

STUDY OF OSTEOPOROTIC FRACTURES

Review of Visit 4 Take-Home Questionnaire

1. General

Review all sections of the take-home questionnaire for completeness. Check to see that all questions have been answered that should be answered. Do not probe further on questions that appear to be answered completely unless:

- (1) the question is answered "don't know"
- (2) there is an obvious contradiction between responses to factual questions. Most of the possible conflicts will be outlined below.
- (3) special instructions are given (below).
- (4) the question has an asterisk next to it. This indicates that the question should always be reviewed because it is subject to misinterpretation.

For "don't know" answers, check to see if the respondent understood the question by reading the question out loud to the participant in interview format. If a question has not been answered that should have been, read the question to the participant. Handle the responses in the same manner as you would any interview question.

For all open ended questions or "other" responses, if the response fits into one of the given categories, code it as such.

Our goal for visit 4 is to try to clarify discrepancies with the participant while she is in clinic. Thus, as outlined below, certain questions should be cross-checked while the participant is in the clinic so any discrepancies can be clarified immediately. In addition, some participants have outstanding inconsistent data from previous visits. We would like to remedy these inconsistencies with the participant during her 4th visit if possible. The coordinating center will send each clinic a list and explanation of these outstanding discrepancies. Please try to resolve them during the participant's visit.

2. Missing data

1. Draw a slash lengthwise through questions and conditional boxes that are NOT APPLICABLE (for example, questions that should be skipped because of the response to a stem question).
2. For questions where the answer is "don't know" or the participant is not able to answer the question, and there is not a "don't know" box to check, write DON'T KNOW across the question in large letters.
3. When a participant refuses to answer a question, write REFUSED in large letters across the question.
4. If the participant may have information at home or may be able to get information that will help answer a question, ask if you can call her at home to get the information. If she agrees to be called at home, write CALL BACK across the question.

3. Specific Questions for Visit 4 Take Home Questionnaire, Version 4.1

Q1. Name, Address, Phone Number

Review participant's name, address, and phone number to ensure that we have the most current.

Q2. Different mailing address in the next year or for part of the next year.

This should include a temporary address such as winter address in Florida, or the address of children where the respondent spends a good part of the year. A place is provided to record the nature of the alternative address. If possible, record in the margin when this new address becomes effective.

Q3. "Next of kin": Name, address, and telephone number

Next of kin should be the relative with whom the participant has the most frequent contact, who would know her health and vital status and who would know the respondents new address if she moved. It will help to know the exact relationship of the next of kin to the participant.

Q4. Name, address, and telephone number of two close friends or relatives who do not live with respondent

A contact is someone who would know the respondents new address if she moved; it does not have to be a person who always knows her whereabouts. If a contact person has to be called to track a participant, it will help to know the contact's relationship to the participant. We will collect information on two contacts.

***Q5. Medicare number.**

This information is crucial for tracking the respondents through Medicare and vital statistics data bases. Most women over age 65 should have a Medicare number, but some may not. Ask to see the participant's Medicare card, and confirm that the number recorded is accurate.

The purpose of recording the participant's Medicare numbers is to provide the study with information about their health and vital status that we might otherwise miss. Reassure reluctant respondents that information obtained as part of this study is strictly confidential and will be used only for research purposes; we will not be sharing any data about them with Medicare or Social Security, nor will it be used to bill for services. A small percentage of respondents may have a "non-standard" Medicare number that has fewer than 11 characters and does not have the familiar Medicare number format with 1 or 2 additional characters at the end. Record this non-standard Medicare number in the spaces provided, starting at the left, and put a slash lengthwise in the spaces that are not applicable.

If respondent indicates that she doesn't know if she has Medicare number, try a call-back.

The next section deals with questions about health and activity **SINCE THE PARTICIPANT LAST COMPLETED A QUESTIONNAIRE FOR THE STUDY.** Please review the questions with the participant to ensure that answers reflect the period between when she last completed a questionnaire for the study (v3 for most participants) and now.

In case of confusion or uncertainty about fractures and medical conditions (Q8-Q12), please refer to the lists provided by the coordinating center to see what the participant reported at the baseline and second visit if necessary.

Q6. Doctor/Health Care

If the participant has changed doctors or place of medical care, make sure a new name, address, and phone number are recorded.

