



CONTACT INFORMATION UPDATE FORM

ID NUMBER:

FORM CODE

DATE: 4/20/2011
Version 1.0

ADMINISTRATIVE INFORMATION

0a. Completion Date: / /
Month Day Year

0b. Staff ID:

0c. Does participant have hearing problem/loss? Yes No 0d. Does participant have cognitive impairment? Yes No

0e. Participant has a spouse in the ARIC study. Yes No 0f. ID number of spouse:
No → **Go to item 0g**

0g. Administrative information: _____

Instructions: *This form is updated any time a participant's information changes.*

INTRODUCTION SCRIPT: "Hello Mr/Mrs [name of participant or proxy]. My name is _____. I would like to verify some of the information we have collected from you [name] in the past. First, your [name's] personal information; I'll read the information we have and you can let me know if anything needs to be changed."

A. VERIFICATION OF IDENTIFYING INFORMATION

1. a. Title: _____

b. First Name: _____

c. Middle Name: _____

d. Last Name: _____

2. Mailing Address:

a. _____

b. _____

c. City: _____

d. County: _____

e. State:

f. Zip Code: -

g. Is this mailing address your [name's] physical address? (i.e. where you [name] live[s])

Yes → **Go to item 3**
No

Physical Address:

h. _____

i. _____

j. City: _____

k. County: _____

l. State:

m. Zip Code: -

3. Home Phone Number: () - (land line)

4. Cell Phone Number: () - Does not use cell phone

5. Email Address: _____ Does not use email

6. Is there another place where you [name] live[s]? Yes

No → **Go to item 9**

Mailing Address:

a. _____

b. _____

c. City: _____

d. County: _____

e. State:

f. Zip Code: -

7. Phone Number at this second residence: () -

8. What time of year do you (does [name]) live at this second residence?

from month to month

9. SSN -- (QxQ: If participant refuses, make field perm. missing)

B. CONTACT PERSON 1

"Now I would like to verify the information we have for your [name's] contacts. These are the people we can contact if we are unable to reach you [name] I'll read the information we have and you can let me know if anything needs to be changed."

10. a. Title: _____

b. First Name: _____

c. Middle Name: _____

d. Last Name: _____

11. Mailing Address:

a. _____

b. _____

c. _____

d. City: _____

e. State: f. Zip Code: -

12a. Telephone #1: () -

b. Telephone #2: () -

c. Telephone #3: () -

13. Relationship: ▼

13a. Is this person either the primary or secondary contact? (check only one)

- Primary
- Secondary
- Neither primary nor secondary

C. CONTACT PERSON 2

14. a. Title: _____

b. First Name: _____

c. Middle Name: _____

d. Last Name: _____

15. Mailing Address:

a. _____

b. _____

c. _____

d. City: _____

e. State:

f. Zip Code: -

16a. Telephone #1: () -

b. Telephone #2: () -

c. Telephone #3: () -

17. Relationship: ▼

17a. Is this person either the primary or secondary contact? (*check only one*)

- Primary
- Secondary
- Neither primary nor secondary

D. CONTACT PERSON 3

18. a. Title: _____

b. First Name: _____

c. Middle Name: _____

d. Last Name: _____

19. Mailing Address:

a. _____

b. _____

c. _____

d. City: _____

e. State:

f. Zip Code: -

20a. Telephone #1: () -

b. Telephone #2: () -

c. Telephone #3: () -

21. Relationship: ▼

21a. Is this person either the primary or secondary contact? (check only one)

- Primary
- Secondary
- Neither primary nor secondary

E. FOLLOW-UP PROXY INFORMATION

“We are asking all our ARIC participants to give us the name of a person that can answer questions about your [name’s] health if you 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] proxy.”

22. Is one of the contact people you have already identified going to be this person for you [name]?”

- Yes
- No → **Go to item 23**

22a. Which contact person is your [name’s] follow-up proxy? → **Go to item 27**

- 1 = Contact #1
- 2 = Contact #2
- 3 = Contact #3

Please identify your [name’s] follow-up proxy.

23. a. Title: _____

b. First Name: _____

c. Middle Name: _____

d. Last Name: _____

24. Mailing Address:

a. _____

b. _____

c. _____

d. City: _____

e. State:

f. Zip Code: -

25a. Telephone #1: () -

b. Telephone #2: () -

c. Telephone #3: () -

26. Relationship: ▼

F. PHYSICIAN INFORMATION

Instructions: *If updating for Annual Follow-up, this form is complete.
Questions 27 – 32 are asked during the recruitment phone call in preparation for the clinic visit.*

“In approximately 6 weeks, we will send you [name] a summary of your study results from this exam visit.”

