## Updated CFD Instructions (QxQs)

This table summarizes changes to the CFD QxQ as of $11 / 11 / 2014$
Changes in the CFD QXQ are highlighted in yellow

| Section in CFD QxQ | Description of Changes in CFD QXQ |
| :--- | :---: |
| Item 2, 2a | $\bullet$ A note on how to record Social Security Number added. |
| Item 4g, pg. 7 | • A note on how to use the catchment map added. |

# ARIC Confidential Data Form <br> CFD, Version C, 12/07/2006 <br> QxQ 11/11/2014 

## General Instructions

The Confidential Data Form (CFD) is used to abstract confidential data from the hospital record and keep it apart from the participant's medical data. All confidential data has been removed from the forms that abstract data from a hospital record for coronary heart disease (CHD), heart failure (HF) or stroke (Hospital Record Form, HRA; Heart Failure Form HFA; Stroke Form, STR).

Confidential data collected on the CFD include the name, social security number, medicare number, date of birth, and address as well as some identifiers to the hospital record (hospital, medical record number, and date of discharge).

## Detailed Instructions for Various Questions

Items 0.a, 0.b and 0.c on this form are primarily for assisting the abstractor in confirming the medical record being abstracted matches the CHI form.
0.a. Hospital Code Number. Using the hospital selection drop down list, enter the two digit code assigned to this hospital. See appendix A for a list of these hospitals. If outside the study community, use the appropriate code (96-99).
0.b Medical Record Number. Enter the medical record number from the hospital chart. This number will be found stamped or typed on almost every page of the hospital record. The easiest place to find it is both on the medical record folder and in the upper right/left hand corner of the face sheet. List the number from left to right. Enter only digits and letters; omit dashes and spaces. Do not add zeroes to the right of the number. If the number changes with each admission, use the appropriate number for the one (admission) being abstracted.
0.c. Date of discharge. Date of Discharge (for nonfatal case) or Death. This information will generally be found on the face sheet. Enter the date as mm/dd/yyyy. If the patient died, then record the date of death. If transferred from acute care to rehabilitation or chronic care in the same hospital, count the date of transfer as the discharge date.

When available, fields Ob and 0 c will be auto-filled for all forms, to ensure conformity. It will be the responsibility of the abstractor to verify, visually, that these extra key fields match the chart being abstracted.

Hospital, medical record number, and discharge date are stored encrypted because of their confidential nature.
0.d. Has the hospital chart been located? Record "Yes" or "No". If response is "no", go to item 6.
_1.a, b, c Name The last, first, and middle names of the participant.
2, 2a. Social Security/Medicare Number. If the SSN is in the chart, copy in question 2a exactly as given including the letter which may be at the end. If for some reason the entire SSN cannot be abstracted, then abstract all digits available, replace missing digits with equal signs and set the field to Query Verified (for example ===-==-1234) (This number is extremely important.) Check all available sheets for it and look at correspondence at the back of the chart.

Medicare numbers are the same as Social Security Numbers, except that Medicare numbers are always followed by a letter. Letters A through E are used for various reasons.
3. Birthdate. Birthdate is usually found on the face sheet of each medical record. Do not use the age given by the physician on the history and physical since it may be incorrect.

## 4. Address Information:

Address information is collected in a fashion to allow easy geocoding of the patient's address and to check on catchment area inclusion.

Addresses will be converted to a code defined by longitude and latitude that will then be used under procedures that safeguard the confidentiality of this information, for two primary purposes. One is to provide quality assurance for the event eligibility based on the (coded) place of residence, and the other is to include aggregate information of the area of residence of the patient for the analyses of the ARIC data.

Each of these analytic steps uses geocoded data as opposed to the actual address. To avoid error in geocoding the addresses however, a complete and accurate transcription of the patient address is needed. The purpose of these question-by-question instructions is to make it easier for the ARIC personnel to accomplish this goal.

Hospital records almost uniformly provide the patient's address and the address of a guarantor. Often the addresses of an immediate relative, a proxy, or contact also are found on the record. The immediate relative is often identified as the guarantor. The location of this information in the hospital record is somewhat variable between hospitals, as is the format.

Our goal is to transcribe the address that corresponds to the place of residence of the patient. Only if the patient's address is not available or incomplete should the address of the relative or that of the guarantor (if different) be transcribed. Even if a full address for the patient is not available, city-state-zip, state-zip, and city-zip combinations are valuable for ARIC to have (especially when zip is available in the $5+4$ format).

Thus, the address of a proxy should only be abstracted if a city-state-zip, state-zip, or city-zip combination is not available for the patient.