Q7. Hospital stays

Use conventional rounding here. 0-4 days = 0.5 weeks, 5-7 days = 1 week and so on.

Q8. Fractures

This next question asks about fractures that have been diagnosed since the last questionnaire was filled out. Make sure the participant knows the date of her last questionnaire. Determine if the fracture has been previously reported by checking the fracture site and date against the list of IDs and fractures provided by the coordinating center. If the fracture was not previously reported, complete a fracture report form during the participant's visit.

Q9-12. Medical conditions

These next questions ask about specific medical conditions that have been diagnosed since the last questionnaire was filled out. Make sure the participant knows the date of her last questionnaire. If there is any doubt as to whether a medical condition was recently diagnosed, please check her previously diagnosed medical conditions on the list provided. Try to clarify any discrepancies with the participant while she is in clinic.

***Q9. Spine fracture, vertebral fracture**

This question should be cross-checked with question 8. If a participant reports yes to question 9, spine fracture should be listed on question 8 and vice versa.

***Q11. Since you last completed a questionnaire, has a doctor told you that you had a stroke?**

This includes mini-strokes but does not include TIAs (transient ischemic attacks). This question should be cross-checked with question #44. If a participant answers yes to this question, #11, then question #44 should also be yes. However, the converse is not necessarily true - just because a participant has "ever" been diagnosed with a stroke, it was not necessarily since she last filled out a questionnaire for the study.

Q13. Weight loss

This question should only be answered "yes" if the participant was trying to lose weight. If she wasn't trying to lose weight, but lost some anyway, this should not be coded as "yes" but coded as "no".

Q14-16. Medications

Although all participants will be filling out the medication inventory form (MIF), medication questions specific to osteoporosis drugs need to be asked here in case the participant hasn't taken them in the past 30 days (the time frame for the MIF). Since osteoporosis drugs tend to be long-acting, it is important to record past use.

The next set of questions (Q17 - Q25) asks about events that have occurred over the **PAST 12 MONTHS**.

Q17-25.

Review with the participant that her answers reflect the past 12 month time period.

***Q19. Hip pain.**

Using the clinic use box, please review in interview format the hip pain question with each participant. Emphasize each aspect of the question making sure the participant understands the complete question:

- a) is the pain really in the hip (upper thigh), groin, or buttocks rather than the leg, knee or lower back?
- b) did they have the pain on at least half (15) or more days of one month?
- c) did this duration of pain occur in the past 12 months?
- d) was this really pain or aching rather than stiffness or some other sensation?

Record the participant's response in the clinic use box (yes, no, don't know). We are reviewing this question in this way because in addition to the question itself, we are also interested in differences in response that occur between the interview and self-administered formats for this somewhat complicated question.

***Q23. Diet**

Purpose: The primary purpose of the dietary questionnaire is to determine the participant's typical diet so that we can determine the amount of calcium, phosphorous, and protein eaten by the participants in an average week.

General issues: The dietary questionnaire is an adaptation of the dietary questionnaire developed for the National Center for Health Statistics by Dr. Gladys Block. The items included in the SOF questionnaire do not include all the possible foods a person could have eaten which contain calcium, but do account for approximately 90% of the average calcium intake in older women.

The dietary questionnaire includes questions about the usual eating habits of the study participants during approximately the past year. The time frame is meant to be a little vague. It is not expected that a participant will be able to remember exactly what she ate during the past year. Rather, the idea is to establish a usual pattern - her current diet at this point in her life. A respondent may object that she "can't remember what I ate yesterday; how could I tell you what I ate in the past year?" Make clear that the idea is not to remember exactly, but to think about the usual pattern or frequency. She does not have to remember how many times she had eggs in the past year. Instead, what she should be able to tell you with reasonable accuracy is that she has eggs "about twice a week."

If parts of the diet questionnaire are incomplete:

- Ask the participant if she had difficulty answering these questions, and try to find out the nature of the difficulty. This will help focus the explanation of what information is needed from the participant.
- Go over the instructions and the example on the take-home form with the participant.
- Help the participant complete the dietary questionnaire in interview format.
- Alternatively, if the participant clearly understands what to do, you may ask her to complete the dietary questions in self-administered format.

Some participants will have completed most, but not all of the items. Go over the missing items with the participant in interview format and help her complete them.

