

## HCHS/SOL Question by Question Instructions Medical History Form (MHE/MHS), Version A

## **General Instructions**

This section of the interview asks questions about personal medical history as well as the medical history of immediate family members (i.e., blood relatives). For the purposes of this form we will be collecting information on parents and brothers and sisters only. Half brothers and half-sisters are specifically excluded from this assessment. Participants are asked to estimate age at onset or diagnosis for some diseases/conditions. A code of "= =" is used when the participant states that the age of onset is "unknown".

The overall layout of this form starts with a determination of doctor-diagnosed medical conditions. Age of onset is determined for select conditions, followed by a determination of history in blood relatives. In the case of family history "no" and "don't know" responses are grouped together in a single check box. A "yes" check box is also provided. Thus we will be determining a known family history for each condition assessed on the form.

## Question by Question Instructions

- Q1 Question assesses participant history of doctor-diagnosed high blood pressure or hypertension. Occasionally, participants will indicate that their doctor told them they have "prehypertension". This should be coded as "no". Women who answer yes to this question are administered a follow-up question, "Was this during pregnancy only" (Q1a). This question is asked because hypertension seen only during pregnancy is considered a different condition compared to women diagnosed with hypertension when not pregnant. Q1b-1d assess family history of doctor-diagnosed high blood pressure or hypertension. Reports of hypertension during pregnancy alone or "pre-hypertension" are coded as no or don't know.
- Q2-2d Questions assess personal and family history of doctor-diagnosed high blood cholesterol. The clinical name for this condition is hypercholesterolemia.
- Q3-3d Questions assess personal and family history of angina as well as participant age at diagnosis for this condition. Chest pain is a hallmark symptom of persons with angina. However, not all persons who experience chest pain have this condition. Therefore, it is important to check the yes box on this set of questions only if they can state that a doctor told them they had angina.
- Q4-4d Questions assess personal and family history of heart attack. The clinical name for heart attack is myocardial infarction. Age when the heart attack occurred is obtained for both the participant and for blood relatives. This latter information is important to ascertain because some studies suggest that history of heart attacks in family members that occur at relatively young ages is a risk factor for heart disease in other family members. Q4b-c assess history of doctor-diagnosed heart attack in biological parents, followed by the age at which first such occurred. Q4d assesses family history of heart attack in brother(s) or sister(s). In rare cases there may be more than one sibling with a history of heart attack. In this case record the younger age at which there was a heart attack. For example, if the participant reported that a

brother had a heart attack at age 50 and a sister had a heart attack at age 40, then you would record 40 as the age for item 4d.

- Q5-5d Questions assess personal and family history of doctor diagnosed heart failure. Another clinical name for this condition is congestive heart failure or congestive cardiac failure. This diagnosis covers a variety of conditions in which the heart is unable to pump a sufficient amount of blood through the body. Heart failure should not be confused with heart attack or myocardial infarction.
- Q6-6d Questions assess personal and family history of doctor diagnosed rheumatic heart disease. Persons with this condition have damaged heart valves, which can be a consequence of untreated streptococcus infection that typically occurred in childhood.
- Q7 Question assesses doctor-diagnosed atrial fibrillation, or specific type of abnormal heart beat (rhythm) which affects the two upper chambers of the heart. Atrial fibrillation can cause sensations of palpations, chest pain and heart failure. Not all palpations or abnormal heart rhythms are atrial fibrillation, so it is important to check the "yes" box only if the participant indicates that a physician specifically diagnosed atrial fibrillation.
- Q8 Question designed to capture other types of heart problems not asked about in Q1-7. If the participant indicates yes, you are provided space to record the name of the condition.
- Q9-9c Questions assess personal and family history of undergoing several cardiac procedures called a balloon angioplasty (or stent) and/or bypass surgery. Both procedures are designed to restore blood flow through arteries which provide critical oxygen to the heart itself. A balloon angioplasty involves running a catheter from an artery in the thigh to the blocked artery located on the outside wall of the heart. A small balloon attached to the catheter is then inflated to open up the passageway. Sometimes a "stent" is left to help maintain the opening.

A coronary artery bypass is sometimes referred to by its acronym "CABG" (pronounced 'cabbage'). This procedure uses healthy arteries harvested from other parts of the body which are then used to 'bypass' damaged arteries supplying blood to the heart. The terms double and triple bypass mean that 2 and 3 arteries supplying blood to the heart have been surgically bypassed.

You should check the 'yes' box on Q9 if the participant has had either an angioplasty or a bypass or both. Similarly, you should check the yes box for Q9a-9c if blood relatives have had either or both procedures.

Q10-10c Question assess personal and family history of doctor diagnosed stroke. An alternate clinical name for this condition is cerebrovascular accident (CVA). There are two major forms of stroke: 1) a thrombosis or embolism is when an artery which supplies oxygen to the brain is blocked, and 2) a hemorrhage in when one of these brain arteries bursts or leaks. Both forms of stroke can cause permanent damage to the brain. Stroke should not be confused with transient ischemic stroke, which is described below.

