HEALTH AND LIFESTYLES OF PEOPLE AGED 50 AND OVER

P2158/P8158 ELSA WAVE TWO NURSE VISIT

PROJECT INSTRUCTIONS

FINAL VERSION

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ABOUT THE STUDY

1.1 Background and introduction to the study

ELSA is a relatively new longitudinal survey and is designed to explore many aspects of older people's lives. As a result, it gathers information about various aspects of respondents' health, economic and social circumstances. The first wave of ELSA, whose field name is 'health and lifestyles of people aged 50 and over', went into the field in 2002 and involved field interviews with more than 12,000 respondents in over 7,000 households. The second wave introduces a nurse visit as well as an interview.

Although there are some exceptions (which will be discussed later), the great majority of our sample have already been interviewed by NatCen on two previous occasions: first as part of the Health Survey of England (HSE) from which we drew our ELSA sample, and then for the first wave of ELSA. Now we will be asking respondents to take part in ELSA for a second time, so this is a particularly important moment in establishing a long-term commitment to the study. We hope to continue to revisit respondents at least every two years so that we can learn how people's lives change into the future.

Over time, the study will allow us to explore many questions, for example:

- How does people's health and level of disability change over time?
- What explains who has good health in later life and who does not?
- When do people retire and how do they plan for their retirement?
- Do people have enough savings to provide for their older age?
- How do people's activities, relationships and quality of life change over time?
- What is the relationship between these different factors?

ELSA is modelled on a similar study in the US (the Health and Retirement Study). A parallel study is being developed in Europe, the Survey of Health, Ageing and Retirement in Europe (some of you will know that NatCen helped with its development). There are also plans to develop similar studies in many other countries of the world, e.g. Canada, Ireland and elsewhere, so ELSA can be seen as part of an international effort to understand ageing and what it means for people. As a result, we will be able to compare experiences across countries and understand how national policies and contexts affect people's lives.

So far, our funding covers two waves of data collection: the survey held in 2002 and the 2004 survey which we are conducting now. Half of the research budget has been provided by the US National Institute on Aging who also fund the Health and Retirement Study mentioned earlier. The remaining funding for the study has been provided by a consortium of UK government departments (Department of Health, Department of Work and Pensions, Office for National Statistics, Department of Environment, Transport and the Regions, Department for Education and Skills, Department of Culture, Media and Sport and HM Treasury).

The study is being carried out by a collaboration between the National Centre, the Department of Epidemiology and Public Health at University College London

(UCL), the Institute for Fiscal Studies (IFS) and academics from Cambridge and Nottingham Universities. The principal investigator in the research team is Professor Sir Michael Marmot, Head of the Department of Epidemiology and Public Health and Director of the International Centre for Health and Society, UCL.

All aspects of the survey, nurse visit and study procedures were piloted in August 2003, and in January 2004.

You (and respondents) can find out more about the study at www.natcen.ac.uk/elsa/. Results from the first wave of ELSA fieldwork were released in December last year. A newsletter summarising the findings was sent to all Wave One respondents and to respondents to this year's pilots. Please read the newsletter, which is included in your packs. The full report of the results of Wave One is available at: www.ifs.org.uk/elsa/. However, you should not give this address to respondents. They will be able to view the report via the NatCen website.

1.2 Summary of the survey design

There are two parts to the survey: an interviewer-administered interview and a visit by a nurse to carry out measurements. Co-operation is entirely voluntary at each stage. Someone may agree to take part in the interviewer stage, but decide not to take part in the nurse visit stage. Since a nurse visit is new to ELSA, we do not know how respondents will react to the nurse stage. However, since many of the respondents have taken part in HSE in the past, most will have been asked to participate in a nurse visit previously, and many will have taken part. The results from the HSE and the Wave 2 pilots suggest that most respondents are willing to take part in the nurse visits and find them a positive aspect of the study.

The interviewer and nurse assigned to a survey point will work together as a team.

An advance letter is sent to each selected address briefly explaining the survey and its purpose. Two other information leaflets given out by the interviewer and the nurse provide the respondent with greater detail.

Fuller details of the sample are given in Section 2. See Sections 4, 5 and 7 for information about associated documents.

1.3 The interviewer visit

Interviews are administered using Computer-Assisted Personal Interviewing (CAPI).

For each household there is a short **Household Questionnaire** that establishes who is resident and collects some basic facts about them and the household. For each selected individual respondent there is an **Individual Questionnaire**, which covers a range of issues including physical health, mental health, economic circumstances etc, and includes a short self-completion section. It is a very long interview, lasting an average of one hour and 45 minutes per person. In effect, this means that in one person sessions, the personal interview takes, on average, one hour and twenty-five minutes. In two-person (concurrent) sessions, they take an average of two hours and five minutes. The length of interviews varies and some respondents will have received very long personal interviews before you visit.

At the end of the interview, the nurse visit is introduced and the interviewer either arranges an appointment for the nurse to visit a few days later or tells the respondent that the nurse will telephone them to arrange the visit.

There are five documents that interviewers give to respondents that you may encounter. The interviewer should have dealt with most of the issues about these documents and so in most cases you will not have to do anything. However, in a small minority of cases the respondent may ask for your help with them. If you send any documents back to the office please make sure that they have the correct serial numbers and person numbers written on them.

- 1. Interviewer self-completion (**blue**) Half the respondents will be left with the self-completion questionnaire to fill in after their interview (the other half will complete it during the interview). Most respondents will post these back to the office themselves but if they give it to you, please post it back with other documents but NOT with the NRF.
- 2. Cheque letter (**white**) We are giving respondents a £10 cheque at the end of their interview. If they have any problems please tell them to telephone the office.
- 3. Reminder consent form for links to administrative data (**orange**) This form is just to remind respondents about the consents they gave us at Wave One. It is for them to keep.
- 4. New consent form for links to administrative data (**yellow**) Some respondents may have been left this form to think about. If they have filled it in then please check it is complete and return it to the office (NOT with the NRF). They should keep the white carbon copy.
- 5. New consent form for linkage to NHS register (pink) same as above.

In the very unlikely event that a respondent wants to withdraw their consent for links to administrative data they should write on a piece of paper (or their copy of the consent form):

- their serial number, check letter, person number
- their full name and address
- 'I withdraw my consent for NatCen to link my survey data to health and/or financial administrative data'
- their signature and the date.

Please then return this to the office.

At Wave 2 we have introduced an "exit" interview. We will be approaching a close friend or relative of an eligible ELSA respondent who has died since Wave 1 to do an interview about the deceased. The aim of the exit interview is to bring closure to the information collected at ELSA Wave 1. The term "exit" refers to exiting from the study. It is the field name and should not be used when discussing the interview with respondents.

1.4 The nurse visit

All **core** sample members are eligible for a nurse visit, except for those conducted by proxy. A nurse will be allocated to each sample point to work with the interviewer.

The nurse should telephone the respondent in ALL cases before the visit in order to arrange or confirm the appointment and to discuss preparation for the visit.

The nurse visits the respondent in their home in order to carry out a series of measurements:

- blood pressure
- grip strength this is a measure of upper body strength, during which the respondent is asked to squeeze a grip gauge up to three times with each hand
- blood samples fasting if possible
- standing height
- sitting height
- weight
- waist and hip measurement
- lung function this is a measure of how much air respondents can blow out from their lungs, and is measured using a spirometer
- balance respondents are asked to stand in three different positions for up to 30 seconds
- leg raise respondents under 70 years old are asked to lift one foot off the ground for up to 30 seconds
- chair rises this is a measure of lower body strength, during which respondents are asked to stand up from a firm chair without using their arms. If they succeed, they are asked to stand up and down as quickly as they can for either five rises if they are aged 70 and over, or up to ten rises if aged 69 and under
- saliva samples.

If a cause for medical concern is identified during the nurse visit then the respondent's GP will be notified (if the respondent gives prior permission).

Four of the measures we will be taking are *physical performance measures*: grip strength, balance measures, leg raise and chair rises. Taken together with the gait speed (or timed walk) measure which is carried out during the personal interview, these performance tests provide a very good measure of the respondent's physical well-being and are an excellent way of tracking change in health over time.

1.5 Self-completion at end of nurse visit

A respondent in one in ten households will be asked to compete a self completion questionnaire about their personal beliefs and well-being. This is in addition to the main self-completion that all respondents (except proxies) will be asked to complete during or after the personal interview. The nurse visit questionnaire is about how respondents feel about themselves and their lives. It takes the form of 43 statements which the respondent is asked to agree or disagree with. Completion of this additional booklet is entirely voluntary. As with a CAPI interview, if the respondent is unwilling to answer all these questions, please encourage them to answer the ones they are happy to answer. Please ensure you take a questionnaire to all nurse visits as you won't know if you'll need it until you are prompted at the end of the CAPI to give it to the respondent.

The aim of using the experimental questions (designed by Carol Ryff) in this questionnaire is to help us determine whether a standard measure of mental health

can be successfully included in ELSA without respondents being overloaded, or feeling that questions we ask are repetitive.

1.6 Survey materials

The following is a list of documents and equipment you will need for this survey. Before starting work, check that you have received the following supplies.

Document Colour Yellow Nurse Record Forms (NRFs) Nurse Record Forms B (NRF Bs) Peach Sample Summary Sheet White Interim appointment record form Orange Consent Booklet - nurse Pink Consent Booklet - respondent Green Grip strength measurement card Orange Survey Leaflet Blue Nurse leaflet Lilac Copy of Genetics leaflet Green Measurement Record Card for respondent Lilac Frankfort plane card White Self completion - Personal beliefs and well being Lemon Copy of appointment record card Orange Broken Appointment Card White Saliva log book White Barcode labels White Protocol card for Balance Measure and Leg Raise White Protocol card for Chair Rise and Grip Strength White Stopwatch instructions for split time White

Equipment

The equipment that is required for this project is as follows:

- Insertion tape
- Spirometer, cardboard mouthpieces
- Thermometer and probe
- Stadiometer
- Scales
- Stopwatch
- Omron, cuffs
- Gripometer
- Blood equipment
- Saliva equipment

The equipment is described in more detail later in the sections on the measurement protocols.

You will receive new ELSA equipment which will be sent out to your home addresses from Brentwood.

2 SAMPLE INFORMATION

2.1 Sample source

The sample for ELSA was originally drawn from the Health Survey for England (HSE). The HSE is a study conducted jointly by the Department of Epidemiology and Public Health, UCL, and the National Centre for Social Research, on behalf of the Department of Health. The major advantage of the HSE sampling source is that extensive data had already been collected about respondents' health (details of morbidity, lifestyle, diets and blood samples).

The Wave One mainstage sample was selected from three separate years of the HSE (1998, 1999 and 2001) to provide a large, representative sample of the English population aged 50 or over living in private households. Most of the sample were interviewed and had a nurse visit, which included many of the HSE biomedical tests that you know about. They were then interviewed for ELSA between April 2002 and March 2003.

The ELSA sample was issued at a **household** level. Almost 60 percent of households in the sample at Wave One had two people eligible for an ELSA interview while the remaining 40 percent had just one. In other words, in almost all cases there are one or two individuals eligible for interview. In a very small percentage of households there were three or more individuals eligible for interview.

2.2 Sample definition

There are three different types of respondents who are eligible to take part in the study:

Core Sample Member (CM)

• Someone born on or before 29th February 1952 who was living within a household which took part in HSE 1998, 1999 or 2001 at the time of the HSE interview and was still living in the household sector within England when they were visited at Wave One. They also took part in Wave One of ELSA.

Young Partner (YP)

• A cohabiting spouse or cohabiting partner of a sample member who was living within a household which took part in HSE 1998, 1999 or 2001 at the time of the HSE interview. All Young Partners were born AFTER 29th February 1952 (since if they had been born on or before 29th February 1952 they would be core members). This means that most of them were aged under-50 when we attempted to interview them at Wave One (though some may have turned 50).

New Partner (NP)

• Someone who is the cohabiting spouse or cohabiting partner of a sample member at the time they are interviewed who either

- (a) joined the household since the HSE (many of whom were interviewed at Wave One) **NP1s**, or
- (b) joined the household since the ELSA Wave One interview **NP2s**. New Partners can be of any age.

Core Partner (CP)

Someone who was living in the household at HSE and was born on or before 29th
February 1952 but did not take part at Wave One because they refused or were
away. They are still eligible to take part because they are a partner of a core
member who took part at Wave One.

Only core sample members are eligible for a nurse visit. The interviewer will explain this, but you may need to confirm to spouses or partners that they are not eligible for a visit.

2.3 Sample information

The sample will be issued monthly. There will be eight monthly periods named EL1 to EL8. The point sizes will vary. Nurses will have the month plus a 3-week mop-up period (interviewers will stop interviewing one week earlier).

Serial numbers

The household serial numbers (serialW2) have 9 digits, and the individual serial number has 11 digits (the 9 digits from the household number, plus 2 digits for person number).

Address and information labels

There are TWO NRF labels. The first gives you the serial number, check letter, issue month, point number, household address, telephone number (where available), date of last interview, and ELSA wave 1 household outcome code.

The outcome codes are as follows:

"110 Fully prod:per" – fully productive household, all interviews in person "120 Fully prod: per/prxy" – fully productive household, at least one interview by proxy

"210 Partially prod" - partially productive household

Label format:

SERIAL ISSUEMTH POINT
ADDR1 ADDr2
ADDr3 PCODE
TELE
Date of last interview Wave 1 HH outcome

Example:

SN:19997000111 G PT:23

45 River Close
Earswick
York
N Yorkshire
YO32 9PY
0113 555678

Tues 14 May 2002

The second NRF label lists the field area, all the names of the sample members in the household, their person numbers, date of births (where available), their sample type (indicated as being either core members (CM), young partners (YP) or new partners (NP)), and their interview status at Wave 1. The interviewer will tell you of any changes to any of the household information when they phone you. There is a space on the NRF for you to note down any important bits of information from them.

Past interview outcome status is identified on the label in the following way:

- INT if the respondent did an ELSA interview, or if the household was not issued at ELSA Wave One and the respondent did an HSE interview and agreed to be re-contacted for a health survey.
- P.INT if the respondent did an ELSA interview by proxy.
- NOT INT where no individual ELSA interview was conducted, or no HSE interview was conducted if the household was not issued at ELSA Wave One.
- REF if they did a Wave one interview and did *not* agree to be re-contacted.
- DECEASED if we know from administrative records that the individual has died.

Label format:

SERIAL CKL Field area

PERSON No. Title Name Surname Type DoB W1Outcome

PERSON No. Title Name Surname Type DoB W1Outcome

Example:

SN:122222211 X FA: 3

01 Mr George Brown CM 1/10/1936 Int

02 Mrs Winifred Brown CM 21/11/1932 Int

3 NOTIFYING THE POLICE

The interviewer with whom you will be working will notify the police about the survey and inform them that the two of you will be working in the area. Your interviewer partner will need to collect some details about your car so that (s)he can fill in the necessary details on the letter to be left with the police. Hopefully s/he will have already contacted you.

You can then tell respondents that the police know all about the survey. Some respondents find this very reassuring, and some will telephone the police to check that you are a genuine survey worker before agreeing to see you.

4 LIAISING WITH YOUR INTERVIEWER PARTNER

You and your interviewer partner will need to work very closely together, so a good working relationship is essential. **The interviewer has been told to make contact with you to set this up before they begin interviewing respondents.** (See Appendix 1 for a summary of this procedure).

The formal lines of communication between you and your interviewer are described in the next section. The informal lines are equally important. An important part of the interviewer's job is to keep you fully informed about the outcomes of all his/her attempts to interview people, whether or not they are productive. We want to minimise the length of time between the interview and your visit. You will therefore need to talk to each other frequently by telephone. Make sure you let your interviewer know the best times to get in touch with you.

Your interviewer has been given an **Appointment Diary** covering the relevant survey period. You should go through this together before you start work.

You should decide together with the interviewer how you are going to make appointments for your visits, i.e. if the interviewer is going to make them for you or if you are going to make them with the respondent by telephone after the interview.

If the interviewer is going to make the appointments for you, let him/her know the days and times on which you are available to see respondents. Make sure you keep a careful note of the times you give her/him. You will need to liaise frequently in order to update this information. **Never** put the interviewer in the situation where (s)he makes an appointment for you in good faith, only to discover you have a prior commitment. Give the interviewer as much flexibility as possible for making appointments. People lead very busy lives nowadays. They are doing something to help us and may not give it the greatest priority.

The interviewer has been asked to give you good warning of all appointments made for you. Make sure the interviewer knows the best times to reach you by telephone. If you want more than two days' notice, tell the interviewer so that she/he can phone through other appointments too.

If you are making the appointments yourself then it may also be helpful for you to give the interviewer a rough idea about your availability so that he/she can let the respondent know.

The interviewer will do everything possible to provide you with an even flow of work and to minimise the number of visits you have to make to an area, but this will be limited by respondent availability. Discuss with the interviewer the time you will need to travel to the area so that he/she can take account of this. Plan together how best to make this appointment system work.

You may also wish to discuss practical details such as parking arrangements.

Where possible, you should be able to see all eligible core sample members in a household one after the other on the same visit. Each visit we expect will take around 1 hour per person. You will of course also need some time to introduce yourself to the household and generally set up equipment. The duration of the visit is likely to vary slightly from nurse to nurse and with respondents of different ages.

Information about each household and details of any appointments that have been made will be passed to you by the interviewer by telephone, and the interviewer-nurse link will also be established. The interviewer will complete each NRF for you, and send on when completed. **However, they will also phone through after each**

interview as well. You will have a Nurse Summary Sheet detailing all the households that have been issued in your area and where nurse visits may be required. Please use this to keep an eye on how your cases are going.

4.1 Nurse Summary Sheet

You will have a nurse summary sheet detailing all the NRFs that you should expect to receive from the interviewers. Please keep this near to your telephone, along with interim appointment record forms. Each time an interviewer phones through an appointment to you, you may wish to open an interim form and complete as directed.

At the end of your assignment, if there are any households for which you have not received a NRF, please call the interviewer to check what the outcome was on those addresses – it is likely that they were not covered by the interviewer, and this information will be useful to us.

The nurse summary sheet has the following information:

- Point number.
- Serial number, address and telephone number of each household.
- Names of those people eligible for nurse visit at point of issue.

For each household you will need to enter:

- The date you received the details from the interviewer
- The outcome for the household:
 - A At least one person agreed to the nurse visit
 - B Eligible respondents were identified but no nurse visit was required
 - C The interviewer did not identify any eligible respondents for the nurse visit
- The date of your appointment and the number of people you measured
- The date(s) you posted the documents back and transmitted the data

4.2 The Nurse Record Form (NRF)

Interviewers are required to complete a Nurse Record Form (NRF) for each issued address (regardless of whether a nurse visit is required).

The Nurse Record Form is both the interviewers' and your responsibility. The interviewer will complete the first two pages. It is your responsibility to fill out the other pages.

On the grid on page 2 the nurse visit status will either be 1, 2 or 3. **Contact only those persons for whom** <u>code 1</u> has been indicated – these are the household members who agreed both to be interviewed <u>and</u> to see you. Code 2 indicates the person was interviewed but refused to see you. Code 3 indicates the person could not be interviewed (they were mentally incapable, refused, etc). In the column to the left of each person's name is their **Person Number**. Whenever you enter a serial number for that person you must use this and <u>only</u> this Person Number.

Occasionally you will find that someone in the household with code 2 (Refused nurse) or code 3 (No interview) decides they want to co-operate after all. If they are code 2 (i.e. refused nurse visit) you **can** take the measurements, as these people have

already completed a full interview. Make a note on the NRF explaining what has happened. If they are code 3 (i.e. not interviewed) you **cannot** take any measurements. Under no circumstances must you measure an individual before an interviewer has completed a full interview on CAPI. Some people in the household may have been interviewed by the interviewer but are younger partners or new partners and so are not eligible for a nurse visit (these people will be indicated on your NRF labels). It is not advisable to conduct any measurements for these people, however, if you feel it is appropriate and safe you may conduct some measurements (e.g. height, weight, physical performance) for them if they adamantly want them, as a gesture of good will. Record what action you took on the NRF, but do not record the information in the CAPI.

You should complete the rest of this form as you begin contacting the address:

- Enter the calls record as normal at question 8.
- Enter the outcome code for all eligible for nurse visit at question 9.
- Enter the reason for refusal at question 10 (very important for us to understand).
- Enter details of broken appointments and other unproductives at question 11.
- For all productive households enter the number of consent booklets obtained, and whether you left any self completions at question 12.
- Code the final household outcome code at question 13, and transfer it to the box on the top right of the front page of the NRF.

If there was more than one sample member in the household and one of them has moved to a different address then the interviewer will trace the person who has moved and, if it is in their area, they will attempt to interview them at their new address. In these cases the interviewer will open a 'NRF B' and will send you a NRF B in the post. In the CAPI program this new household will have the same serial number as the first household but with a '2' at the end rather than a '1'. The peach NRF B is almost identical to the yellow NRF. The only difference is that it won't have NRF labels on the front so the details of the sample members will be written on by the interviewer. You will not be issued with new barcode labels for the person who has moved so use the same ones you were issued with. You may want to cross through the address on the top left of the sheet for your information.