27. Would you like us to also send this summary to your [name's] physician or provider of medical care?

Yes.....

No → **Go to item 30**

28. a. First Name: _____

b. Last Name: _____

29. Mailing Address:

a. Clinic/Building: _____

b. _____

c. _____

d. City: _____

e. State:

f. Zip Code: -

G. OPHTHALMOLOGIST OR EYE SPECIALIST INFORMATION

“If you [name is] are 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. Would you like us to send this report to your [name’s] eye specialist?

Yes.....

No → **Form is complete**

31. What is the name of the doctor, ophthalmologist, or eye specialist you [name] saw concerning your [name’s] vision?

a. First Name: _____

b. Last Name: _____

32. Mailing Address:

a. Clinic/Building: _____

b. _____

c. _____

d. City: _____

e. State:

f. Zip Code: -



CONTACT INFORMATION UPDATE FORM

Appendix 1

Drop-down menu items for 'Relationship' questions on the CIU.

AUNT
BROTHER
BROTHER (IN LAW)
BROTHER (STEP)
COUSIN
DAUGHTER
DAUGHTER (IN LAW)
DAUGHTER (STEP)
EX WIFE
FATHER
FATHER (IN LAW)
FATHER (STEP)
FRIEND
GRAND CHILD
HUSBAND
MOTHER
MOTHER (IN LAW)
MOTHER (STEP)
NEIGHBOR
NEPHEW
NIECE
PASTOR/MINISTER/PRIEST
SISTER
SISTER (IN LAW)
SISTER (STEP)
SON
SON (IN LAW)
SON (STEP)
UNCLE
WIFE
OTHER - SPECIFY IN NOTE LOG



Appendix 2

Follow-Up by Proxy

A very important goal of the Atherosclerosis Risk in Communities (ARIC) Study is to keep track of any major changes in your health. This information is important for answering scientific questions about heart disease and other health conditions. You are the best source of information regarding your health, but there may be times when you are not able to provide these details yourself. We are asking you to provide us with the name of a person that can answer questions about your health if you cannot. This person will be considered your “proxy” for the ARIC Study. The person you designate would only be contacted once per year, should you be unable to respond. Only your ARIC center can contact your proxy.

What is a proxy?

A proxy is someone who can “stand in” for you and tell us about your health when you cannot because of illness.

Why is a proxy needed?

For almost 20 years you have been providing information about your health to ARIC. This important information should not be lost, even when you are unable to provide it yourself.

What does a proxy do?

Should it be necessary we would ask your proxy to answer questions about your health, just like the questions you have been asked each year by the ARIC staff.

Whom should I name as my proxy?

You should select someone who knows you well enough to provide health information about you. For example, your proxy can be the person who has your power of attorney, your legal health care proxy, or your legal next-of-kin (including your spouse, son, daughter, brother, sister, etc).

Am I allowed to change my proxy?

Yes, you may change your proxy at any time by either calling ARIC or by indicating your wishes at your annual ARIC phone call.

Will you give my earlier information to my proxy?

No, all of your information is strictly confidential and will not be provided to your proxy.

What would you like me to do now?

Using the attached form please indicate whom you have chosen to be your proxy. Please indicate his/her name, contact information, relationship to you, sign the form and mail it to the ARIC field center in the enclosed envelope.

We have sent a copy of this form for your own records and one to give to your proxy. This material should be kept by him/her so he/she understands your wishes as a participant in the ARIC Study.

If you have any questions call Mr/Ms. ARIC Study Manager at (xxx) xxx-xxxx



INSTRUCTIONS FOR CONTACT INFORMATION UPDATE (CIU) FORM (7/31/2013) (CIU, VERSION 1, 4/20/2011)

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. Some participants with cognitive impairment require 'proxy consent' for participation in the clinic visit— this person may or may not be the 'follow-up proxy'. The proxy information collected in the CIU should be the 'follow-up proxy' as defined in Appendix 2 of the CIU form.

II. Detailed Instruction for Each Item

- 0a. Enter the date on which the update information was collected.
- 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.

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.

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.

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 cannot. This person will be considered your “follow-up proxy” for the ARIC Study. Only your ARIC center can contact your 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 are the participant's proxy. In item 22a, record which contact person is the proxy.
- 23-26. Record or verify the proxy's name, address, telephone numbers and relationship to the participant.

If updating for follow-up, this form is complete. Questions 27 – 32 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 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 selected and agree, today we will take a photograph of the back of one of your eyes. If we find a medical condition in your eye we can send a report to your 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