- Q11 Question assesses personal history of doctor-diagnosed mini-stroke or (TIA) transient ischemic attack (TIA). These mini-strokes can cause stroke-like symptoms caused by temporary blockages in the arteries supplying blood to the brain (confusion, numbness, weakness on one side of the body, etc). The short duration of symptoms is the main difference between TIA and stroke, which is assessed in Q10-10c. Short duration is defined as less than 24 hours.
- Q12 Question assesses personal history of balloon angioplasty or other surgery on the arteries of the neck to prevent a stroke. Balloon angioplasty (with or without a stent) can be used to clear blocked or partially blocked arteries in the neck which supply blood to the brain. A carotid endarterectomy can also be performed, in which the arteries in the neck are surgically opened and cleaned.
- Q13-13c Questions assess personal and family history of abdominal aorta aneurysm (AAA) or ballooning of the aorta. The aorta is the largest artery in the body and is attached to the heart. All blood which has been replenished with oxygen by the heart passes through the aorta as it travels to other parts of the body. The ballooning of the aorta is caused by a weakness in the wall of this artery. Rupture of an AAA or weakened aneurysm can cause death.
- Q14-14c Questions assess personal and family history of peripheral arterial disease (PAD) or blocked arteries of the legs. This condition is sometimes referred to as peripheral vascular disease (PVD). This condition is caused by partial blockages of the large arteries which supply blood to the lower extremities. It can cause pain when walking and in its more severe forms, pain while at rest, loss of sensation in the legs, and the need to amputate one or both legs due to gangrene (decay of tissue). If the participant indicates in Q14 that they had have PAD/PVD then you administer Q15, which inquires about treatment for this condition.
- Q15 Question inquiries about the treatment for peripheral arterial disease. This question is only be asked if participant responds "Yes" to Q14.
- Q16 and 16a Questions assess personal history and age at onset of diabetes. Diabetes mellitus is a group of diseases in which the body cannot produce or effectively use insulin, a hormone which is used by the body to process sugars and other foods as energy for the body. This inability to process sugars and other energy sources can lead to chronically high levels of glucose circulating through the body. Some participants may indicate that a doctor has told them that they have "pre-diabetes". These individuals do not meet the strict definition of diabetes and should be coded "no" on Q16.

Participants answering yes to Q16 are then administered Q16a-16d. These questions will be used to further classify those with diabetes (e.g., insulin-dependent diabetes). Q16a assesses age at onset; Q16b should only be administered to women since it asks about diabetes during pregnancy (called gestational diabetes). Q16c asks if they are being treated with insulin (which can be injected, inhaled or administered by a pump). Those responding yes to this question are asked in Q16d if insulin was the first type of medicine used to treat their diabetes.

Q16e-16g Questions assess family history of diabetes. Mentions of "pre-diabetes' should be coded as "No or Don't Know" unless the relative progressed to a doctor-diagnosed diabetes diagnosis.

- Q17 Question assesses personal history of doctor-diagnosed kidney disease. This is a general question meant to cover a wide variety of kidney-related diseases such as acute or chronic renal failure (a loss of kidney function) and kidney stones.
- Q18 Assess personal history of doctor-diagnosed liver disease. If the participant is unsure of what you mean by liver disease you can give examples such as hepatitis and cirrhosis. Those responding yes are administered Q18a-18d. Hepatitis (Q18a) is caused by a group of viruses leading to damage to the liver. Those responding yes to this question are asked which type they have (e.g. Type A, Type B, etc). Some participants will not know which sub-type they have. In this case check "Don't Know". Q18c asks if the participant has cirrhosis (scarring of the liver). Cirrhosis is commonly caused by chronic, excessive alcohol consumption or exposure to the Hepatitis C virus. Q18d is designed to capture any other type of liver disease not asked about in Q18a-18c.
- Q19 Question assesses personal history of heartburn and acid regurgitation. Note that these are both symptoms and not diagnoses. Q19a is asked of participants who answer yes to Q19.
- Q20 These follow-up questions assess the frequency of these symptoms. Read all response options until the participant answers. You may need to repeat the response options. Q20a is administered if the participant responds yes to Q20.
- Q21-21c Questions assess personal and family history of doctor diagnosed migraine (with or without aura). Migraine is a neurological disorder which causes prolonged severe headaches, sensitivity to light and noise, nausea and vomiting. An aura sometimes precedes a migraine attack which is experienced as a perception of strange light (e.g., bright lights, streaks of light across the field of vision, etc). Interviewer can also use the following text in Spanish to explain migraines: *síntomas que le avisan que le va a dar el dolor conocido como aura*.
- Q22 Question assesses personal history of doctor-diagnosed blood clot in a leg vein or lung which required blood thinning medication. Blood clots are also known as a thrombus or thrombi. Examples of blood thinning medication include heparin, warfarin or coumadin. If the participant indicates that they had a doctor-diagnosed clot that was not treated with medication, then you should check the "no" box for this question.
- Q23 Question asks the participant if they have painful inflammation or swelling of the joints that limits activity. This question asks about symptoms and does not require a doctor diagnosis. If the participant indicates that they have painful swelling and/or inflammation but do not report activity limitation associated with this condition, then check the "no" box for this question. Q23a-23c assess the same activity limitation due to painful swelling and/or inflammation in family members.
- Q24 Question assesses personal history of doctor-diagnosed sleep disorders. If the participant is unsure of what you mean by sleep disorders, you can give examples such as insomnia and restless legs syndrome. Those responding "no or don't know" to this question or don't know are not administered Q25 and 25d.1. Those who respond "yes" to this question are then asked which sleep disorder they have.