Optional script when using interview format

"These questions ask about how often you eat certain foods and about how much of them you eat when you do eat them. I want to know, on average, how many times per day, per week, per month or per year you eat each food. I will also ask you to compare the portion you usually eat with a typical medium portion size."

"Let's try an example together. Can you tell me, please, how often you drink apple juice? How many times per day, per week, per month or per year?"

(Pause) "When you do drink apple juice, how large is your portion in comparison with a medium size glass of apple juice (about 8 ounces)?"

Show the participant how you would record her answer, and then go over the rest of the examples for apple juice.

Specific issues and problems

1. Food frequencies

- The respondent is to indicate the number of times per day, per week, per month or per year that they eat the item. The time frame chosen should be the one that best reflects the usual pattern and gives the most accurate estimate. There may be several equally valid ways of recording the frequency. Hence "7 times per week" could also be "once per day." However, "365 times per year" should be recorded as "1 time per day".
- Occasionally a person thinks they are supposed to translate all their frequencies into the same unit, as for example, translating everything into "per month". This produces poor estimates. Answers should be in terms of the time frame that is most appropriate for the individual foods.
- Foods that are eaten rarely, never, or less than once a year should be recorded as "0 times per _____" and not simply skipped over.
- When two or more foods are included in the same category, i.e. "bread, rolls, crackers," they are to be thought of altogether, i.e. "subject eats bread or rolls or crackers 2 or 3 times every week." In

situations where one food in the category is eaten very frequently, i.e. bread twice a week, and the other very infrequently, i.e. crackers twice a year, then record the frequency for the one eaten more often.

- There are no seasonal foods in the food list. However, if a participant ate a food much more frequently at one time of the year than another, you need to calculate a weighted average of their consumption. For example, if she drank milk 7 times a week during the four winter months (hot chocolate), but only 3 times a week during the rest of the year, multiply 7 (times a week) x 4 (weeks per month) x 4 (months) = 112 times. Then multiply 3 (times a week) x 4 (weeks per month) x 8 (months) = 96 times. Add the two (112 + 96 = 208 times during the year). To get an average frequency, you can then divide 208 (times per year) by 52 (weeks per year) which gives about 4 times per week. Enter 4 per week as the average frequency.

- If the participant says that the frequency "varies" unsystematically from time to time, ask them to choose an average. For example, say: "If you had to choose just one pattern as typical for you, how often would you say you eat [FOOD]?"

2. Serving size

- Serving sizes are obtained by comparison with a typical medium serving, which is listed next to the food on the questionnaire.

- For all the food items listed, a small portion is about one-half the medium serving size shown, or less. A large portion is about one and one-half times as much or more. Eggs can be used as a simple example of what large and small portion sizes are in comparison to a medium; one egg is considered "small" and three eggs would be considered "large".

- If the respondent says she doesn't know what the medium portion size is (e.g. 8 ounces of milk) in relation to what she usually has, just check large if she usually has substantial more than other people her age, and small if she usually has substantially less than other people her age.

- A respondent who checks the same serving size for every food may not be thinking very hard about her answers. The interviewer should query her about the portion sizes to see if the portion size checked is really her best estimate. However, it is not uncommon for most (e.g. 70%) of portion sizes even in a well thought through questionnaire to be "medium." Only if ALL the portion sizes are the same is there any cause for concern.

3. Do not expand the categories to include similar foods, e.g. cheese and cheese spreads do not include cottage cheese because cottage cheese has a much lower calcium content per serving. As another example, egg whites are not equivalent to whole eggs, because the whites of large eggs have only 3 mg of calcium while the yolks have about 27 mg of calcium.

