ENGLISH LONGITUDINAL STUDY OF AGEING (ELSA)

HEALTH AND LIFESTYLES OF PEOPLE AGED 50 AND OVER

P8796 WAVE 4

NURSE VISIT PROJECT INSTRUCTIONS

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1 ABOUT THE STUDY

1.1 Background and introduction to the study

ELSA is a 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. ELSA respondents are interviewed every two years and have a nurse visit every four years. The first wave of ELSA, the field name of which is 'health and lifestyles of people aged 50 and over', went into the field in 2002 and involved field interviews with around 12,000 respondents in over 7,000 households. The second wave which started in 2005 introduced a nurse visit as well as an interview. The third wave, which went into the field in 2006, had a core interview again. It did not include a nurse visit but included a Life History interview, a new interview designed to gather information about the respondent's life from birth up until the present day. At Wave 3 we also introduced a refreshment sample of 2,847 households to replenish the younger age groups (i.e. 50-53 year olds), bringing the total issued sample size to 13,615 households. Wave 4 once again involves a nurse visit.

For the mainstage of the survey, we will again be introducing a new refreshment sample, this time adding respondents aged 50 to 74 years.

Although there are some exceptions (which will be discussed later), the great majority of our sample have already been interviewed by NatCen on four previous occasions: first as part of the Health Survey of England (HSE) from which we drew our ELSA sample, and then for the first, second and third waves of ELSA. Now we will be asking respondents to take part in ELSA for a fourth time. 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 has been developed in Europe, the Survey of Health, Ageing and Retirement in Europe. There are also similar studies in many other countries of the world, e.g. Korea, China 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 are able to compare experiences across countries and understand how national policies and contexts affect people's lives.

So far, our funding covers four waves of data collection: the surveys held in 2002, 2004 and 2006, and the 2008 survey which we are conducting now. Half of the research budget has been provided by the US National Institute on Aging which also funds the Health and Retirement Study mentioned above. The remaining funding for

the study has been provided by a consortium of UK government departments (including, for example, the Department for Work and Pensions and the Department of Health).

The study is being carried out by a collaboration between the National Centre for Social Research, the Department of Epidemiology and Public Health at University College London (UCL), the Institute for Fiscal Studies (IFS) and academics fromother 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. This research has been approved by both the ELSA team and by the National Hospital for Neurology and Neurosurgery and Institute of Neurology Joint Research Ethics Committee.

Most aspects of the survey, nurse visit and study procedures for Wave 4 were piloted in November 2007.

You (and respondents) can find out more about the study at www.natcen.ac.uk/elsa/. The report on the findings from Wave 3 will be published in July 2008.

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. The results from Wave 2 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 respondent by the interviewer briefly explaining the survey and its purpose. At the end of their interview, the interviewer will then give the respondent two information leaflets about the nurse visit and DNA sample to provide the respondent with more 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 checks who is still living with the ELSA sample member(s) 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 paper questionnaire. 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 (depending on the method you agree with the interviewer).

During their interview respondents will be asked to complete a self completion questionnaire (**blue**), either during or after their interview. If the self-completion is left behind with the respondent then the interviewer may arrange with the respondent for you to collect it when you do your visit. The interviewer will write on the NRF if you need to collect the self completion questionnaire and you will be reminded about this by the CAPI at the beginning of your visit. If the respondent has lost their self-completion questionnaire, please give them a new one to complete. If the respondent has completed the self-completion questionnaire, please ensure that it has the respondent's serial number on and post it back with other documents but NOT with the NRF

There are a few other 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. 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.
- 2. 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). The respondent should keep the white carbon copy.
- 3. 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.

Since Wave 2 we have been carrying out "end of life" interviews if a sample member has died, and we will be carrying out these interviews at Wave 4. We will be approaching a close friend or relative of an eligible ELSA respondent who has died since Wave 3 to do an interview about the deceased. The aim of the end of life interview is to bring closure to the information collected for ELSA.

1.4 The nurse visit

All **CORE MEMBERS** who are interviewed at Wave 4 are eligible for a nurse visit, except for those who are interviewed by proxy. A nurse will be allocated to each sample point to work with the interviewer.

