- Don't know .....  D

11. Did a neurologist make your [name's] Parkinson's diagnosis?

- Yes .....  Y → **GO TO QUESTION 13**
- No .....  N
- Don't know .....  D

12. Specify the type of doctor who made the Parkinson's diagnosis:

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13. How old were you (was [name]) when you [name] first noticed the symptoms of Parkinson's disease?

→ **IF COMPLETE, GO TO QUESTION 16a**

14. In what year did you [name] first notice the symptoms of Parkinson's disease?

→ **IF COMPLETE, GO TO QUESTION 16a**

15. About how long ago did you [name] first notice the symptoms of Parkinson's disease?  
Would you say:

- a. Within 2 years .....  A
- b. 3-5 years ago .....  B
- c. 6-10 years ago .....  C
- d. 11-15 years ago .....  D
- e. More than 15 years ago .....  E

**“Did you [name] have any of the following symptoms around the time of diagnosis:”**

16a. Trembling or shaking in any part of your [name's] body?

- Yes .....  Y
- No .....  N

16b. Slowness in moving, such as walking or performing a task?

- Yes .....  Y
- No .....  N

16c. Smaller handwriting than it was once?

- Yes .....  Y
- No .....  N

16d. Dragging a foot, shuffling feet, or taking smaller steps while walking compared to the past?

Yes .....  Y  
No .....  N

16e. Difficulty getting up from a chair or sofa or getting out of a car?

Yes .....  Y  
No .....  N

16f. Any other symptoms?

Yes .....  Y → **LIST UP TO 3 OTHER SYMPTOMS IN QUESTIONS 17a, 17b, 17c**  
No .....  N

*[If any 'Yes' response to questions Q16a through Q16f, then answer Q18 and Q19.]*

**“Specify the other symptoms you [name] experienced around the time of diagnosis.”**

17a. 1<sup>st</sup> other symptom: \_\_\_\_\_

17b. 2<sup>nd</sup> other symptom: \_\_\_\_\_

17c. 3<sup>rd</sup> other symptom: \_\_\_\_\_

18. Did any of these symptoms start on only one side of your [name's] body?

Yes .....  Y → **GO TO QUESTION 20a1**  
No .....  N  
Don't know .....  D

19. Were any of these symptoms ever more severe on one side of your [name's] body compared to the other side?

Yes .....  Y  
No .....  N

**D. MEDICATION**

**“Now I will read the names of some common medications used for treating Parkinson’s disease. Please tell me if you have ([name] has/had) ever taken any of these medications for more than a month.”**

	<p>Have you (Has/Had [name]) ever taken [medication] for more than a month?</p> <p>Yes.....Y  No.....N → <b>NEXT ROW</b>  Don't know...D → <b>NEXT ROW</b></p>	<p>Did the medication ever help with Parkinson's symptoms?</p> <p>Yes.....Y  No.....N  Don't know...D</p>	<p><i>[For the interviewer – select one of the following 2 prompts based on the vital status of the participant.]</i></p> <p>If speaking to the participant or to the proxy/informant and the participant is alive:  Do you (Does [name]) still take the medication?</p> <p>If speaking to the proxy/informant and the participant is not alive:  Did [name] take the medication during the last year of his/her life?</p> <p>Yes.....Y  No.....N  Don't know...D</p>
<p><b>Carbidopa</b>  <i>(kar bi DOE pa)</i>  <b>or levodopa</b>  <i>(lee voe DOE pa)</i>  <b>such as Sinemet</b>  <i>('SIN uh met),</i>  <b>Stalevo</b> <i>(stay-LEH-vo),</i>  <b>Parcopa</b>  <i>(par KOE pa), or</i>  <b>Rytary</b>  <i>(RYE tare ee)</i></p>	<p>20a1  <input type="checkbox"/></p>	<p>20a2  <input type="checkbox"/></p>	<p>20a3  <input type="checkbox"/></p>
<p><b>Pramipexole</b>  <i>(pram i PEX ole)</i>  <b>or Mirapex</b>  <i>(MEER a peks)</i></p>	<p>20b1  <input type="checkbox"/></p>	<p>20b2  <input type="checkbox"/></p>	<p>20b3  <input type="checkbox"/></p>
<p><b>Ropinirole</b>  <i>(roe PIN i role)</i>  <b>or Requip</b>  <i>(REE kwip)</i></p>	<p>20c1  <input type="checkbox"/></p>	<p>20c2  <input type="checkbox"/></p>	<p>20c3  <input type="checkbox"/></p>
<p><b>Rotigotine</b>  <i>(roe TIG o teen) or</i>  <b>Neupro</b>  <i>(NEW pro)</i></p>	<p>20d1  <input type="checkbox"/></p>	<p>20d2  <input type="checkbox"/></p>	<p>20d3  <input type="checkbox"/></p>