Return completed NRFs and NRF Bs to the office.

See Section 10.1 for more details about the NRF and how to complete it.

4.3 The interim appointment form

It is possible that you or the interviewer will set up appointments earlier than the NRF can arrive and before the information is transferred across the link. In these cases you will need to complete an interim appointment form. The interviewer will tell you the following information that you will need to write on to this form.

Complete the following details on page 1:

- Enter the household serial number, name, address, and telephone number.
- Enter the date the information was phoned through by the interviewer, and the date of the household interview.
- Write any additional useful information (e.g. parking information).

Complete grid on page 2 for each respondent eligible for a nurse visit:-

- enter their Person Number
- enter their full name and title (eg Mr. John Anderson)
- circle a code to indicate their sex (1= male, 2=female)
- enter their age at the date of the Household interview
- enter nurse status:
 - ring code 1 if that person agreed to see the nurse
 - ring code 2 if that person refused to see the nurse
 - ring code 3 if that person was not interviewed no visit needed
- enter the appointment date and time (if appropriate)

Always make sure you **read back the person number and name** to the interviewer so that you are both sure the information has been transferred correctly, and check against your nurse summary sheet. It is essential that this part of the process is completed successfully.

5 WHAT THE RESPONDENT KNOWS ABOUT YOUR VISIT

The interviewer introduces your visit at the end of the interview by reading out the following:

There are two parts to this survey. You have just helped with us with the first part. We hope you will also help us with the second part, which is a visit by a qualified nurse to collect more medical information and carry out some measurements. (I would like to make an appointment for the nurse to come round and explain some more about what is required. May I suggest some dates and times and see when you are free?)

The box below shows the general points given to interviewers to help them answer questions about your visit.

Information you may need to know if the respondent asks you questions about the

nurse visit

- It is an integral part of the survey the information the nurse collects will make the survey even more valuable.
- The nurse is highly qualified (Grade E or above). They have all had extensive experience, working in hospitals, health centres etc, and have also been especially trained for this survey.
- If the respondent wants, they will be given the results of the measurements carried out by the nurse. If they like, this information will also be sent to their GP.
- They are <u>not</u> committing themselves in advance to agreeing to everything the nurse wants to do. The nurse will ask separately for permission to do each test so the respondent can decide at the time if they do not want to help with a particular one.
- Their local medical ethics committee has been consulted and has given their approval to the survey.

If a person is reluctant, the interviewer is asked to stress that all they wish to do is arrange for you to go and explain what is involved. They point out that by agreeing to see you they are not necessarily agreeing to take part in all, or any, of the tests. We hope your general professional approach will convince nervous respondents more effectively than can an interviewer.

Unlike other studies, all respondents will be aware that they will be invited to give us a blood sample before the nurse visit. There are two reasons for this. Firstly, respondents will be asked to fast (if appropriate) before giving blood and, as you will only be visiting them once, they need to be told about this beforehand. Secondly, two of the blood samples are taken for the purpose of genetics research and so we are are required by law to give respondents enough time to decide whether they want to give consent for their DNA to be extracted from a blood sample you may take.

At the end of the interview each respondent is given an appointment record card describing preparation needed for your visit (see below), and a green Genetics Leaflet which explains the genetics research . The interviewer will also give each eligible respondent a lilac Nurse Leaflet which briefly describes the purpose of your visit.

5.1 Appointment Record Card

The interviewer will give each eligible respondent an orange Appointment Record Card. This confirms the appointment time (if appropriate) and reminds them that we would like them to avoid eating, smoking, drinking alcohol or doing any vigorous exercise for 30 minutes before you arrive. It also asks them to wear light, non-restrictive clothing.

A copy of the Appointment Record Card is in your workpack for your information. You will need to go through it very carefully with the respondent when you telephone them before your visit (see section 6.1).

Since we are asking some respondents to fast for the blood samples, the card also gives information about what they can eat on the day of their appointment. If the nurse visit is before 1pm, the respondents are asked not to eat or drink anything (apart from water) on the day of the appointment. If the nurse appointment is between 1pm and 6pm, the respondents can have a light breakfast of items listed on the Appointment Record Card before 8am but are not to eat or drink anything (except water) after 1pm. If the appointment is after 6pm, they are instructed that they can have a usual breakfast and a light lunch of items listed on the Appointment Record Card before 1pm. They are asked not to eat or drink anything (except water) after 1pm.

If you ask a respondent to fast, you should tell them to drink water during the fast.

6 WHAT TO DO ON INITIAL CONTACT

6.1 Telephoning respondents before the visit

Your initial contact with respondents should be by telephone. You should keep your introduction short and concise. Some of the people you approach may be hesitant about continuing with the survey, and if you say too much you may simply put them off. The general rule is keep your initial introduction brief, simple, clear and to the immediate point. An example of how to introduce yourself on the telephone is given below.

Say who you are:

"I am a nurse called"

Say who you work for:

"I work for The National Centre for Social Research"

Remind respondents about their interview:

"A few days ago you saw an interviewer about the English Longitudinal Study of Ageing and (s)he told you that I would like to come and see you." (Remind respondent of appointment, if already set up by the interviewer).

For most people this will be enough. They will be happy to talk to you about preparations for your visit and all you will have to do is explain what your visit will cover and what you want them to do. Others will be reluctant and need further persuading. Build on what has gone before. Be prepared to answer questions about the survey. Some respondents may have forgotten what the interviewer told them about the survey's purpose or what your visit involves. You should therefore be prepared to explain again the purpose of the study and about your visit. You may also need to answer questions, for example, about how the household was sampled. Some points you might need to cover are shown in the following box.

- who you are working for the National Centre for Social Research (NatCen),
 University College London (UCL) and the Institute for Fiscal Studies (IFS)
- who is funding the study half of the funding is from various government

departments and the other half is from the National Institute on Aging in the United States.

- *why the study is being carried out -* (see Section 1).
- *what you are going to do -* (see Section 1.4).
- *how the respondent was selected* (see Section 2) Once a household has been selected, we cannot replace it with another. Otherwise we would no longer have a proper sample of the population and would not be able to learn about change by following the same families.
- *the confidential nature of the study* individual information is not released to anyone outside the research team.
- *how much time you need* this varies a bit but it is best to allow around 60 minutes for each person plus another 15 minutes per household (to put equipment away and so on).

Only elaborate if you need to, introducing one new idea at a time. Do <u>not</u> give a full explanation right away - you will not have learned what is most likely to convince that particular person to take part. Do not quote points from the boxes except in response to questions raised by the respondent.

Be careful to avoid calling your visit a "health check". One of the most common reasons given for respondents refusing to see the nurse is "I don't need a medical check - I have just had one". Avoid getting yourself into this situation. You are asking the respondent to help with a survey.

If the respondent is willing for you to carry out your visit you will need to go through the appointment record card with them and do the following:

- 1. Confirm or arrange the date and time of your appointment.
- 2. Explain that they should not eat, smoke, drink alcohol or do any vigorous exercise for 30 minutes before your visit.
- 3. Ask them to wear light, non-restrictive clothing and to avoid wearing thick belts or long garments that will prevent you from seeing their feet (this is important for the physical performance measures).
- 4. Find out if they are eligible to have a blood sample taken by asking if they:
 - have a clotting or bleeding disorder
 - have ever had a fit / convulsion
 - are taking anticoagulant drugs (such as Warfarin, protamine or acenocoumarol)
 - (are pregnant).
- 5. If they are eligible to have a blood sample taken then you will need to determine if they are eligible to fast. Respondents will NOT be eligible to fast if they:
 - are aged 80 or over
 - are diabetic and on treatment
 - are malnourished or otherwise unfit to fast in your judgement (One of the
 pieces of information you may want from the interviewer when they
 telephone you after their visit is if the respondent seems particularly frail).

If they are eligible and willing to fast, then you will need to explain the fasting rules (see section 5.1). Emphasise that they can take their medication as normal.

6.2 Being persuasive

It is essential to persuade reluctant people to take part, if at all possible.

You will need to tailor your arguments to the particular household, meeting their objections or worries with reassuring and convincing points. This is a skill that will develop as you get used to visiting respondents. If you would like to discuss ways of persuading people to take part, speak to your Nurse Supervisor (or your Area Manager).

6.3 Broken appointments

If someone is out when you arrive for an appointment, it may be a way of telling you they have changed their mind about helping you. On the other hand, they may have simply forgotten all about it or had to go out for an urgent or unexpected reason.

In any case, make every effort to re-contact the person and fix another appointment. Start by leaving a **Broken Appointment Card** at the house saying that you are sorry that you missed them and that you will call back when you are next in the area. Add a personal note to the card. Try telephoning them and find out what the problem is. Allay any misconceptions and fears. Make them feel they are important to the success of the survey. A chat with your interviewer partner might help. (S)he might be able to give you an indication of what the particular respondent's fears might be, and may have notes that would tell you when would be the most likely time to find the respondent at home. Keep on trying until you receive a definite outcome of some sort.

6.4 The number of calls you must make

You are asked to keep a full account of each call you make at a household on the **Nurse Record Form**. Complete a column for each call you make, include telephone calls to the household as well as personal visits. Note the exact time (using the 24-hour clock) you made the call, and the date on which you made it. In the notes section keep a record of the outcome of each call - label your notes with the call number.

You must make at least **4 personal visits per respondent** before you can give up. Each of these calls must be at different times of the day and on different days of the week. However, we hope you will make a lot more than four calls to get a difficult-to-track down respondent. If you fail to make contact, keep trying.

What you might mention when introducing the study:

- * It is a national study (half funded by the National Institute on Aging and half by the British Government).
- * ELSA is a very important study.
- * It will allow us to understand people's experiences of getting older and how services should accommodate the changing population's needs.
- * It is hoped that interviews will be carried out every two years with a nurse visit every four years (funds are not yet available for Wave 3

- and onwards). However the study remains voluntary and the respondent can make a choice at each occasion.
- * It will provide the government with accurate and up-to-date information on the health of the older population, and an understanding of the relationship to people's economic and social circumstances.
- * The information from the survey cannot be obtained from any other
- * The information is available to all political parties.
- * The information will be needed by whichever government is in office.
- * Results will be published and reported in the national press. Findings will be sent to respondents. No individuals can be identified.
- * The survey covers the whole population, including people who have little contact with the health services as well as people who make more use of them.
- * To get an accurate picture, we must talk to all the sorts of people who are aged 50 and over the healthy and the unhealthy, those who use the NHS and those who use private medicine, and those who like the current government's policies and those who do not.
- * Services for the elderly are very important and without their help in this survey valuable information for planning these will be lost.
- * Each person selected to take part in the survey is vital to the success of the survey. Their household has been selected. No one else can be substituted for them.
- * No-one outside the research team will know who has been interviewed, or will be able to identify an individual's results.

7 CARRYING OUT THE NURSE VISIT

7.1 Who to visit

You can only interview and measure respondents who have completed a full individual interview with the interviewer and who are core sample members. Respondents must have completed this interview **before** you see them.

7.2 *Nurse visit documents*

The Nurse Schedule is on computer (CAPI). As well as the computer schedule, you will use four other documents during the interview itself: the office consent booklet, the respondent's consent booklet, the measurement record card, and the grip strength record card. The Office Consent Booklet contains the forms the respondent has to sign to give written consent for:

- blood pressure readings to be sent to their GP
- lung function readings to be sent to their GP

- blood samples to be taken
- blood test results to be sent to their GP
- blood sample for storage for future analysis
- blood sample for DNA extraction and storage
- saliva samples to be collected

7.3 General tips on use of the documents and computer program

Read out the questions in the Nurse Schedule **exactly as worded**. This is very important to ensure comparability of answers. You may think you could improve on the wording. Resist the temptation to do so. Enter the code number beside the response appropriate to that respondent indicating the answers received or the action you took.

Some questions take the form of an instruction to you to enter something without needing to ask the respondent a question. In most cases these instructions have "NURSE:" written at the beginning of them.

When you get a response to a question which makes you feel that the respondent has not really understood what you were asking or the response is ambiguous, repeat the question. If necessary, ask the respondent to say a bit more about their response.

7.4 Preparing the documents/computer

Before you leave home, you should connect your computer to the modem (separate instructions about this are provided) and pick up any work which is ready for you. To ensure that the information from the interviewer has been transferred onto your computer, you should view the household schedule(s) for the household(s) that you intend to visit on that trip. If the interviewer's information has been successfully transferred, the computer will show you the information about the members of that household, and you can go ahead with that household. If the information has not been transferred electronically, it will ask you if you want to enter the information manually. It is better to wait until the information is transferred electronically, but if you have an imminent appointment, you will need to enter it manually from the NRF or Interim Appointment Record. Entering the data manually will take several minutes, so you should do this before you leave home, or at least before you enter the respondent's household.

If there is a household with two sample members in it and one of them has moved to a new address and the information has not been transferred in time for your visit then you will need to open a NRF B in the CAPI. To do this:

- Go into the address menu and select the original household serial number and press enter.
- Use the 'down' arrow key to highlight the link 'Hhold? [Open new Hhold questionnaire?] and press enter.
- Enter '2' when asked for the household number.
- The check letter will be one higher than for household 1 (ie if it was 'G' for household 1, it will be 'H' for household 2).

When you arrive at the household, you should enter the household schedule and check that it is the right one by looking at the serial number and/or viewing the

information about the household members. You should also check carefully that you enter the respondent's correct serial number on all the documents.

7.5 Introducing your measurement tasks

The interviewer will have introduced your visit, but has been told to give only a brief outline of what it is about. (S)he will have told respondents that you are the best person to explain what your visit is about.

So, at the beginning of your visit before you make any measurements, you will need to explain what you hope to do during your visit and to reassure nervous respondents that every stage is optional.

If the respondent wishes, they and their GPs will be given their blood pressure and lung function readings. If they consent to giving us a blood sample, they will be given the results of the blood test (by letter) and these can also be sent to their GP if they wish.

8 THE CONSENT BOOKLETS

Never prepare the Consent Booklet in advance of your visit. There is a serious danger that you will use the wrong one for the wrong person. It is all too easy to do in the stress of the moment.

Use a blue pen when completing the booklets, and ensure that signatures are always in pen, not pencil. Use capital letters and write clearly. Do not erase any of the personal information. If necessary, cross out errors and rewrite so that any corrections can be seen.

Consent Booklet – Personal Copy: Write the serial number, check letter, person number and name on the front of the booklet.

Consent Booklet - Office Copy: Write the address at which you are interviewing in the box at the top of the Consent Booklet. Stick a serial number barcode in the appropriate box. Be sure you use the correct barcode for the respondent – check their name and date of birth on the sheet of barcode labels. Accuracy is vital.

Enter your Nurse Number at Item 1 and the date on which you are interviewing at Item 2.

Complete Items 3 to 5 <u>before</u> you start using the computer to collect the information from the respondent.

At Item 3 record the **full** name of the respondent. We will be using this to write a thank-you letter to the respondent giving them their test results (if they wish), and to write to their GP (with their permission) to give him/her their test results. The name by which the GP knows the respondent is checked, if appropriate, during the interview. This may, for example, be a maiden name.

Ask the respondent for his/her date of birth and enter this in the boxes provided at Item 5. The respondent may say they have already given it to the interviewer. Explain that you have been asked to get it again as it will help ensure the right documents get put together.

Items 6 to 8 are completed during the course of your interview.

At Item 6 you write in the name, address and telephone number of the respondent's GP, if the respondent gives consent for blood pressure, lung function and/or blood test results to be sent to the GP. If a respondent does not know the name of her/his GP, leave the top line blank (otherwise the computer will send out nonsense letters like *Dear Dr. Ash Grove Practice*).

Fill in the full name and address of the GP on each individual's Consent Booklet for a household, even when all members have the same GP. Each individual is treated separately once they reach the office.

At Item 7 record how complete you believe the GP address to be. If you are sure that a letter posted out of the area to that address would arrive, then ring code 1.

Item 8 is very important. Throughout the visit you record here the outcome of your requests for permission for:

- a) The blood pressure results to be sent to the GP
- b) Lung function results to be sent to the GP
- c) Blood samples to be taken
- d) Blood sample results to be sent to their GP
- e) Blood sample results to be sent to the respondent
- f) Blood sample storage for future analysis
- g) Blood sample for DNA extraction and storage
- h) Saliva samples to be collected

By the end of the interview every respondent should have **EIGHT** codes ringed at Item 8.

There are SEVEN different Consent Forms contained in the Consent Booklets:

- 1 Blood pressure information to GP.
- 2 Lung function results to GP.
- 3 a) Blood sample to be taken.
- **3 b)** Natcen to inform GP of blood result.
- **3 c)** Remaining blood to be stored for future analysis.
- Extraction and storage of DNA for use in future medical research studies.
- 5 Saliva to be tested for cortisol and future medical research studies of causes, diagnoses, treatment or outcome of disease.

The CAPI will prompt you to complete these different consent forms as you go through the nurse schedule. You will be prompted to:

- ask the respondent to read, sign and date the office copy;
- to tick the relevant box on the respondent's personal copy;
- to circle the appropriate consent code on the front of the office copy of the Consent Booklet.

The Consent Booklet also contains a venepuncture check-list and two despatch notes for the blood samples. These are described in section 13D.

9 THE NURSE SCHEDULE

9.1 Organising the interview

Before setting out to carry out any interviews, you must check to make sure that you have received the household information through manual input. You will not be able to conduct the interview without having done this.

You should also have contacted the respondent(s) before visiting the household to establish whether bloods are likely to be taken and whether he/she should fast (see Section 5.1).

When you arrive at the household, before starting to carry out your interview, check whether any of the people you have come to see have eaten, smoked, drunk alcohol or done any vigorous exercise in the last 30 minutes. This could affect their measurements. If someone has done any of these things, arrange to see other members of the household first in order to give time for the effects to wear off. In addition you will be asked by the CAPI to check whether the respondent has fasted for the specified time for the blood test.

Similarly if someone in the household wants to eat, smoke or drink alcohol in the near future (eg one person is going out and wants a snack before they leave) then try to measure that person first. Adapt your measurement order to the needs of the household.

You may feel that if you try to rearrange things in this way, you are likely to lose an interview with someone you may not be able to contact again. In such cases, give priority to getting the interview, rather than rearranging the order.

9.2 *Getting into the Nurse Schedule*

Once you have switched your computer on and entered the keyword, you will see the Project Menu on the screen. The Project Menu will look something like this:

COI	DE PROJECT	PERIOD		
1 2	P8158 P8158	PRACTICE		

To get into the nurse schedule, type in the number next to P8158 without practice written next to it (in the above example, you would type in <2> and press <Enter>). You will then be asked to enter the password for ELSA, which will be given to you at the briefing. This done, you will be taken to the Action Menu, where you should type <I> if you want to enter information.

You will then see the Address Menu, which shows the serial numbers of all the addresses in your sample point, and will look like this (but longer):

		ADDRESS MENU				
Survey: P81	58					
SERIAL	NOTES		STATUS	OUTC	DONE	RET
000001011				00		
000001021				00		
000001031				00		
000001041				00		

Using the arrow keys, move the highlight bar until it rests on the household in question, then press <Enter>. The highlight bar will start off on the first address, which in the above example would be serial number 000001011. If you wanted to work on, say, serial number 000001041, you would press your down arrow three times then press <Enter>.

The next menu you will see is the Household Menu, which, for the example serial number given above (000001041), would look like this:

		HOUSEHOLD MENU	
Survey: P82	158	Area: 000	Addr: 00104
HHOLD	NOTES	STATUS OU	JTC DONE
HHOLD1		3 0	0
HHOLD?	[OPEN NEW I	HHOLD QUESTIONNAIRE]	

Just press <Enter> to get into Household 1.

Then you will get a screen that asks you to enter the check letter, which you will find on the NRF label.

You are now in the nurse schedule and ready to start entering data.

If you want to practice at home before 'going live', at the Project menu you should type in the number next to the P8158 Practice slot (in the above example, this would be number <1>) and press <Enter>. Then follow the instructions as above. Some 'dummy' households have been put into this slot for you to practice on (See Section 9.8).

9.3 Household information

The household information should be checked or completed before making the visit.

The first thing you may be asked to do is to enter the first line of the address.

ScrOut

This screen will be displayed when entering details manually from the interim appointment form.

HHDate

This is necessary to allow the computer to calculate the respondent's age at the time of the interviewer visit, as this is the age that dictates which sections of the schedule apply. You will find this date at Q.3 on the NRF.

Intro - OC

This set of questions will appear if you have to enter this information manually. You will be asked to enter the data found on page 2 of the interim record form, i.e. person number, name, sex, age and outcome of interviewer visit. From this information, the computer will work out how many individual schedules are required, and which questions should be asked of each individual.

It is important that you enter the individuals in ascending order of person number. Otherwise, you will find it very confusing to find your way around the computer program.

More

At the end of the information for each individual, the computer will ask you if there is anyone else who was seen by the interviewer. If you enter 'yes', another row on the household grid will be created for you to complete. If you enter 'no', that signifies that you have entered details of all eligible persons in that household.

