

Chapter 9

Socio-Demographic Information

ADMINISTRATION

There are two versions of this questionnaire – one for U.S. participants and another for the Danish cohort. This interview was designed to be administered by an interviewer; however, when necessary, it may also be mailed and self-administered. At the top of the form, there is a box "For Internal Use Only" in which to check the way in which the interview was completed. It is important that this box be completed accurately by study personnel. There are two panels for the SDI information. The first is Panel 2 (SDI) and the second is Panel 2a for the Offspring Generation only (Proband Grandchild Enumeration).

METHODS

Participant is to answer each question in Panel 2 by following skip patterns specified in the questionnaire. For questions requesting "Year or Age", participant can provide either response. The participant should be instructed to provide whichever – year or age – he or she is most likely to remember accurately. Enter the information as provided by participant.

Panel 2: SocioDemographic Information

Questions Q1-4b will be asked solely of those who previously had an invalidated DOB:

Question Q1 – Date of Birth: Four digits should be used for year of birth. Two numbers should be entered for the month, including leading zero is applicable. If applicable, leading zeros should be entered for day. For example, the date of birth for a person born on January 5, 1915 would be formatted as:

DAY: 05 Month: 01 Year: 1915

Question Q2 – Source of Birth Date: Select only one box for birth date source. If participant has a birth certificate in his/her possession, birth certificate should be marked. In the absence of a birth certificate, mark the item that participant most commonly uses when s/he needs to provide a proof of age. If the participant uses a source not listed as one of the choices on the questionnaire, write this source in block letters on the line provided next to "other (Please Specify)".

Question Q2a – Birth Date Verification: This question requests that the birth date source mentioned above be used to verify the participant's birth date. Select either "yes" or "no" to indicate whether the birth date was confirmed or matched by viewing the source document. If the birth date is not verified, select "no" and state the reason on the line provided.

Questions Q3a and Q3b – Birth Place: Follow skip patterns as specified in the questionnaire. Write down the names of places on the lines provided. Participant should answer any or all information that s/he recalls.

Questions Q4a and Q4b – Birth Place-International: Participant is asked to provide the name of the country where s/he was born, if not born in the US. Write down the year when participant came to the US using 4 digits (1915) on the line provided. If participant is unable to remember the year, ask for his/her age at the time when s/he arrived in the US. If applicable, leading zero should be entered for age (e.g., if participant was 7 years old when he or she came to the U.S. write 07).

Question 5 – Childhood residence. Participant is asked to provide the name of the city/town, county, state, and country where s/he lived the majority of his/her childhood, prior to age 16.

Question 6a– Current Housing Situation: Select the **one** best choice that describes the participant's current housing situation, and then follow skip patterns as indicated. If the participant resides in a dwelling that does not match one of the provided choices, select "other" and describe the dwelling type on the line provided.

Question 6b – Number of Persons in Household: Record the number of people who live in the household with the participant on the line provided. Do not count the participant in this estimate, only those who live with him/her. If there are 0 people living in the household aside from the participant, skip to Q6f.

Question 6c – Living Arrangements: Check the boxes that best describe the relations of the people counted in 6b as living with the participant. Mark all that apply and use the line provided near "other" to describe the relation of any cohabitant not covered in the provided choices.

Question 6d – Date moved into assisted living/special housing of older adults: For those participants that selected assisted living/special housing for older adults in Q6a, please enter the date (day/month/year) that this occurred.

Question 6e – Date moved into nursing home: For participants that selected nursing home in Q6a, please enter the date (day/month/year) that this occurred.

Question 6f – Health Insurance: Participant is asked whether s/he has some form of health insurance (taken from FHS).

Question 6g – Type of Health Insurance: For participants responding that they have health insurance, record the form of their health insurance from the options given (also taken from FHS). Please record yes, no, or don't know for each option.

Question 6h – Prescription Drug Coverage: Participant is asked whether s/he has prescription drug coverage.

Questions 7, 8, 9 – Gender, Hispanic Origin and Race/Ethnicity: These questions are only asked of new participants at Visit 2. These items are *self-assigned*. For Question 9, race, ask participant to choose all that apply. If participant's *self-identified* race is not among the categories listed, mark "other" and ask participant to specify the *self-identified* other race. Write this other race in block letters on the line provided. Show the respondent the card so that s/he can see the choices provided.

Question 9a – Additional education: Asked only of returning participants. Participant is asked whether s/he has completed an additional degree or higher level of learning since last in-person visit.