<b>Pergolide</b> (PER goe lide) <b>or Permax</b> (PER maks)	20e1 <input type="checkbox"/>	20e2 <input type="checkbox"/>	20e3 <input type="checkbox"/>
<b>Selegiline</b> (she-LEJ uh leen) <b>such as Eldepryl</b> (EL-deh-prell) <b>or Zelapar</b>	20f1 <input type="checkbox"/>	20f2 <input type="checkbox"/>	20f3 <input type="checkbox"/>
<b>Rasagline</b> (ra SAJ uh leen) <b>or Azilect</b> (AZ-ah-lekt)	20g1 <input type="checkbox"/>	20g2 <input type="checkbox"/>	20g3 <input type="checkbox"/>
<b>trihexyphenadyl</b> (try hex ee FEH nih dill) <b>or Artane</b> (ar-TAIN)	20h1 <input type="checkbox"/>	20h2 <input type="checkbox"/>	20h3 <input type="checkbox"/>
<b>Amantadine</b> (a MAN ta deen) <b>or Symmetrel</b> (SIM uh trel)	20i1 <input type="checkbox"/>	20i2 <input type="checkbox"/>	20i3 <input type="checkbox"/>

[For the interviewer - ask Q21 if all Q20a1, Q20b1, Q20c1, Q20d1, Q20e1, Q20f1, Q20g1, Q20h1, and Q20i1 are recorded as "No" or "Don't know".]

21. These medication names may be unfamiliar to you. Have you (Has/Had [name]) ever taken ANY prescribed medication for Parkinson's disease for more than a month?

- Yes .....  Y  
 No .....  N → **GO TO QUESTION 22**  
 Don't know .....  D → **GO TO QUESTION 22**

21a. Did that medication ever help in controlling your [name's] symptoms?

- Yes .....  Y  
 No .....  N

[For the interviewer – select one of the following 2 prompts based on the vital status of the participant.]

21b. If speaking to the participant or to the proxy/informant and the participant is alive:  
 Do you (Does [name]) still use that medication now?

If speaking to the proxy/informant and the participant is not alive:  
 Was [name] using that medication during the last year of his/her life?

- Yes .....  Y  
 No .....  N

**E. FAMILY AND PHYSICIAN INFORMATION**

22. Does anyone else in your [name's] family have Parkinson's disease that was diagnosed by a doctor? This would include biological (natural) parents, full (whole) biological brothers or sisters, or biological children.

- Yes .....  Y
- No .....  N → **GO TO QUESTION 24**
- Don't know .....  D → **GO TO QUESTION 24**

**“Which other family members have had Parkinson’s disease? Is it your [name’s] ...”**

23a. Father

- Yes .....  Y
- No .....  N

23b. Mother

- Yes .....  Y
- No .....  N

23c. Brother

- Yes .....  Y
- No .....  N

23d. Sister

- Yes .....  Y
- No .....  N

23e. Son

- Yes .....  Y
- No .....  N

23f. Daughter

- Yes .....  Y
- No .....  N

**“Thank you for answering my questions. It would also be helpful if I could contact your [name’s] health care providers and ask them to tell us more information about your [name’s] health status. If you agree to do this, I will send you a form that tells your [name’s] health care providers that you authorize the ARIC study to collect this information from them. After you sign that form and mail it back to me, I will contact your health care providers. Again the information will only be used for research purpose and will be kept confidential.”**

24. May I send you this release form and an addressed envelope for you to mail the release form back?

- Yes .....  Y
- No .....  N → **GO TO QUESTION 27**



[For the interviewer – select one of the 2 prompts based on the vital status of the participant for questions 25 and 26.]