Certain food that are very similar to the food on the list, and have the about the same calcium content, such as nonfat dairy products, can be included. These foods are limited to the following:

- Dairy products

- 1) lowfat cheese can be included with "cheeses" (Nonfat cheese should not be included as the calcium content may differ greatly from other cheeses).
- 2) nonfat milk can be included with "milk"
- 3) nonfat yogurt and frozen yogurt can be included with "yogurt"

- Breads

- 1) diet breads can be included with "breads"

- Sweets
calcium 1) ice milk (194 mg of calcium per cup) can be included with "ice cream" (204 mg per cup)

4. Summary review of diet questionnaire

- Review the questionnaire for omissions (skipped foods, missing information) and other special problems.
- All frequencies and portion sizes should be filled in. If the participant simply can't estimate a portion size or frequency, leave blank and write over the answer space "DON'T KNOW."
- Foods that are eaten rarely, never, or less than once a year should be recorded as "0 times per _____" and not simply skipped over.
- Check for unreasonable frequencies (i.e. ice cream 5 times per day) and verify them with the participant.
- If the answers are all the same (i.e. all "1 time per day" or all "medium" servings) go over each answer with the participant until it can be determined that the answers are valid.
- Check to be sure that milk has not been double counted. Milk poured on cereal should not be double counted as milk consumed as a beverage, and vice versa.

*Q24. Physical Activity: Did you participate in any physical activities, recreation or sports in the past 12 months?

We are collecting physical activity data for several reasons: to describe the changing patterns of activity in our cohort and to assess the role of physical activity in the risk of osteoporosis and other outcomes (frailty and function) in the elderly. Physical activity for this study is defined as any movement produced by skeletal muscles that results in energy expenditure.

The same format that was used at baseline and for the visit 2 pre-bone loss cohort will be used at visit 4. However, since most activities previously listed were not done by even 1% of our cohort, we have shortened the list to include those activities reported by at least 1% of participants. Because it is important to record all activity regardless of whether it is in our list or not, we may get a large number of "other" codes. Be sure to provide sufficient descriptions of the other activities so that they may be coded. For activities not listed, refer to the extended list of activities used at baseline and where appropriate, fill in the correct code.

Each kind of activity should be listed on a separate line. Read the list back to the participant, coding the activities in the clinic use box to the left as you read. Probe for "anything else that you did in the past 12 months?" Prompt the participant to think of activities that she does in the winter months as well as the summer months. (While you can postpone entering the code number for each kind of activity until after the interview, make sure that you have enough information to permit you to do so. If, for example, someone says she played tennis, probe whether it was singles or doubles, if she danced, find out what kind of dancing. Each activity that bears a separate code number in the list at the top of the page should appear on a separate line, and the three follow-up questions answered for each. On the other hand, if she tells you that she went hiking one day and walked the other six days, these may be entered on one line.)

If the participant lists more activities than can fit on the lines, circle the 6 activities that she did most frequently, and obtain follow-up information on these activities.

Once you have the list of everything the respondent did in the last 12 months make sure that the frequencies per week, and the times per week are complete. The first follow-up question asks for number of weeks per year she does the activity. Note that the frequency of weeks is number of weeks in the past year. Be sure to include any seasonal variations in this estimate. For weeks per year, just add the number of weeks from the more active time (4 weeks per month for 4 months = 16 weeks) to the number of weeks from the less active time (2 weeks per month for 8 months = 16 weeks) to get total number of weeks (32 weeks). To compute an average for number of times per week, just take an average of the number of times during the busy seasons and the number of times during the less busy season (i.e. 4 times per week plus 2 times per week averages out to 3 times per week).

For each activity listed, ask the participant, "*Each time that you [ACTIVITY], for how many minutes on average do you actually [ACTIVITY]? Count only the time that you are actually doing it.*" If she says that the amount of time varies, probe for the average time. Record the response in the clinic use box. Note: for bowling, each game played counts for about 10 minutes of actual activity.

Q25. Urine Control

Many older adults experience involuntary loss of urine. We are collecting this information because incontinence is a highly prevalent condition in the elderly that has the potential to affect one's activities or way of life. In addition, incontinence affects people in different ways. If the questions are completely filled out, they do not need to be reviewed verbally with the participant. If any of the questions are not complete, ask them in interview format.

Q25b. If you do not use a pad or special absorption protection, how much urine usually leaks?

Many women may have to estimate the answer to this question if they always wear protection. If the participant says she always wears pads or protection, then ask her to estimate what she would happen if she didn't have the protection in place - would the floor get wet? or just her outer clothes, or just her underclothes? Make sure the participant is answering as if no absorption protection is being used.

Q25d. Do you consider this leakage a problem?

This question is subjective. "Problem" can mean anything. What we want to know is if the participant considers her incontinence a problem (whatever "problem" exactly means to her is not as important as just the fact that she considers it one). Some women may feel it is a problem, others may not.

