

<b>FORM:</b>	<b>9 – WHI EXTENSION STUDY PARTICIPATION STATUS</b>
<b>Version:</b>	8 – October 1, 2005
<b>Description:</b>	Completed by Field Center (FC) staff; 1-page form; key-entered at FC.
<b>When used:</b>	At any contact during the WHI Extension Study in which the participant’s follow-up status or newsletter status changes.
<b>Purpose:</b>	To document a change in participant’s status.

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### GENERAL INSTRUCTIONS

1. At the beginning of the WHI Extension Study, the participant’s follow-up status from WHI will carry over to WHIX. Newsletter status will be set to “1 - Receive newsletter” for extension participants who do not have a status of dead or absolutely no contact.
2. Use this form as needed to change the follow-up or newsletter status of WHI Extension Study participants. See *Section 9.5 – Changes in Participation Status* for more details of follow-up options and changing participation status.
3. Deceased and lost-to-follow-up participants: Do not complete *Form 9 – Participation Status* for a participant identified as deceased or lost-to-follow-up. Complete *Form 120 – Initial Notification of Death* (for deceased participants) or *Form 23 – Search to Locate Participant* (for lost-to-follow-up participants), as appropriate. With data entry of *Form 120* and/or *23*, WHIX will automatically update a participant’s follow-up and/or intervention status on the member status screen and will stop newsletter mailings. [See also *Section 9.4.1 – Initiating a Search to Locate Participant (Form 23)*].
4. Complete Items 1 - 3 identifying the date, staff person completing the form, and source of information.
5. Complete Items 4 and 5 as indicated by type of change in status.  
**Note:** Completion of “Item 4 – Change in Follow-up Status” is required when a participant who was previously marked as lost-to-follow-up on *WHI1591 – Participants Who Are Lost to Follow-up* is located.
6. Review the form for completeness and forward to Data Entry.
7. Data Entry: Key-enter the form into the Member Status screen. See *Section 10.5.2 – Updating Participant Status* for specific instructions on how to key-enter this form. Initial the first page after key-entry.
8. File the key-entered form in the participant’s file.

### Item Instructions

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|----|----------------------------|--|
| 1. | Effective Date             | <p>Record the date on which:</p> <ul style="list-style-type: none"> <li>• A participant tells the FC she wants to change her status to resume follow-up activities that had previously stopped, or</li> <li>• A FC staff member changes the participant’s status when she becomes unwilling to participate in follow-up activities and retention activities have failed.</li> </ul>  |
| 2. | Completed by               | Standard 5-digit WHI employee ID of staff person completing the form.  |
| 3. | Source of Information      | <p>The source of the information about the change in the participant’s status. Mark one only to identify who provided the responses for the form.</p> <p>1 - Participant: The woman on whom the form is being completed.<br/>           2 - Family member or friend: Include household members, even if not related.<br/>           3 - Physician: This is a physician outside of WHI.<br/>           4 - FC staff member: Use this only if you are inactivating a participant and you are not in voice contact with any of the above.<br/>           8 - Other: Mark if the above categories do not apply.<br/>           5 - CCC database update: for <u>CCC use only</u>. Do not mark. FCs cannot key-enter this code.</p>  |
| 4. | Change in Follow-Up Status | <p>The new follow-up status to which the participant is changing (this may be an increase or decrease in follow-up activities). See <i>Section 9.5 – Changes in Participation Status</i> for guidelines on when to change status.</p> <p>1 - Full follow-up: Mark if the participant indicates that she is willing to follow the regular contact schedule including completing all routine phone calls, mail contacts, or other activities.</p> <p>2 - Proxy follow-up: Mark if the participant is unable to respond to forms (both interview- and self-administered) because she can no longer communicate orally or in writing (e.g., due to a stroke or dementia). Fill in the proxy name, relationship to participant (e.g., if proxy and participant are brother and sister, record brother), address, and phone number, as well as the reason why the participant is no longer able to complete the forms personally. Complete item 4.1 (type of follow-up) only if applicable.</p> <p>Data Entry: Key-enter the proxy information in the Personal Information screen in WHIX.</p> <p>4 - Partial or Custom follow-up: Mark if the participant is unable or unwilling to continue phone contact, CCC mail contact, or if she asks to have a contact that is different from routine contacts. Indicate which contact types are to be discontinued by completing item 4.1 (type of follow-up) when applicable. Specify any changes from the routine contact schedule when applicable</p> <p>5 - No follow-up: Mark if the participant wants no follow-up (no phone and no mail contact), and retention activities have failed. Women in this category should be contacted periodically to ask them to reconsider participation. However, if a woman is hostile towards WHI and unlikely to change and indicates that she wishes <u>no further contact ever</u>, select the "8 – Absolutely no contact" option instead.</p> |

- 8 - Absolutely no contact: Judiciously select only if the participant has become hostile to WHI and is unlikely to change and should never be contacted to ask her to reconsider participation in the WHI Extension Study. Ideally, the participant has put her request in writing. Proxy and personal contacts should not be contacted.
- 6 - Deceased. Do not mark this item. (FCs cannot key-enter this code.) This category will remain on the form for continuity with earlier versions of the form and to provide a link between the form and the various reports that use this data item. WHIX automatically updates this category based on data entry of *Form 120 – Initial Notification of Death*.
- 7 - Lost-to-follow-up. Do not mark this item. (FCs cannot key-enter this code.) Lost-to-follow-up status is based on data entry of specific forms (e.g., *Form 33 – Medical History Update* and *Form 23 – Search to Locate Participant*) and can no longer be selected at the FC’s discretion. WHIX automatically updates this category when appropriate. This category remains on this version of the form for continuity with earlier versions of the form and links to relevant reports.
- 4.1. Type of follow-up  
(For codes 2 and 4)
- For participants indicating “2 – Proxy follow-up” or “4 – Partial follow-up” in item 4.
- 2 - No phone: Mark if the participant requests no telephone contact from FC staff.
- 3 - No CCC mail: Mark if the participant requests no mail contact from the CCC.
- Note:** Type of follow-up may also be applicable for participants indicating “2 - Proxy follow-up.” Only complete type of follow-up for the participants if they specifically request no phone or no mail follow-up. “2 - No phone” or “3 – No CCC Mail” may be indicated if requested by proxy.
5. Change in Newsletter  
Status
- Change in newsletter status. All participants receive an annual newsletter, unless they request otherwise.
- 0 - Refuse newsletter: Mark if the participant requests that she not receive the WHI Extension Study newsletter.
- 1 - Receive newsletter: Mark if the participant requests that she receive the WHI Extension Study newsletter after having previously requested that it be stopped.