The interviewer should contact you after each interview they do to let you know the following information:

- Whether the respondent(s) agreed or refused to have a nurse visit
- The appointment time (if the interview is making the appointment) or any information about the respondent's availability
- Changes to the respondent's address or telephone number
- Parking instructions if relevant
- Any concerns they have about whether the respondent is able to give blood or fast
- Any other information about the respondent which may be of use e.g. reluctance or concerns about particular measures

You 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 visit is carried out in the respondent's home and involves 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

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 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 Nurse Record Forms (NRFs) Blue Nurse Record Forms B (NRF Bs) Purple Nurse summary sheet White Interim appointment record form Orange Consent booklet Orange Grip strength measurement card Yellow Survey leaflet Blue Nurse leaflet Lilac Genetics leaflet Green Measurement record card for respondent Lilac White Frankfort plane card Appointment record card Yellow Broken appointment card White Barcode labels White White Protocol card for balance measure and leg raise 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
- Salivettes and log book

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 measurements (e.g. weight) because of equipment not working. If there is a problem with your equipment please contact Brentwood or your supervisor straight away.

With regards to the Tanita THD-305 Scales – 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 remainder of the equipment is described in more detail later in the sections on the measurement protocols and in your standard NatCen nurse 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). Most ELSA sample members will have had a nurse visit at HSE (as well as at ELSA Wave 2).

2.2 Existing sample

The existing sample comprises two different elements: the Wave 1 sample and the Wave 3 refreshment sample.

A. Wave 1 sample

The majority of the sample were issued at ELSA Wave 1 and were selected from households that participated in the Health Survey for England (HSE). The HSE years selected for Wave 1 were 1998, 1999 and 2001. The majority of our sample was first interviewed as part of the HSE in one of these years. Most were then interviewed a second time at ELSA Wave 1. Wave 1 is considered to be the baseline for ELSA. Therefore, at Wave 2 we only followed up people who were in productive households at Wave 1. This meant that at Wave 2 each issued household had had at least one productive interview at Wave 1.

Most of the Wave 1 sample would have completed a Wave 2 and Wave 3 interview, a Wave 2 nurse visit and some also a Life History interview, however, some sample members may have missed one or more of these interviews. And some sample members have become eligible by moving into an ELSA household since the time of the HSE interview and so may have joined the study later than others.

B. Wave 3 refreshment sample

The existing sample also includes those individuals who were introduced to ELSA at Wave 3 when we refreshed the younger sample members (ages 50-53) so that our sample continued to include the full range of age groups. These sample members were taken from HSE 2001, 2002, 2003 and 2004. We selected people aged 50 to 53 and their Old/Young partners. Again, all of the households issued at Wave 4 from the Wave 3 refreshment sample had a least one productive interview at Wave 3.

2.3 Wave 4 refreshment sample

There is a new refreshment sample at Wave 4, this time covering people aged between 50 and 74.

For Wave 4, we identified people from households that took part in HSE 2006 who could potentially become core members, along with their cohabiting Young or Old

partners. The interviewer may also interview new partners of core members who have joined the household since HSE.

We are issuing 3,504 individuals in 2,116 households as part of the refreshment sample.

2.4 Sample definition

There are two main different types of respondents who are eligible to take part in the study: Core Members and Partners (of which there are different types). The interviewer will attempt to interview all Core Members and Partners. The Core Members are the people who we are most interested in and we want as many Core Members as possible who are interviewed in person at Wave 4 to have a nurse visit.

However, we only want you to carry out a nurse visit with Partners if they request one (to you or the interviewer) as we are less interested in the data from these sample members. We are allowing you to carry out nurse visits with Partners if they request one as we know that some Partners are unhappy that they were not allowed a nurse visit at Wave 2. We have permission from the ethics committee to carry out nurse visits with Partners. You may take all the measures for partners that they wish.

Existing sample

Core Member (CM)

- Original Sample: 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 1. They also must have participated at ELSA Wave 1.
- Wave 3 refreshment sample: Someone aged between 50 and 53 at 1st March 2006 who was living within a household which took part in HSE 2001-2004 and was still living in the household sector within England when they were first approached for ELSA at Wave 3. They must have participated at ELSA Wave 3.

Young Partner (YP)

- Original Sample: A cohabiting spouse or cohabiting partner of a Core Member who was living within a household which took part in HSE 1998, 1999 or 2001 at the time of the HSE interview. These Young Partners were born AFTER 29th February 1952.
- Wave 3 refreshment sample: A cohabiting spouse or cohabiting partner of a Core Member who was living within a household which took part in HSE 2001, was aged under 50 at 1st March 2006 and was still a cohabiting spouse or partner of a Core Member when first approached for ELSA at Wave 3.