The next section of questions (Q26-Q46) asks about the participant's **CURRENT lifestyle practices.**

Review all questions following guidelines outlined in Section 1.

Q26. Living Arrangement

These questions ask about the participant's living arrangement. Living arrangement may be an indication of self-sufficiency or dependency, and changes in living arrangement may be indicative of declining health. Living arrangement also provides an estimate of potential environmental exposures and services that may affect one's health. Only one answer should be checked.

Q27a. Who do you live with?

More than one answer can be checked.

Q29. How many city blocks or their equivalent do you walk each day as part of your normal routine?

Walking as part of the daily routine includes walking to the store because the respondent has no other way to get there, walking around a shopping mall because there is no other alternative, etc. Do not include walking up and down the isles of the grocery store, for example, or walking around the house while cleaning. A general rule of thumb should be to include only walking of distances of a block or more at a time. This will generally be done outside or in a large shopping mall or similar setting.

Q30. How many city blocks or their equivalent do you walk each day for exercise?

Walking for exercise includes any regular walking by the participant done specifically for its exercise value. This would include walking to the store, the post office or senior center because she "wants the exercise." For those with irregular exercise habits or who walk for exercise every other day, add up the total blocks for a week and then divide by 7 to get a daily average. If the respondent says that city blocks in her area are much longer or shorter than the 12 to a mile indicated, convert the blocks she walks to miles and then compute blocks per day based on 12 to the mile.

Q31-33. Caffeine Use.

The responses to these questions should be straightforward. Note that only colas or other soft drinks (such as Mountain Dew, Pepsi, Coca-cola, Tab, Dr. Pepper) containing caffeine should be included in question 33 (i.e. do not count Seven-Up or uncaffeinated colas such as Root beer). If the participant has difficulty in reporting the number of cups or cans, probe further. Stress the idea of a typical or average day. For example, for a participant who reports 2 cups of coffee per day during the week but only 1 per day on the weekend, the quantity consumed should be recorded as 2 per day. If, after probing, the participant cannot determine the number of cups or cans, ask her to give her best guess.

Q34. Current Alcohol Consumption

General issues: If anyone asks what drinking alcohol has to do with osteoporosis, simply explain that we are not suggesting that they are related, that we are simply exploring a variety of subjects that some people think might be related, that we're simply trying to learn more about what kinds of things do and do not contribute to this condition and what might help prevent it. But don't volunteer this kind of explanation unless you are asked.

If the questions are completely filled out, they do not need to be reviewed. If either of the questions are not complete, ask them both in interview format.

Some common problems that might account for incomplete questions are discussed below.

Frequency

If the participant writes down the precise number of times she had a drink during the past 30 days, translate it into one of the existing codes. For example, if she wrote, "5 or 6 times altogether," simply check the box for "1 or 2 days a week".

If she had difficulty answering because she "didn't drink at all some weeks but drank fairly often other weeks," probe "How about the average week during the last 30 days?" If the respondent has trouble coming up with an average per week, ask her about the frequency or actual number of drinks in the different weeks, record what she says on the questionnaire, then compute the average and record the correct answer. If in the process of answering, she describes her complete pattern for the month and the average becomes obvious, simply check the appropriate box on the basis of her more detailed answer.

Quantity

The question asks for the number of drinks of all types of alcohol the participant usually has on days when she drinks any alcohol.

If the participant has trouble estimating the number of drinks on days when she had alcohol, probe for the "typical day" or for "most of the days when you had a drink". Note that this question does not average in the days when she had nothing to drink. If she tells you that she drinks a quart of beer or a fifth of wine per week, record the answer verbatim so that equivalent number of drinks can be calculated later.

If the answer spans a range (i.e. "It must have been 3 or 4"), probe: "And if you had to choose one number, would you say it was probably 3 or 4?" If she reports "5 or 10", probe "Could you narrow that a little? Do you think it was closer to 5 or closer to 10?" in the hope that she will come up with a more precise number in between.

If she shows any self-consciousness about giving you a high number, it's important that you appear (and that you are) calm, non-judgmental and accepting of whatever she says and does, making her feel that you understand and are not easily shocked.

Q35. Do you currently smoke cigarettes?

Q35b. On the average, how many cigarettes did you usually smoke per day?

