UK Biobank

Verbal Interview stage

Version 1.1

http://www.ukbiobank.ac.uk/

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This manual details the Interview procedure at an Assessment Centre of the UK Biobank

Contents

1. Introduction

1.1: This manual details the Interview procedure at an Assessment Centre of the UK Biobank. This takes place at the 3rd 'station' of the Assessment Centre visit, together with the measurement of blood pressure and arterial stiffness, as listed in Table 1.

Table 1: Sequence of assessment visit

	Visit station	Assessments undertaken
1	Reception	• Welcome & registration • Generating a USB key for Participants
2	Touchscreen Section	• Consent • Touchscreen questionnaire • Hearing Test • Cognitive function tests
3	Interview & blood pressure	• Interviewer questionnaire • Blood pressure measurement • Measurement of arterial stiffness
4	Eye measurements	• Visual acuity • Refractometry • Intraocular pressure • Optical Coherence Tomography
5	Physical measurements	• Height (Standing and Sitting) • Hip & Waist measurement • Weight and bio-impedance measures • Hand-grip strength • Ultrasound Bone Densitometry • Spirometry
6	Exercise fitness test	• Exercise fitness/ECG test
7	Sample collection	• Blood samples collected • Urine sample collected • Saliva sample collected
8	Web-based diet questionnaire	• Dietary assessment

1.2: Throughout this document, the term 'Participant' signifies a study participant who is taking part in the Assessment Centre process, regardless of whether they eventually give or withhold consent to take part in the UK Biobank study.

1.3: The collection of data from assessment visits uses the direct data entry system of the Assessment Centre Environment (ACE).

1.4: At the start of their visit, each participant is issued with a USB key at the Reception station. This acts as a participant identifier, containing participant ID, name, date of birth and gender. As the participant progresses between stations the USB key acts as an identifying token. The USB key is encrypted so can only be read by assessment centre computers. None of the participant's test data is transferred to the USB key. At the end of the assessment visit all identifying data on the USB key is removed.

2. Staff

This interview is carried out by trained members of staff. The Assessment Centre Manager oversees that all staff work in accordance with the procedure.

3. Preparatory procedures at start of day

3.1: The device that measures arterial stiffness (pulse-wave velocity monitor) is switched on.
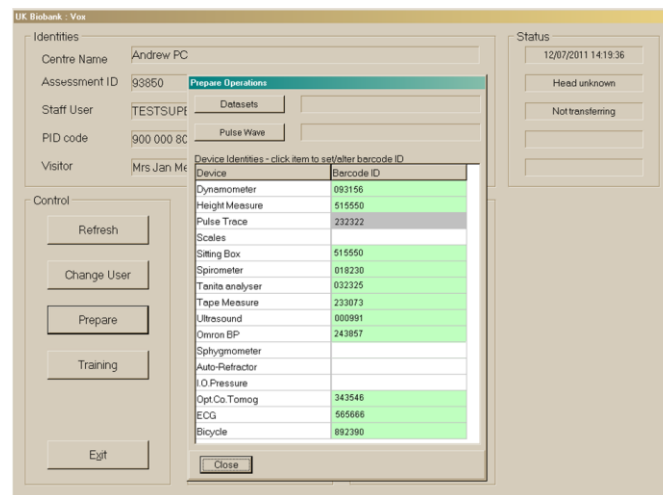
3.2: The staff member inserts a username and password to operate the system.

3.3: A barcode scanner is used to enter the unique identifier of the pulse-wave velocity monitor and Omron blood pressure monitor. This identifier is a barcode sticker placed on all equipment once it has been approved and calibrated, and allows the coordinating centre to monitor and diagnose any faulty equipment.

4. Interview process

4.1: The verbal interview is designed to find out more details about the participants' country of birth, occupation and medical history.

4.2: The participant is seated in a curtained office for privacy. The participant's USB key is inserted into the computer.

The following sequence is followed:

1. Interview: Part 1
2. First measurement of blood pressure
3. Interview: Part 2
4. Measurement of Pulse Wave Velocity
5. Second measurement of blood pressure

4.3: The participant is informed that questions asked in the interview (for example, about place of birth, occupation and medical history) may be influenced by responses given by them in the touchscreen questionnaire. They are reassured that, other than such 'linked' questions, interviewers do not know what responses have been entered in the touchscreen.