If, after entering 'no' at *More*, you realise that there are other household members to be added, you can do this by pressing <End> then the Up Arrow key, and changing *More* from 'no' to 'yes'.

OpenDisp

This will summarise the information that you have entered, so that you can check it is correct before proceeding. Note that it will only display information about

individuals who were interviewed by the interviewer, as these are the only individuals who *you* can interview.

For all individuals who were seen by the interviewer, *OpenDisp* shows the person number, name, sex, age, and whether or not a nurse visit was agreed.

SchDisp

In addition to the details given at *OpenDisp*, this gives you the schedule number for each respondent. Once you have checked the grid at *SchDisp*, press <Ctrl+Enter> to bring up the Parallel Blocks screen (see Section 9.7), from which you can either exit the household (by pressing <Alt+Q>), or select an individual schedule (by highlighting the schedule and pressing <Enter>), or go into the admin block (see section 9.6).

9.4 Individual information

The individual information should be collected when you are in the household.

Info

If the respondent has already agreed to a nurse visit, this question will check that you wish to interview him/her. You should code 'yes' if you want to carry on with the interview straight away, and 'no' if the respondent has changed his/her mind about being interviewed. If neither of these options apply, you should press <Ctrl + Enter> and select one of the other individual schedules.

RefInfo

If the respondent did not agree to a nurse visit, you still have to enter a small amount of information. This is because people sometimes change their minds about seeing the nurse, once they see other household members being measured. If a 'refused' respondent does have a change of heart, code 'yes', and the schedule will continue. If you code 'no', you will be taken right to the end of the schedule.

StrtNur/NurDate/DateOK

The start time and date are necessary because the computer's internal time is not always right. The date is also used to check the respondent's age.

NDoBD - DispAge

These questions act as a check that you are in the right schedule, and that you have recorded the respondent's date of birth correctly.

B. Blood Pressure

BPMod-BPOffer

Everyone (except those who are pregnant) is eligible for blood pressure measurements. The protocol in Section 13B explains how to take blood pressure readings. You will be taking three readings.

BPConst - If you code 'refused' here, the computer will skip you past the measurement. You should code 'unable' if the respondent is prepared to co-operate, but for some reason it is not possible to take the measurement (eg the Omron is broken or there is some physical reason). In either case, you will be asked to record the reason.

ConSubX - Blood pressure can be higher than normal immediately after eating, smoking, drinking alcohol or taking vigorous exercise. This is why respondents are asked to avoid doing these for 30 minutes before you arrive. As already suggested (in section 9.1) if you can juggle respondents within a household around to avoid having to break this "half-hour" rule, do so. But sometimes this will not be possible and you will have to take their blood pressure within this time period - in which case enter all the codes that apply.

OMRONNo - Always note down the *National Centre* serial number for the Omron you are using. Sometimes we identify an equipment problem and wish to be able to track down all readings that have been taken using the particular piece of equipment.

CufSize - See Section 13B for how to select the correct cuff size. If you have a particularly large respondent and the large adult cuff is too small, contact your Nurse Supervisor. She holds a small stock of "thigh" cuffs which can be used to take the blood pressure of very large people. These are used on the arm in the same way as the ordinary cuffs. If you use one of these cuffs, record in the CAPI *Extra large adult cuff* used by opening a memo. If the respondent has a very small arm then you may use a small cuff and record this in a memo in the CAPI.

AirTemp - (See also Section 13A)

Blood pressure can be affected by air temperature. For this reason, we wish to measure the air temperature in the room at the time blood pressure is being taken. You are supplied with a thermometer and probe. Section 13A contains the full protocol.

Wait until you have got your respondent resting with their blood pressure cuff on. Then set up the thermometer on a surface close to where they are sitting. Immediately prior to taking blood pressure, record the temperature. Then switch the thermometer off so that the battery does not run flat.

Remember to check that the thermometer has reached its final reading. It can take several minutes to do this if it is, say, moved from a cold car to a warm house.

If the air temperature is not within the specified range (15-25°C), please try to alter it – perhaps by opening or closing windows and/or doors.

BPReady – This instruction reminds you of the five minute wait, and to check that the 'Ready to measure' symbol is lit before taking the readings. It also reminds you that during the wait you can prepare the documents, and equipment if appropriate, for the rest of Nurse Visit. The documents are:

- Consent booklet office copy
- Consent booklet respondent copy
- Grip strength measurement card

- Measurement record card
- Saliva home log book (but only for respondents under 80)
- Nurse self-completion (have this to hand, but do not complete the details unless you are prompted to leave a copy).

BPRead - Record the blood pressure readings in the order shown on the screen. Double check each entry as you make it to ensure you have correctly entered the reading. If you have got to this point and then become aware that you are not going to be able to get a reading after all, you should enter '996' then press <End>. This will automatically enter '999' in each box, to save you having to type it in 12 times.

YNoBP - If you did not get any full readings, you are asked to enter one of three codes. Code 1 should be used if you attempted to take a blood pressure measurement but were unsuccessful. Use code 2 if you did not attempt to take blood pressure for reasons other than a refusal. If you got a refusal, use code 3.

NAttBPD - If you failed to get a reading, or you only managed to obtain one or two readings, enter a code to show what the problem was. If necessary, write in full details at *OthNBP*.

DifBPC - Code whether the readings were obtained without problem, or whether any problems were experienced.

GPRegB, GPSend, ConsFrm1 - If you obtained at least one blood pressure reading, you are asked to collect details of the respondent's GP. If the person agrees to the results going to their GP, turn to the second page of the Consent Booklet (Consent Form 1 - Blood Pressure to GP). Explain you have to get written consent in order to send the blood pressure readings. Fill in the respondent's name at the top of the form. Ask the respondent to read, sign and date the form. Tick the relevant box on the respondent's personal copy.

Then turn to the front of the Consent Booklet and ring consent code 01. Ask the respondent for the name, address and telephone number of their GP. If possible, obtain the postcode. Record this at items 6 and 7 of the Consent Booklet (if you have not already done so). If your respondent does not know their GP's full address and/or postcode, look it up in the relevant telephone directory later (public libraries hold telephone directories for the whole country). Do your best to get hold of the phone number as well - including the local area code. You may find it useful to keep a notebook containing the address details of local GPs given by previous respondents, as if you are working in the same area, you will almost certainly come across several people with the same GP, and this will save you having to keep looking up the same GP's details if a respondent cannot give them to you.

BPOffer - Offer the respondent his/her blood pressure readings. If (s)he would like them, enter them on the Measurement Record Card (MRC), which you will have in your work packs. Remember to fill in the details on the front of the MRC including your name and the date of the nurse visit. If a respondent has a raised blood pressure you must give her/him advice based on the result. This will be calculated by the computer and will appear on the screen for you to read out exactly as written. Write any advice given onto the MRC.

It is <u>not</u> the purpose of this survey to provide respondents with medical advice. Nevertheless, many respondents will ask you what their blood pressure readings mean. Section 13B contains detailed guidelines on how to inform respondents about their blood pressure readings. Make sure you are very familiar with this guidance. We wish it to be strictly followed. It is very important that as little anxiety as possible is caused, but at the same time we have a duty to advise people to see their GPs if their blood pressure is raised.

C. Grip Strength

MMGSWil

The preamble explains what will be required for the grip strength measurement. Then all respondents are asked if they are willing to take part in the measurement. If they are unwilling or unable, you will be asked to record the reason.

MMGSDom

This question asks about which is the respondent's dominant hand. If the respondent is ambidextrous then enter either hand and put a note about this in a memo.

MMGSSta

Check that the respondent has not had a recent hand injury, or surgery to either hand in the last six months. Record whether the respondent has the use of both hands. If they do not have the use of one (or both) of their hands, specify which hand(s) they are unable to use. If the respondent is unable to use either hand, the measurement will be stopped.

MMGSInt

Position the respondent correctly, adjust the gripometer to their hand size (see Section 13C) and ensure it is reset to zero. Explain the procedure again and demonstrate it. Let the respondent have a practice with one hand. Be sure to reset the gripometer to zero afterwards.

MMGSN1-MMGSD3

Record three measurements for each hand if the respondent has use of both hands, starting with the reading for the non-dominant hand, followed by the reading for the dominant hand. If the respondent does not have use of both hands, record the three measurements for the hand that the respondent does have the use of.

MMGSTP - MMGSPrO

Record the respondent's position during the test and any problems taking the measures.

D. Blood sample

BlIntro

All sample members who give consent are eligible for a blood sample to be taken. The only exceptions to this rule are people with clotting or bleeding disorders, people with a history of fits or convulsions, people who are currently on anticoagulant drugs (eg Warfarin, protamine, acenocoumarol) and pregnant women.

ClotB

Explain the purpose and procedure for taking blood. Check if the respondent has a clotting or bleeding disorder or is on anticoagulant drugs, such as Warfarin, protamine, acenocoumarol. These are very uncommon. If you find someone with these problems, **do not** attempt to take blood, even if the disorder is controlled.

By clotting or bleeding disorders we mean conditions such as haemophilia and low platelets, ie thrombocytopenia. There are many different types of bleeding/clotting disorders but they are all quite rare. The reason these respondents are excluded from blood sampling is that:

- a) the integrity of their veins is extremely precious
- b) we do not wish to cause prolonged blood loss

For the purposes of blood sampling, those who have had, for example, a past history of thrombophlebitis, a deep venous thrombosis, a stroke caused by a clot, a myocardial infarction, or an embolus are NOT considered to have clotting disorders.

Some respondents might be taking anticoagulant drugs such as Warfarin, protamine, acenocoumarol which thins their blood so that they do not stop bleeding easily. If this is the case, then do not take a blood sample. You will need to check this with respondents, particularly with the elderly.

Aspirin therapy is not a contraindication to blood sampling.

If you are uncertain whether a condition constitutes a contraindication to blood sampling, the Survey Doctor will be happy to answer your queries.

Fit

Respondents who have ever had a fit (eg epileptic fit, convulsion) should not be asked to provide a blood sample. This applies even if the fit(s) occurred some years ago.

BSWill

Initial verbal consent to take a sample. If the respondent refuses, you will record why and the module will be skipped.

FastAsk

You should have been in contact with the respondent before visiting the household to determine if it was safe for them to fast. If you advised them that it was not safe to fast you should code 2. If the respondent is aged 80 or over they should not fast, but this will be automatically calculated and this question will not appear. In either case you should take a sample which would not include the fasting tube.

If you determined that it *was* safe for the respondent to fast, or did not manage to contact them, you will now ask further questions about when and what they last ate.

DateLEat - FastBl

These questions determine whether the respondent can give a fasting sample, i.e. whether they have fasted for a sufficiently long time and have eaten only the food specified on the appointment record card. See section 13D for more detail. Note that the CAPI calculates this from the time on your laptop, so it is important to check that your laptop displays the correct time and date.

BSCons Code14 - Obtaining consents

As blood taking is an invasive procedure we need to obtain written consent as well as verbal consent to take it. This has to be obtained from the respondent <u>in all cases</u>. If you **cannot** obtain written consent, the computer will direct you to ring consent codes 06, 08, 10, 12 and 14 on the Consent Booklet and filter you round the remaining questions.

There are three further written consents we wish to obtain in relation to blood sampling – consent to send the results to the GP, consent to store a small amount of the blood, and consent for the extraction and storage of DNA from the sample. You should seek to obtain all these consents before you take any blood. On **no** account should you ever take blood before you have obtained written consent to do so from the respondent.

Small quantities of blood are being stored in special freezers in order that further analysis may be undertaken in the future. Future analysis will definitely <u>not</u> involve a test for viruses (e.g. HIV (AIDS) test).

The questions on the CAPI take you step by step through all the procedures for obtaining consents. Make sure you follow these carefully – recording consent codes as instructed and giving reasons for refusals, if applicable. There are two blood sample consent forms – Consent Form 3 (with parts a, b and c); and Consent Form 4. For each consent required, the CAPI will direct you which sections to complete and what to code on the front of the consent booklet.

In summary:

- Try to reassure respondents about the process, and be prepared to answer their concerns. You will need to explain to the respondent the need for written consent and how important it is.
- Obtain written consents on 'Consent Forms 3 Blood Samples' and 'Consent Form 4 Genetics Study'. Remember to enter the respondent's name at the head of these forms before asking the respondent to sign. Tick the relevant box on the respondent's personal copy of the Consent Booklet.
- Obtain consent to take a blood sample.
- Obtain consent to send results to GP.
- Obtain consent to store blood.
- Obtain consent for extraction and storage of DNA.
- Check that you have ringed the correct consent codes on the front of the Consent Booklet.

Taking a blood sample

Having checked that you have all the appropriate signatures, and ringed the appropriate codes, you are ready to take the blood sample. See the protocol in Section 13D for how to proceed. The CAPI will only direct you to take samples for which the respondent has given consent and a fasting sample if eligible (*TakeSa1*).

If you obtain a sample, note down any problems at *SamDifC* and complete the relevant parts of the venepuncture checklist. Record which sample tubes you have filled at *SampF1 - SampF6*.

If you do not manage to get any blood, you will record this at *SampF1 - SampF6* and then explain why not at *NoBSM*. If you do not get any blood ring consent codes 06, 08, 10, 12 and 14 on the Consent Booklet. If you have already ringed codes 05, 07, 09, 11 and 13 you should cross these codes out.

If you obtain a blood sample, remember to label the blood tubes immediately. Double check you have used the correct barcode label on the tubes and Consent Booklet. Complete the despatch note, remembering to record if the respondent has fasted or not at question 6, and pack the safebox now.

Then ask the respondent if (s)he would like to receive the results of the blood sample analysis (*SnDrSam*). If yes, ring consent **code 09** on the front of the consent booklet. If not, ring **code 10**. If they wish to receive their results, you should tell them that this will take about three months. Note that information from DNA testing will NOT be given to respondents or to their GP as we cannot generate meaningful data at an individual level.

E. & F. Height and weight

You should be able to measure the height and weight of most of the respondents. As well as standing height, we are also measuring respondent's sitting height. In some cases it may not be possible or appropriate to take the respondent's height and weight. Do not force a respondent to be measured if it is clear that the measurement will be far from reliable but whenever you think a reasonable measurement can be taken, do so. You are asked to record the reliability of your measurements at *RelHite* and *RelWaitB*. Examples of people who should **not** be measured are:

- Chairbound respondents should not have their standing height measured.
- If after discussion with a respondent it becomes clear that they are too unsteady on their feet for these measurements.
- If the respondent finds it painful to stand or stand straight, do not attempt to measure standing height.

It is strongly preferable to measure height and weight on a floor which is level and not carpeted. If all the household is carpeted, choose a floor with the thinnest and hardest carpet (usually the kitchen or bathroom).

Read the preamble at the question called *HtIntro*. If further explanation is required, say that although many people know their height and weight, these measurements

are not usually up to date or are not known with the precision required for the survey. The reason for wanting to know accurate heights and weights is in order to relate them to other health measures.

If the height or weight is refused or not attempted, the respondent is asked to estimate their height or weight. You are given a choice of whether to enter their estimate in metric or imperial measurements.

RelHite and RelWaitB

You are asked here to code whether you experienced problems with the measurement and, if you did, to indicate whether you felt the end result was reliable or unreliable. As a rough guide, if you think the measurement is likely to be more than 2 cms (3/4 inch) from the true figure for height or 1 kg (2 lbs) from the true figure for weight, code as unreliable.

G. Waist and hip circumferences

WHMod-WHRes

Waist and hip measurements are taken from all respondents except those who are chairbound and those who have a colostomy or an ileostomy. Each measurement is taken twice, to improve accuracy. Fuller details are of how to do this are given in Section 13G.

Record the two measurements to the nearest millimetre. Always record the response to one decimal point (eg 95.4). The computer will not allow you to enter a response without a decimal point, so even if the measurement comes to, say, exactly 96cm, you must enter '96.0'. If you do enter a measurement ending in '.0', the computer will ask you to confirm this.

If your second measurement differs from the first by 3cm or more, the computer will give you an error message, and instruct you to either amend one of your previous responses, or to take a third measurement.

Amend a previous response if: you have made a mistake when entering the measurement, eg entered '65.2' instead of '75.2'.

Take a third measurement if: there is another reason for the measurements being different.

If in doubt, take a third measurement rather than over-writing one of the previous two. The computer will automatically work out which two to use. If you do decide to take a third measurement, the computer will ask you to enter both waist and hip measurements again, even if only one of the two sets of measurements was more than 3cm apart.

If anyone refuses to have these measurements taken, record why.

At *WJRel* and *HJRel*, record how reliable the waist and hip measures are, and whether any problems that were experienced were likely to increase or decrease the measurement. This information is important for analysis of the results. As a general

rule, if you believe that the measurements you took are 0.5cm more or less than the true measurement because of problems you encountered (e.g. clothing the respondent was wearing), this should be counted as unreliable.

Offer to write the measurements on the Measurement Record Card for the respondent.

H. Lung Function

LFInt - HaStro

Everyone is eligible for a lung function measurement except for those who have had abdominal or chest surgery in the last three weeks, have had eye surgery in the past four weeks, have been admitted to hospital with a heart complaint in the last six weeks or are pregnant or those with a trachiostomy

ChestInf, Inhaler and InHalHrs - these questions collect information about respiratory infections and use of inhalers which could affect someone's lung function measurement.

Before you start, as with the blood pressure procedures, always read out the preamble contained in the Schedule at *LFIntro*. Tell the respondent that the GP is best placed to interpret the readings. By telling them in advance that you cannot interpret the readings, you will avoid the embarrassment of seeming to be covering up afterwards.

LFWill - If you code 'no' here the computer will skip you past the measurement. You should only code 'no' here if the respondent refuses to do the measurement. If you are unable to obtain the measurement because of another reason this is coded later on.

SpirNo - Record the three digit serial number of the spirometer here.

LFTemp – We wish to measure the air temperature in the room at the time lung function is being measured because very high or very low temperatures affect the accuracy of the spirometer. You are supplied with a thermometer and probe. Section 13H contains the full protocol.

Set up the thermometer on a surface close to where the respondent is sitting. Immediately prior to measuring lung function, record the temperature. Then switch the thermometer off so that the battery does not run flat.

Remember to check that the thermometer has reached its final reading. It can take several minutes to do this if it is, say, moved from a cold car to a warm house.

If the air temperature is not within the specified range (15-35°C – note that this is different from the range for blood pressure), you will be asked to try to alter it – perhaps by opening or closing windows and/or doors. If unable to do this, you will be directed to go back to question LFWill and change it to code 3 (unable to take lung function).

LFRec - Explain the procedure and demonstrate the test.

Blow[1]-**Blow**[3] - Get the respondent to carry out three blows. For each blow record **FVC**, **FEV** and **PF**. Remember to press the Clear Button at the end of each reading. At **Technique** record whether or not the respondent's technique was satisfactory. (The definition of technically satisfactory blow is given in Section 13H).

If no reading was obtained enter '0'. If you get to this section in the measurement and find you will not be able to take **any** readings, enter 9.95. This will take to you to the end without having to type 0 at each individual reading.

LFStand - Record whether the respondent was sitting or standing for the measurements.

LFResp – Record a code to show the outcome of your attempt to obtain the lung function readings. Use code 1 if all three blows were obtained and technically satisfactory. Use code 2 in cases where some blows were obtained which were technically satisfactory. Use code 3 if no technically satisfactory blows were obtained. Use code 4 if the respondent refused. Use code 5 if you did not attempt to measure lung function for some reason than other refusal.

ProbLF – If not all three blows were obtained or were not technically satisfactory record the reason why. Use all codes that apply.

YNoLF and **NoAttLF** - Record here why the lung function measurement was refused or not attempted. If no lung function readings were obtained circle **code 04** on the front of the consent booklet.

LFSam - NCIns1

If you obtain a lung function reading ask these questions. If you have not already asked the respondent, check if they are registered with a GP. Check with the respondent if the results can go to their GP. If they agree, turn to **Consent Form 2 - Lung function to GP** in the Consent booklet. Explain that you have to get written consent in order to send the lung function readings to their GP. Fill in the respondent's name at the top of the form and ask them to sign and date the form.

Then turn to the front of the Consent booklet and ring consent **code 03**. If you have not already done so, ask for the name, address and telephone number of the GP (see the section on blood pressure for collecting the GP's details).

*NCIns*2 – Offer the lung function readings to the respondent. If (s)he would like them, enter them on the Measurement Record Card (MRC). The computer will automatically calculate the highest lung function readings for you to record on the MRC. Never attempt to interpret these readings. This has to be done in the office, taking other information about the respondent into account.

I. Balance, Leg raise and Chair rise

Balance

MmBCInt

Explain the purpose of conducting the balance tests, saying that you will describe and demonstrate each exercise in turn.

MmBCSc - MmBCCh

These questions check whether the respondent has had any recent surgery, injury or any other health problem that may affect the balance measurements and remind you to take extra care that it is safe for the respondent to do the measures.

