



## INSTRUCTIONS FOR CONTACT INFORMATION UPDATE (CIU) FORM (10/08/2024)

### I. General Instructions

The purpose of the Contact Information Update [CIU] form is to maintain the most current contact information for each ARIC cohort participant. There are different occasions at which the information in the CIU is confirmed or updated:

- a) during the follow-up interview,
- b) during reception for the clinic visit, after the participant has signed the consent,
- c) during recruitment for a visit (either clinic, home or long-term care facility).

The CIU form confirms the participant's demographic information and updates their contact information that may have been collected a year ago. Unlike other forms that are completed during the visit, this form already contains data from the ARIC study's central database. There is only one record per participant in the database, reflecting the participant's most current contact information.

As the ARIC cohort ages, it is becoming more important to collect a 'follow-up proxy' for each participant. This proxy is someone who can answer questions about the participant's health when the participant is unable to provide that information themselves. The proxy information collected in the CIU should be the 'follow-up proxy' as defined in Appendix 2 of the CIU form. Note, staff are now able to identify multiple proxies on this form using item 22a.

### II. Detailed Instruction for Each Item

- 0a. Enter the date on which the update information was collected, or the data are confirmed and no changes are made
- 0b. The person at the clinic who has collected the information enters his/her code number in the boxes provided.
- 0c. Record whether the participant has hearing problems or hearing loss. This information is initially pre-filled with information gathered from administrative notes and notelogs in the ARIC database at the time of the old Data Management System is taken offline (April 2011). This information should be reviewed and confirmed.
- 0d. Record whether the participant has cognitive problems. This information is initially pre-filled with information gathered from administrative notes and notelogs in the ARIC database at the time of the old Data Management System was taken offline (April 2011). This information should be reviewed and confirmed.
- 0e-f. Record whether the participant has a spouse in the ARIC study. If yes, record the ID of the spouse.
- 0g. This item is for field center administrative use.

## INTRODUCTION

"Hello Mr/Ms [name of participant]. My name is \_\_\_\_\_. *I would like to verify some of the information we have collected from you over the telephone. First, your personal information; I'll read the information we have and you can let me know if anything needs to be updated.*"

### A. VERIFICATION OF IDENTIFYING INFORMATION

- 1a-d. Read the participant's title, first, middle and last name. If there is a question about the spelling of any of the names, verify the spelling.
- 2a-g. Read the mailing address to the participant, stressing that you need the mailing address that might be different from the participant's residential or physical address, and verify its accuracy. Determine whether the mailing address is the same as the participant's residential or physical address.
- 2h-m. If the mailing address is not the participant's physical address, enter the participant's physical address here.
3. Confirm the home (or land line) telephone number.
4. Confirm the cell phone number. If they do not have a cell phone, check the box 'does not use cell phone'.
5. Enter or confirm their email address. If they do not use email, check the box 'does not use email'.
6. Record whether the participant lives somewhere else. If they do, record the mailing address in items a-f.
7. Record the phone number at this second residence.
8. Record the time of year the participant lives at this residence, i.e. between what two months that they live there.
9. Verify the participant's social security number.

If participant requests that SSN not be used by the study, first gently try to get them to allow us to use the last 4 digits.

If they still want SSN not to be used, in whole or in part, the following steps need to be taken:

CSCC deletes SSN (or first 5 digits) from V5INFO 6.

Field center deletes SSN (or part of it) from CIU 9 (if blanked out altogether, set field status to missing and add note log)

### B. CONTACT PERSON 1

*"Now I would like to verify the information we have for your contact persons, to help us get in touch with you if we are not able to reach you. I'll read the information we have and you can let me know if anything needs to be updated."*

- 10 – 13 Read the name, address, telephone number and relationship of the first contact person on the form to the participant (see Appendix 1 for a list of the relationships available in the drop down menu). Record if this contact is considered the participant's primary, secondary or neither primary or secondary contact. Ask if any of it needs to be updated.

Enter or confirm email address of the first contact person in Question 11.c. If the contact person does not use email, set special missing value for this question. If there are notes that were already recorded in Question 11.c. and need to be kept, either copy and paste the notes to the notelog of Q11.c. or enter the information into a relevant, existing field (such as address 1 or 2 or phone number).