Old partner (OP):

 Wave 3 refreshment sample: A cohabiting spouse or cohabiting partner of a Core Member, who was living within a household which took part in HSE 2001, was aged over 53 at 1st March 2006 and was still a cohabiting spouse or partner of a Core Member when first approached for ELSA at Wave 3.

New Partner (NP)

 A cohabiting spouse or cohabiting partner of a sample member (who was not living in the household at HSE). At each wave we pick up new partners, who have joined the household since the last visit. New partners identified at Wave 1 are called NP1s, new partners identified at Wave 2 are called NP2s, new partners identified at Wave 3 are called NP3s and any new partners found at Wave 4 will be classified as NP4s.

Core Partner (NP)

 These are people who were selected to be potential Core Members from HSE but did have participate at their first ELSA interview (i.e. Wave 1 for the original sample or Wave 3 for the Wave 3 refreshment sample).

Wave 4 Refreshment sample

Potential Core Member:

 Someone aged between 50 and 74 at 1st March 2008 who was living within a household which took part in HSE 2006 and is still living in a household sector in England at the time of the ELSA Wave 4 interview.

Young partner:

 A cohabiting spouse or cohabiting partner of a potential core member at the time of HSE 2006, who is aged under 50 at 1st March 2008 and who is still a cohabiting spouse or cohabiting partner of a potential core member at the time of the ELSA Wave 4 interview.

Old partner:

 A cohabiting spouse or cohabiting partner of a potential core member at the time of HSE 2006, aged over 74 at 1st March 2008 and who is still a cohabiting spouse or cohabiting partner of a potential Core Member at the time of the ELSA Wave 4 interview.

New Partner:

 As with the existing sample, any new partners who are in a cohabiting relationship with a Core Member in the Wave 4 refreshment sample will also be eligible to be interviewed.

Address and information labels

There are two labels on the front of each NRF:

Address Label

The address label has the following information:

S: 10 1304611 T	P: 101 FA: 0
Address 1	
Address 2	
Address 3	
Address 4	
Address 5	
Post code	
T: 020 8898 7907	

Key:

S = Serial number and check letter. The household serial number is 9 digits long (the individual serial number is 11 digits - 9 digits from the household serial number and 2 digits for the person number)

P = Point number

FA = Field area

T = Telephone number

Information label

There is one information label per address. An example information label is shown below. We have shown only those people in the household who are eligible for the ELSA study, alongside their person numbers (used in the CAPI household grid).

```
S: 130460311 T

Pno – Name – Age – Fasted at W2 - Saliva
01 - Thomas Macintosh - 76 – Yes - Sal
02 - Ruby Johnson - 69 - No – NoSal
- - - -
- - - -
```

Key:

S = Serial number and check letter.

Pno = Person number (used in the CAPI household grid)

Fasted at W2 – Whether or not they fasted at Wave 2

Yes: Was asked to fast at Wave 2 and did fast No: Was asked to fast at Wave 2 and did NOT fast

(blank): Was not asked to fast at Wave 2 (for whatever reason)

Saliva – Whether will be asked to give a saliva sample or not

Sal: Will be asked to give saliva sample

NoSal: Will not be asked to give saliva sample

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.

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 sections. 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 (which you can write on the appointment preference form).

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 again using the nurse appointment preference form. 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 the people who need a nurse visit 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 your 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 No nurse visit was required
- 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 interviewer's and your responsibility. The interviewer will complete the first two pages. It is your responsibility to fill out the other pages.

When you receive the NRF write on the box on the front the date you received it from the interviewer.

On the grid on page 2 the nurse visit status will either be 1, 2, 3, 4 or 5. **Contact only those persons for whom <u>code</u> 1 or 4** has been indicated – these are the household members who agreed both to be interviewed **and** to see you. Code 1 indicates that a core member agreed the nurse visit. Code 4 indicates that Partner requested a nurse visit. Code 2 indicates a Core Member was interviewed but refused to see you. Code 3 indicates a Core Member could not be interviewed (e.g. they were mentally

incapable, refused, etc). Code 5 indicates that a Partner did not request a nurse visit. 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 **only** this Person Number.

Occasionally you will find that someone in the household with code 2 (Core Member who refused nurse), code 3 (Core Member who was not interviewed) or code 5 (Partner who did not request nurse visit) decides they want to have a nurse visit after all. If they are code 2 (i.e. Core Member who refused nurse visit) or code 4 (Partner who did not request 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. Core Member who was 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.