Question 10 – Educational Attainment of Participant:

New Participant: Participant is asked to choose the category corresponding to the highest degree or level of education s/he has **completed**. Do not select the choice unless the person has completed that level of education. For example, if the participant has completed half of 5th grade, select 4 grade. Only one response should be marked. Show the respondent the card so that s/he can see the choices provided. If the participant has had vocational training, check the box for vocation training and jot down the number of year of vocational training s/he had on the line provided.

Returning Participant: If a returning participant responded Yes to Q9a, then ask the participant what additional degree or higher level of education s/he has completed. Be sure to choose the category corresponding to the highest degree or level of education s/he has **completed**. Do not select the choice unless the person has completed that level of education. Only one response should be marked. Show the respondent the card so that s/he can see the choices provided. If the participant has had new vocational training since our home visit, check the box for vocation training and jot down the number of years of vocational training s/he had on the line provided.

Question 11a – Participant's Occupation: Question 11a asks about participant's **main** occupation during most of his/her life. If participant worked on a farm or a family business, specify whether this work was paid or unpaid. If participant never worked, check the box provided for "never worked" and skip to Question 12a. Ask participant to provide this information as briefly as possible. Write down participant's response in block letters. ***Please Note:*** If the participant is currently working, be sure that the occupation jotted down here represents the role s/he played in his/her **main occupation**, which may not necessarily be related to the type of work s/he is currently performing especially if the participant is working part-time or on a 'side job'. The participant should be encouraged to report only one occupation which should be his/her primary occupation for most of his/her life. However, if the participant insists that he/she had more than one **main** occupation, list all and include them on separate lines or clearly separate them with " ;".

Question 11b – Number of Subordinates: Participant is asked to provide the number of subordinates s/he had when s/he **stopped** working from his/her main occupation. We are defining 'subordinates' as those employees who had a lower rank than the participant and who reported to him/her as their supervisor. If participant had more than 1,000 subordinates, write "999". If the person does not know, write don't know.

Please Note: If the participant is still working at his/her **main** occupation, you may enter the current number of subordinates. If the participant is currently unemployed or working in a job outside of his/her main occupation (i.e. part-time, 'side job', etc.) or has retired, enter the number of subordinates the participant had when s/he stopped working from his/her **main** occupation.

Questions 12a to 12c– Marital Status: In **Q12a**, participant is asked about his/her current marital status. Only one response should be marked for current marital status and skip patterns should be followed as specified in the questionnaire. **Q12a1** asks returning participants only if they have gotten married since the first in-person visit. **Q12b** asks for the participant's year or age when his/her marriage began. Please note, that for those participants who have been married more than once, this question refers solely to his/her **first** marriage. Whenever the participants are unable to provide the year when their first marriage began, ask them to provide the best estimate for their age at the time of their first marriage. **Q12c** asks for the total number of times the participant has been married including his or her current marriage.

Note: If the participant is not married but is cohabiting with a partner (male or female), please so indicate in the comments section of the DES. Enter the information about this relationship as if the person had been married to his/her partner. Here we want to capture long term cohabiting relationships in which the couples were not formally married.

SPOUSE/PARTNER: Questions 13-14: This set of questions pertains to the spouse/partner to whom the participant has been married or lived with the longest.

Question 13 – Educational Attainment of Participant's Spouse/Partner: *New* participant is asked to choose the category corresponding to the highest degree or level of education his/her spouse/partner has **completed**. Do not select the category unless the participant's spouse/partner has completed that educational level. For example, if the spouse/partner has completed half of 5th grade, select 4th grade. Only one response should be marked. If participant has been married or lived with a partner more than once, the question should be answered for the spouse/partner to whom s/he was married or lived with for the longest time. Show the respondent the card so that s/he can see the choices provided.

Question 13a – Current Employment: *All participants* are asked if they are currently employed at a paying job. Please answer Yes or No. If no, skip to Question 13d. If yes, go to question 13b.

Question 13b – Number of Hours Working Per Week: If currently working (Q13a is Yes), record the number of hours per week that the participant is currently working as full time (≥ 32 hrs/week) or part-time (< 32 hrs/week). Then go to Question 13c.

Question 13c. - Primary Occupation: Question 13c asks for the participant's current primary occupation if working. If the participant insists that he/she had more than one **main** occupation, list all and include them on separate lines or clearly separate them with " ;". Examples of occupation include janitor, farm laborer, bus driver, postal clerk, registered nurse, teacher, auto mechanic, lawyer, doctor, accountant, housewife, unpaid work on a farm, etc.).

Question 13d – Current Unpaid Volunteer or Community Work: Question 13d asks if the participant currently does unpaid volunteer or community work. Please answer Yes or No and follow-the skip patterns after that response.