4.4: The staff member records whether or not the participant has completed their pre-visit 'aide-memoire' questionnaire. Participants were asked to complete this at home before the visit in order to help them to answer questions on their medications, major operations, family history of diseases, birth weight, whether they were breast fed, and their place of birth. This pre-visit questionnaire is returned to the participant after they complete the interview section (as identifiable details are not kept at the assessment centre for longer than necessary).

5.   Interview (part one): place of birth

5.1: Place of birth: If the participant entered on the touchscreen questionnaire that country of birth was England, Scotland, Wales or 'elsewhere', the interviewer was prompted to ask them about their **'Place of birth in the UK'** OR **'Country of birth'**.

The interviewer asks: "*What is the town or district you first lived in when you were born?"*

The interviewer is provided with a tree structure that lists place names and counties in England, Wales and Scotland. They were instructed to enter at least the first 3 letters of the town/village/place that the participant provides. If there are too many matches to the first 3 letters, no place names appear, and more letters need to be entered. If there is more than one listing of the relevant place name, then they were asked to choose the one with correct district or county. In order to narrow down the search, the interviewer may also need to type in the district or county to find a match. If they cannot find the place name, they were instructed to use the **Enter Other** facility to enter free text to state the town, county (or district) and country. If the participant does not know, there is the option to enter **Unknown**. Place of birth in the UK is then converted into North and East co-ordinates.

5.2: Country of birth: For participants born outside England, Scotland or Wales, the interviewer asked:

"*In the touch screen questionnaire you said you were born elsewhere, can you now tell me what is your country of birth?*

A pop-up screen shows an alphabetical list of 296 countries, from which the interviewer can select one by clicking on it or using the 'Search' function at the bottom of the box to enter a country name.   At least 3 letters are required for the search to produce a list. If the interviewer cannot find the country or the participant does not know, they can either enter a free text entry using the **Enter Other** button or use the **Unknown** button at the bottom of the pop-up screen.
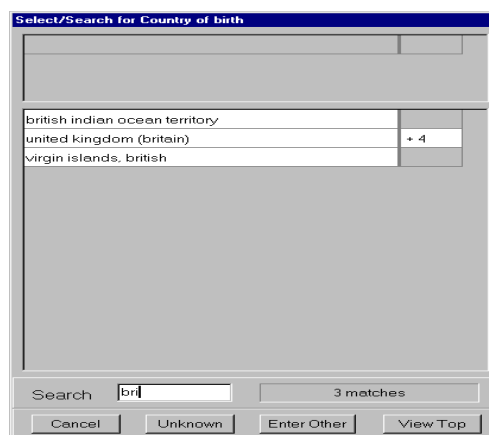
6. Interview (part one): parent's date of birth

This question was only asked in an early version of the touchscreen questionnaire.

The interviewer asks: "*Can you now tell me what is your father's date and month of birth?*"

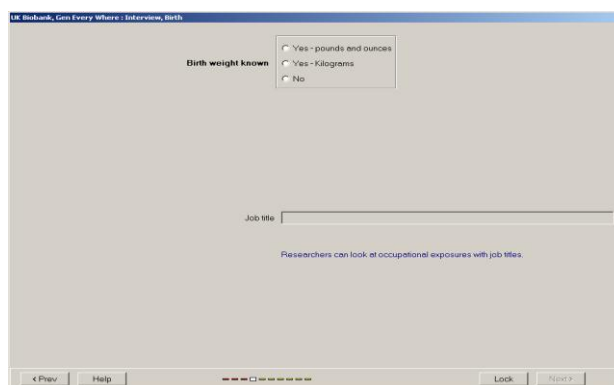Data on the day and month of birth are selected, if known.

The interviewer asks: "*Can you now tell me what is your mother's date and month of birth?*"

Data on the day and month of birth are selected, if known.

7. Interview (part one): birth weight

7.1: The interviewer asks: "*Can you tell me your birth weight?*

The interviewer can enter the weight in pounds and ounces or kilograms depending on the participant preference. The response **No** was entered if the participant does not know or cannot remember.