Some scenarios to consider are shown below; they illustrate the use of the address entry panel on the form (see the corresponding examples of completed forms in the Appendix).

| A. Patient | Guarantor: Employer | Closest Relative: Daughter |
| :---: | :---: | :---: |
| Name/Address | Name/Address | Name/Address |
| Lindsey Lakeland | Jack A. Spratt | Gertrude Spoil |
| 123 Willowtree Ln, Apt. D-321 | Bank of America Center, Suite | P.O. Box 12345 |
| W-S, NC 27104 | 306-E | Route 7 |
|  | 137 East Franklin Street | Germanton, NC 27019 |
|  | Chapel Hill, NC 27514-3628 |  |
| B. Patient |  |  |
| Name/Address |  |  |
| Eric A. Whitsel |  |  |
| Bank of America Center, Suite 306-E |  |  |
| 137 East Franklin Street |  |  |
| Chapel Hill, NC 27514-3628 |  |  |
| C. Patient | Guarantor: Father |  |
| Name/Address | Name/Address |  |
| Eric A. Whitsel | Eric B. Whitsel, Sr. |  |
|  | Bank of America Center, Suite 306-E |  |
|  | 137 East Franklin Street |  |
| Chapel Hill, NC 27516 | Chapel Hill, NC 27514-3628 |  |

Special reference needs to be made to abbreviations, since these are frequently used in addresses and often reflect idiosyncratic rather than standard abbreviations.

Numbered highway addresses can be challenging to abstract and require careful attention. Consider 1098 US Hwy 15-501 S. It should be entered in three fields as follows: [4.B.3] Number = 1098, [4.B.6] Name = US HWY 15 501, and [4.B.8] Name Suffix = S. Please note that with this address, [4.B.6] Name may contain numbers (in this case, 15 501), and that [4.B.7] Name Type remains blank (although we know 15501 is a highway). In other words, [4.B.6] Name is best defined in such cases by including both components ("US HWY" and "15 501") in this single field.

We also want to mention that you will occasionally encounter addresses that seem to defy attempts to divide them without making assumptions. In our experience, such addresses are thankfully uncommon.
4.a. 0 Is this the patient's address? This question determines whether the address listed is that of the participant or that of a proxy. It is singularly important because it collects information to help differentiate between addresses of patients and their proxies (who may not live with one another).

If the participant's complete address is available, answer Yes.
If there is no address listed for the participant, answer no and use the proxy's address.
If only a partial address is available for the participant, but a complete address is available for the proxy, the participant's address is still used, even though it is incomplete. Answer yes.
4.a. 1 Whose address (relationship to patient)? If question 4.a. 0 is ' $N o$ ' then list the relationship between the proxy and the participant.
4.b. Address Information This item has been divided into five major components: [4.b.1] PO Box, Box and/or Route and Number and Street Number; [4.b.2-4] Street Number; [4.b.5-8] Name; [4.b.9-12] Unit; and [4.B.13] Other. Pertinent fields should be completed only when necessary. Other fields should remain blank.
4.b. 1 If there is no PO Box, Box \& or Route and Number, leave blank. PO Box, Box \& or Route and Number should include all relevant descriptors and numbers, e.g. "PO BOX" (post office box), "BOX", "R" (route), "RR" (rural route), et cetera. For example, if the address in the medical record is "Route 16, Box 14-A", item 4.B.1 = ROUTE 16 BOX 14 A.
4.b. 2 Street Number Prefix (refers only to prefixes for the number in 4.b.3.) If there is no street number, leave blank. This item is designed for alphanumeric characters that may precede street numbers and may be separated from them by a hyphen. Hyphens should be dropped at data entry. An example might be B-21 East Main Street. The "B" would be entered in 4.b.2.
4.b. 3 Street Number This question should include numeric street data only. If there is no street number, leave blank. For example, if the address is B 21 Main Street, " 21 " would be recorded in 4.b.3.
4.b.4. Street Number Suffix (refers only to suffixes for the number in 4.b.3.) This item is designed for alphanumeric characters that may follow street numbers and may be separated from them by a hyphen. Hyphens should be dropped at data entry. An example might be 21-B East Main Street. The "B" would be entered in 4.b.4. If there is no suffix, leave blank.
4.b.5. Street Name Prefix This item typically refers to street directions (e.g. EAST; NORTH; SOUTH; WEST) or their common abbreviations and combinations (e.g. E; N; NE; NO; NW; S; SE; SO; SW; W). Generally, only a prefix or a suffix [question 4.b.8.]—but not both—are available. For example, if the address is 21-B East Main Street, the " $E$ " is entered in item 4.b.5. If there is no street prefix, leave blank.
4.b.6. Street Name This item refers to the name of the street, avenue, etc. If the address is 21B East Main Street, then "Main" would be entered into item 4.b.6. Digits must be used for entering numbered street names. For example " 1300 South Second Street" should be entered as - street prefix "S", and street name "2ND", and "ST" as street type; "Five Public Square" should be entered as " 5 Public Square". The "street number" for any street must also be expressed as digits (although street number prefix and/or suffix could be letters).
4.b.7. Street Name type This item refers to the type of roadway used in the address. If the address is 21-B East Main Street, then "St" would be entered into item 4.b.7. If none leave blank.
4.b.8. Street Name Suffix This item typically refers to street directions (e.g. EAST; NORTH; SOUTH; WEST) or their common abbreviations and combinations (e.g. E; N; NE; NO; NW; S; SE; SO; SW; W). Generally, only a suffix or a prefix [question 4.b.5.], but not both, are available. For example, if the address is 21-B Main Street East, the " $E$ " is entered in item 4.b.8.
4.b.9, 10, 11, $12 \underline{\text { Unit Type/Unit Prefix/Unit Identifier/Unit Suffix Item [4.b.9] Unit Type usually }}$ designates a building, apartment or other unit in a residential complex or neighborhood. These units are often abbreviated in standard format e.g. "BLDG", "APT" et cetera. They are often labeled by an alphanumeric identifier and prefix or suffix. If none leave blank.