MmSSInt - MmSSNa

Go through the protocol for the side-by-side stand and record whether the respondent was able to hold this position for 10 seconds, and if not, record the time of how long the position was held. If the side by side stand was not attempted, code the reason.

MmSTInt - MMSTNa

These questions are asked if the respondent was able to hold the side-by- side stand for 10 seconds. Go through the protocol for the semi-tandem stand and record whether the respondent was able to hold this position for 10 seconds, and if not, record the time of how long the position was held. If the semi-tandem stand was not attempted, code the reason.

MmFTInt - MmFTNa

These questions are asked if the respondent was able to hold the semi-tandem stand for 10 seconds. Go through the protocol for the full tandem stand and record whether the respondent was able to hold this position for the desired amount of time (10 or 30 seconds depending on the age of the respondent – see section 13I), and if not, record the time of how long the position was held. If the full tandem stand was not attempted, code the reason.

Leg raise

MmLOInt - MmLSNa

These questions are asked if the respondent is aged 69 or under and successfully passed the side by side stand. Go through the protocol for the Leg raise and record whether the respondent was able to hold this position for 30 seconds, and if not, record the time of how long the position was held. If the respondent can perform this exercise for 30 seconds then repeat with the respondent's eyes shut. If the leg raise with eyes open or eyes closed was not attempted, code the reason.

Chair rise

MmCRAv

The availability of a suitable chair is asked as respondents can only participate in this exercise if there is a suitable chair available (as described in Section 13I).

MmCrInt

Demonstrate and explain the procedure of standing up from a suitable chair without the use of their arms.

MmCRSc

This question asks the respondent if they would feel safe performing a rise from a chair without using their hands. If the participant cannot rise *without* using their arms, ask them to try to stand up *using* their arms.

MmCRRe

Record whether the respondent could stand up from a chair with or without using their arms. If they cannot perform this exercise, record the reason at the next question.

MMRRInt - MMRRSc

If the respondent was able to perform a single chair rise without using their arms, explain the protocol for the appropriate number of repeated chair rises to the respondent and demonstrate. Ask the respondent if they would feel safe repeating this action 5 times if the respondent is aged 70 or over or 10 times if the respondent is aged 69 or under.

MMRRStt - MMRRTTi

Record the total amount of chair rises completed and record the time taken to complete the chair rises. If the respondent is aged 69 or under then record the time taken to reach 5 chair rises *as well as* the time taken to complete 10 chair rises.

MMRRNa

If the respondent is 70 or over and cannot complete 5 chair rises or the respondent is 69 or under and cannot perform 10 chair rises, record the reason.

J. Saliva

The respondent's logbook explains <u>how</u> and <u>when</u> to take each sample and also contains questions we would like them to answer <u>at the time</u> they take their samples. The Saliva module is a step-by-step guide to talking through the logbook with the respondent. Note that as there is a mix of instructions for you and for the respondent, text that should be read out is coloured red while nurse instructions are in black.

SalIntro

Explain the purpose and procedure for the saliva module and ask for verbal consent.

SalCons

Complete **Consent Form 5 - Saliva Sample**. Explain the need for written consent and ask the respondent to read, sign and date the office copy. Tick the relevant box on the respondent's personal copy. Circle consent code 15 on the front of the Consent Booklet.

SalPrep

Fill in the respondent's details on the front of the logbook. Ensure you have the correct sheet of barcode labels for the respondent: **check** with the respondent their name and date of birth on the label sheet. Stick one barcode label to the front of the log book and one on the transparent plastic bag. Write the respondent's first name on the label on the plastic bag.

SalGive

Give the kit to the respondent and explain about the kit and the logbook.

SalWhen

Talk through the section on 'When to take your saliva samples' in the logbook. Check that the respondent understands when to take the first and second sample.

SalHow

Talk through the section on 'How to take a sample'. Then ask the respondent to provide a test sample using one of the spare salivettes.

SalFirs

Turn to page 4 and talk through the instructions for taking the orange (first) sample.

SalQues

Show the respondent questions 2 - 6 for the orange (first) sample. Explain that the logbook also contains questions to answer at the time of the samples. These will help us understand the respondent's activities and the levels of stress they are experiencing at different times.

SalSec

Talk through the remainder of page 5. Explain that the respondent should be careful to follow the instructions about what they can eat or drink before the second sample. If the respondent seems unsure about what they can do, it may be best for them not to eat, drink or brush their teeth until after the second sample. Explain that after that, they can do whatever they like for the rest of the day but should not eat, drink or brush their teeth for at least 15 minutes before they take the other samples.

SalSend

Show pages 6 - 8 which relate to the other samples. Then talk through further questions (questions 26-36) and instructions for returns of the samples. Emphasise that the respondent should be sure to put their samples in the transparent plastic bag that has their name on the label and return them as soon as they can. Point out the ELSA Freephone number for if they have any questions and show the respondent the times Helen is available.

SalNo

If the respondent is not willing to give samples, circle consent code 16 on the front of the Consent Booklet.

9.5 Finishing the interview

Ensure that you have all the correct codes ringed on the front of the Consent Booklet. If any results are to go to the GP (consent code 01, 03, or 07 ringed) check that you have their correct details. This is vital in case we need to telephone or write to the GP with any abnormal results. The GP address should be as full as possible, and the telephone number should include the local area code.

Thank the respondents for all their help. We will be writing to thank them as well.

Once you have finished entering information onto the computer, you should press <Ctrl+Enter> then <X> (for eXit (after admin)). The computer will ask you if you

wish to save the data, and your only options are 'yes' or 'cancel'. If you select 'cancel', you will stay in the schedule, so to get out you must press 'yes'.

You will then be at the Household Menu again, where you should press <Esc> to return to the address menu. Press <Esc> again to return to the Action Menu, at which point the data will be scrambled for confidentiality. At the Action Menu, press <Q> for Quit, then switch off the laptop.

9.6 The admin block

For each household in which you do any work, you must complete an 'admin block', which contains various pieces of information which must be kept separate from the individual schedules for reasons of confidentiality. Most of the items in the admin block are self-explanatory, but please note the following:

At *NChoice*, you cannot select code '5' until you have completed all the individual schedules and you are ready to transmit data for the full household back to the office. Before that point, you cannot go beyond this question.

The outcome code for each respondent at *NurOutc* will nearly always be filled in for you, so in most cases you will just need to check that it is correct and press <Enter>, and fill it in on the NRF.

If you did not complete any nurse schedules for a household, at *NOutC* you will be asked to enter a household outcome code (931, 941, 951 or 961). If you completed at least one nurse schedule for a household the household outcome code will be 921. You do not need to enter this code in CAPI but it will appear on the Address Menu at OutC for completed addresses.

The respondent's name and GP details should be copied from the front page of the consent booklet, which is why you are instructed to keep all the consent booklets from a household until work at that household is complete. If you have inadvertently sent back a consent booklet before completing the admin block, you should leave the GP details blank (by pressing <Enter>) and coding '2' at YGPBlank. This will indicate to the staff at the office that we need to pull out that consent booklet to get the GP details. It is important that you do not enter 'don't know' at the GP details questions, unless you really do not know the details. If you have collected the details (or think you may have done so), but do not have access to them, always enter a blank.

The computer will not consider the household as complete until the admin block is fully completed. You will not need to complete the admin for households where there is no work for you to do, all you do for these cases is enter code 3 at ScrOut.

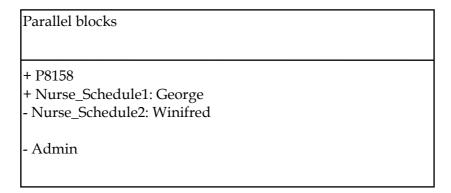
9.7 Parallel blocks

The computerised nurse schedule consists of three main components:

- 1. The household information
- 2. The individual schedule(s)
- 3. The admin block

Each component is known as a 'parallel block'. This means that you can enter any component at any time, no matter where you are in the schedule.

The way to move between parallel blocks is by pressing <Ctrl+Enter>, which brings up a window called 'Parallel Blocks'. This screen is the 'gateway' to the other components of the schedule. It lists all the possible blocks you could go into, and looks like this:



The list of blocks will vary depending on the number of people in the household. There will always be a 'P8158' and an 'Admin' for each household. In addition, there will be a 'Nurse_Schedule' for each eligible individual in the household (in the above example, there are two eligible individuals).

It is important to remember that 'Nurse_Schedule[1]' is the individual schedule for the *first person entered in the household grid*. This is why you must enter the details in person number order. If you entered, say, person number 4 at the top of the grid, then that person would be allocated 'Nurse_Schedule[1]', even though (s)he is not person number 1. In larger households, this could get very confusing!

If the individuals are entered in the wrong order (e.g. if a household member is added to the grid late) and you subsequently find yourself unsure as to which 'Nurse_Schedule' corresponds to which person number, you should enter each 'Nurse_Schedule' in turn and look at the details given on the first screen until you find the person you want.

The final thing to note about the parallel blocks screen is the '+' or '-' which precedes each block. All blocks will have a '-' to start with, and this will turn into a '+' when the computer is satisfied that that block has been fully completed. In the above example, the nurse has completed the household grid and the schedule for George, but has not yet done the schedule for Winifred.

9.8 Practice interview

The practice serial numbers you have been given are as follows:

Serial	Check letter		
100000011	P		

122222211	E
133333311	M
144444411	V
155555511	C
166666611	K
177777711	S
188888811	A
199999911	Н

Address check: 35 Northampton Square

10 COMPLETING THE NRF AND RETURNING WORK

10.1 Recording the outcome of your attempts to interview and measure

Interviewers are required to complete a Nurse Record Form (NRF) for each issued address (regardless of whether a nurse visit is required).

At the top of the first page you will find the NRF labels (see Section 2.3). There is also a space for interviewers to write any tips about the household location or the occupants that they feel you might find useful – this may include a change of address. Question 2 will indicate which address you should visit (i.e. original or new).

Interviewers will have circled an outcome at Question 1 on the front page. Your follow-up instructions depend on the outcome they have coded (either A, B, C). Please follow these instructions carefully.

Question 1 - Interviewer outcome summary:

Code A - At least one eligible respondent has agreed to the nurse visit.

Code B – Respondents were eligible for the nurse visit, but NO nurse visit required (e.g. if they all refused).

Code C – Interviewers did not identify anyone who was eligible for the nurse visit (e.g. could not trace address).

So if B or C are traced no nurse visit is required.

If code C is ringed, all you need to do is code 931 at Q.13, open the serial number in CAPI and enter code 3 at ScrOut, and return the NRF.

The interviewer completes Part A if s/he has circled A or B at question 1. For your information, they are asked to record if someone who took part at Wave 1 has died (Question 5), or moved into an institution (Question 6).

Interviewers complete Question 7 if they identified respondents eligible for the nurse visit. Those who require a nurse visit will have been assigned a nurse status of 1. Status code 2 is for those who refused the nurse visit (but did the main interview), and code 3 is for eligible respondents who did not participate in the main interview (e.g. refused).

At Question 7, interviewers are also asked to record details of any nurse appointments they have set up. Make sure you study these carefully.

You will be directed to Question 8 if at least one person requires a nurse visit. Please record details of each call you make to the household (either by telephone or face-to-face).

At Question 9, you will need to transfer the name and person number for those with a nurse status code of 1 or 2 at Question 7. Please circle an individual outcome code for each person. You will be prompted to enter this outcome code in the CAPI admin block.

Individual Outcome Codes:

Use code 80 if the person was given a nurse status code of 2 at Question 7. There is nothing for you to do.

Use code 81 if you went through the whole schedule with the respondent and completed all the relevant questions. This code applies <u>even</u> if the respondent refused any of the measurements.

If someone breaks an appointment and you never manage to make contact with them again, ring code 85, not code 82.

A proxy refusal (84) is the situation where someone refuses on behalf of someone else - for example, a husband who says he will not allow his wife to be seen by a nurse. Obviously you should do your best to try and see the person yourself but sometimes this is not possible.

Codes 86-88 should be used only if the respondent is unavailable for interview for these reasons throughout the whole of your fieldwork period. If they are likely to return, and be fit to be seen during that time, then try again later.

Question 10 - Complete this for each person who refused to allow you to interview them (i.e. those you coded 83-84 at Question 7).

Question 11 – Complete for each person coded 85-89 at Question 7.

Question 12 – Complete for all households with an individual outcome of 81. First enter the number of consent booklets obtained. Then record whether you were prompted to leave a Personal Beliefs and Wellbeing questionnaire. If yes, please enter a self-completion status code:

- Code 1 if completed by the respondent, to be posted back by you
- Code 2 if you left it with the respondent to complete and send back themselves
- Code 3 if the respondent did not complete the self completion (eg r efused)

Question 13 – You need to assign a household outcome code to each NRF. This code is then transferred to the CAPI admin block.

Household outcome codes:

- Code 921 represents at least one productive interview.
- Code 931 should be used if no nurse visit was required (eg all respondents refused the visit the interviewer will have circled B at question 1, or all respondents were ineligible for the nurse visit).
- Code 941 should be used if you attempted to conduct the nurse visit, but this resulted in an unproductive outcome.
- Code 951 should be used if eligible respondents were identified, but you were not able to cover the address.
- Code 961 should be used if you need to reallocate to another nurse.

Finally, before returning the NRF to the office, you must complete two of the three boxes on the top right-hand side of the front page. To do this, you will need to go into the address menu on the computer, and locate the serial number which corresponds with that address.

The *Slot name* can be found at the top right of the address menu screen, next to the word 'Period'. It will be the first three letters of the field month. Copy this into the 'Slot Name' box

The *Return/trip number* can be found in the column on the far right of the screen, headed 'RET'. Copy this number into the 'Return/trip No' box.

Please enter the *Final Outcome* in the top box using the summary on the back page of the NRF.

10.2 Returning work

Please post the NRFs and consent forms back to the yellow team in Brentwood once you have interviewed everyone eligible in the household. Transmit back to the office at regular intervals throughout the fieldwork period. Keep all the work to be returned together for that household and transfer as soon as the household is complete. Referral back to GPs and respondents, in the event of any serious abnormalities, can be seriously delayed if work is not returned on time.

Before returning work, check that you have all the documents you should have and that they are properly serial numbered and so on. Check that they match with your NRF entries. You should return a Consent Booklet for each person with an individual outcome code of 81.

Send the NRF to the office when you have completed everything you have to do at a household.

- Pin together the NRF and Consent Booklets and any grip strength measurement cards and return them in one envelope.
- Send any interview documents given to you by the respondent (e.g. self completion) separately.
- Do not entrust other people to post your envelopes always post them yourself.

CAPI questionnaire data will be transferred back to the office via the modem. The computer will decide what to transmit - you do not need to tell it which addresses to take and which to leave. Remember you still need to return the paper documents.

When your assignment is completed, make your last return of work as follows:

- Do your last Return-of-work via modem, by selecting 'T' for 'transmit/Return data to HQ' from the Action menu. Follow the instructions on the screen.
- Then carry out the 'End of Assignment clear-out' routine by selecting 'E' from the Action menu. This routine requires the use of the **Backup disk** for the last time.

At the end of your assignment, check that you have accounted for all the serial numbers on the Summary Sheet.

11 INFORMATION FOR HANDLING NURSE EQUIPMENT

The same precautions and lifting techniques should be applied when handling nurse equipment as with any other loads that we need to carry in our day to day activities.

Although the ELSA nurse equipment is within the weight guidelines advised by the Health and Safety Executive, we feel that we must stress that caution should be taken when lifting equipment.

Please read the following advice to ensure you are aware of the correct lifting techniques:

- Don't jerk or shove twisting may cause injury.
- Grip loads with palms of hands, not fingertips. Don't change your grip while carrying.
- Bend your knees when lifting loads from the ground. Lift with your legs and keep your back straight. Lift in easy stages – floor to knee, then knee to carrying position.
- Hold weights close to the body. Take care when lifting equipment from the boot of your car, position the equipment to avoid stretching at the same time as lifting.
- Evenly distribute load. Not all on one shoulder or hand.
- Use shoulder straps as much as possible.

- Don't carry more than you need to. Try to pack the supplies you need for the day and keep spare supplies in the car.
- Take extra care on stairs, making more than one journey if necessary.
- If you think a trolley would be useful, we can arrange for one to be provided. Please ring your Nurse Supervisor in the first instance who will make any necessary arrangements with the Area Manager.

You must advise the *National Centre* of any existing condition or pre-disposition to injury, e.g. pregnancy or previous back injury.

Please refer to your Survey Nurses' Manual for more information about Health and Safety.

12 CONTACTS

12.1 The Project Team

Your nurse supervisor is the person you should consult if you have any queries about your equipment, how to use it in the field or any other problems you might have relating to carrying out the interview and measurements.

If you have any other queries relating to this project then you should contact:

- Hayley Mew on 020 7549 8544, Kate Cox on 020 7549 8542, or Dan Philo on 020 7549 9555.
- Audrey Hale, Helen Selwood or any member of the Yellow Team.

In an emergency where the program is failing, you can contact the programmer who is Sven Sjodin on 020 7250 1866.

12.2 The Survey Doctor

Dr James Nazroo of UCL is the 'Survey Doctor'. James is responsible for providing nurses with medical support and for liaising with GPs with respect to measurement or blood sample abnormalities which are detected as a result of this survey.

If you want to contact James:

- First phone his work number: 020 7679 1705.
- If he is not there leave him a message **AND then** ring him at home: 01634 891 849.
- If he is not at home leave him a brief message saying that you have left a full message on his work phone. You should **ALSO** then phone his mobile number: 07766 133 781.
- If he is not able to answer his mobile phone please leave him a brief message saying that you have left a full message on his work phone.

If you need to leave a message with the Survey Doctor, leave the following details:

- Your name
- Contact telephone number
- If you want the Survey Doctor to ring you back at a specific time etc.

13 PROTOCOLS OF MEASURES IN ELSA NURSE VISIT

- A. Recording ambient air temperature
- B. Blood Pressure
- C. Grip Strength
- D. Blood samples
- E. Standing and Sitting Height
- F. Weight
- G. Waist and hip measurement
- H. Lung Function
- I. Physical performance measures Balance, Leg raise and Chair rises
- J. Saliva samples

A. RECORDING AMBIENT AIR TEMPERATURE

The thermometer

You have been provided with a digital thermometer and probe. This instrument is very sensitive to minor changes in temperature. It is therefore important that you record temperature at the appropriate times in your routine. It can also take a few minutes to settle down to a final reading if it is experiencing a large change in temperature (e.g. coming into a warm house from a cold outside).

Immediately after you have settled the respondent down to rest for five minutes prior to taking their blood pressure, set up the thermometer to take a reading. Just prior to recording the blood pressure note the temperature and record it when the computer prompts you to do so. Always switch it off after taking a reading, to avoid battery problems. The thermometer automatically switches off if you have left it on for more than 7 minutes. You will also need to enter the temperature before the lung function reading. Note that the acceptable temperature range for the blood pressure measurement is 15-25°C, while for the lung function measure it is 15-35°C.

Place the thermometer on a surface near the Omron. Do not let the probe touch anything - you can for example let it hang over the edge of a table. Do not put it on top of the Omron as it will be warm.

Please note that you must enter the temperature to one decimal place - do not round it to the nearest degree. For example, enter '21.2', not just '21'. If you do not enter a decimal point, the computer will give you a warning. If the temperature is exactly, say, 21 degrees, then all you need to do is suppress the warning and it will automatically fill in the '.0' for you. Otherwise, you must go back and amend your answer. As a further check, it will also ask you to confirm that a temperature ending in '.0' is correct.

Instructions for using the thermometer

- 1. The probe plug fits into the socket at the top of the instrument.
- 2. Press the completely white circle to turn the instrument on. To turn off, press the white ring.

- 3. Before taking a reading off the display, ensure that the reading has stabilised.
- 4. Be careful of the probe it is quite fragile.
- 5. When "LO BAT" is shown on the display the battery needs replacing, take no further readings.
- 6. The battery in your thermometer is a long-life battery and should last at least one year. However, should it run low please purchase a new battery. Take the old one with you to ensure it is the same type. Claim in the usual way.
- 7. To remove an old battery and insert a new one, unscrew the screw on the back of the thermometer.

B. BLOOD PRESSURE

Eligibility

High blood pressure is an important risk factor for cardiovascular disease. It is important that we look at the blood pressure of everyone in the survey using a standard method so we can see the distribution of blood pressure across the population. This is vital for monitoring change over time, and monitoring progress towards lower blood pressure targets set in the Health of the Nation.

Protocol For Blood Pressure Recording: Omron Hem-907

This section describes the protocol for measuring blood pressure using the Omron HEM 907. More detailed information may be obtained from the instructions booklet inside the box. If you have any further questions or problems then please contact your nurse supervisor.