8. Interview (part one): Job title

8.1: If the participant entered in the touchscreen questionnaire that they are currently employed or self-employed, the interviewer is prompted to ask them to describe their job.

8.2: The job title is coded according to a tree structure, categorised according to the Standard Occupational Classification 2000[1]. Unless the interviewer is familiar with this classification structure, the simplest way to correctly code the participant's job title is to follow the algorithm provided below[2].

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[1] Office of National Statistics. Standard Occupational Classification 2000. London: Crown copyright; 2000.
[2] Algorithm and occupational coding notes provided courtesy of Ms Krys Baker, Senior Data Manager, CRUK Epidemiology Unit, University of Oxford: Oxford.
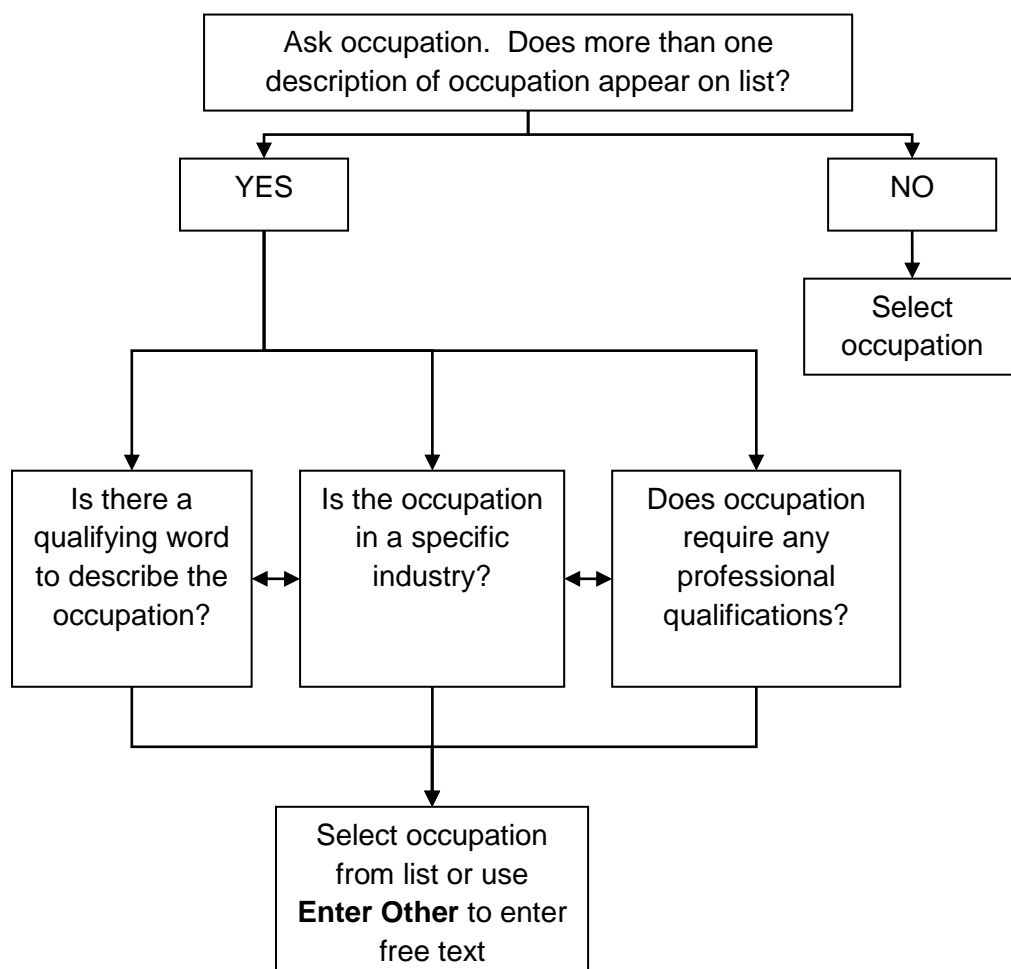
8.3: The interviewer asks: "C*an you tell me what your job title is?"*

The '**Search'** facility is used to enter what the participant has described. If there is only one match, the job title is selected and a pop-up box will appear describing the parent categories for the occupation that is selected. [For example, if '*consultant, engineering, chemical'* was selected, the parent branch for this is 'Professional occupations science and technology professional' – this is provided so that the interviewer can check that the parent category for the occupation is correct].