Most people answer this question easily, but some who smoke only on special and/or infrequent occasions may find it hard to answer. If the respondent gives a clear answer which you cannot readily convert into a number of cigarettes per day or per week, the response should be written as given and converted to cigarettes per day before entry of the data.

If, on the other hand, she says that she smoked only on special occasions (like parties or dances), probe to determine how often that happened. Intermittent smoking should be recorded in the following fashion:

- "0.5 per day" if the average use is less than one cigarette a day but more than one cigarette per week
- "0 per day" if the average use is less than one cigarette per week

For example, if a woman states that she smoked two or three cigarettes during the average week, record "0.5 per day". If, on the other hand, she indicates that her pattern has changed sharply, record the number smoked per day and the length of time she followed each pattern; for example, write "one pack per day for 7 years, 3 cigarettes per day for last 18 months." A weighted average will need to be computed before data entry.

NOTE: Q35b should be answered in cigarettes per day. Consult Table 3.1 below for converting packs per week or month into cigarettes per day. Recently, companies have begun marketing packs of cigarettes with 25 cigarettes per pack. Clarify current use of cigarettes per pack before entering the number of cigarettes smoked.

Table 3.1
Smoking Habit Conversions

<u>Use per week</u>	<u>Cigarette use per day</u>
1/2 pack	1
1 pack	2
1 1/2 packs	4
2 packs	5
2 1/2 packs	7
3 packs	8
3 1/2 packs	10
4 packs	11
4 1/2 packs	12
5 packs	14
1 carton	28
1 1/2 cartons	42

Note: If answered in terms of a month, divide by 4 to convert to number per day.

Q36-38. Sleep and Nap Habits

Quantity and quality of sleep change with age. These questions are designed to determine how much each participant sleeps and whether or not she feels she gets the sleep that she needs. In addition, determining sleep and nap periods will give us an estimate of time spent inactive.

"Regular naps" in this case, does not necessarily mean everyday, but it does mean at least once per week on a regular basis.

Q39. Dizziness: Do you sometimes have trouble with dizziness?

We are interested in dizziness because not much is known about how it relates to falls and fractures or functional decline. We also don't know very much about the pathophysiology of dizziness or the prevalence of different types of dizziness.

"Sometimes" refers to any bouts of dizziness experienced in the last few years that the participant remembers. Include even a singular bout of dizziness, if it caused trouble.

Q39b. Would you describe your dizziness as

For each type of dizziness, the participant should have checked yes or no for whether or not it describes her type of dizziness. If none of the descriptions fit the dizziness that the participant experiences, then she should describe her dizziness in the other category. If she doesn't know, write DON'T KNOW in the other box.

Q40. Dental history

We are collecting information on dental health because tooth loss or decay may be a sign of osteoporosis. Hence, it is important that the participants include capped and crowned teeth as "natural" teeth. We want to know how many of their own teeth they've lost or had pulled SINCE THE BEGINNING OF THE STUDY.

Q41. Health Coverage

Determination of type of health coverage will be useful for clarifying Medicare usage and vital statistics.

***Q42. Sisters' fracture history**

The importance of family history of osteoporosis as a risk factor for hip fracture and other types of fracture is still controversial. The occurrence of a hip fracture in a participants' sister may indicate an increased risk of fracture for the participant herself. We want to know if any of the participant's sisters have had a new hip fracture SINCE THE START OF THE STUDY. And if so, what age the sister was when the hip fracture occurred. Use the clinic use box to verify with the participant that the sister's hip fracture occurred since the start of the study (i.e. fracture was not reported at baseline).

In addition, probe to make sure the reported sister is truly a "full blood" sister.

Q43. Hip Replacement

Review completeness of the month and year of all hip replacements.

Q43b. Why did you have your hip replaced?

For each hip, the participant may check more than one reason.

Q44. Extended Medical History (Comorbidity)

We are collecting information on a long list of medical conditions. This information will be valuable in studying patterns of aging and frailty.

Emphasize that a physician must have told the participant that she has or had the condition. These questions should be answered "Yes" even if the participant qualifies the response with:

- "at times"
- "slight or mild"
- "yes, but everyone my age has it"
- "yes, but it doesn't bother me" or
- "that's what my doctor says, but I don't agree (or believe him)"

This format is designed so that each participant should respond, either yes or no, to every medical condition listed. If a doctor has told her that she has a given condition, then she answers whether she is currently being treated for the condition by a doctor.