For example, if the address in the medical record includes "Apt A-1", then item [4.b.9] Unit Type = APT; [4.b.11] Unit Identifier $=$ A, and [4.b.12] Unit Suffix $=1$. When two units are included in the same address, e.g. "Bldg A Apt 1", both units and identifiers should be recorded and separated by a forward slash "/", as follows: [4.b.9] Unit Type = BLDG/APT; [4.b.11] Unit $\underline{\text { Identifier }}=\mathrm{A} / 1$. Note that item [4.b.12] Unit Suffix should remain blank in the latter example.
4.b.13. Other Formal names (e.g. professional or business offices, residential neighborhoods or complexes, and assisted-living or skilled nursing facilities) that may accompany street addresses are typically superfluous. They should be separated from the remainder of the address and recorded in item [4.b.13].
4.c.1. City The city of residence for the address being transcribed. Please recognize that abbreviations of city (W-S, G’boro, Mnpls, Bham, Pgh, NYC, Brklyn, LA, SD, et cetera) must be transcribed in full into the address entry panel.
4.d.1. County The county of residence for the address being transcribed. If the county is unavailable or suspect, leave blank. It can be compared to information from the Federal Information Processing Codes returned by the geocoding vendor at the time of analysis. NOTE: Some states do not have cities that reside in counties, so county information may not be available.
4.e. State The state of residence for the address being transcribed. Abbreviations for states should follow the standard U.S.P.S. two-character format (a table of abbreviations can be found on the next page).
4.e.1 Country (enter only if not in U.S.A.) The country of residence for the address being transcribed if not U.S.A.
4.f. Zip Code The zip code associated with the address being transcribed. If available, zip code information in $5+4$ format should be transcribed in full, nine digits.
4.g. Composite Address: The DMS will populate the composite address. A map to check address in the catchment is available. Copy and paste the composite address or type the address on the map to determine if the address is in the ARIC catchment area.

5a. Cohort Status. Check the cohort roster to determine if the event is for a cohort member. If so, record case as C "ARIC Cohort" in 3a.

If the event is not an ARIC cohort member but it does meet selection criteria for community surveillance, record 'S' "Community Surveillance" for question 5.a. (NOTE: A cohort participant may or may not meet the criteria for community surveillance but if it is a cohort participant code "C" not "S")

If the event is being abstracted for the Jackson Heart Study and the case is NOT also an ARIC cohort member, record J "JHS Cohort-not ARIC cohort" for question 3a. Use the current JHS cohort rosters to determine eligibility. (If the event is a Jackson Heart Study Participant and also an ARIC cohort, code the event as " C " not " J ".)

## 5.b. Is the patient's address in the ARIC Community surveillance catchment area?

5b. Is the decedent's address in the ARIC community surveillance catchment area? If the address is determined by the abstractor to be in the ARIC catchment area, record " $\gamma$ ".

If the address is determined by the abstractor as not being in the ARIC catchment area and if the participant is either an ARIC or JHS cohort, record " $C$ ".

If the address is determined by the abstractor as not being in the ARIC catchment area and if the participant is neither an ARIC nor JHS cohort, the abstractor should enter " $O$ ".