If there is more than one match, the interviewer will need to probe further to find a qualifying word to describe the occupation, by asking:

"*Is the occupation in a specific industry?"* OR "*Does the occupation require any professional qualifications?"* in order to help them to find the correct match. If the participant has more than one job, only the main job title is recorded. If a match cannot be found, then **Enter Other** is selected for the interviewer to type in a free text field for the job title or **Unknown** if the participant cannot complete this question.
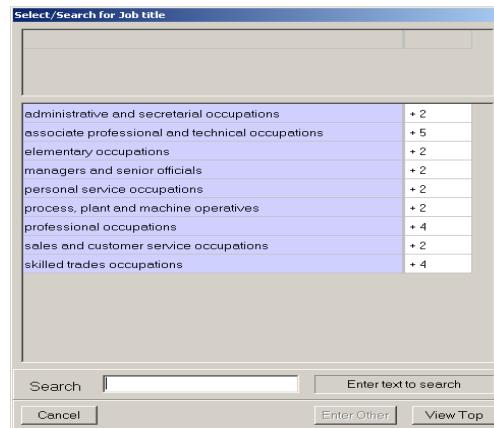
Below are some additional notes that helped the interviewers to code job titles.

- Some occupations are coded to the type of establishment in which they are employed: e.g. teachers are coded across the range from primary school to higher education establishments (such as universities);

- In most cases there is a keyword and a qualifying word or industry for an occupation (e.g. Clerk, wages or Clerk (law courts)). In both cases Clerk is the key word, the qualifying word and industry are wages and (law courts).

- Some occupations are listed alone with no other descriptions (e.g. cartoonist, coastguard).

- In some cases having professional qualifications determines the job title assigned. This applies in the main to engineers, but this information may also be useful in other cases if a choice of job titles is offered (e.g. accounts or legal profession).

- There may be more than one way to describe an occupation. A person who works behind a bar may be coded as: attendant (bar), barmaid, barman, barperson, helper (bar), worker (bar). All of these have the same code (9225), so there may be several options to arrive at the correct code.

- Civil service workers have their own codes according to grade and then department in brackets (e.g. Band 7 (Customs and Excise), Band G (Welsh Office), LOII (DSS)), so it is useful to ask a civil service worker what their grade and department is.

8.4: After completing this part of the interview, the participant is informed that they will now take the first of two measurements of blood pressure (please see the accompanying documentation for blood pressure for more details).

9. Interview (part two): cancer

9.1: On the interview's screen will be a box that tells them if the participant has answered in the touchscreen questionnaire that they have been told by a doctor that they have cancer (or that they are not sure). It will state either that the touchscreen questionnaire provided no data or that data is required.

If data is required, the interviewer asks: "*In the touch-screen you selected that you have been told by a doctor that you have cancer, could you now tell me what type of cancer?*"

The interviewer, clicks on the **Record Cancer** button and each type of cancer is coded according to a tree structure.

If no data is required, the interviewer checks with the participant that this is the case.
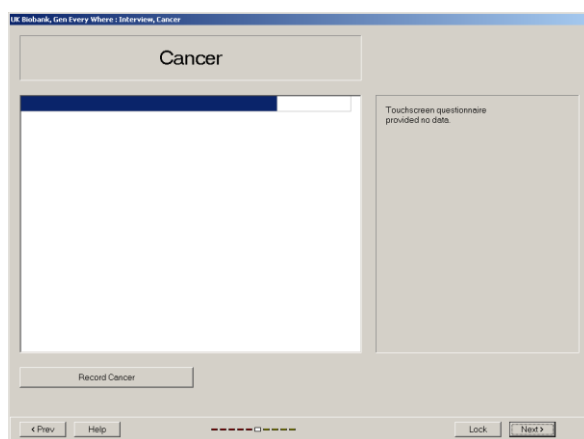
9.2: The stems for the tree are system-based so, for instance 'oesophageal cancer' can be found under 'Gastrointestinal system'. A '**Search'** facility can also be used to find the cancer (but this system works by matching by letters, so searching under 'Gastric cancer' will not provide a match for 'stomach cancer' in the tree). The Cancer tree is based on very simplified ICD-10 coding. It generally does not include histopathological diagnoses or specific anatomical locations (e.g., breast cancer is not split up into areola/nipple, upper-inner quadrant, axillary tail etc.). Rare cancers are not listed and required free-text entry, which was subsequently coded by medical-trained UK Biobank staff.

