



INSTRUCTIONS FOR THE MEDICAL CONDITIONS UPDATE FORM (01/22/2014) (MCU updated 7/25/2014)

I. General Instructions

The purpose of the MCU form is to provide a single place to record updates on select medical conditions. If the participant has previously reported any of the medical conditions, the corresponding questions will not be asked, which will reduce the participant's interview time as well as the interviewer's data collection burden. The questions are only asked if the participant has never reported the condition in any previous AFU or SAF interview. This form is not completed for deceased participants.

This form contains questions that were previously part of the AFU and SAF. The single occurrence form will be empty in the event that a participant never previously reported any of the medical conditions and those questions should be asked during the subsequent annual and semi-annual follow up calls. If the participant had reported on the medical condition previously, that data is prefilled.

Interviewers may also need to request authorization to contact the participant's physician for information on selected health problems, additional to that reported by the participant during the AFU interview. When the participant reports that he/she has been diagnosed for the first time as having heart failure by a physician during the time frame specified in the AFU or SAF, the interviewer initiates the process that enables JHS to send that physician a request to complete the Physician Heart Failure Survey Form (PHF).

Consent to Release Protected Health Information

The PHF form is sent to each physician to whom the participant provides consent to release medical information to JHS. An example of the Consent to Release Protected Health Information is provided at the end of these QxQ instructions (Appendix 1). In addition, consent for access to the participant's medical records is also needed to investigate admissions to emergency rooms or admissions to hospitals that are located outside of the JHS Study Areas. JHS Exam 5 staff requested permission to access medical records (from the participant or their proxy) at the time of consent for Exam 5. A signed medical release is also required for cohort participants who did not participate in Exam 5 if their response to the AFU determines the need to contact their care provider.

II. Detailed Instructions for Each Item

Administrative information

- 0a. Enter the date of contact or the date the form is last updated in DMS. This field will be overwritten each time the form is completed.
- 0b. Enter the staff ID of the telephone follow-up interviewer who last updates this form. This field will be overwritten each time the form is completed.
- 0c. Enter whether the participant or the proxy/informant is being interviewed. This field will be overwritten each time the form is completed.

Section I

This section is asked of the participant only. If the proxy/informant/other person is contacted and the

participant is reported to be alive, go to section 2, item 6.

1. Ask the participant whether a doctor told them they had high blood pressure since their last contact.
- 1a-b. Enter the date and contact year that the participant tells you 'yes' a doctor told them they have this condition.
2. Ask the participant whether a doctor told them they had diabetes since their last contact.
- 2a-b. Enter the date and contact year that the participant tells you 'yes' a doctor told them they have this condition.
3. Ask the participant whether a doctor told them they had chronic lung disease since their last contact.
- 3a-b. Enter the date and contact year that the participant tells you 'yes' a doctor told them they have this condition.
4. Ask the participant whether a doctor told them they had asthma since their last contact.
- 4a-b. Enter the date and contact year that the participant tells you 'yes' a doctor told them they have this condition.
5. Ask the participant whether a doctor told them they had peripheral vascular disease since their last contact.
- 5a-b. Enter the date and contact year that the participant tells you 'yes' a doctor told them they have this condition.

Section II

This section is asked of the participant or the proxy/informant. This section will be skipped if the participant has ever reported HF in a previous interview.

- 6-8e. These items are only completed for participants who have never reported heart failure or a weak heart. The name of the physician who indicated that the cohort member has heart failure or has a weak heart is recorded in question 8.a. If the physician's name is unknown or the information is unavailable, enter the name of the clinic, emergency service or hospital service where the encounter took place. In addition to the name of the establishment, indicate whether this is an emergency service, an outpatient clinic, or other facility. A release of medical records is not requested if the physician's name is unknown, nor for encounters that occurred in an emergency service, an outpatient clinic or a hospital, nor is a PHF form sent.

Record the name and address of the physician's address in items 8a-8d. Then enter the date heart failure or weak heart was diagnosed in month/year format (specific day is not needed) in item 8e. If in the sequence of items 8-8e the participant reports being told by a physician of a weak heart or heart failure while in a hospital service, the name of the hospital is recorded prior to asking item 10 (At that time, were you (Was [name]) hospitalized or did you [name] stay in a hospital observation unit?). If the answer to item 9 is Yes, the hospital or medical facility is recorded in items 11a or 11a1, even if it corresponds to the same facility recorded in items 8b-8e.