The shaded column on page 2 will indicate for each respondent whether or not the interviewer left behind a self completion which you need to collect and return to the office (see Section 1.3 for more info).

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

- Enter the calls record as normal at question 8. Include the date when you called and what the status of that call was.
- Once you have made an appointment with the respondent there is space on the top of the front page to record the date of the appointment.
- Enter the outcome code for all respondents 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 for whom you obtained a consent booklet and a completed self-completion questionnaire 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 eligible 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 create 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 **purple** NRF B is almost identical to the **blue** 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 (orange). The interviewer will

tell you over the phone the following information that you will need to write onto this form.

Complete the following details on page 1:

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

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 is a Core Member and agreed to see the nurse
 - ring code 2 if that person is a Core Member and refused to see the
 - ring code 3 if that person is a Core Member and was not interviewed no visit needed
 - ring code 4 if that person is a Partner and requested a nurse visit
 - ring code 5 if that person is a Partner and did not request a nurse visit
- 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.
- An independent Research Ethics Committee has been consulted and has given 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 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 a yellow 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 a yellow 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 and Appendix 2).

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. This is also written on the appointment record card to remind respondents.

We would ask that you let the respondent know that you will be contacting them again the night before the visit to encourage them to remind them of the fasting rules (if appropriate) and to emphasises the importance of drinking water if they are fasting.

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. This is particularly important for ELSA as it is a panel study and we are trying to measure how people change over time.
- 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 **not** 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. Remind them to drink a good amount of water if they are fasting.
- 5. 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 Ensure they DO NOT give blood if they have EVER suffered a fit, even if this occurred in early childhood.
 - are taking anticoagulant drugs (such as Warfarin, protamine or acenocoumarol)
 - are pregnant (not very likely with ELSA respondents!).
- 6. 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 to 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.

6.5 Approaching respondents in institutions

It is possible that a respondent who is eligible for a nurse interview has moved into an institution (i.e. a nursing or a care home). Respondents in institutions are still eligible for a nurse visit as long as they have an interview in person.

If any of your respondents have moved into an institution you must ensure that the interviewer has provided you with the details of the contact person at the institution, such as a Care Home Manager. Please contact this person (before contacting the respondent) to explain the purpose of the survey and content of the nurse interview. It is important that you explain the measurements that are involved and check whether it would be safe to carry out each of them with the respondent.

If the institutional contact agrees to the nurse visit you will need to check that the respondent is contactable by phone, so you can explain the nurse visit, and if so that you have the correct details for them. If you are unable to contact the respondent by telephone you will need to visit the respondent in person before their nurse interview to explain what it involves and what they need to do to prepare for the nurse visit (e.g. fasting).

Please bear in mind when visiting institutional residents that although they have all been capable of completing an interview with the interviewer, as the nurse you must make your own assessment as to whether they are capable of understanding and consenting to the nurse measurements, as well as physically capable. If you feel that a procedure has not been understood please DO NOT take the measurement.

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 (or are Partners who have requested a nurse visit). 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 complete three other documents during the interview itself: the consent booklet, the measurement record card, and the grip strength record card. The consent booklet contains the forms the respondent has to sign to give written consent for:

- blood pressure 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
- lung function readings to be sent to their GP
- saliva sample to be taken

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 for 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.

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

- Go into the address menu and select the original household serial number.
- Select 'Create new household' [Alt N].
- 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 enter this new household schedule you should 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 GP 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 BOOKLET

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 orange 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.

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) Blood samples to be taken
- c) Blood sample results to be sent to their GP

- d) Blood sample results to be sent to the respondent
- e) Blood sample storage for future analysis
- f) Blood sample for DNA extraction and storage
- g) Lung function results to be sent to the GP
- h) Saliva sample to be collected

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

There are FIVE different consent forms contained in the consent booklet:

- **1** Blood pressure results to GP.
- **2 a)** Blood sample to be taken.
- **2 b)** NatCen to inform GP of blood result.
- **2 c)** Remaining blood to be stored for future analysis.
- **3** Extraction and storage of DNA for use in future medical research studies.
- 4 Lung function results to GP.
- 5 Saliva sample to be taken

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 form;
- to circle the appropriate consent code on the front of the Consent Booklet.

The Consent booklet also contains two despatch notes for the blood samples. These are described in Section 12D.