9.3: For each cancer entered, the interviewer is asked to enter the date of the **first** diagnosis using a pop-up screen that entry of the year or the age of cancer diagnosis, depending on the participant's response. The pop-up screen uses the participant's date of birth to determine what their age was in each year.

If the participant cannot recall the date but can give an approximation, it is preferable to provide an estimated date rather than enter **Unknown**. For instance, if the participant can only estimate they had an event in their 'early 20's', then 21 or 22 years old is entered. Only the age/year of the first cancer diagnosis is recorded (i.e. recurrences of the same cancer nor occurrences in multiple site [e.g., breast cancer in both breasts] were not recorded).

9.4: Once a cancer site has been selected it is listed on the screen. If a cancer is selected incorrectly, it can be removed by simply selecting it again and a prompt appears confirming if it would like to be removed.

9.5: If the participant has not been diagnosed with cancer, the interviewer clicks **Next**.

10.   Interview (part two): other illnesses

10.1: On the interview's screen will be a box that tells them if the participant has responded in the touchscreen questionnaire (or if they were not sure) that they had been told by a doctor that they have one or more of the following illnesses: heart attack, angina, stroke, high blood pressure, blood clot in leg (DVT), blood clot in lung, emphysema/chronic bronchitis, asthma or diabetes. These will already be selected in the illness tree.
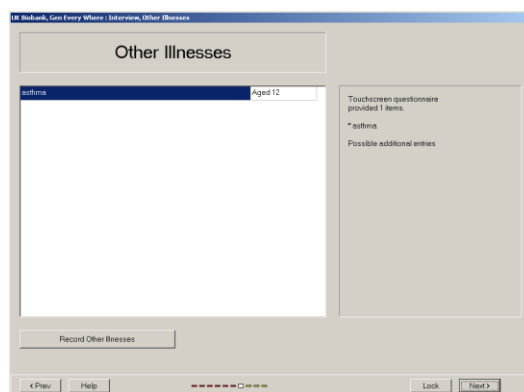
If data is required, the interviewer asks:

"In the touch screen you selected that you have been told by a doctor that you have other serious illnesses or disabilities, could you now tell me what they are?"

If no data is required, the interviewer checks with the participant that this is the case.

10.2: To record an illness, the interviewer selects the **Record other illness** button to bring up a tree structure similar to the Cancer tree (i.e. organized by system and loosely based on ICD-10 codes). For each illness entered, the interviewer records the date of the **first** diagnosis using the same pop-up screen displayed in the Cancers question. If the participant cannot recall the date but can give an approximation, it is preferable to provide an estimated date rather than enter **Unknown**. If the illness cannot be found in the tree, then **Enter Other** is chosen and it is typed in the free-text option.

10.3: If during the interview it appears these have been incorrectly selected, the responses can be removed by clicking on the illness.

10.4: If the participant has not been diagnosed with cancer, the interviewer clicks **Next**.

11.   Interview (part two): Operations

11.1: On the interview's screen will be a box that tells them if the participant has answered in the touchscreen questionnaire that they have had major operations (or that they are not sure). It will state either that the touch-screen questionnaire provided no data or that data is required.
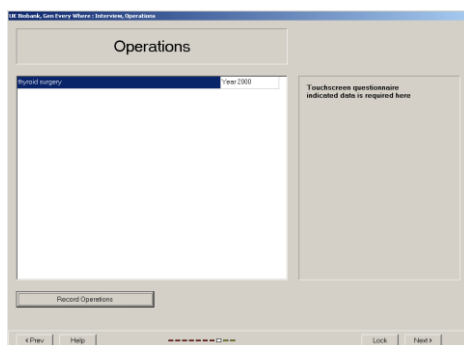
If data is required, the interviewer asks: "*In the touch screen you said that you have had a major operation. Could you now tell me what the operation was?*"

If no data is required, the interviewer checks with the participant that this is the case.