Script:

If speaking to the participant: **"The JHS study would like to ask your doctor to tell us more about your health. If you agree to do this, I will send you a form that tells your doctor that you authorize the JHS study to get this information. Once you sign that form and mail it back to me, I will contact your doctor's office."**

If speaking to the proxy/informant/other: **“The JHS study would like to ask [name’s] doctor to tell us more about his/her health. If you agree to do this, I will send [name] a form that tells the doctor that [name] authorizes the JHS study to get this information. Once [name] signs that form and mails it back to me, I will contact the doctor’s office.”**

9. If yes, remember to update the PHF (Physician Heart Failure Survey Form) item 0c once the release form is sent to the participant. When the release form is returned, change answer on PHF item 0c. This will help reconcile the requested and returned releases from the participants. A PHF form is not sent if the physician’s name is unknown, nor for encounters that occurred in an emergency service, an outpatient clinic or a hospital (thus, a release of medical information is not requested). In such a case, a special missing value for Item 9 is set to ‘Not applicable.’

JHS now requests a PHF form of all newly reported diagnoses of heart failure/weak heart, whether or not the participant reports being hospitalized at that time. Thus, if the physician’s name and location information are known, a release of medical information and a PHF are requested even if the participant responds “yes” to question 10 (“At that time, were you (Was [name]) hospitalized or did you [name] stay in a hospital observation unit? ”)

10. Indicate whether the participant was hospitalized for heart failure or a weak heart. This includes observation stays in a hospital. “Observation stay” is an administrative term of how an overnight visit is billed. Observation stays are usually less than 24 hours, but they may be up to several days long. We only want visits that are at least overnight in the hospital or observation area. Admissions to "rule out", as well as discharge diagnoses of heart failure/weak heart are both coded YES.

11a-11b. The term "hospitalized" includes staying overnight or hospital observation in any acute or chronic care facility which excludes nursing homes. Emergency room only or outpatient only visits not involving an overnight stay are coded as NO. If the participant or informant is unsure, doesn't know or can't provide information about the overnight hospitalization(s), enter NO. Select hospital from drop down list. If the hospital is not on the drop down list, enter the hospital name. Enter the admission date in month/year format (specific day is not needed).

12. This question specifically asks about a physician-diagnosed atrial fibrillation.

12a-12b. Enter the date and contact year that the participant tells you ‘yes’ a doctor told them they have this condition.

Script:

If speaking to the participant: **“Since we last contacted you, have you been told by a doctor or health professional that you have:”**

If speaking to the proxy/informant/other: **“Since we last contacted [name], has [name] been told by a doctor or health professional that he/she has:”**

13a-13d2. These questions refer to conditions and diagnoses mentioned by the participant’s physician or other health professional. Do not define or describe these conditions. If the participant has not heard the term or does not know the meaning of the condition, enter as No. Enter the date and contact year that the participant tells you ‘yes’ a doctor told them they have the conditions.

CLOSURE SCRIPT:

"Thank you very much for answering these questions. You have previously provided us with information on how to contact you. To help us contact you in the future, please tell me if the information I have is still correct."

[Update the CIU form as necessary.]

"Thank you very much for answering these questions. We will call _____ in about six months."



Appendix 1

Consent to Release Protected Health Information

I hereby give my consent for:

_____ *doctor(s) and/or health care provider(s)*

to provide information from my medical records, including treatments and/or hospitalization between: _____ and _____

to the *Atherosclerosis Risk in Communities (JHS) Study* at the University of _____

Purpose, Restrictions, and Re-disclosure:

The health information that is released will be used only for research purposes by the JHS study at its Field Center at the University of _____ and the JHS Coordinating Center at the University of North Carolina at Chapel Hill, and will be held in strict confidence. **All information released WILL NOT be re-disclosed.** I place no limitations on information pertaining to diagnosis and history of illness to be used for research by JHS.

Revocation Statement and Expiration:

I understand that my participation in JHS is not conditioned upon signing this authorization and that I may revoke the authorization at any time by requesting such in writing to the JHS Study Field Center at ____ < **address, phone number** > ____, except to the extent that action has already been taken in accord with this consent. This consent is effective upon signing and shall remain valid for the duration of the JHS study (2011-2016). A photocopy of this document is as valid as the original.

Name: _____ Date: _____

(PLEASE PRINT)

Signature _____

If legal representative or proxy, sign below and state relationship and authority to do so:

Signature of legal representative/proxy: _____

Relationship/Authority _____ Date _____