Many women will admit to some form of a given condition, but only those conditions specifically diagnosed by a physician should be recorded.

Definitions of listed medical conditions for EXTENDED MEDICAL HISTORY

Hypertension or high blood pressure?

Most women will be aware of a diagnosis of hypertension if it is present. Include treated and untreated hypertension, but do not include women who were told on one or two occasions that they had an elevated blood pressure which later returned to normal and did not require specific treatment. Include women who say they have high systolic (the upper number) blood pressure. The vast majority of women with a diagnosis of hypertension will have been treated with medications, although some will have received only dietary treatment.

Abnormal EKG, ECG, or electrocardiogram

This includes any type of arrhythmia, including "extra beats", atrial fibrillation, tachycardia, premature ventricular beats, couplets. It will also include most women who have had a heart attack (though they may not realize that their EKG is abnormal). Do not include heart murmur or a history of palpitations without a specific abnormality on the EKG.

Heart attack, coronary, or myocardial infarction

Most women will know whether they've had an MI. If you are not sure, ask if they spent several days in the hospital; people with MIs are almost always hospitalized for at least several days.

Angina, angina pectoris

Characterized by chest pain, often accompanies physical effort or stress. Almost always treated with medication.

Heart murmur

Diagnosed by listening to heart with stethoscope. Include "clicks" or floppy valves, "leaky" valve, rheumatic heart disease.

Congestive heart failure, enlarged heart

Congestive heart failure (CHF) is the inability of the heart to maintain a circulation sufficient to meet the body's needs. Marked by breathlessness and abnormal retention of sodium and water, resulting in edema, with congestion in the lungs. Enlarged heart will usually be diagnosed by xray. Usually treated with low salt diet, diuretics, and other medications.

***Stroke**

Stroke refers to neurological abnormality, including weakness, numbness, slurred speech, or partial loss of vision, which lasted at least 24 hours and was diagnosed by a physician at the time it occurred or within a few weeks. Do not include episodes of a "transient ischemic attack" or TIA, which are similar to strokes but are limited to 24 hours or less of symptoms. If the respondent says the doctor told her she had a "mini-stroke," record "yes." Stroke includes a blood clot in the brain or bleeding in the brain.

Cross check this question with question #11. If Q#11 is answered yes, then this question must be answered yes; however, the converse is not necessarily true.

Gallstones

Stone formed in the gallbladder or the bile duct. Usually diagnosed by an ultrasound examination, although occasionally with x-rays.

Pneumonia

Infection of the lungs with fever; usually requires antibiotics and hospitalization. Include "walking pneumonia", double pneumonia, etc.

Diabetes, sugar diabetes, or high blood sugar

Any confirmed diagnosis of diabetes mellitus should be recorded. Do not include elevated blood sugar during pregnancy ("gestational diabetes") if it did not persist or recur later in life. Do not include "borderline diabetes" unless the participant received a medical treatment (insulin or an oral medication) for this condition. Be sure the participant does not confuse high blood sugar with high blood pressure.

Hyperthyroid: high thyroid, Grave's disease, or overactive thyroid gland?

Hyperthyroidism will almost always have been treated (by surgery, medication, or radiation treatments) if it was diagnosed. Many women who initially suffered from an overactive thyroid will later develop an underactive thyroid because of the treatment given. Do not include thyroid conditions which are not specifically associated with hyperthyroidism (such as goiter, thyroid nodule or tumor, or problems with metabolism) unless participant was told it was accompanied by an overactive thyroid.

Hypothyroid: low thyroid, underactive thyroid

An underactive thyroid is a condition which generally requires lifelong replacement therapy with thyroid hormone. In this condition, the body does not produce enough of its own thyroid so the hormone must be taken orally. Some women may develop hypothyroidism from the treatment initially given for hyperthyroidism.

Seizures, epilepsy, or convulsions?

Include any seizure or convulsion documented since childhood.

Glaucoma

Group of eye diseases characterized by an increase in intraocular pressure, changes in the optic disk and typical visual field deficits. Most women will be treated for this condition with medication or surgery. Include women with "high" pressure in the eye if diagnosed by a doctor.