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 the other eligible member(s) 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 (e.g. 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 logged on to CMS, the first menu displayed is the MAIN MENU screen from which all subsequent menus and screens are selected. The MAIN MENU allows you to select several options on the work you want to commence. To access ELSA nurse work, you will need to select VIEW AMEND LOADED WORK. This display's the projects/slots by survey month that have been loaded on to your laptop.

To get into the nurse schedule, select **P8796** which will then display a screen with all serial numbers of all the addresses in your sample (plus related information). Use the arrow keys to select the household you would like to work on, then press <Enter>.

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

You MUST practice at home before 'going live', at the **MAIN MENU** you can select working at home **_PRACTICE INTERVIEW** _ select project. The screen displays all the address serial numbers for practice interviewing (calls will not be made/entered when practice interviewing). **Do not** use a practice interview slot for a visit to a respondent's home.

9.3 Household information

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. You will also be asked to enter whether or not the respondent is eligible for the saliva sample by looking at the label on the front of the NRF. This is printed on the NRF Information Label under Saliva. If it says 'Sal' on the label they are eligible for the saliva sample; if it says 'NoSal' they are not eligible.

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 9.15), 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 9.14).

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.

IntSc1 - IntSc4

Please check page 2 of the NRF to see whether or not the interviewer arranged with the respondent for you to collect the Blue self-completion questionnaire and code this at IntSc1. Check with the respondent whether they have completed it yet or not:

- If the respondent has already completed the self-completion questionnaire and it has been sent back to the office then code 1 at IntSc2. You do not need to do anything further about this.
- If the respondent has completed the questionnaire but not yet returned it, you will be instructed by the CAPI to put the questionnaire in a pre-paid envelope and post it back to the office. Please do NOT return the questionnaire with the NRF.
- If the respondent has not yet completed the questionnaire, then please ask them to complete it. If they no longer have the questionnaire then please give them a new copy. Again please do NOT return the questionnaire with the NRF.

9.5 Blood pressure

BPMod-BPOffer

Everyone (except those who are pregnant) is eligible for blood pressure measurements. The protocol in the NatCen standard nurse protocols 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 (e.g. 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. If you are able to do this remember to change your answer at this question so it shows that they haven't done the activity (i.e. smoked) in the past 30 minutes. 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 NatCen 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 the NatCen standard nurse protocols 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 the NatCen standard nurse protocols)

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.

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
- Grip strength measurement card
- Measurement record card

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.

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 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 **not** the purpose of this survey to provide respondents with medical advice. Nevertheless, many respondents will ask you what their blood pressure readings mean. The NatCen standard nurse protocols contain 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.

9.6 Grip Strength

MMGSWII

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 has use of only one hand please record this as the dominant hand, and if the respondent is unable to use either hand, the measurement will be stopped.

MMGSInt

It is important you explain and **demonstrate** the test procedure. Position the respondent correctly, adjust the gripometer to their hand size (see the NatCen standard nurse protocols) 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.

9.7 Blood sample

BIIntro

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

This is the 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 - BIReady

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 12D 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. However, we have now added new questions to check that the CAPI's calculations about how many days and hours ago the respondent last ate are correct. If they are not correct you should code this in the CAPI and it will ask you to give the correct details which will be used to work out whether the respondent is eligible to give a fasting blood sample or not.

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 **in all cases**. If you **cannot** obtain written consent, the computer will direct you to ring consent codes 04, 06, 08, 10, and 12 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 **not** involve a test for viruses (e.g. HIV (AIDS) test).

If a respondent queries why we are analysing their DNA again, this is because we would like to examine any changes in telomere length. A helpscreen has been added to the DNA consent question *ConsDNA*. 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 2 (with parts a, b and c); and Consent Form 3. 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 2 Blood Samples' and 'Consent Form 3 Genetics Study'. Remember to enter the respondent's name at the head of these forms before asking the respondent to sign.
- 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 12D 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 at the venepuncture questions at the end of the CAPI. 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 04, 06, 08, 10, and 12 on the consent booklet. If you have already ringed codes 03, 05, 07, 09, and 11 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 7, 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 07** on the front of the consent booklet. If not, ring **code 08**. 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.

9.8 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 *Htlntro*. 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.

9.9 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 the NatCen standard nurse protocols.

Record the two measurements to the nearest millimetre. Always record the response to one decimal point (e.g. 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.

9.10 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. the NatCen standard nurse protocols contain the full protocol for this measure.

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, PF and FEV1pc**. 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 the NatCen standard nurse protocols).

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 14** 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 4 - 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 13**. 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).