Equipment

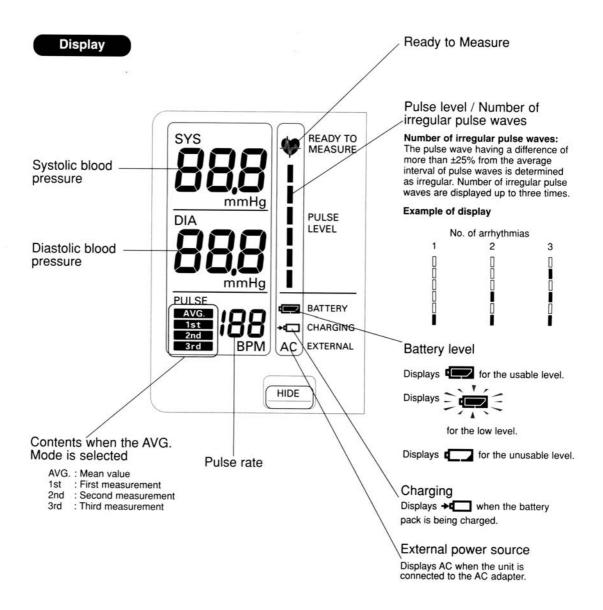
Omron HEM 907 blood pressure monitor Standard adult cuff (22-32 cm) Large adult cuff (32-42 cm) AC adapter

The Omron HEM-907 blood pressure monitor is an automated machine. It is designed to measure systolic blood pressure, diastolic blood pressure and pulse rate automatically at pre-selected time intervals. On this study three readings are collected at one-minute intervals.

The Omron 907 is equipped with a rechargeable battery, which is usable for approximately 300 measurements when fully charged. To recharge the battery, connect the monitor to the mains. A battery symbol will appear in the CHARGING display when the battery is charging. When ready to use the symbol will disappear. A dark battery symbol in the BATTERY display indicates that the battery is charged and the machine is usable. The battery can be charged in approximately 12 hours. When the battery symbol in the BATTERY display starts to flash there are 20-30 measurements left, you need to charge the battery soon. When a light battery symbol appears in the BATTERY display the battery needs to be put on charge immediately. The Omron 907 is **NOT** designed to work off the mains adaptor; it should be run off the battery power pack. The mains adaptor should ONLY be used to charge the battery pack.

PLEASE REMEMBER TO CHARGE THE BATTERY!

The picture below shows the main features of the Omron HEM-907.



Preparing the respondent

The respondent should not have eaten, smoked, drunk alcohol or taken vigorous exercise in the 30 minutes preceding the blood pressure measurement as blood pressure can be higher than normal immediately after any of these activities.

Ask the respondent to remove outer garments (e.g. jumper, cardigan, jacket) and expose their **right** upper arm. The sleeve should be rolled or slid up to allow sufficient room to place the cuff. If the sleeve constricts the arm, restricting the circulation of blood, ask the respondent if they would mind taking their arm out of the sleeve for the measurement.

Selecting the correct cuff

Do **not** measure the upper arm circumference. Instead, choose the correct cuff size based on the acceptable range which is marked on the inside of the cuff. You will note that there is some overlap between the cuffs. If the respondent falls within this overlap range then use the **standard** cuff where possible.

The appropriate cuff should be connected via the grey air tube to the right end side of the monitor.

Procedure

Wrap the correct sized cuff round the upper **right** arm and check that the index line falls within the range lines. Use the left arm only if it is impossible to use the right. If the left arm is used, record this on the schedule. Locate the brachial pulse just medial to the biceps tendon and position the arrow on the cuff over the brachial artery. The lower edge should be about 1-2 cm above the cubital fossa (elbow crease).

Do not put the cuff on too tightly as bruising may occur on inflation. Ideally, it should be possible to insert two fingers between cuff and arm. However, the cuff should not be applied too loosely, as this will result in an inaccurate measurement.

The respondent should be sitting in a comfortable chair with a suitable support so that the right arm will be resting at a level to bring the antecubital fossa (elbow) to approximately heart level. They should be seated in a comfortable position with the cuff applied, their legs uncrossed and their feet flat on the floor.

Explain that before the blood pressure measurement we need them to sit quietly for five minutes to rest. They should not smoke, eat or drink during this time. Explain that during the measurement the cuff will inflate three times and they will feel some pressure on their arm during the procedure.

After five minutes explain that you are starting the measurement. Ask the respondent to relax and not to speak until the measurement is completed as this may affect their reading.

How to operate the monitor

See Picture of Omron HEM-907 monitor above.

- 1. Switch the monitor on by pushing the **ON/OFF** button. Wait for the **READY TO MEASURE** symbol to light, indicating the machine is ready to start the measurement (approx 2 sec).
- 2. Check that the **MODE** Selector is set to **AVG** and the **P-SET** (pressure setting) Volume is set to **AUTO**.
- 3. Press the **START** button to start the measurement. The cuff will now start to inflate and take the first measurement. When the first measurement is complete the LCD displays show systolic pressure, diastolic pressure, and pulse rate. Record the readings on the interview schedule.
- 4. Blood pressure will then be recorded at one-minute intervals thereafter. After each interval record the readings from the LCD displays on the interview schedule.
- 5. After the three measurements are complete press the **ON/OFF** button to turn off the power and remove the cuff.

If there are any problems during the blood pressure measurements or the measurement is disturbed for any reason, press the **STOP** button and start the procedure again. If the respondent has to get up to do something, then ask them to sit and rest for five minutes again.

Error readings

They appear on the LCD display:

Er1, **Er2**. Check that the tube connecting the cuff to the monitor is properly inserted and is not bent. Check that the cuff is properly wrapped around the arm. Repeat the measurement.

Er3. Check that the tube connecting the cuff to the monitor is not bent. Repeat the measurement.

Er4. This could be because of a motion artefact. Ask the respondent to sit as still as possible and take the measurement again. If you still get another Er4 error reading, it could be because the respondent has a very high blood pressure. Set the P-SET Volume to 260 and repeat the measurement.

Er5, **Er6**. Check that the cuff is properly wrapped around the arm. Repeat the measurement.

If any of these error readings persist record that it wasn't possible to get a reading and explain to the respondent that this sometimes happens. Then contact Brentwood and inform them that there is a problem with the monitor.

Er7, Er8. Check that the respondent does not move, ask the respondent to sit as still as possible and take the measurement again. If you still get an error reading the pulse may be irregular. Do NOT palpate the pulse. Record that it wasn't possible to get a reading and explain to the respondent that this sometimes happens.

Er9. Technical fault. Contact Brentwood immediately and inform them that there is a problem with the monitor.

Feedback to respondents

If the respondent wishes, you should record details of their readings on their Measurement Record Card.

In answering queries about a respondent's blood pressure it is very IMPORTANT to remember that it is <u>not</u> the purpose of the survey to provide respondents with medical advice, nor are you in a position to do so as you do not have the respondent's full medical history. But you will need to say something. What you say in each situation has been agreed with the Department of Health, and the CAPI will instruct you to read these comments out. It is very important that **you make all the points relevant to the particular situation and that you do not provide a more detailed interpretation as this could be misleading**. Read the instructions below very carefully and make sure you always follow these guidelines.

The comments should be based on the last two of the first three readings you take from the **Omron HEM-907.** The advice you will be prompted to give will be based on the **higher** of the last two readings. If the first reading is higher than the other two, explain that the first reading can be high because people are nervous of having their pressure taken.

Definitions of raised blood pressure differ slightly. It has been decided that we should adopt the ones given below for this study. It is important that you adhere to these definitions, so that all respondents are treated in an identical manner.

SURVEY DEFINITION OF BLOOD PRESSURE RATINGS				
Rating	<u>Systolic</u>		Diastolic	
Normal	<u>5ystone</u> <140	and	<u> </u>	
Mildly raised	140 - 159	or	85 - 99	
Moderately raised	160 - 179	or	100 - 114	
Considerably raised	180 or more	or	115 or more	

Points to make to a respondent about their blood pressure (given on screen):

Normal:

'Your blood pressure is normal'

Mildly raised:

'Your blood pressure is a bit high today.'

'Blood pressure can vary from day to day and throughout the day so that one high reading does not necessarily mean that you suffer from high blood pressure.'

'You are advised to visit your GP <u>within 3 months</u> to have a further blood pressure reading to see whether this is a once-off finding or not.'

Moderately raised:

'Your blood pressure is a bit high today.'

'Blood pressure can vary from day to day and throughout the day so that one high reading does not necessarily mean that you suffer from high blood pressure.'

'You are advised to visit your GP <u>within 2-3 weeks</u> to have a further blood pressure reading to see whether this is a once-off finding or not.'

Considerably raised:

'Your blood pressure is high today.'

'Blood pressure can vary from day to day and throughout the day so that one high reading does not necessarily mean that you suffer from high blood pressure.'

'You are <u>strongly</u> advised to visit your GP <u>within 5 days</u> to have a further blood pressure reading to see whether this is a once-off finding or not.'

Note: If the respondent is <u>elderly</u> and has <u>severely raised blood pressure</u>, amend your advice so that they are advised to contact their GP within the next week or so about this reading. This is because in many cases the GP will be well aware of their high blood pressure and we do not want to worry the respondent unduly. It is however important that they do contact their GP about the reading within 7 to 10 days. In the meantime, we will have informed the GP of their result (providing the respondent has given their permission).

Action to be taken by the nurse after the visit

If you need to contact the Survey Doctor, do not do this from the respondent's home-you will cause unnecessary distress. See Section 12.2 for information about how to contact the survey doctor.

Pulse - for all respondents the survey doctor routinely checks fast and slow pulse rates so no further action is necessary.

The chart below summarises what action you should take as a result of the knowledge you have gained from taking a person's blood pressure readings. For this purpose you should only take into account **the last two of the three readings** you take. We do not want you to use the first reading as it is prone to error for the reason stated above.

BLOOD PRESSURE	ACTION
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Normal/mild/moderate BP	No further action necessary
Systolic < 180 mmHg and Diastolic < 115 mmHg	If you feel that the circumstances demand further action, inform the Survey Doctor who will then inform the respondent's GP immediately if he deems it necessary.**
Considerably raised BP	Contact the Survey Doctor at the earliest opportunity and he will
Systolic > 180 mmHg or Diastolic > 115 mmHg	inform the respondent's GP.**
	If the respondent has any
	symptoms of a hypertensive crisis* contact the survey doctor
	immediately or call an ambulance.
	The Survey Doctor must be
	informed as soon as possible.**

NB: < less than; > greater than or equal to.

- * A hypertensive crisis is an extremely rare complication of high blood pressure. Its signs and symptoms include diastolic BP > 135 mmHg, headache, confusion, sleepiness, stupor, visual loss, seizures, coma, cardiac failure, oliguria, nausea and vomiting.
- ** You must still contact the Survey Doctor even if the respondent tells you that their GP knows about their raised BP.

All high or unusual readings will be looked at by the Survey Doctor when they reach the office. If the reading is high, then the Survey Doctor will contact the respondent directly.

C. GRIP STRENGTH

Introduction

In international studies, comparability of measurements across countries, languages and cultures is very important. One way of getting reliable, easily comparable data on the physical ability of different populations is to measure relevant dimensions directly. In the ELSA nurse visit we will be asking you to carry out the isometric hand-grip strength measure, which comes from a European study on ageing called SHARE. Hand-grip strength affects every day function (such as raising the body weight or holding heavy objects) and declines with age. It is measured with a gripometer which consists of a gripping handle with a strain-gauge and an analogue reading scale. The measurement will be given to all respondents. There is no lower or upper age limit, but there are certain exclusions on safety grounds (see below).

Sometimes you will need to provide information in order to convince people of the importance of the grip-strength test. They may want to know more about what is involved. If the person is reluctant, use the arguments given in the first paragraph to try to get them to change their mind.

Exclusion criteria

Those with swelling or inflammation, severe pain or recent injury, and those with surgery to the hand in the last 6 months **should not** take the grip strength test. If there is a problem with one of the respondent's hands, just take measurements on the other hand.

Demonstrations

Demonstrate the grip-strength test for the respondent. It is very important that you demonstrate the measurement correctly. Experience has shown that respondents follow more closely what the nurse does rather than what s/he says. If the respondent indicates that s/he does not understand how to handle the gripometer, demonstrate it again rather than relying on repeating verbal instructions. Repeat the demonstration only once. If the respondent still does not understand, skip the test and continue the interview. Do not 'coach' the respondent.

To some respondents the detailed verbal instructions may seem unnecessary. It may help to say that you are going to explain each test to the respondent in detail since this is the best way to make sure that everyone does the test in a similar manner.

Accuracy

The accuracy of the tests depends on the effort exerted by the respondent and the conscientiousness of the interviewer. Consequently it is crucial that the examination protocol be observed painstakingly. Insufficient effort on the part of the respondent will cause the test results to be inadequate for analysis.

Procedure

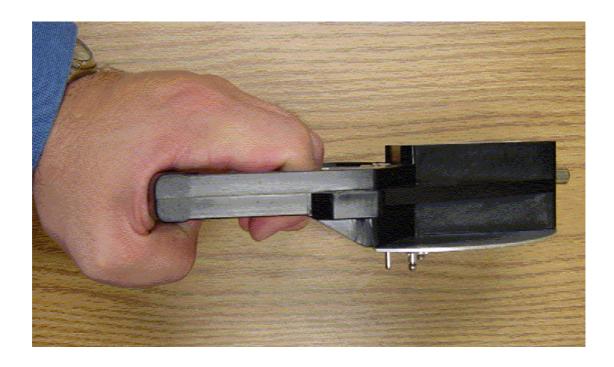
- Explain and **demonstrate** the test procedure. You can use the Grip Strength Protocol Script Card if you wish.
- The respondent should preferably stand up but if not possible then sitting in an upright chair is fine.
- Large rings may need to be removed.
- **VERY IMPORTANT:** Adjust the lever of the gripometer so it suits the respondent's hand. To do this (see also pictures below):
 - (1) Put the black bar of the gripometer on the pads at the top of their palm. If it is in the right position the metal bar (the grip) should rest on the middle piece of the four fingers.
 - (2) If the metal bar is not in the right position you will need to lift the metal lever on the side of the gripometer and rotate the metal bar (the grip) until it is in a more suitable position for the respondent. Then repeat step (1).
 - (3) You can check that there is a good fit by asking the respondent to grip the gripometer the middle section of their fingers should be flat across the top of the metal bar. If they are not then you will need to readjust it.
 - (4) When you have got a good fit, replace the lever on the side of the gripometer.

- Make sure the respondent keeps their upper arm tight against their trunk.
- The forearm should be at a right angle to the upper arm. If the respondent is finding the gripometer too heavy to hold it in this position then they can use their free hand to rest the gripometer on. You could also provide this support if appropriate. If the respondent needs to do the measure in a seated position then they could use a table for support. However, try and make sure that their forearm is still at a right angle to their upper arm.
- The dial should face outward.
- Allow the respondent to have a practice with one hand.
- Before each measurement, make sure that the arrow is reset at zero.
- Ask the participant to squeeze as hard as they can for a couple of seconds.
- Record the value on the scale **to the** *nearest* **whole number** (e.g. 12). To get an accurate reading you should look directly down on the scale. Record the result on to the Grip Strength Measurement Card.
- Record three values with each hand alternating between hands, starting with the non-dominant hand (six values all together).
- Do not include measurements carried out incorrectly.
- Return the Grip Strength Measurement Card to the office with the NRF.

Aligning the Gripometer with the hand



Gripometer lever on second phalanx in gripping action



D. BLOOD SAMPLE

Eligibility

All core sample members, with the following exceptions, are eligible to give blood.

People with clotting or bleeding disorder

By clotting or bleeding disorders we mean conditions such as haemophilia and low platelets, i.e. thrombocytopenia. There are many different types of bleeding/clotting disorders but they are all quite rare. With these problems, do not attempt to take blood, even if the disorder is controlled. (People who have a past history of thrombophlebitis, a deep venous thrombosis, a stroke caused by a clot, a myocardial infarction or an embolus are NOT considered to have clotting disorders and should not be excluded).

- People who have ever had a fit
- People who are not willing to give their consent in writing.
- People who are currently on anticoagulant drugs, eg Warfarin therapy. Some respondents might be taking anticoagulant drugs such as Warfarin, protamine or acenocoumarol which thin their blood so that they do not stop bleeding easily. If this is the case, then do not take a blood sample. Aspirin therapy is NOT a contraindication to blood sampling.

Pregnant women

If you are uncertain whether a condition constitutes a contraindication to blood sampling, the Survey Doctor will be happy to answer your queries.

Consent

As blood taking is an invasive procedure we need to obtain written consent as well as verbal consent to take it. This has to be obtained from the respondent **in all cases**.

If you cannot obtain written consent, the computer routes accordingly. **On no account** should you ever take blood before you have obtained written consent to do so from the respondent.

There are further written consents we wish to obtain in respect of blood sampling - consent to send the results to the GP, consent to store blood for future analysis, and consent to extract and store DNA. You should seek to obtain all these consents before you take any blood. However, it is not a requirement that respondents consent to all parts. For instance, they may consent to blood collection for immediate laboratory analysis, but not to extraction of DNA. However, if the respondent does not consent to the extraction of their DNA then you should not take blood for the fifth and sixth tubes (see box below). Even if there is no consent given for specimen storage, we would still like to collect blood for immediate analysis, provided of course the respondent consents to blood collection.

The consent form explicitly mentions that HIV tests will not be performed, so that the participants are not placing themselves at risk of financial disadvantage (because some insurance companies may disqualify people, or demand higher premiums, if they have ever been **tested** for HIV, regardless of the result of the test), simply from taking part in the survey.

The questions on the schedules take you step by step through all the procedures for obtaining consents. Make sure you follow these carefully - recording consent codes as instructed and giving reasons for refusals, if applicable. In summary, what you do is:

- a. Ask the respondent if they would be willing to have a blood sample taken. Try to reassure respondents about the process, and be prepared to answer their concerns. You will need to explain to the respondent the need for written consent and how important it is.
- b. Obtain written consents on the appropriate **Blood Sample Consent Form.**
- c. Obtain consent to store blood.
- d. Obtain consent to extract and store DNA.
- e. Obtain consent to send laboratory results to the respondent
- f. Obtain consent to send laboratory results to GP
- g. Check that you have ringed the correct consent codes on the front of the Consent Booklet.

Having checked that you have all the appropriate signatures, and ringed the appropriate codes, you are ready to take the blood sample. If you obtain a sample, note down any problems at SamDifC. If you do not manage to get any blood, explain why not at NoBSM

Purpose

A blood sample will be collected from respondents who give consent for this. The blood will be analysed for the following:

Fibrinogen – A protein necessary for blood clotting. High levels are also associated with a higher risk of heart disease.

Total cholesterol – Cholesterol is a type of fat present in the blood, related to diet. Too much cholesterol in the blood increases the risk of heart disease.

HDL cholesterol – This is 'good' cholesterol which is protective for heart disease.

Triglycerides - Together with total and HDL cholesterol, they provide a lipid profile which can give information on the risk of cardiovascular disease.

Ferritin and Haemoglobin – These are measures of iron levels in the body and are related to diet and other factors.

C-reactive protein – The level of this protein in the blood gives information on inflammatory activity in the body, and it is also associated with risk of heart disease.

Apolipoprotein E – This is involved in the transport of cholesterol and plays a protective role.

Fasting glucose and Glycated haemoglobin – Both indicate the presence or risk of type 2 diabetes, which is associated with an increased risk or heart disease.

Genetics – Genetic factors are associated with some common diseases, such as diabetes and heart disease, and relate to general biological aspects of the ageing process.

The blood will **not** be tested for any viruses, such as HIV (AIDS).

Equipment

Tourniquet
Alcohol swabs
Cotton gauze
Vinyl gloves
Adhesive dressing

Micropore tape Set of labels for blood sample tubes Royal mail 'safebox' Vacutainer holder
Vacutainer needles 21G (green)
Vacutainer needles 22G (black)
Butterfly needles 23G
Needle disposal box
Vacutainer plain red tubes
Vacutainer EDTA purple tubes
Vacutainer citrate blue tubes
Vacutainer fluoride grey tubes

The blood tubes

If the respondent has fasted and has given consent for DNA extraction then **SIX** tubes need to be filled. They should be filled in the following order so that, if a

situation arises where there will be insufficient blood to fill all the tubes, the analyses with the highest priority can still be undertaken.

First	4mL citrate tube (blue)
then	6mL plain tube (red)
then	2mL fluoride tube (grey)
then	4mL EDTA tube (purple)
then	4mL EDTA tube (purple)
finally	4mL EDTA tube (purple)

If the respondent consents to blood collection and DNA extraction but not other parts of the consent form, you should still draw ALL SIX vials of blood. If they do not consent to DNA extraction then you should only draw the first FOUR vials. You can then reassure the respondent that no tests will be done where consent has not been granted. If the respondent has not fasted, the grey tube will not be taken.

Preparing the respondent

Ask the respondent if they have had any problems having blood taken before.

- 1. Explain the procedure to the respondent. The respondent should be seated comfortably in a chair, or if they wish, lying down on a bed or sofa.
- 2. Ask the respondent to roll up their left sleeve and rest their arm on a suitable surface. Ask them to remove their jacket or any thick clothing, if it is difficult to roll up their sleeve.

The antecubital fossae may then be inspected. It may be necessary to inspect both arms for a suitable choice to be made, and the respondent may have to be repositioned accordingly.