Cataracts

Usually characterized by cloudy lens.

Disease of the retina

Any disease of the retina, such as macular degeneration, or a detached retina.

Parkinson's disease

Parkinson's disease is a degenerative process of the brain which results in a characteristic tremor and gait disturbances. Most, but not all, will receive medication for this disorder.

Dementia or Alzheimer's disease

Organic loss of intellectual function. Alzheimer's - progressively degenerative disease of the brain, of unknown cause.

Depression

A morbid sadness, dejection, or melancholy that lasts for at least 3 months.

Liver disease, cirrhosis, chronic hepatitis

Any form of diagnosed liver disease. Do not include acute hepatitis that resolved.

Chronic kidney disease

Any medical problem related to kidney stones, albumin in the urine, dialysis.

Chronic obstructive lung disease: chronic bronchitis, asthma, emphysema, COPD

Any diagnosed chronic lung disease: bronchitis - inflammation of airway passages to and within the lungs; asthma - recurrent attacks of labored or difficult breathing; emphysema - pathologic accumulation of air in tissues or organs. Do not include ACUTE attacks of bronchitis or upper respiratory infection.

Other lung disease: tuberculosis, fibrotic lung disease

Any other diagnosed lung disease, including TB or fibrotic lung disease. Do not include acute attacks of bronchitis.

Ulcer: stomach, peptic, duodenal

Ulceration of mucous membrane of stomach or duodenum, due to action of the acidic gastric juices. Should be confirmed by x-ray ("GI series") or endoscopy (putting a lighted tube in the stomach).

***Arthritis (of the various body areas)**

Many women will admit to some form of joint pain or rheumatism, but only those conditions specifically diagnosed by a physician should be recorded. If the participant has checked yes to arthritis in any specific body area, either osteoarthritis or rheumatoid arthritis should also be checked in most cases.

***Osteoarthritis or degenerative arthritis**

Non-inflammatory degenerative joint disease, accompanied by pain and stiffness. Many women who have been diagnosed with arthritis will not be able to accurately define what type of arthritis they have. Determining if the arthritis was accompanied by inflammation or not may help to distinguish osteoarthritis (no inflammation) from rheumatoid arthritis (inflammatory).

***Rheumatoid arthritis**

Chronic systemic disease primarily of the joints. This type of arthritis is accompanied by inflammation.

***Arthritis (type unknown)**

This category should only be used if the participant knows she has arthritis but is not sure of the type. Try to determine the type with her by asking about whether or not she has inflammation (yes usually means it's rheumatoid). If you do not feel you can accurately determine the type, then use this category.

If either rheumatoid arthritis or osteoarthritis are checked "yes", but none of the "arthritis in specific body areas" are checked yes, then double check with the participant that her arthritis is not in any of the listed body areas.

Anemia

Low blood count, low iron. Person may feel unusually tired. Doctor may have prescribed supplemental iron.

Fracture of the spine or fracture of the vertebrae?

Vertebral fractures may occur with or without symptoms of back pain, but they are always diagnosed by an x-ray of the spine.

Q45. Has a doctor EVER told you that you have cancer?

For each type of cancer, indicate whether or not the participant is currently under treatment.

Q46. Extended Symptom History

Emphasize that the symptoms should have been present in the past week. These questions should be answered "Yes" even if the participant qualifies response with:

- "at times"
- "slight or mild"
- "yes, but everyone my age has it"
- "yes, but it doesn't bother me"

This format is set up so that each participant should respond, either yes or no, to every symptom listed. Some of the symptoms may seem a bit redundant but it is important to include the same list of symptoms that we use with the functional status questionnaire as to why a person might limit her activity. Strict definitions of the symptoms are not important. What is important is the participant's subjective opinion of whether or not she has a given symptom, regardless of how it is specifically defined.

If the participant says yes she has had the symptom in the past week, then make sure the number of days in the past week is coded (1 to 7).

- e. Swelling in legs or ankles - also called edema.
- f. Chest pains or discomfort - also called angina pectoris.
- h. Joint stiffness - stiffness in joints, not pain or discomfort which is asked about in parts i and j.

Clinic Use Boxes

Please fill out the clinic use boxes on the last page as to the type of visit and source of the information.