25. If speaking to the participant or to the proxy/informant and the participant is alive:  
Did you [name] see a movement disorder specialist or neurologist for Parkinson’s disease in the past 5 years?

If speaking to the proxy/informant and the participant is not alive:  
Did [name] see a movement disorder specialist or neurologist for Parkinson’s disease while [name] was alive?

Yes .....  Y  
No .....  N → **GO TO QUESTION 26**

**“What is the contact information for the movement disorder specialist or neurologist?”**

25a. Doctor Name: \_\_\_\_\_  
25b. Clinic or Institution Name: \_\_\_\_\_  
25c. Address \_\_\_\_\_  
25d. City: \_\_\_\_\_ 25e. State:   
25f. Telephone Number: () -

26. If speaking to the participant or to the proxy and the participant is alive:  
Do you [Does name] see another type of doctor who regularly takes care of you [name] for Parkinson’s disease? This could be your [name’s] family doctor or general doctor.

If speaking to the proxy and the participant is not alive:  
Did [name] see other type of doctor who regularly took care of [name] for Parkinson’s disease while [name] was alive? This could be [name’s] family doctor or general doctor.

Yes .....  Y  
No .....  N → **GO TO QUESTION 27**

**“What is the contact information for the other doctor?”**

26a. Doctor Name: \_\_\_\_\_  
26b. Clinic or Institution Name: \_\_\_\_\_  
26c. Address \_\_\_\_\_  
26d. City: \_\_\_\_\_ 26e. State:   
26f. Telephone Number: () -

27. PDI Completion Status:

- a. Complete ..... A
- b. Partially complete; contact again..... B
- c. Partially complete; unable to complete (done) ..... C

**CLOSURE SCRIPT:**

*[For the interviewer – select a closure script based on the answer to Q27.]*

If Q1 is recorded as ‘A’ or ‘C’, and Q27 is recorded as ‘A’ or ‘C’, read the closure script and continue with Q28. Update the CIU form as necessary.

**“Thank you for agreeing to answer these questions.”**

If Q27 is recorded as ‘B’, read the closure script, save the form and resume when the participant/proxy is able to finish the interview.

**“May I contact you again to finish the interview? When would be a good time?”**

If Q1 is recorded as ‘E’, and Q27 is recorded as ‘A’, read the closure script; save and close form.

**“Thank you for your time today. Please contact the ARIC staff if you decide that you would like to participate in the future.”**

**F. INTERVIEW EVALUATION**

*[For the interviewer – Q28-Q29e are only completed when Q1 is recorded as ‘A’ or ‘C’, and Q27 is recorded as ‘A’ or ‘C’.]*

28. Please evaluate your confidence in the informant’s answers.

- Confident ..... c
- Questionable ..... q
- Unreliable ..... u

Did the informant have any of the following difficulties in the interview?

29a. Hearing

- Yes ..... Y
- No..... N

29b. Cognitive (e.g. memory)

- Yes ..... Y
- No..... N

29c. Speaking

- Yes ..... Y
- No..... N

29d. Other

Yes .....  Y  
No .....  N

29e. Specify other difficulties the informant encountered during interview:

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*[For the interviewer – Q30-Q33 are only completed when Q1 is recorded as ‘A’, ‘B’, ‘C’ or ‘D’, and Q27 is recorded as ‘A’ or ‘C’.] See the QxQ for instructions.*

30. Who responded to the questions regarding this participant?

a. Participant .....  A → **GO TO QUESTION 32**  
b. Participant with help .....  B  
c. Proxy/Informant .....  C

31. Helper or proxy relationship to participant?

a. Spouse .....  A  
b. Child .....  B  
c. Other family member .....  C  
d. Friend .....  D  
e. Health care provider .....  E

32. Other comments?

Yes .....  Y  
No .....  N → **SAVE AND CLOSE FORM**

33. Specify comments:

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