



INSTRUCTIONS FOR CONTACT INFORMATION UPDATE (CIUG) FORM (6/5/2023)

I. General Instructions

The purpose of the Contact Information Update [CIU] form is to collect and maintain the most current contact information for each ARIC GEN2 cohort participant. There are different occasions at which the information in the CIU is confirmed or updated:

- a) during recruitment for a visit,
- b) during reception for the clinic visit, after the participant has signed the consent,
- c) during the follow-up interview,

The CIU form collects and then updates the participant's demographic information, and their contact information. There is only one record per participant in the database, reflecting the participant's most current contact information.

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.
- 0d. Record whether the participant has cognitive problems. Initially in the GN2 study, this should be set to 'No'.
- 0e-f. Record whether the participant has a spouse in the study. If yes, record the ID of the spouse.
- 0g. This item is for field center administrative use.

A. IDENTIFYING INFORMATION

- 1a-d. Collect 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. This item will be verified during future contact with the participant.
- 2a-g. Collect 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. Collect the home (or land line) telephone number.
4. Collect the cell phone number. If they do not have a cell phone, check the box 'does not use cell phone'.

5. Collect 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. Collect 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, set field status to missing and add a note log.

B. CONTACT PERSON 1

"Now I would like to collect/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 Collect 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.

C. CONTACT PERSON 2

- 14 – 17 **Repeat the procedure for the second contact person.** Collect 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.

D. CONTACT PERSON 3

- 18 – 21 **Repeat the procedure for the third contact person.** Collect 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.

E. PROXY INFORMATION

This has been removed for the GEN2 study.

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

This has been removed for the GEN2 study.