11.2: Women will already have been asked about hysterectomy and bilateral oophorectomy in the touch-screen questionnaire and if this was selected it will appear on the operation list. If during the interview it appears these have been incorrectly selected, the responses can be removed, by clicking on the illness. A pop-up box will then prompt the interviewer if the entry is to be removed.

11.3: To record an operation, the interviewer selects the **Record Operations** button to bring up a tree structure similar to the Cancer tree (i.e. organized by system and loosely based on ICD-10 codes). The search facility is used by entering at least 3 letters of the operation type in the 'Search' box, which are then matched with letters anywhere in names included in the operations tree. This may not provide a match because a different name is used in the operations tree, in which case alternative names for the operation type are tried.

For **each** operation entered, the interviewer records the date using the same pop-up screen displayed in the Cancers question (either the participant's age or year at the time of the operation are specified, giving an approximation if the participant cannot recall the exact age/date). If the participant cannot recall the date but can give an approximation, it is preferable to provide an estimated date rather than enter **Unknown**. If the operation cannot be found in the tree, then **Enter Other** is chosen and it is typed in the free-text option.

11.4: Participants may choose to give the interviewer their entire operative history and this is understandable as a "major" operation means different things to different people. The interviewer is trained to find the best match for many minor operations such as removal of skin lesions (this would be entered as Skin operation). **NOTE:** Information about operations may be used in detecting important conditions that might otherwise be missed (e.g. it is checked whether removal of a skin lesion, or some other kind of biopsy, was done for cancer), which is then recorded explicitly by going back to the relevant screen.

11.5: If the participant has not had an operation, the interviewer clicks **Next**.

## 12.   Interview (part two): prescription and over-the-counter medicines

12.1: If the participant indicated in the touchscreen that they were taking any of the following classes of medications: blood pressure lowering, cholesterol lowering, hormone-replacement therapy or oral contraceptive pills, then these will already be listed in the **Current Treatments** box. The interviewer is asked to record the name of the medication within the class. In addition, if the participant indicated in the touchscreen that they were taking particular common over-the-counter treatments (such as aspirin, ibuprofen etc.), these will also be listed. It will state either that the touch-screen questionnaire provided no data or that data is required.

If data is required, the interviewer asks: "*In the touch screen you said you are taking regular prescription medications. Can you now tell me what these are?*"

If no data is required, the interviewer checks with the participant that this is the case.

12.2: Information about regular prescription medications should include any regular treatments taken weekly, monthly or 3 monthly (e.g., depot injections). Short-term medications, such as a 1 week course of antibiotics for an infection or analgesics taken 2 days ago for a migraine, should not be included. Information only on prescription medication that is actually taken is recorded (if the participant has had something prescribed but does not actually take the drug, it is not entered). Medications they have recently stopped taking are not recorded. Over-the-counter medications, vitamins and supplements are collected in the touchscreen questionnaire. This information is not collected again, unless for some reason the participant has forgotten to record it in the touch-screen.

12.3: To enter a medication, the interviewer uses the **Search** facility, by entering at least 3 letters of the generic or trade name of the treatment in the 'Search' box, which are then matched with letters anywhere in names included in the treatment list. A list of possible matches will appear and a match is selected by double-clicking on the treatment; it will then appear in the **Current Treatments** panel. Both generic and trade names can be used to search for treatments. Preparations that are not available in Britain will not be listed and will have to be entered using the free-text option in the **Unlisted** button.
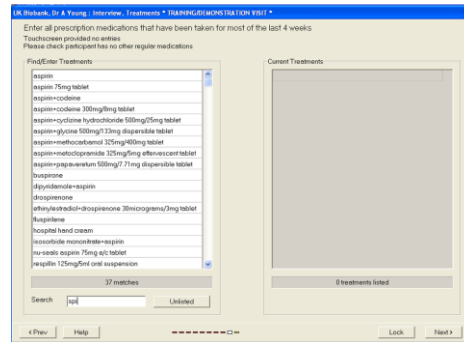
12.4: The current treatment list provides some doses and formulations. For the purpose of UK Biobank, this additional information was not collected. Therefore an entry of 'aspirin' is sufficient even though the list presented will include 'aspirin EC – enteric coated', different dose formulations, dispersible or non-dispersible tablets. Participants were not asked to include doses on their aide-memoire. If the participant has the trade name and dose, the dose information was ignored and the lowest dose entered that was displayed.   If a participant is taking a trial drug, as they may not be certain what this contains, then 'Trial drug' is entered as free-text in the **Unlisted** facility.