3. Do **not** ask the respondent to clench his/her fist.

Select a suitable vein and apply the tourniquet around the respondent's arm. However, it is desirable to use the tourniquet applying minimal pressure and for the shortest duration of time. Do not leave the tourniquet in place for longer than 2 minutes.

Ask the respondent to keep his/her arm as still as possible during the procedure.

4. Put on your gloves at this point.

Clean the venepuncture site gently with an alcohol swab. Allow the area to dry completely before the sample is drawn.

Taking the sample

You will be taking a maximum of six tubes. Everyone who is eligible and willing to have their blood taken should give at least three tubes of blood (the blue, red and first purple tubes). If the respondent has fasted they will also give blood for the grey tube (you cannot return for a second visit to take a fasting blood sample). If the

respondent has given consent for DNA extraction you should also draw blood for the second and third purple tubes. The CAPI programme will instruct you about which tubes you should draw blood for.

If the respondent agreed to fast or you could not contact them before the visit to tell them to fast then you will need to determine whether or not they have fasted adequately to give a fasting blood sample. You will be prompted to check with the respondent that they have not eaten or drunk anything (except water) in the last five hours. Respondents who have taken medication in the last five hours are eligible to give a fasting blood sample and you do not need to make a note.

If the respondent is eligible and willing to give the sample, complete the consent form obtaining the relevant signatures to take the blood sample and to send the results to the respondent's GP.

Venepuncture is performed with a green twenty one gauge vacutainer needle or butterfly.

Grasp the respondent's arm firmly at the elbow to control the natural tendency for the respondent to pull the arm away when the skin is punctured. Place your thumb an inch or two below the vein and pull gently to make the skin a little taut. This will anchor the vein and make it more visible. Ensure the needle is bevelled upwards, enter the vein in a smooth continuous motion.

Remember to take the tubes in the correct order. The first tube should always be the blue citrate tube, followed by the large plain tube with the red cap followed by the grey fluoride tube (if the respondent has fasted) and then the three EDTA tubes (or only one if the respondent refused to give consent for DNA extraction). The vacutainers should be filled to capacity in turn and inverted gently on removal to ensure complete mixing of blood and preservative.

Release the tourniquet (if not already loosened) as the blood starts to be drawn into the tube. Remove the needle and place a cotton gauze firmly over the venepuncture site. Ask the respondent to hold the pad firmly for three minutes to prevent haematoma formation.

If venepuncture is unsuccessful on the first attempt, make a second attempt on the other arm. If a second attempt is unsuccessful, DO NOT attempt to try again. Record the number of attempts on the Schedule.

Record which arm the sample was drawn from (or both).

IMPORTANT WARNING

Never re-sheath the needle after use.

Do not allow the disposal box to become overfull as this can

present a potential hazard.

Check on the venepuncture site and affix an adhesive dressing, if the respondent is not allergic to them. If they are allergic, use cotton gauze secured with micropore.

If the respondent has fasted for the blood sample then when you have finished taking blood allow the respondent to eat something as soon as possible.

Fainting respondents

If a respondent looks or feels faint during the procedure, it should be discontinued. The respondent should be asked to lie down with their feet elevated.

If they are happy for the test to be continued after a suitable length of time, it should be done so with the respondent supine and the circumstances should be recorded. They may wish to discontinue the procedure at this point, but willing to give the blood sample at a later time.

Disposal of needles and other materials

Place the used needles, the used cotton gauze and the vacutainer holders in the sharps box and put gloves etc in the self-seal disposal bag. The needle disposable box should be taken to your local hospital or GP practice for incineration. Telephone them beforehand, if you are not sure where to go.

If you have difficulties with finding a hospital or practice, contact your local pharmacist. If you need to pay a fee for the sharps box disposal, you will be fully reimbursed. Please telephone Brentwood to let them know the cost per sharps box before you give them to the pharmacy. If you come across any problems with the disposal, contact the Survey Doctor or Brentwood. The sealed bag can be disposed of with household waste as long as it does not have any items in it that are contaminated by blood.

Needle stick injuries

Any nurse who sustains such an injury should seek immediate advice from their GP. The nurse should inform his/her nurse supervisor of the incident, and the nurse supervisor should inform the survey doctor.

Respondents who are HIV or Hepatitis B positive

If a respondent **volunteers** that they are HIV or Hepatitis B positive, do **not** take a blood sample. Record this as the reason on the Schedule. You should never, of course, seek this information.

Sending blood samples to laboratories

The samples are sent to the Royal Victoria Infirmary Laboratory in Newcastle-upon-Tyne. It is important that all samples are sent properly labelled and safely packaged and that they are despatched immediately after they have been taken.

Labelling the Blood Tubes

- Label the tubes as you take the blood.
- Use the set of serial number barcode labels to label the vacutainer tubes.
- You have one sheet of labels per respondent check the serial number, person number, full name and date of birth printed in the top left of each one.
- Attach one serial number barcode label to every tube that you send to the lab.
- Do **not** write any information (such as date of birth) on the labels.

Important

We cannot stress too much the importance of ensuring that you label each tube with the correct serial number for the person from whom the blood was obtained. Apart from the risk of matching up the blood analyses to the wrong person's data, we will be sending the GP the wrong results. Imagine if we detect an abnormality and you have attached the wrong label to the tube!

On DESPATCH:

The Office Consent Booklet contains two separate Despatch Notes that should be filled in for each blood sample (one for Newcastle, and one for Brentwood).

Completing the Newcastle Blood Despatch Note

- Affix the respondent's barcoded serial number label at question 1 do so very carefully. This should both correspond to the serial number on the label on page 1 of the Consent Booklet and to those you have stuck on the tubes.
- Complete items 2, 3, and 4. Check that the date of birth is correct and consistent with entry on the nurse schedule and the tube label.
- At Item 5 enter your Nurse Number.
- At Item 6 code if the respondent fasted for at least 5 hours before the blood sample was taken.
- At Item 7 ring a code to tell the laboratory whether or not permission has been obtained to store part of the blood. Your entry here should correspond to your entry at Item 8f on the front page of the booklet.
- At Item 8 tick each of the tubes collected.

Completing the Office (Brentwood) Blood Despatch Note

At item 6, affix a serial number barcode label that corresponds to those used on the Newcastle Despatch Note, the tubes, and the front of the consent form.

- Tick the samples you are returning at item 1. This indicates what we should expect back from the laboratory. Note if any of the samples were incomplete.
- Code the respondent's sex at item 2.
- Write in their date of birth at item 3 (check this corresponds with the barcode labels, NRF etc.).
- Write in the date the blood is taken at item 4.
- Write in the date the blood is despatched at item 5. This tells us the date you sent the samples to the labs.
- Write in your nurse number at item 7.

If you have only achieved an incomplete blood sample (e.g. have only filled one tube), please state this clearly on both copies of the despatch note and give the reason.

Packaging the blood samples

All tubes from one person should be packed together in one despatch container with the Newcastle Despatch Form.

You will be given Royal Mail Safeboxes which contain:

- An absorbent insert
- A transparent bag
- 1. Insert the blood sample tubes in the pockets of the absorbent insert.
- 2. Roll the insert
- 3. Place the rolled insert in the transparent bag and place into the leak proof sample compartment (this is the larger of the two compartments). Be sure to put it in the correct side!
- 4. Place the Newcastle Despatch Note in the compartment next to the sample compartment.
- 5. Close the box please note, once closed the box cannot be re-opened. Do not seal the mailing box with tape.

Despatching blood samples

You will be sending all the bloods, properly labelled and safely packaged, to the Royal Victoria Infirmary Laboratory in Newcastle-upon-Tyne. Pack the tubes for each respondent separately from those of other members of the household.

- Post the safe-box directly into a letter-box it is already paid for.
- Post the bloods in a standard letter box in <u>all</u> instances except rare circumstances,
 e.g. your local letter box is very old and does not take the safeboxes and you do
 not pass another on your daily route. If you do have to make a trip to the post
 office you will be able to get a fee.

Do not take the safe box to the post office because you dislike or distrust them. They are very expensive and save time so that you can get on with other things.

- The samples should be posted within 24 hours of being taken.
- Try to avoid taking a sample if you think that you will be unable to post it within 24 hours.
- If you miss the Saturday post collection, the sample must be posted on the following Monday morning.
- If you are unable to post the samples immediately, they can be stored at room temperature.

When you have posted the samples, fill in the time and date of posting on the Office Copy of the Despatch Notes and return this to Brentwood with the Consent Forms.

E. HEIGHT MEASUREMENT

Introduction

For ELSA, nurses are taking the height (both standing and sitting) and weight. It is important to measure everyone possible and to get both height and weight measurements from everyone who takes part as both are used to calculate BMI (Weight kg/height M²).

Accuracy is very important and we need to make sure that everyone is measuring in **same way**.

STANDING HEIGHT MEASUREMENT

The equipment

You are provided with a portable stadiometer. It is a collapsible device with a sliding head plate, a base plate and four connecting rods marked with a measuring scale.

Please take great care of this equipment. It is delicate and expensive. Particular care needs to be paid when assembling and dismantling the stadiometer and when carrying and repacking it in the bag provided.

- Do not bend the head or base plate.
- Do not bend the rods.
- Do not drop it and be careful not to knock the corners of the rods or base plate pin.
- Assemble and dismantle the stadiometer slowly and carefully.

The stadiometer will be sent to you in a tennis bag. Always store the stadiometer in the bag when it is not in use and always pack the stadiometer carefully in the bag whenever you are sending it on by courier.

The rods

There are four rods marked with a measuring scale divided into centimetres and then further subdivided into millimetres. (If you are not familiar with the metric system note that there are ten millimetres in a centimetre and that one hundred centimetres make a metre). The rods are made of plastic and you must avoid putting any kind of pressure on them which could cause them to break. Be very careful not to damage the corners of the rods as this will prevent them from fitting together properly and will lead to a loss of accuracy in the measurements.

The base plate

Be careful not to damage the corners of the base plate as this could lead to a loss of accuracy in the measurements.

Protruding from the base plate is a section onto which you attach the rods in order to assemble the stadiometer. Damage to the corners of this section may mean that the rods do not stand at the correct angle to the base plate when the stadiometer is assembled and the measurements could be affected.

The head plate

There are two parts to the head plate; the plate and the spirit level. Please be careful as experience has shown these are easily broken.

Assembling the stadiometer

- 1. Lie the base plate flat on the floor area where you are to conduct the measurements.
- 2. Take the first rod, it should fit snugly into the base plate. Place the other three rods in the correct order, one on top of each other.

Dismantling the stadiometer

Follow these rules:

- 1. Before you begin to dismantle the stadiometer you must remember to lower the head plate to its lowest position, so that the blade is lying flat against the base plate.
- 2. Remove one rod at a time.

The Protocol

- 1. Ask the respondent to remove their shoes in order to obtain a measurement that is as accurate as possible.
- 2. Assemble the stadiometer and raise the headplate to allow sufficient room for the respondent to stand underneath it. Double check that you have assembled the stadiometer correctly.
- 3. The respondent should stand with their feet flat on the centre of the base plate, feet together and heels against the rod. The respondent's back should be as straight as possible, preferably against the rod but NOT leaning on it. They should have their arms hanging loosely by their sides. They should be facing forwards.
- 4. Move the respondent's head so that the Frankfort Plane is in a horizontal position (i.e. parallel to the floor). The Frankfort Plane is an imaginary line passing through the external ear canal and across the top of the lower bone of the eye socket, immediately under the eye (see diagram on the Frankfort Plane Card in your workpack). This position is important if an accurate reading is to be obtained. An additional check is to ensure that the measuring arm rests on the crown of the head, i.e. the top back half. To make sure that the Frankfort Plane is horizontal, you can use the Frankfort Plane Card to line up the bottom of the eye socket with the flap of skin on the ear. The Frankfort Plane is horizontal when the card is parallel to the stadiometer arm.
- 5. Instruct the respondent to keep their eyes focused on a point straight ahead, to breathe in deeply and to stretch to their fullest height. If after stretching up the respondent's head is no longer horizontal, repeat the procedure. It can be difficult to determine whether the stadiometer headplate is resting on the respondent's

- head. If so, ask the respondent to tell you when s/he feels it touching their head by raising an arm.
- 6. Ask the respondent to step forwards. If the measurement has been done correctly the respondent will be able to step off the stadiometer without ducking their head. Make sure that the head plate does not move when the respondent does this.
- 7. The head plate attachment contains the pointer from which to read the measurement. Look at the arrow within the pointer and take the reading from this point and record the respondent's height in centimetres and millimetres. You may at this time record the respondent's height onto their Measurement Record Card and at the question *MbookHt* you will be asked to check that you have done so. At that point the computer will display the recorded height in both centimetres and in feet and inches. At *RelHite* you will be asked to code whether the measurement you obtained was reliable or unreliable.
- 8. Height must be recorded in centimetres and millimetres, eg 176.5 cms. If a measurement falls between two **millimetres**, it should be recorded to the **nearest even millimetre**. For example, if the respondent's height is between 176.4 and 176.5 cms, you should round it down to 176.4. Likewise, if a respondent's height is between 176.5 and 176.6 cms, you should round it up to 176.6 cms.
- 9. Push the head plate high enough to avoid any member of the household hitting their head against it when getting ready to be measured.

Height refused, not attempted or attempted but not obtained

At *RespHts* you are asked to code whether the measurement was taken, refused, attempted but not obtained or not attempted. If for any reason you cannot get a height measurement, enter the appropriate code at this question and you will automatically be routed to the relevant follow up questions (*ResNHi and NoHtBC*) which will allow you to say why no measurement was obtained.

Additional points - all respondents

- 1. If the respondent cannot stand upright with their back against the stadiometer and have their heels against the rod (e.g. those with protruding bottoms) then give priority to standing upright.
- 2. If the respondent has a hair style which stands well above the top of their head, (or is wearing a turban), bring the headplate down until it touches the hair/turban. With some hairstyles you can compress the hair to touch the head. If you cannot lower the headplate to touch the head, and think that this will lead to an unreliable measure, record this at question *RelHite*. If it is a hairstyle that can be altered, e.g. a bun, if possible ask the respondent to change/undo it.
- 3. If the respondent is tall, it can be difficult to line up the Frankfort Plane in the way described. When you think that the plane is horizontal, take one step back to check from a short distance that this is the case.
- 4. You may need to tip the stadiometer to read the height of tall respondents.

5. If the respondent has long hair then you may need to tuck it behind their ear in order to position the head properly. If you do this then ask permission to touch it first!

SITTING HEIGHT

Why we do this test

We measure sitting height as well as standing height to get an idea of body proportions, i.e. the length of the legs relative to the body trunk. Although both trunk and leg length reflect conditions in childhood as well as genetic factors, the length of the leg is thought to be a better indicator of early life conditions (nutrition) affecting growth.

Eligibility

Everyone who gives consent is eligible for this test.

Procedure

- 1. Remove the top 1 or 2 sections of the measuring rod
- 2. Find a hard chair with as flat a seat as possible. Place the base of the stadiometer on the chair with the measuring rod at the back
- 3. Ask the respondent to sit on the base plate with his/her back to the rod. Ensure that the respondent is sitting as far back and as upright as possible. Try to ensure that the rod is as vertical as possible. Check that their back is as straight as possible
- 4. Position the head in the Frankfort Plane. Bring the head plate down until it gently rests on the highest part of the subject's head. Press down to flatten their hair if necessary.
- 5. Take the height reading indicated by the arrowhead. As with standing height, sitting height must be recorded in centimetres and millimetres, eg 176.5 cms. If a measurement falls between two **millimetres**, it should be recorded to the **nearest even millimetre**. For example, if the respondent's height is between 176.4 and 176.5 cms, you should round it down to 176.4. Likewise, if a respondent's height is between 176.5 and 176.6 cms, you should round it up to 176.6 cms.

Troubleshooting:

- 1. On being instructed to sit back as far as possible many people will lean against a measuring rod. Encourage them to sit upright, so that the rod is vertical.
- 2. If there isn't a suitable chair or table it might be possible to use stairs: in some houses there are a few steps and then a level section on which you can place the base plate (the measure can then be taken with the respondent's thighs supported). As a last resort, measure sitting height with the respondent on the floor: place the base of the stadiometer onto the floor with the measuring rod against a wall. Ask the respondent to sit on the base plate with their back against

the rod and their legs as straight as possible lying in front of them. Take care that the subject is sitting upright. Continue as above. Before you attempt to take the measure with the respondent seated on the floor you should ensure that both you and the respondent are satisfied that this will be safe.

F. WEIGHT MEASUREMENTS

Introduction

For ELSA, nurses are taking the height (both standing and sitting) and weight. It is important to measure everyone possible and to get both height and weight measurements from everyone who takes part as both are used to calculate BMI (Weight kg/height M²).

Because of this, it is particularly important that if you have any **problems with equipment** that you sort them out as soon as possible. We could lose a lot of weight measurements because of equipment not working. If there is a problem with your equipment please contact Helen Selwood or your supervisor straight away.

Equipment: Tanita THD-305 Scales

The scales take four 1.5v AA batteries. Please ensure that you have some spare batteries with you in case you need to replace them. If you need to change the batteries, please claim the money back in the usual way. The batteries used are commonly available. We don't want to lose measurements because of faulty equipment, and you might have to go to back to a household if this happens.

The battery compartment is on the bottom of the scales. As there is no on/off switch, when you receive your scales the batteries may be packed separately or one of the batteries may have been turned the wrong way round. Before going out to work, place the batteries correctly and check that the scales work. If they do not, check that the batteries are connected properly and try new batteries. If they do still not work, report the fault to your Area Manager/Health Manager or directly to Brentwood.

When you are storing the scales or sending them through the post please make sure you remove the batteries to stop the scales turning themselves on.

The reading is only in metric units, but as for height, the computer provides a conversion. If the respondent would like to know their weight in stones and pounds you will be able to tell them when the computer has done the calculation.

The Protocol

- 1. Weigh the respondent on a hard and even surface if possible. Carpets may affect measurements. The CAPI will ask you to code what surface you did the measurements on.
- 2. Switch on the scales by pressing the button on the bottom right hand corner of the scales. The readout should display 888.8 momentarily. If this is not

- displayed check the batteries. If the batteries are OK, report the problem to Brentwood. While the scales read 888.8 do not attempt to weigh anyone.
- 3. Ask the respondent to remove shoes, heavy outer garments such as jackets and cardigans, heavy jewellery, loose change and keys.
- 4. Turn the scales on with your foot again. Wait for a display of 0.0 before the respondent stands on the scales.
- 5. Ask the respondent to stand with their feet together in the centre and their heels against the back edge of the scales. Their arms should be hanging loosely at their sides and their head should be facing forward. Ensure that they keep looking ahead it may be tempting for the respondent to look down at their weight reading. Ask them not to do this and assure them that you will tell them their weight afterwards if they want to know.
- 6. The posture of the respondent is important. If they stand to one side, look down, or do not otherwise have their weight evenly spread, it can affect the reading.
- 7. The scales will take a short while to stabilise. The weight reading will flash on and off when it has stabilised. If the respondent moves excessively while the scales are stabilising you may get a false reading. If you think this is the case reweigh the respondent.
- 8. The scales have been calibrated in kilograms and 100 gram units (0.1 kg). Record the reading into the computer at the question *Weight* before the respondent steps off the scales. At question *MBookWt* you will be asked to check that you have entered the respondent's weight onto their Measurement Record Card. At that point the computer will display the measured weight in both kilos and in stones and pounds.
- 9. The scales should switch off automatically a few seconds after the respondent steps off them.

WARNING

The maximum weight registering accurately on the scales is 130 kg ($20\frac{1}{2}$ stone). If you think the respondent exceeds this limit code them as "Weight not attempted" at *RespWts*. The computer will display a question asking them for an estimate. Do not attempt to weigh them.

Additional Points

Do not weigh a respondent if they are too frail or unable to stand up straight (or anyone who is pregnant). If the respondent is quite frail or unstable, put the scales near a stable surface so the respondent can steady themselves.

The scales are fragile and expensive. Put them on the floors of your car, not the back seat, or carry them around in the boot of your car in the stadiometer bag. Be careful with the corners as they are easily damaged.

Make sure you know how your scales work: have a practice with friends and family.

Weight refused, not attempted or attempted but not obtained

At *RespWts* you are asked to code whether the measurement was taken, refused, attempted but not obtained, or not attempted. If for any reason you cannot get a weight measurement, enter the appropriate code at this question and you will automatically be routed to the relevant follow up questions (*ResNWt* and *NoWtBC*) which will allow you to say why no measurement was obtained.

G. WAIST AND HIP CIRCUMFERENCES

Purpose

There has been increasing interest in the distribution of body fat as an important indicator of increased risk of cardiovascular disease. The waist-to-hip ratio is a measure of distribution of body fat (both subcutaneous and intra-abdominal). Analyses suggest that this ratio is a predictor of health risk like the body mass index (weight relative to height).

Equipment

Insertion tape calibrated in mm, with a clear plastic buckle at one end.

The tape is passed around the circumference and the end of the tape is inserted through the buckle at the other end of the tape.