Q25 Read each listed sleep disorder to the participant and check the box if they have the condition. Check all conditions that apply. Insomnia is the inability to sleep and/or the ability to remain asleep. Restless leg syndrome is characterized by the urge to move limbs in order to reduce uncomfortable sensations. Excessive daytime sleepiness is the primary symptom of narcolepsy. Sleep apnea is present when there are long pauses in breathing during sleep (e.g., 10 or more seconds between breaths) which cause lowered circulating oxygen levels in the bloodstream. Q25e is used to record any doctor-diagnosed sleep disorder not listed above. Check the box and write in the name of the disorder.

Interviewer can also use the following text in Spanish to explain sleep disorders: b. Síndrome de piernas inquietas – cuando siente un deseo profundo de mover las piernas mientras está durmiendo o reposando c. Narcolepsia – cuando se queda dormido(a) de repente, especialmente durante el día d. Apnea – que deja de respirar mientras duerme

- Q25d.1 This question is only asked if the participant responds "Yes" to Q25d, apnea. Assess whether the participant has been prescribed a CPAP or BIPAP machine to treat their sleep apnea. A continuous airway pressure (CPAP) device uses a small compressor to pump a controlled stream of air through a mask worn while sleeping. A bilevel positive airway pressure (BIPAP) device works in a similar fashion except that it provides differing air pressure level during breathing in and while exhaling.
- Q26-26d Questions assess personal and family history of doctor-diagnosed cancer. Those responding no to Q26 are not administered Q26a-26d. Those that respond yes are administered a list of possible cancers; check all that apply. Q26b-26d assess family history of any type of cancer or malignant tumor.

Interviewer can also use the following text in Spanish to explain types of cancer: c. Cuello de la matriz – cuello del útero d. Leucemia o linfoma – cáncer de la sangre (Leucemia) o cáncer de los ganglios linfáticos (linfoma) l. Del útero – de la matriz

For male participants this is the end of the questionnaire; Q27-39 are administered to female participants only.

- Q27 Question assesses the age which their menses began (also known as menarche). Participants may be uncertain as to when their menses began. Encourage the participant to provide their best estimate.
- Q28 Question assesses if the participant currently has menstrual periods. 'Currently' can be defined as during the last year. If they report an irregular cycle, check "yes" for this question.
- Q29 Question assesses whether the participant has ever had a hysterectomy. Those responding "No" are not administered Q30. Those responding "Yes" are asked to indicate if both ovaries where removed, if both ovaries were not removed, or if they were uncertain if ovaries were

removed. Only one box should be checked. You should check the box "Yes, without removal of both ovaries", if the participant indicated that only one ovary was removed.

- Q30 Question asks the participant to indicate the age when she had the surgery.
- Q31 Question assesses whether the participant has reached menopause (change of life). If asked, 'menopause' can be defined as having no menstrual period during the past 12 months. Participants who answer "No" or who respond that they are uncertain do not answer Q32. There are two possible yes responses: 'natural' and 'surgical'. Surgical menopause occurs when premenopausal women have both ovaries surgically removed, often when undergoing a hysterectomy (surgical removal of the uterus).
- Q32 Question asks the participant to estimate the age at menopause.
- Q33 Question ascertains whether the participant is currently pregnant.
- Q34 Question asks if the participant has ever been pregnant, and if yes, the participant is administered Q35.
- Q35 Question assesses the number of times she has been pregnant.
- Q36 Question assesses the number of live births she had. A live birth is defined as the delivery of a baby even if the baby subsequently died. This may be a particularly sensitive question for women who have experienced the loss of an infant or child.
- Q37 Question assesses lifetime use of birth control pills or other birth control medications.
- Q38 Question asks the participant if she is taking any hormones other than birth control pills. You should emphasize the second half of this question to avoid confusion with Q37. Examples of hormones include hormone replacement therapies such as Premarin, which is a form of estrogen. If the answer to Q38 is "No", the questionnaire is finished.
- Q39 If participant answers "Yes" to Q38, ask participant Q39. Assess if supplements taken are to supplement natural hormones. If needed, clarify that hormone pills, creams, patches, suppositories, as well as herbal products, qualify as "Yes" if taken as post-menopausal therapy or to supplement natural hormone levels.