Question 13e – Number of Hours Volunteering Per Week: If currently volunteering, record the number of hours per week that the participant is currently volunteering as full time (≥ 32 hrs/week) or part-time (< 32 hrs/week).

Questions 14a and 14b are for New Participants ONLY

Question 14a – Occupation of Participant's Spouse/Partner: **Question 14a** asks about the main occupation of participant's spouse/partner during most of the spouse's/partner's working life. If the participant has been married or lived with a partner more than once, the question should be answered for the spouse/partner to whom s/he was married or lived with for the longest time. Ask the participant to provide this information as briefly as possible. Write down the participant's response in block letters. If a participant's spouse/partner never worked, check the box next to "never worked" and skip to Question 15a. **Please Note:** If the participant's spouse/partner is currently working, be sure that the occupation written down here represents the role s/he played in his/her *main occupation*, which may not necessarily be related to the type of work s/he is currently performing especially if the participant's spouse/partner is working part-time or on a 'side job'. The participant should be encouraged to report only one occupation which should be his/her spouse's/partner's primary occupation for most of his/her life. However, if the participant insists that the spouse/partner had more than one **main** occupation, list all and include them on separate lines or clearly separate them with " ;".

Question 14b – Number of Subordinates of participant's spouse/partner: Participant is asked to provide the number of subordinates his/her spouse/partner had when the spouse/partner **stopped** working. We are defining 'subordinates' as those employees who had a lower rank than the participant's spouse/partner and who reported to him/her as their supervisor. If participant's spouse/partner had more than 1,000 subordinates, write "999". If the respondent does not know, write don't know.

Please Note: If the participant's spouse/partner is still working at his/her main occupation, you may enter the current number of subordinates. If the participant's spouse/partner is currently unemployed or working in a job outside of his/her main occupation (i.e. part-time, 'side job', etc.) or has retired, enter the number of subordinates the participant had when s/he stopped working from his/her main occupation.

Ask Q15a-Q15d only of new participants, unless it is missing in visit 1

Question 15a – Highest Annual Combined Household Income: This question asks about the highest annual combined household income participant and anyone in his/her family attained when participant and/or his/her spouse/partner were working. Participant should include income from all sources such as wages, salaries, self-employment, governmental sources, help from relatives, rent from properties, interest, dividends, and any other income sources. Only one answer should be marked. Since this is a sensitive question, use the income response form to elicit the response. Participants tend to feel more comfortable when asked to point to their income level on the response form rather than to verbally state their response to this particular question. **If the participant was/is living with someone with whom they did NOT or don't share their income, the participant should report his/her income only, i.e., not the combined income with his/her living partner. If the incomes of the spouse/partner were/are pooled, then the combined income should be reported. Please note that, for those who have had a change in marital status, the *highest annual income when working* may not necessarily be the income they earned when together. If the participant earned more while living and working on his/her own than s/he did when living with a spouse/partner, the highest income should be reported.**

Question 15b – Time Estimate of Earned Income: The participant is asked to provide a time interval for when this highest level of annual combined household income was earned. If the participant is unable to provide the time interval in the format of a range between the two years in which this income was earned (i.e. "Year 1910-Year 1925"), s/he may provide the age range s/he was during the time this income was earned (i.e. "Age 35-50").

Question 15c – Dependents on Income: Question 15c asks about the **maximum** number of **household** members, **including participant**, who depended on this income. Provide the maximum number of household members on the line provided. If applicable, leading zeros should be entered.

Question 15d – Rate of Difficulty: Question 15d asks the participants to rate the level of difficulty they and their family experienced when paying for the very basics during most of their life. Read the 5 choices out loud (with the exception of 'don't know' or 'refused') and ask the participants to select the one best choice. Mark only one response.

Ask Q16a-Q16b only of new participants

Questions 16a-16b – Housing Ownership and Value: These questions ask about ownership and financial value of participant's principal place of residence. Follow skip patterns as specified in the questionnaire. Mark only one answer per question. For Q16b, ask the participant to point to the correct choice on the response form.

Ask Q17 only of new participants, unless it is missing in visit 1

Questions 17 - Financial Assets: This question asks about the value of any financial assets participant may have. Assets refer to bank accounts, retirement accounts, investments, such as stocks and bonds, and other financial assets. Only one answer per question should be marked. Ask the participant to point to the correct choice on the response form.

Note: Questions 15d through 16a will be asked of the Danish cohort.