Eligibility

The respondent is ineligible for the waist and hip measurement if they:

- a. are chairbound
- b. have a colostomy or ileostomy

If (a) and/or (b) apply, record this on the computer (question *WHPNABM*). If there are any other reasons why the measurement was not taken, record this on the computer and type in the reason.

Preparing the respondent

You will have asked the respondent to wear light clothing for your visit. Explain to the respondent the importance of this measurement and that clothing can substantially affect the reading.

If possible, without embarrassing you or the respondent, ensure that the following items of clothing are removed:

- all outer layers of clothing, such as jackets, heavy or baggy jumpers, cardigans and waistcoats
- shoes with heels
- tight garments intended to alter the shape of the body, such as corsets, lycra body suits and support tights

If the respondent is wearing a belt, ask them if it would be possible to remove it or loosen it for the measurement.

Pockets should be emptied.

If the respondent is not willing to remove bulky outer garments or tight garments and you are of the opinion that this will significantly affect the measurement, record this on the Schedule at questions *WJRel* and/or *HJRel*.

If possible, ask the respondent to empty their bladder before taking the measurement.

Using the insertion tape

All measurements should be taken to the nearest millimetre. If the length lies between two millimetres, then round to the nearest even millimetre. For example, if the measurement is halfway between 68.3 and 68.4, round up to 68.4. And if the measurement is halfway between 68.8 and 68.9, round down to 68.8.

Please note that you must enter the measurement to one decimal place - do not round it to the nearest centimetre. For example, enter '78.2', not just '78'. If you do not enter a decimal point, the computer will give you a warning. If the measurement is exactly, say, 78cm, then all you need to do is suppress the warning and it will automatically fill in the '.0' for you. Otherwise, you must go back and amend your answer. As a further check, the computer will also ask you to confirm that a measurement ending in '.0' is correct.

Ensure the respondent is standing erect in a relaxed manner and breathing normally. Weight should be evenly balanced on both feet and the feet should be about 25-30cm (1 foot) apart. The arms should be hanging loosely at their sides.

If possible, kneel or sit on a chair to the side of the respondent.

Pass the tape around the body of the respondent and insert the plain end of the tape through the plastic buckle at the other end of the tape.

To check the tape is horizontal you have to position the tape on the right flank and peer round the participant's back from his/her left flank to check that it is level. This will be easier if you are kneeling or sitting on a chair to the side of the respondent.

Hold the buckle flat against the body and flatten the end of the tape to read the measurement from the outer edge of the buckle. Do not pull the tape towards you, as this will lift away from the respondent's body, affecting the measurement.

Measuring waist circumference

- 1. The waist is defined as the point midway between the iliac crest and the costal margin (lower rib). To locate the levels of the costal margin and the iliac crest use the fingers of the right hand held straight and pointing in front of the participant to slide upward over the iliac crest. Men's waists tend to be above the top of their trousers whereas women's waists are often under the waistband of their trousers or skirts.
- 2. Do not try to avoid the effects of waistbands by measuring the circumference at a different position or by lifting or lowering clothing items. For example, if the respondent has a waistband at the correct level of the waist (midway between the lower rib margin and the iliac crest) measure the waist circumference over the waistband.
- 3. Ensure the tape is horizontal. Ask the participant to breathe out gently and to look straight ahead (to prevent the respondent from contracting their muscles or holding their breath). Take the measurement at the end of a normal expiration. Measure to the nearest millimetre and record this on the schedule. Remember the rounding rule that if the length lies between two millimetres, then round to the nearest even millimetre
- 4. Repeat this measurement again once you have measured the hip circumference.
- 5. If you are of the opinion that clothing, posture or any other factor is significantly affecting the waist measurement, record this on the schedule.

Measuring hip circumference

- 1. The hip circumference is defined as being the widest circumference over the buttocks and below the iliac crest. To obtain an accurate measurement you should measure the circumference at several positions and record the widest circumference.
- 2. Check the tape is horizontal and the respondent is not contracting the gluteal muscles. Pull the tape, allowing it to maintain its position but not to cause indentation. Record the measurement on the schedule to the nearest millimetre. Remember the rounding rule that if the length lies between two millimetres, then round to the nearest even millimetre
- 3. If clothing is significantly affecting the measurement, record this on the schedule.
- 4. Repeat this measurement again once you have done the second waist measurement.

General points

The tape should be tight enough so that it doesn't slip but not tight enough to indent clothing. If clothing is baggy, it should be folded before the measure is taken.

If the respondent is large, ask him/her to pass the tape around rather than having to "hug" them. Remember though to check that the tape is correctly placed for the measurement being taken and that the tape is horizontal all the way around.

If your second waist or hip measurement differs by 3cm or more from the first, the computer will give you a warning. If you have made a mistake when entering the figures (e.g. typed 78.2 instead of 68.2), you should type over the mistake. If it was not a mistake, you should suppress the warning and take a third measurement.

If you have problems palpating the rib, ask the respondent to breathe in very deeply. Locate the rib and as the respondent breathes out, follow the rib as it moves down with your finger. If your respondent has a bow at the back of her skirt, this should be untied as it may add a substantial amount to the waist circumference.

Female respondents wearing jeans may present a problem if the waistband of the jeans is on the waist at the back but dips down at the front. It is essential that the waist measurement is taken midway between the iliac crest and the lower rib and that the tape is horizontal. Therefore in this circumstance the waist measurement would be taken on the waist band at the back and off the waist band at the front. Only if the waistband is over the waist all the way around can the measurement be taken on the waistband. If there are belt loops, the tape should be threaded through these so they don't add to the measurement.

Recording problems

We only want to record problems that will affect the measurement by more than would be expected when measuring over light clothing. As a rough guide only record a problem if you feel it affected the measurements by more than 0.5cm. We particularly want to know if the waist and hip measurements have been affected differently.

H. LUNG FUNCTION

Purpose

Lung function tests objectively assess respiratory impairment if it is present. We will be measuring forced expiratory volume in one second (FEV 1), forced vital capacity (FVC) and peak expiratory flow (PEF). These measures can be reduced for a wide range of reasons, eg physical unfitness, smoking, chronic bronchitis, asthma that has been poorly controlled for many years, some muscular disorders and many others. At a population level, these measures tell us a lot about the respiratory health of the population, and are also indicators of general health.

The definition of an acceptable level of lung function depends on the person's age, sex and height. A diagnosis of abnormality is not based on measurement on a single occasion but is rather based on several measurements and on the person's clinical history. Prior to making the measurement, we wish you to explain this to the respondents.

Eligibility

All respondents are eligible, including any chairbound respondents, unless they:

- a) have had abdominal or chest surgery in the preceding three weeks.
- b) have been admitted to hospital with a HEART complaint in the preceding six weeks.
- c) have had eye surgery in the preceding 4 weeks.
- d) are pregnant.
- e) Those with a trachiostomy.

Equipment

The Vitalograph Escort spirometer and case

1 litre calibration syringe Disposable cardboard mouthpieces

Use of the spirometer

- 1. Allow the spirometer to equilibrate to room temperature before the lung function tests are performed. Unpack it as soon as possible and keep it away from the sun, fires or radiators.
- 2. Explain the test to the respondent. Demonstrate the blowing technique and ask the respondent to practise using a mouthpiece alone.
- 3. Turn on the spirometer using the on/off button. Check that the "low battery" symbol is not showing. (Note that the Micro will power down automatically if it is not used within two minutes.)
- 4. Wait a few seconds until the "blow" symbol appears, accompanied by two beeps.
- 5. Instruct the respondent to perform a forced expiratory manoeuvre as described below. If the blow is technically unsatisfactory, turn off the spirometer and redo steps 3 onwards.
- 6. On completion of the blow, the LCD will display FVC. Record this in the CAPI. Press the "down arrow" to display (in turn) FEV1 and PEF. Record in the CAPI.
- 7. **Switch off** the spirometer between each blow. This is important, otherwise the figures displayed will be those from the best of a series of tests, and not necessarily the last blow performed. We need to record all the results from three technically satisfactory blows.
- 8. Offer to record the lung function readings on the respondent's Measurement Record Card. Choose the highest reading of FVC, FEV1 and PEF, even if they come from different blows.
- 9. The CAPI will prompt you for the total number of blows the respondent made (including technically unsatisfactory or practice blows) and whether the respondent was standing or sitting (the latter is acceptable only for chairbound subjects).

Instruction of the respondent

Satisfactory measurement of lung function depends as much on adequate instruction and encouragement of the respondent as on the technical capacity of the spirometer.

- 1. The respondent should stand up (unless chairbound) and loosen tight clothing. Dentures need not be removed.
- 2. Explain that "you must try to blow out as much air as possible as hard and as fast as you can".
- 3. Demonstrate the correct technique yourself, using a mouthpiece unconnected to the spirometer. Explain that the mouthpiece should be held in place by the lips rather than the teeth and the lips should be wrapped firmly around it.
- 4. Demonstrate a blow, pointing out (afterwards) the need for full inspiration, a vigorous start to exhalation (for maximum peak flow) and sustained expiration (for accurate measurement of forced vital capacity). The blow should be at least 3 seconds duration and not interrupted by coughing, laughing or leakage of air. The torso should remain in an upright position throughout the blow (not hunched over at the end).
- 5. Give the respondent a clean disposable mouthpiece. Allow the respondent at least one practice blow with the mouthpiece alone. Correct their technique and offer further instruction or encouragement as necessary.
- 6. Attach the respondent's mouthpiece to the flowhead and hand the spirometer to them gently (sudden jerks can destabilise the unit). If a single beep sounds at this point, wait for the spirometer to stabilise, indicated by a further double beep, before proceeding with the test.
- 7. Ask the respondent to take as deep a breath as possible, keeping the spirometer away from their mouth, and then to hold the mouthpiece with their lips and seal their lips around it. Check that the spirometer is held below the flowhead and the subject's hand is not obstructing the flowhead outlet.
- 8. Then say "now blow!". As the respondent is blowing encourage him/her by saying "keep going, keep going, keep going...". Observe the respondent closely for satisfactory technique (see item 4 above).
- 9. Record the results as described in items 6-8 in the 'Use of spirometer' section above.
- 10. Aim to obtain **three technically satisfactory blows**. Most subjects should be able to manage this but there may be some who cannot. You must strike a balance between encouragement and over-insistence. Do not declare a blow unsatisfactory on the basis of the result alone. Pay close attention while the respondent is performing the test and repeat your demonstration a second or third time if necessary.

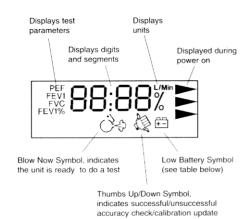
Technically unsatisfactory blows

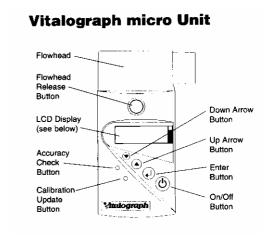
- Unsatisfactory start: excessive hesitation or "false start". It is probable that the spirometer will not record this blow (or record FVC as zero), but sometimes it will give a spurious reading.
- Laughing or coughing, especially during the first second of the blow. Some people will cough a little towards the end of expiration (particularly if this extends to 5 or 6 seconds) but this is acceptable.
- Holding the breath against a closed glottis (Valsalva manoeuvre). This results in spuriously high PEF!
- Leakage of air around the mouthpiece.
- Obstruction of the mouthpiece by tongue or teeth.
- Obstruction of the flowhead outlet by hands.

If the spirometer takes more than 3 seconds to display FVC after the end of the blow, it is likely that the results (particularly for FVC) are spurious. The test should be repeated.

The Structure of the Spirometer

Vitalograph micro Display





Symbol (on or flashing)	Condition	Result	Action
	Battery Low	You can perform test	Replace PP3 battery
+-	Battery nearly dead	You cannot perform test	Replace PP3 battery

Important points to note

- 1. Take a spare battery with you in case of battery failure.
- 2. Whenever the "ON" button is pressed to perform a new test, ensure that the spirometer is placed on a flat surface with the mouthpiece pointing upwards.
- 3. The respondent should hold the unit with the handle pointing **downwards** during the testing.
- 4. Once a month or after every 50 respondents remove the flowhead and clean it hot soapy water and allow it to dry overnight before refitting.
- 5. When necessary clean the exterior with a lint-free damp cloth. Do NOT clean the two white cylindrical filters on the top of the unit.

Calibration/accuracy test

- 1. Ensure that the spirometer and syringe have been in the same temperature environment for at least an hour.
- 2. Connect the spirometer, by the flow head, to the syringe and pump through a few litres of air. Then disconnect the spirometer.
- 3. Switch on the spirometer and press the small top most button to the left of the arrow keys. The display will show a number.
- 4. Check display is 01 if not adjust with up/down arrow keys.

- 5. Press the left arrow key (the enter button) and wait until display shows blow now symbol and thumbs down.
- 6. Making sure the syringe piston is fully withdrawn, connect the syringe to the flow head.
- 7. Using one swift, smooth stroke pump in the volume of air (about 1 second). Don't cover the outlet with your hand.
- 8. Listen for a double beep then withdraw the piston fully and repeat step 7 until 5 beeps occur. It is very important to wait for the double beep before withdrawing the piston each time.
- 9. If "thumbs up" is displayed, the spirometer has been correctly calibrated.
- 10. If a 'thumbs down' sign appears on the display, then the spirometer is outside the accuracy requirements contact Brentwood to arrange for a replacement.
- 11. Press the "On/Off" button to switch off.

Fault finding guide - see HSE

Nothing is displayed when the "ON" button is pressed:	 Replace battery Display panel failure – contact Brentwood The "ON" button is not being held down for long enough. 	
False readings suspected:	Ensure the unit is being held correctly during the test.Re-test accuracy.	
Calibration values vary greatly:	Ensure the correct calibration procedure is being followed.Start calibration syringe stroke sharply.	

I. PHYSICAL PERFORMANCE MEASURES

Introduction and purpose

The purpose of these tests is to objectively measure the overall health and level of disability of a large population of people aged 50 and over. Taken alongside the walking speed measurement that the interviewer takes, these measures form a battery of tests that have been shown to be highly predictive of level of disability, future use of health care and mortality. These tests will allow us to gather very important information about the respondents.

Eligibility criteria for the tests

You should be able to take measurements of nearly all of the respondents. However, in some cases it may not be possible or appropriate to do so. Do not force a respondent to be measured if it is clear that the measurement will be far from reliable, but whenever you think a reasonable measurement can be taken, do so. Also, do not take a measurement if you or the respondent consider it unsafe to do so. The measurements are introduced by some check questions. If the respondent answers positively at these questions s/he may not be able to complete the tests. Stop, discuss what the test involves and make your decision. If it has been decided to exclude a respondent from one test, do not automatically exclude them from the other tests. The CAPI will direct you to the next measure, and you should discuss each one in turn with the respondent.

Respondents should **not** be measured if:

- they are chairbound or wheelchair bound (although they may be able to do some of the tests).
- after discussion with them it becomes clear that they are too unsteady on their feet for these measurements.
- they find it painful to stand.
- you or the respondent consider it unsafe to conduct the measurement.

If the respondent is not willing to take part in the tests, for example saying that they are too busy, code as **Refused** and code the reason for refusal. DO NOT use the 'Not attempted' code for these cases.

Encouragement

Follow the instructions in the Protocol as closely as possible to describe the test and how to perform it properly. Do not provide additional encouragement beyond the language provided by the detailed instructions. After each measure, acknowledge the respondent's efforts but do not give feedback, as this may be discouraging. Neutral phrases such as "Thank you" or "That's fine" are examples of the kinds of things you could say, but you say whatever you are most comfortable with.

To some respondents the detailed verbal instructions may seem unnecessary. It may help to say that you are going to explain each test to the respondent in detail since this is the best way to make sure that everyone does the test in a similar manner.

Demonstrations

First explain and then demonstrate each manoeuvre for the respondent. Remind the respondent not to begin to do the manoeuvre until after you have demonstrated it. It may help to achieve this if the respondent is seated during your explanation and demonstration. It is very important that you demonstrate each step correctly. Experience has shown that respondents follow more closely what the interviewer does rather than what s/he says. If the respondent indicates that s/he does not understand the manoeuvre, demonstrate it again rather than relying on repeating verbal instructions. **Repeat the demonstration only once**. If the respondent still does not understand, skip the test and move to the next one. Do not 'coach' the respondent.

Aids

Walking Aids such as canes, walkers or crutches may <u>not</u> be used for the single and repeated chair stands test or for the balance or leg raise tests.

Safety precautions and prevention of injuries

Obstructions that could cause accidents should be removed. The participant should be questioned to ensure that the instructions have been understood. If a participant is uncomfortable performing a specific test or if you feel that a procedure is not safe for a given individual, the test should not be performed. If necessary, stabilise them lightly holding their arm or allowing them to lean against you until their feet are in position. If they feel unsteady, even with support, don't let them try the procedure. When the participant is performing the test, stand close enough to assist them if they begin to falter but far enough away not hinder them if they have to use their arms to maintain their balance. The respondent should ideally be positioned between you and a stable surface, such as a wall or table.

If you find yourself in a situation where the respondent appears to lose balance, you may want to help them to recover their balance by placing both hands on their trunk. If the respondent begins to fall it is not safe to try to catch them. It is more appropriate to attempt to steady them or, if necessary, to slowly ease them to the floor. Do not hold their arm, hold around their body. This will prevent the respondent **and you** from becoming injured.

If the respondent does fall call for help if appropriate, but if they are not injured, help them by first having them get on their knees or on all fours. Place a chair next to the respondent and have them support themselves onto the chair. If assistance is needed, lift under the shoulders – do not hold their arm, hold around their body. Do not try to lift the respondent alone from the floor or put yourself at risk. Remember to seek help if it is needed and to complete a report for any incident of this kind.

If the respondent loses their balance or falls, do not attempt to complete the measures.

It is strongly preferable to conduct the chair rise and balance measurements on a floor that is level and not carpeted. If all the household is carpeted, choose a floor with the thinnest and hardest carpet.

Footwear

It is strongly suggested that this activity is performed in shoes with very low or no heels. It is hard to perform normally with shoes with heels on. Ask the respondent if the footwear they are wearing is what they wear most of the time around the house. Soft soled, heel-less slippers, or just socks or tights should not be worn, since they may cause the respondent to slip. The respondent can do the measures in bare feet if they do not have appropriate shoes.

Content of balance measures

The balance measure (including leg raises) evaluates the respondents' ability to balance, using five components: side-by-side, semi-tandem and full tandem, and for

those aged 69 and under, leg raise with eyes open and leg raise with eyes closed. The CAPI programme will work out the respondent's age for you so you do not need to worry about selecting the correct route. However, you should understand how the measures differ between age groups.

- All ages start with the side by side for 10 seconds.
- If they pass the side by side they should then do the semi-tandem stand for 10 seconds.
- Respondents who pass the semi-tandem stand should then do the full tandem stand. If the respondent is aged 69 and under they should attempt the full tandem stand for 30 seconds. If the respondent is 70 or over they should only do the full tandem stand for 10 seconds.
- People aged 69 and under who successfully pass the side by side stand should then attempt the one-leg stand with their eyes open for 30 seconds.
- If respondents successfully pass the one-leg stand with their eyes open they should attempt it again with their eyes shut, again for 30 seconds.

For the side by side, semi-tandem and full-tandem stands, respondents are **not** permitted to practice first. For the one-leg stand, respondents are allowed one practice.

The positioning of the feet correctly is very important. If a respondent is unable to assume any of the positions themselves, do not help them by moving their feet. However, you can provide them support whilst they get into position. If they are unable to get into the correct position, record in the CAPI that the measure was not attempted. Splayed feet are also not permitted.

Equipment

The only equipment that you will need for the balance measures is a stopwatch.

For simple timing (i.e. without the split function):

- To get into the stopwatch mode repeatedly press the **MIDDLE** button labelled 'Mode' until 'SP' is shown at the bottom of the stopwatch display.
- To reset the stopwatch press the LEFT button labelled 'lap/reset'.
- To start the stopwatch press the **RIGHT** button labelled 'St./Stp'.
- To stop the stopwatch press the **RIGHT** button labelled 'St./Stp'.

For split timing (i.e. for timing 10 chair rises):

- To start the stopwatch press the **RIGHT** button labelled 'St./Stp'.
- To take the time at the 5th rise press the **LEFT** button labelled 'lap/reset'.
- To take the time at the 10th rise press the **RIGHT** button labelled 'St./Stp'.
- Then write down the time on the display (i.e. the time for the 5th rise).
- To find out the time at the 10th rise press the **LEFT** button labelled 'lap/reset'.
- To reset the stopwatch press the LEFT button labelled 'lap/reset'.

You should be given a Split-time Stopwatch Instruction Card in your briefing pack. You may want to take this with you on visits to remind you how to use the stopwatch.

Nurse script

You have been provided with a script card for each measure so that you can read the instructions when you are away from the CAPI.

1) Side-by side stand

Balance and co-ordination are needed to carry out successfully every day locomotor function at reasonable speeds and to prevent falls. The exercise is used as a screen for the ability to do the semi- and full tandem stands.