### **C. CONTACT PERSON 2**

- 14 – 17 **Repeat the procedure for the second contact person.** Read the name, address, telephone number and relationship of the second contact person on the form to the participant (see Appendix 1 for a list of the relationships available in the drop down menu). Ask if any of it needs to be updated.

Enter or confirm email address of the first contact person in Question 15.c. If the contact person does not use email, set special missing value for this question. If there are notes that were already recorded in Question 15.c. and need to be kept, either copy and paste them to the notelog of Q15.c. or enter the information into a relevant, existing field (such as address 1 or 2 or phone number).

### **D. CONTACT PERSON 3**

- 18 – 21 **Repeat the procedure for the third contact person.** Read the name, address, telephone number and relationship of the third contact person on the form to the participant (see Appendix 1 for a list of the relationships available in the drop down menu). Ask if any of it needs to be updated.

Enter or confirm email address of the first contact person in Question 19.c. If the contact person does not use email, set special missing value for this question. If there are notes that were already recorded in Question 19.c. and need to be kept, either copy and paste them to the notelog of Q19.c. or enter the information into a relevant, existing field (such as address 1 or 2 or phone number).

### **E. PROXY INFORMATION**

*“We are asking all our ARIC participants to give us the name of a person that can answer questions about your health if you [name] cannot. This person will be considered your [name’s] follow-up proxy for the ARIC Study. Only your ARIC center can contact your [name’s] follow-up proxy.”*

For living participants, ask the following question to obtain authorization to share information about ARIC with the proxy initially (once), and then only if there is a change in proxy or consent: “Do we have your permission to send your proxy (you) information about the ARIC Study?” Record or update the response to this question on the Proxy Consent Tracking (PXY) form. This question is not asked and the PXY form is not completed for deceased participants, or if you are speaking with someone other than the participant or their proxy.

See Appendix 2 for a full description of what a proxy is. This can be used to describe proxy to the participant.

22. Record or verify whether one of the contacts recorded is the participant's proxy. In item 22a, record which of the contacts is/are the proxy. Multiple contacts may be selected if the participant has multiple proxies.

Note, if one or more of the recorded contacts is/are the participant's proxy/proxies, **and** the participant would still like to add an additional proxy, staff should go back and add this proxy as one of the Contacts (1/2/3). The next section (23-26) should only be used if the participant has only one proxy and that person is neither Contact #1, Contact #2, nor Contact #3. A notelog can be added to item 18 to identify additional contacts who are not proxies.

- 23-26. Record or verify the proxy's name, address, telephone numbers and relationship to the participant.

Enter or confirm email address of the first contact person in Question 24.c. If the contact person does not use email, set special missing value for this question. If there are notes that were already recorded in Question 24.c. and need to be kept, either copy and paste them to the notelog of Q24.c. or enter the information into a relevant, existing field (such as address 1 or 2 or phone number).

If updating for follow-up, this form is complete. Questions 27 – 32f are asked during the recruitment phone call in preparation for the clinic visit.

#### **F. PHYSICIAN INFORMATION**

*"In approximately 6 weeks, we will send you a summary of your [name's] study results from this exam visit."*

27. Record whether the participant would like a summary of the study results sent to their physician or health care provider.
- 28a-b. Read the first and last names of the participant's physician. If there is a question as to spelling of any of the names, verify the spelling. If the participant has changed physicians, enter the new name.
- 29a. Read the Clinic/Building name to the participant and verify its accuracy or ask if there is one if the field is empty.
- 29b-f. Read the mailing address to the participant and verify its accuracy. If the participant changed physicians, enter the new address.

#### **G. OPHTHALMOLOGIST OR EYE SPECIALIST INFORMATION**

"If you are [name is] selected and agree, we will take a photograph of the back of one of your [name's] eyes. If we find a medical condition in your [name's] eye we can send a report to your [name's] eye specialist."

30. Record whether the participant would like a report of the eye exam sent to their eye specialist.
- 31a-b. Record or verify the name of the eye specialist. If there is a question as to spelling of any of the names, verify the spelling.

Ask for the ophthalmologist or eye specialist's mailing address and record or verify

32a. Clinic/Building name

32b-f. Mailing address