If the address could not be determined by the abstractor after all means available to resolve, the abstractor should enter " $U$ " (undetermined).
5.c. Abstractor Investigation of Undetermined in Q5b. If item 5.b. $=U$ then field center needs to work through all available resources or contact Coordinating Center to resolve whether patient's address is in or out of catchment, then return to this form and fill out Q5.c. Based on
the information available, the abstractor will record the status of the address based in the following:

If the address is determined by the abstractor to be in the ARIC catchment area, record Y. If the address is determined by the abstractor as not being in the ARIC catchment area and if the participant is either an ARIC or JHS cohort, record "C".
If the address is determined by the abstractor as not being in the ARIC catchment area and if the participant is neither an ARIC nor JHS cohort, the abstractor should enter " O ".
If, finally the address could not be determined by the abstractor, "U" (undetermined)
For JHS Cohort, if the answer to 5 b is " $U$ ", select only " $Y$ ", " $C$ ", or " $U$ " for 5c.
6. Date of data collection: Record the date on which the form was completed.
7. Code number of person completing this form: The field center staff member who has performed the abstraction and completed the form must enter his/her valid ARIC code number in the boxes provided.

## Example A

ARIC
Atherosclerosis Risk in Communities

## CONFIDENTIAL DATA FORM



INSTRUCTIONS: For "multiple choice" and "yes/no" type questions, circle the letter corresponding to the most appropriate response. If a letter is circled incorrectly, mark through it with an "X" and circle the correct response.


## Appendix B

## Example A

CONFIDENTIAL DATA FORM (CFDB screen 2 of 2)

| 4.5.5. Name Pefix: | 4.0.13 Ohler |
| :---: | :---: |
| $\square \square$ |  |
|  |  |
| $\square \square \square\|\square\| Q \mid \square \square \square$ | ${ }^{\text {4.c.1 Cily: }}$ WIN STON SA |
| 4.6.7. Name tye: | WIINSTION SA |
| LN ${ }^{\text {a }}$ | L\|EMM |
| 4.b.8. Name suffix: | 4 4.1. Conys: |
| $\square \square$ | F\|OR|S|Y|TH| |
| 4.69 Unit Type: |  |
| A P PT | 4.e Sate |
| 4.b.10 Unit Prefix: | NC |
| D\| | 4.e.1 Comant (ff rot USA): |
| 4.6.11. Unit Identifer |  |
|  |  <br> $\square$ |
| 4.0.12 Unit Suffix: | 4.f.iip code: |
| $\square \square \square$ |  |

## Example B



Atherosclerosis Risk in Communities

INSTRUCTIONS: For "multiple choice" and "yes/no" type questions, circle the letter corresponding to the most appropriate response. If a letter is circled incorrectly, mark through it with an "X" and circle the correct response.

b. First Name:

| E | R | I | C |  |  |  |  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |

c. Middle Name:

2. Social Security Number:


2a. Medicare Number

3. Date of birth:


4a.1. Whose address (relationship to patient)?

4.b. Address Information
4.b.1. PO Box, Box, \&/or Route:

4.b.2. Number Prefix:

4.b.3. Number:

4.b.4. Number Suffix:


## Appendix B

## Example B

CONFIDENTIAL DATA FORM (CFDB screen 2 of 2)


## Appendix B

## Example C



Atherosclerosis Risk in Communities

## CONFIDENTIAL DATA FORM

ID NUMBER: $\square$ CONTACT YEAR $\square$ FORM CODE: | C | F | D |
| :--- | :--- | :--- | VERSION: B DATE: 03/22/05

INSTRUCTIONS: For "multiple choice" and "yes/no" type questions, circle the letter corresponding to the most appropriate response. If a letter is circled incorrectly, mark through it with an "X" and circle the correct response.

CONFIDENTIAL DATA FORM (CFDB screen 1 of 2)

b. First Name:

| E | R | I | C |  |  |  |  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |

c. Middle Name:

2. Social Security Number:


2a. Medicare Number

3. Date of birth:


Appendix B

## Example C

CONFIDENTIAL DATA FORM (CFDB screen 2 of 2)


## Appendix C

## Example A



## CONFIDENTIAL DATA FORM

Atherosclerosis Risk in Communities
ID NUMBER: $\square$ CONTACT YEAR : $\square$ FORM CODE: $\square$ VERSION: C DATE: 12/07/06
INSTRUCTIONS: For "multiple choice" and "yes/no" type questions, record the letter corresponding to the most appropriate response. If a letter is circled incorrectly, mark through it with an "X" and circle the correct response.


## Appendix C

Example B


## Appendix C

Example C
ARIC
Atherosclerosis Risk in Communities

ID NUMBER: $\square$ CONTACT YEAR $\square$ FORM CODE: |  |  |  |
| :--- | :--- | :--- | :--- | CONFIDENTIAL DATA FORM

INSTRUCTIONS: For "multiple choice" and "yes/no" type questions, record the letter corresponding to the most appropriate response. If a letter is circled incorrectly, mark through it with an "X" and circle the correct response.