Procedures

Explain the purpose of the tests:

"I would now like to carry on with some more physical performance measurements, this will involve asking you to move your body in different ways. I will first describe and show each movement to you, then I'd like you to try to do it. If you cannot do a particular movement, or if you feel it would be unsafe to try to do it, please tell me and we'll move on to the next one. Let me emphasize that I do not want you to try to do any exercise that you feel might be unsafe. Do you have any questions before we begin?"

Check the respondent's status. Ask 'Do you have any problems from recent surgery, injury or other health conditions that might prevent you from standing up from a chair and balancing?' If the answer is 'yes', discuss with them whether they should attempt each test given their physical problems after describing each test. Do not assume a respondent is too physically limited to attempt a test without discussing it with them. However, remember that the respondent's health is paramount.

First explain and then demonstrate the side by side stand to the respondent:

Now I will show you the FIRST movement. I want you to try to stand with your feet together, side by side, for about 10 seconds. You may use your arms, bend your knees or move your body to maintain your balance, but try not to move your feet. Try to hold this position until I tell you to stop. When I want you to start, I will say: 'ready, begin'. **DEMONSTRATE.** Do you feel that would be safe?

If the respondent says 'no', do not attempt this movement.

If the respondent says it is safe say 'When I want you to start, I will say 'ready, begin'. Ask the respondent to stand up. Stand to the side of the respondent. Say: 'ready, begin.' Press the start button to **start the stopwatch as soon as the respondent gets into the position and is free of support**. If necessary provide gentle support to the respondent's arm to help them into the position. Say: 'ready, begin' and then let go of their arm.

Stop the stopwatch and say 'stop' after 10 seconds or when the participant steps out of position or grabs your arm.

If the participant is unable to hold the position for 10 seconds, record the time in seconds to two decimal place in the CAPI. If the respondent did not attempt the measure, record the reason.

If the participant is successful record this and the programme will direct you to the semi-tandem stand.

2) Semi tandem stand

Explain and demonstrate the semi-tandem stand to the respondent:

'Now I will show you the NEXT movement. I want you to try to stand with the side of the heel of one foot touching the big toe of the other foot for about 10 seconds. You may put either foot in front whichever is more comfortable for you. You may use your arms, bend your knees or move your body to maintain your balance, but try not to move your feet. Try to hold this position until I tell you to stop. When I want you to start, I will say: 'ready, begin'. **DEMONSTRATE.** Do you feel that would be safe?

If the respondent says 'no', do not attempt this movement.

If the respondent says it is safe say 'When I want you to start, I will say 'ready, begin'. Ask the respondent to stand up. Stand to the side of the respondent. Say: 'ready, begin.' Press the start button to **start the stopwatch as soon as the respondent gets into the position and is free of support**. If necessary provide gentle support to the respondent's arm to help them into the position. Say: 'ready, begin' and then let go of their arm.

Stop the stopwatch and say stop after 10 seconds or when the participant steps out of position or grabs your arm.

If the participant is unable to hold the position for 10 seconds, record the time in seconds to two decimal place in the CAPI. The programme will direct you to the chair raise. If the respondent did not attempt the measure, record the reason.

If the participant is successful record this and the programme will direct you to the full tandem stand.

3) Full Tandem stand - If the respondent is aged 50-69

Explain and then demonstrate the full tandem stand to the respondent using the following script:

Now I will show you the NEXT movement. I want you to try to stand with the heel of one foot in front of and touching the toes of the other foot for about 30 seconds. You may put either foot in front whichever is more comfortable for you. You may use your arms, bend your knees or move your body to maintain your balance, but try not to move your feet. Try to hold this position until I tell you to stop. **DEMONSTRATE**. Do you feel that would be safe?

If the respondent says 'no', do not attempt this movement.

If the respondent says it is safe say 'When I want you to start, I will say 'ready, begin'. Ask the respondent to stand up. Stand to the side of the respondent. Say: 'ready, begin.' Press the start button to **start the stopwatch as soon as the respondent gets into the position and is free of support**. If necessary provide gentle

support to the respondent's arm to help them into the position. Say: 'ready, begin' and then let go of their arm.

Stop the stopwatch and say *stop* after <u>30 seconds</u> or when the participant steps out of position or grabs your arm.

Record the outcome in the CAPI. If the respondent is successful the CAPI will direct you to the leg raises.

If the participant is unable to hold the position for 30 seconds, record the time in seconds to two decimal place in the CAPI. If the respondent did not attempt the measure, record the reason.

4) Full Tandem stand - If the respondent is aged 70+

Explain and then demonstrate the full tandem stand to the respondent using the following script:

Now I will show you the NEXT movement. I want you to try to stand with the heel of one foot in front of and touching the toes of the other foot for about 10 seconds. You may put either foot in front whichever is more comfortable for you. You may use your arms, bend your knees or move your body to maintain your balance, but try not to move your feet. Try to hold this position until I tell you to stop. **DEMONSTRATE**. Do you feel that would be safe?

If the respondent says 'no', do not attempt this movement.

If the respondent says it is safe then allow them to practise the position once. Then say 'When I want you to start, I will say 'ready, begin'. Ask the respondent to stand up. Stand to the side of the respondent. Say: 'ready, begin.' Press the start button to start the stopwatch as soon as the respondent gets into the position and is free of support. If necessary provide gentle support to the respondent's arm to help them into the position. Say: 'ready, begin' and then let go of their arm.

Stop the stopwatch and say stop after $\underline{10 \text{ seconds}}$ or when the participant steps out of position or grabs your arm.

Record the outcome in the CAPI. If the respondent is successful the CAPI will direct you to the leg raise. If the participant is unable to hold the position for 10 seconds, record the time in seconds to two decimal places in the CAPI. If the respondent did not attempt the measure, record the reason.

5) Leg raise with eyes open

This measure should only be carried out if the respondent is aged between 50 and 69 and if they passed the side by side stand.

The leg raises should be performed adjacent to a stable surface, e.g. a table or wall and the nurse should be positioned to the other side of the participant.

The respondent can put their raised leg in front, to the back or to the side but they should not hook it round or rest it on their other leg.

First explain and then demonstrate the move to the respondent:

Now I will show you the NEXT movement. I want you to try to stand on one leg, whichever one you want, and raise the other leg off the ground a few inches. Stand for as long as you can – I will stop you at 30 seconds. You may use your arms, bend your knees or move your body to maintain your balance, but try not to move your feet. Try to hold this position until I tell you to stop. **DEMONSTRATE.** Do you feel that it would be safe to do this?

If the respondent says 'no', do not attempt this movement.

If the respondent says it is safe, then allow them to practise the position once (if after this practice you or the respondent feel that it would be unsafe to proceed, the measure should be discontinued). Then say 'When I want you to start, I will say 'ready, begin'. Ask the respondent to stand up. Stand to the side of the respondent. Say: 'ready, begin.' Press the start button to **start the stopwatch as soon as the respondent raises one foot off the ground and is free of support**. If necessary provide gentle support to the respondent's arm to help them into position. Say: 'ready, begin' and then let go of their arm.

Stop the stopwatch and say 'stop' either a) when the raised leg touches the floor as the respondent loses their balance or b) after 30 seconds, whichever happens first.

Record the outcome in the CAPI. If the participant is unable to hold the position for 30 seconds, record the time they held the position for. If the participant is successful record this and the CAPI will direct you to the leg raise with eyes shut.

For the leg raise measure, you should allow the respondent to have up to two 'false starts', ie they lose their balance and put their leg down almost **immediately** after you start timing. If they lose balance after this stage then you should not consider it as a false start and you should record the time they held the position for.

6) Leg raise with eyes shut

This measure should only be carried out if the respondent passed the leg raise with their eyes open.

First explain and then demonstrate the position to the respondent:

Now I would like you to repeat the procedure one more time, this time with your eyes closed. I want you to close your eyes, and try to stand on one leg, whichever one you want, and raise the other leg off the ground a few inches. Stand for as long as you can - I will stop you at 30 seconds. You may use your arms, bend your knees or move your body to maintain your balance, but try not to move your feet. Try to hold this position until I tell you to stop. **DEMONSTRATE.** Do you feel that it would be safe to do this?

If the respondent says 'no', do not attempt this movement.

If the respondent says it is safe then allow them to practise the position once (if after this practice you or the respondent feel that it would be unsafe to proceed, the measure should be discontinued). Then say 'When I want you to start, I will say

'ready, begin'. Ask the respondent to stand up. Stand to the side of the respondent. Say: 'ready, begin.' Press the start button to **start the stopwatch as soon as the respondent raises one foot off the ground, has their eyes closed and is free of support**. If necessary provide gentle support to the respondent's arm to help them into position. Say: 'ready, begin' and then let go of their arm.

Stop the stopwatch and say 'stop' either a) when the raised leg touches the floor as the respondent loses their balance, or b) if they open their eyes, or c) after 30 seconds, whichever happens first.

If the participant is unable to hold the position for 30 seconds, record the time they held the position for.

If the participant is successful record this.

7) Chair rise measure

Content

The chair rise provides a measure of lower body strength, and has two components: a single rise without the use of arms, and repeated rises from a firm chair. The repeated chair rise test differs depending on the respondent's age, as follows:

- Age 69 and under 10 chair rises
- Age 70 and over 5 chair rises

Equipment

- 1. Stopwatch (see instructions above)
- 2. Chair

This should be an armless, straight-backed chair. Kitchen or dining chairs may be suitable in many homes. If an ideal chair is not available, the following criteria for chair selection should be used in the order given:

- a) Armless, rather than with arms.
- b) Firmness: the firmer the better.
- c) Do not use beds, cots, folding chairs, garden chairs, chairs with wheels or chairs that swivel.

a) Single Chair Rise

This exercise is used to screen for the ability to do repeated chair stands. Please note the chair rise should not be conducted on anyone who is not able to stand up without assistance. Walking aids (such as walker or cane) are not permitted in this test.

First check for availability of a suitable chair.

Explain and then demonstrate the move to the respondent:

The next test measures the strength in your legs. I want you to try to stand up from a firm straight-backed chair, like a dining chair. First, fold your arms across your chest and sit so that your feet are on the floor; then stand up keeping your arms folded across your chest. **DEMONSTRATE.** Do you feel it would be safe to do this?

If the participant cannot rise without using arms, say 'Okay, try to stand up using your arms'.

Place the back of the chair against a wall to steady it. You should stand next to the respondent to provide assistance if they lose their balance. The respondent's feet should remain on the floor if possible.

Record the outcome of the single chair stand.

If the respondent refuses to try the single chair stand or is unable to stand on their own without using their arms to push off, then do not attempt to administer the repeated chair rises.

b) Repeated Chair Rises

This is a further test of lower body strength, balance, and endurance. It involves measuring the time required to stand up from a chair and sit down in a chair five or ten times without using their arms.

Use the same chair in the same place as in the single chair rise.

If the respondent is aged 50 to 69:

If the respondent completed the single chair rise without using their arms, they are eligible to attempt the repeated chair rises.

Explain and then demonstrate the move to the respondent:

Now I would like you to repeat the procedure but this time I want you to stand up straight as quickly as you can 10 times, without stopping in between and without using your arms to push off. After standing up each time, sit down and then stand up again. Keep your arms folded across your chest. I'll be timing you with a stopwatch. **DEMONSTRATE.** Do you feel it would be safe to do that?

There is no need to demonstrate the full ten rises. Rise twice, counting out loud 'one, two', sit back down and say 'all the way through to...' and rise two more times counting out loud 'nine, ten'.

Ask the respondent to resume the sitting position they were in just before standing up, with their feet resting on the floor and their arms folded across the chest. When the participant is properly seated, say 'ready, begin'. **Start the stopwatch WHEN YOU SAY THIS**. Count out loud as s/he rises each time, up to ten times. A rise is complete when the respondent is fully standing with their back straight. When the respondent completes the fifth rise, press the split timer on the stopwatch. Continue counting out loud. When the respondent has straightened up completely for the tenth time, stop the stopwatch. The respondent's feet should remain on the floor if possible during the rises.

Stop if the participant becomes too tired or short of breath during the repeated chair stands. Also stop:

- If the participant uses their arms,
- If after 1 minute the participant has not completed all the rises,

• At your discretion, if you are concerned for the participant's safety.

If the participant stops and appears to be fatigued before completing the rises, ask *Can you continue?* If the participant says "Yes," continue timing until 60 seconds has elapsed. If they say 'no', stop the stopwatch and record the number of completed stands they did without using their arms.

Be careful to enter the time from the first five stands first, before retrieving the time for the 10 stands from the stopwatch's memory. See instructions above. Use the stopwatch instruction sheet if necessary.

If the respondent is aged 70 or over:

If the respondent completed the single chair stand without using their arms, they are eligible to attempt the repeated chair rises.

Explain and then demonstrate the move to the respondent:

Now I would like you to repeat the procedure but this time I want you to stand up straight as quickly as you can 5 times, without stopping in between and without using your arms to push off. After standing up each time, sit down and then stand up again. Keep your arms folded across your chest. I'll be timing you with a stopwatch. **DEMONSTRATE.** Do you feel it would be safe to do that?

There is no need to demonstrate the full five rises. Rise twice, counting out loud 'one, two', sit back down and say 'all the way through to five'.

Ask the respondent to resume the sitting position they were in just before standing up, with their feet resting on the floor and their arms folded across the chest. When the participant is properly seated, say 'ready, begin'. **Start the stopwatch WHEN YOU SAY THIS**. Count out loud as the respondent rises each time, up to five times. A rise is complete when the respondent is fully standing with their back straight. When the respondent has straightened up completely for the fifth time, stop the stopwatch. The respondent's feet should remain on the floor if possible during the rises.

Stop if the participant becomes too tired or short of breath during the repeated chair stands. Also stop:

- If the participant uses their arms,
- If after 1 minute the participant has not completed all the rises,
- At your discretion, if you are concerned for the participant's safety.

If the participant stops and appears to be fatigued before completing the five stands, ask *Can you continue?* If the participant says "Yes," continue timing until 60 seconds has elapsed. If they says 'no' stop the stopwatch and record the number of stands completed by the respondent without using their arms.

Record the outcome of the repeated chair rise in the CAPI.

J. SALIVA SAMPLING

Why we are doing this test

We plan to measure cortisol levels in saliva. Cortisol levels vary with "stress" so the results can be used to explore the relationship between "stress" and other aspects of the respondent's health.

Eligibility

All core members aged 79 and under who give their written consent are eligible for this test.

Equipment

6 Salivettes in a holder (Providing one extra for the respondent to do a practice sample with the nurse and a spare one to be left with the respondent) Transparent plastic bag to put the salivettes in Jiffy envelope to post the bag of samples back Log book

Procedure

- 1. Obtain written consent on the appropriate Consent Form. Explain why written consent is needed and how important it is.
- 2. Explain why we are interested in people's saliva.
- 3. With your demo Salivettes show the respondent how to flip off the cap and take out the cotton swab (you and the respondent should not touch the swab). Talk through putting it in the mouth to soak (you don't have to actually do it yourself). The plastic coat on the swab should not be peeled off. The swab should be gently chewed until it is saturated, which usually takes about a minute. Then put the swab back into the Salivette and cap it.
- 4. Ask the respondent to provide a practice sample to check they are doing it correctly this can then be discarded.
- 5. Explain the timings of the sample, mentioning the coloured tubes.
- Tube 1 (orange) is to be used for an early morning sample, upon waking. The respondent should take care to be fully awake and should be sitting up in bed.
- Tube 2 (pink) is to be used 30 minutes after awakening (i.e. 30 minutes after doing the orange sample).
- Tube 3 (blue) is for a sample at 7pm.
- Tube 4 (green) is for a sample just before the respondent goes to bed.
- Emphasise that the samples must be taken on the <u>same</u> day.
- 6. Say that the date and time should be written on the label, **in biro** while collecting the sample. Without a recorded sampling time the cortisol results will be impossible to interpret.
- 7. Explain the rules about not eating and drinking or brushing teeth for 15 minutes before doing the test as this will produce false high or low cortisol levels. The instructions say "Have a 'clean' mouth for at least 15 minutes before you take the sample (no eating, brushing teeth or drinks including water)".
- 8. Go through the logbook with the respondent and point out the questions they must answer. There are questions that need to be answered when they are

- carrying out the samples and there is a final set of questions at the end to be completed after doing the last sample.
- 9. Give them the transparent plastic bag to put the samples in and the padded envelope with which to post this bag of samples and logbook. Samples can be kept in the fridge until posted but the respondent should send samples as soon as possible.
- 10. Answer any queries the respondent has if you can. Inform them that if they have queries after the interview, or if they need more salivettes, they should call Helen Selwood in the yellow team at Brentwood. The telephone number is on the front of the logbook.

Make sure that the respondent understands:

- They should start whenever they wake on the day not at a set time.
- All samples are to be taken on the same day and then posted back on the following day.
- How to take the sample correctly (i.e. not to handle the cotton swab and how to put the parts of the tube back together these problems are usually alleviated during the practice sample they do in your presence).
- If they are worried that they will not be able to take the samples at the set times they should do them as close as they can to the right times and write down the actual times they did them.

Respondents' frequently asked questions

- 1. What hormone do you look for in the saliva and how can you measure stress levels from that?
 - Cortisol is the hormone we look for in the saliva. It has many functions in the body and is associated with stress. The concentration of cortisol in saliva is directly related to the concentration of cortisol in your system.
- 2. Will the samples be OK in the post; will they get broken or go off?

 We have had many samples posted back and have not experienced any problems. The salivettes are plastic and very robust, and the saliva samples are still valid even if they are in the post for a few days.
- 3. Will I get the results?
 - The results will not be given to you, this is one of the parts of the study where we look at groups of people and not individuals, it is also a relatively new part of the screening.
- 4. What if I do not have a stressful event during my day?

 If you do not have a stressful event, or do not feel stressed at any point on the day, the samples will still be valid, just put down in the logbook that there were no stressful events during your day. We are interested in the people who have stressful days as a comparison to those who don't.
- 5. If I am doing something very unusual that day should I still complete the test? If you are going to be at the dentist we ask people to wait a day to do the test. For other events as long as it is noted in the logbook that the day was busier and not a typical day it is still fine to do the test. As with all parts of the study, if the

participant feels that it would not be suitable, for example if they are attending a funeral or wedding then it is fine to wait a day.

- 6. Can I take my medication during the day? It is fine to take medication and vitamins whenever you normally take them. Just note it down at the back of the logbook.
- 7. Can I do the samples at the weekend, when I have fewer things to do/ am usually less stressed?

We are asking everyone to try and do the test on a weekday, and are interested in days when people feel stressed. This will allow us to compare the results for people who are working with those who have retired. However, people can do it on weekends if necessary.

14 APPENDIX 1: SUMMARY OF NURSE-INTERVIEWER LIAISON

- The interviewer will contact you before he/she starts work (or you must contact her/him). You should:
 - Provide the interviewer with information for the police letter
 - Provide the interviewer with information to reassure respondents on Appointment Diary

- Discuss preferred method of making appointments
- If appropriate, provide availability for Appointment Diary
- If respondent agrees to a nurse visit, the interviewer gives him/her an Appointment Record Card with either:
 - a provisional appointment for you to confirm
 - without appointment for you to set up
- The interviewer will highlight preparation details on card & tell respondent nurse will be contacting them to talk in more detail.
- Interviewer also leaves genetics leaflet and nurse leaflet with the respondent.
- Interviewer calls to inform you of nurse visit, or if no nurse visit needed
 - Check/collect telephone number you have for the respondent on the nurse summary sheet is
 - Ask for any additional relevant information (e.g. interviewer should inform you of deafness/sight issues, other health issues identified during interview).
 - If appointment is very soon complete Interim Appointment Record Form
- Interviewer posts NRF (or NRF B) to nurse
- Keep your Nurse Sample Sheet handy, for example by phone

15 APPENDIX 2: CHECKLIST FOR WHEN YOU TELEPHONE THE RESPONDENT BEFORE YOUR VISIT

- After interviewer phones contact respondent ASAP
 - Refer to Appointment Record Card
 - Either <u>confirm</u> or <u>arrange</u> day and time of visit
 - Discuss preparations and suitable clothing

- Discuss whether fasting is appropriate (see below)
- Where relevant, clarify rules of fasting

• Respondent should NOT fast if

- They are aged 80 years or over
- Diabetic and on treatment (OK if controlling by diet and not on treatment)
- They have a clotting or bleeding disorder or on anti-coagulant drugs (e.g. warfarin, protamine or acenocoumarol)
- Has ever had fits (epileptic, convulsion, convulsion associated with high fever)
- You don't feel comfortable about it (e.g. respondent seems frail or confused, or your interviewer has expressed concern about their health)

• If you ask the respondent to fast

- Refer to Appointment Record Card when talking to respondent
- They must fast for 5 hours prior to visit
- Tell them they *should* drink water
- Refer to fasting guidelines on appointment record card rules depend on time of appointment
- Respondent should take medication as usual
- If appointment is over a week away, suggest calling them again to check for any changes in health status