12.5: If medication was incorrectly entered on the touchscreen, the entry can be removed by clicking on the medication name.

12.6: On completion, the **Current treatment** box is checked to ensure all the treatments are entered.

12.7: The final screen displays a summary of the data recorded and allows the interviewer to go back and complete any details that appear to be missing or incorrect. The interviewer also checks with the participant that it is correct.

12.8: The 'Next' button is selected to move to the measurement of arterial stiffness and the second blood pressure measurement.

13.   References

1. Office for National Statistics (2000): http://www.ons.gov.uk/about-statistics/classifications/archived/SOC2000/index.html (accessed 09/05/2011)

2. NHS Data Model and Dictionary Service (2011): http://www.datadictionary.nhs.uk/web_site_content/supporting_information/clinical_coding/international_classification_of_diseases_%28icd-10%29.asp?shownav=1 (accessed 09/05/2011)

14   Appendix: Supplementary notes on the interviewer questionnaire

14.1: Data Privacy

There is an automatic lock-out for the interviewer questionnaire if there is no action on the screen for 5 minutes. After that time, the staff member needs to log in again by re-entering their username and password.

Similarly, if required to leave the interview, there is a 'Lock' button on the bottom right hand corner of the screen. This locks the interview until an authorized person can recommence the interview with their ID and password.

14.2: Navigation between questions and screens

After completing a screen, the '**Next'** key on the bottom right hand side of the screen moves to the next screen of questions. The interview program will not allow you to move forward to next screen until all information required on displayed screen has been provided. Questions on previous screens can be altered by navigating back with the '**Prev'** button.

The question for which information is next required will be highlighted on the screen (with all other questions faded). After a question is answered the program automatically proceeds to the next question, except when multiple answers are possible (e.g. list of illnesses or treatments). In the latter case, either information is entered on the next question or the 'Return' key on the keyboard is pressed to proceed.

After answering all questions on a screen they will be displayed for checking. If an answer needs to be changed, a click on the mouse causes either the appropriate pop-up box to appear or the response to change. (Note: For some questions, changing the response may result in additional questions being displayed that need to be answered in order to complete the screen.)

14.3: Links to touch screen questionnaire

The following interview questions are linked to the touchscreen questionnaire:

Touch screen question	Interviewer question
Where were you born?	If participant selected England, Scotland or Wales on touch screen, they will be asked their residence at birth. If 'Elsewhere' was selected they will be asked their country of birth.
Which of the following describes your current situation? (question on employment situation)	If participant indicated they are currently employed, recently retired or self-employed on touch screen, they will be asked their current/last main job title.
Has a doctor ever told you that you have had cancer?	If participant selected 'Yes' or 'Unsure' touch screen, system will prompt to ask what kind of cancer and age/year of diagnosis.
Have you had any major operations?	If participant selected 'Yes' or 'Unsure' on touch screen, system will prompt to ask what type of operation and age/year done.
Has a doctor ever told you that you have any other serious medical conditions?	If participant selected 'Yes' or 'Unsure' about 'Other serious medical conditions' on touch screen, system will prompt to ask what conditions and age/year of diagnosis.
Has a doctor ever told you that you have had any of the following list of various common serious medical conditions (i.e. heart attack, stroke, angina, etc.)?	Their touch screen responses to the specific questions on common serious medical conditions will be displayed on the interview screen so that you can confirm them and ask more details about these key conditions.
Do you regularly take any prescription medications?	If participant selected 'Yes' or 'Unsure' on touch screen, system will prompt to ask about their prescription medicines.