LIFE EVENTS (Adapted from CHS)

I am now going to ask you about a number of events that commonly happen in people's lives and that can affect your health. In some cases, I will ask whether the event has happened to you or a member of your family in the past six months. In other cases, I will ask only whether it happened to you. When I ask a question about a spouse, I am referring to both married spouses and unmarried partners who live together. Please respond "yes" if the event happened and "no" if it did not.

Question 18 – Job change or loss during the past six months.

Question 18a – Time frame of job change or loss

Question 18b – Positive or negative experience

Question 19 – Grandchild birth during the past six months. This is also to include the birth or great grandchildren or great-great grandchildren.

Question 20 – Care for sick or disabled relative become problematic during the past six months.

Question 20a – Has this care become significantly harder in last month

Question 21 – Significant change in personal finances during the past six months

Question 21a – Time frame of change in personal finances

Question 21b – Positive or negative experience

Question 22 – Did you, a close friend, or a close family member have a serious accident or illness during the past six months

Question 22a – Time frame of when this accident/illness occurred

Question 23 – Have you, your spouse/partner, or member of immediate family been assaulted or robbed during the past six months

Question 23a – Time frame for when this robbery occurred

Question 24 – Any important relationships become significantly worse during the past six months

Question 24a - Time frame for when this relationship worsened

Question 25 – Did someone you were close to die during the past six months? If a participant reports multiple deaths in this timeframe, enter the information for the closest relative's death in Q25, 25a, and 25b. Use Q26 for reporting details of additional deaths.

Question 25a – Time frame for when this person died

Question 25b – Deceased person's relationship to you

Question 26 – Any other important events happen to you or your spouse/partner in the last six months that made this period significantly different from a typical year?

Question 26a – Describe event. If more than one death in past six months reported during Q25, enter information on additional deaths here as well as any other events.

Question 26b – Was the event a positive or negative experience

CES-D

The CES-D should be administered to the participant by the examiner except under rare circumstances when it is acceptable for it to be self-administered (e.g. if the participant can't hear the examiner, or refuses to answer the examiner). If this is the case, please indicate the CES-D was self-administered at the top of Panel 11. If the participant cannot complete the CES-D, it should NOT be administered to a proxy.

CES-D: Participant Version

I am going to read you a list of ways you might have felt or behaved during the past week or past seven days. After I read an item, please look at this card and tell me how often you have felt this way during the past week.

Refer to Card in Appendix B

Response Options for Questions 15-24:

- Rarely or none of the time (less than 1 day)
- Some or a little of the time (1 to 2 days)
- A moderate amount of time (3 to 4 days)
- Most of the time
- Refused or don't know

Question 1 – Bothered by things that don't normally bother you

Question 2 – Trouble keeping my mind on what I was doing

Question 3 – Felt that everything I did was an effort

Question 4 – Felt depressed

Question 5 – Felt hopeful about the future

Question 6 – Felt fearful

Question 7 – Sleep was restless

Question 8 – I was happy

Question 9 – I felt lonely

Question 10 – I could not get going

Panel 2a: Enumerating the Grandchildren of the Proband Generation

This panel will be asked of the offspring generation only.

The Offspring generation will be asked about their biological children during in-home Visit 2. This is intended to allow us to enumerate the number of potential grandchildren of the proband generation available for possible recruitment during another funding cycle. We will NOT contact these individuals as part of Visit 2 or Visit 2 follow-up. The information we intend on collecting from the Offspring generation about their biological children (ie the grandchildren of the proband) is: number of biological children with recent spouse/partner, biological child relationship (son or daughter), name of child, date of birth, vital status, current address if living, date of death if deceased, and information on biological children with additional spouses/partners. We will collect gender, date of birth, name, current address, vital status, and date of death if applicable, for future contact using the following questions:

Question 1: Ask the offspring generation participant if they have any biological children with their most recent spouse/partner. If yes, go to question 2. If no, go to question 3h.

Question 2: How many biological children do you have with your most recent spouse/partner?

Question 3: Complete a-g for each biological child.

Question 3a: Relationship (son or daughter).

Question 3b: Child's name (first, middle, last (maiden if applicable)).

Question 3c: Child's date of birth (day/month/year).

Question 3d: Vital status. Alive go to 3e, deceased go to 3f.

Question 3e: Geographic Location (Country, State, City, Zip Code). Go to 3g.

Question 3f: Date of death (day/month/year).

Question 3g: If more than one child from Question 2, go to 3a for next child. If only one child or no children with current/most recent spouse/partner, go to 3h.

Question 3h: Did you have any biological children with another spouse/partner? If YES, go to 1 and begin new sheet. If NO, end interview.