Only provide the respondent with lung function readings if they request them.

9.11 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 12I), 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 12I).

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.

9.12 Saliva

Only pre-selected respondents are eligible to have a saliva sample (see Section 12J). If a respondent is not eligible then circle 16 on the front of the consent booklet.

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.

SalSter

Check whether the respondent is taking steroids at the moment. There is a list of common steroids displayed for you. If you are not sure whether or not the respondent is taking a steroid then code yes and add a note on the CAPI. You should go ahead and ask the respondent to give a saliva sample whether they are taking steroids or not.

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 Chris is available.

SalNo

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

9.13 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, 15, or 13 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 <Alt+Q> (for Quit form (after admin)).

9.14 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, or 951). 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 code '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.

9.15 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:

Parallel blocks	
+ + Nurse_Schedule1: George - Nurse_Schedule2: Winifred - Admin	

The list of blocks will vary depending on the number of people in the household. There will always be a 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.

9.16 Practice interview

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

Serial

100000011

12222211

133333311

144444411

155555511

166666611

177777711

18888811

199999911

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 2.4). 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 or B). 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 – No Nurse Visit required.

The interviewer completes Part A if s/he has circled A at question 1. For your information, they are asked to record if someone who took part at Wave 3 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 (Core Member) or 4 (Partner). Status code 2 is for those Core Members who refused the nurse visit (but did the main interview), code 3 is for Core Members who did not participate in the main interview (e.g. refused) and code 5 is for Partners who did not request a nurse visit and therefore are not eligible.

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 to 4 (i.e. not 5) 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 79 if the respondent is a Partner and you went through the whole schedule with them and completed all the relevant questions. This code applies **even** if the respondent refused any of the measurements.

Use code 81 if the respondent is a Core Member and you went through the whole schedule with them and completed all the relevant questions. This code applies **even** 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 79 or 81. Enter the person number of each person with either of these outcome codes and code whether or not you obtained a consent booklet and collected a self-completion questionnaire for these respondents. Also write the total number of consent booklets obtained and self-completion questionnaires collected at this household.

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 (e.g. 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.

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 Pink 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 79 or 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.

11 CONTACTS

11.1 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:

- Kate Cox on 020 7549 7026, or Natasha Wood on 020 7549 7039
- Chris Shaw or any member of the Pink Team.

In an emergency where the program is failing, you can contact the programmer who is Sven Sjodin on 020 7549 7093.

11.2 The Survey Doctor

The main 'Survey Doctor' for ELSA is Dr Ian Forde of the Department of Epidemiology and Public Health at University College London. Ian 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. However, Ian and Jenny Mindell (the survey doctor for HSE and NDNS) will be sharing responsibility for dealing with urgent queries about ELSA.

Urgent queries

If you have an urgent query please telephone **07770 537238**. This phone will be diverted to lan or Jenny's telephone depending on who is on call at the time. If neither doctor answers please leave a message.

This is the schedule for who is on call during 2008:

May		Jenny
Jun	1 2-15 16-30	Jenny Ian Jenny
Jul	1-13 14-31	lan Jenny
Aug		Jenny
Sept		lan
Oct		lan
Nov		Jenny

Dec Jenny

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.

Non-urgent queries

For non-urgent queries please call **020 7679 1656**. This is the number for the secretary of the Department of Epidemiology and Public Health (Sheema Ahmed) who will either connect you to lan if he is available or will pass on a message to him.

12 PROTOCOLS OF MEASURES IN ELSA NURSE VISIT

Most of the protocols for the measures in the ELSA nurse visit are the same as those in the Standard NatCen Nurse Protocols and we have therefore not repeated them here. Please make sure that you are familiar with the Standard Nurse Protocols for all the measures included in the ELSA nurse visit.

In this document, we have only included protocols for the three measures which have instructions which are specific to ELSA, which are not covered in the Standard Nurse Protocols.

- 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

- As in standard NatCen Nurse Protocols
- I. Physical performance measures Balance, Leg raise and Chair rises
- J. Saliva Sampling

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

This applies even if the fit(s) occurred some years ago or even in childhood (e.g. epileptic fit, convulsion)

- 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.. Please also note that:

- Clopidogrel and aspirin (and other such anti-platelet drugs, listed in BNF section 2.9 so drug code is 02.09.00) are NOT anti-coagulants (which are listed in BNF section 2.8, so drug codes 02.08.01 and 02.08.02).
- People would know if they are on anti-coagulants, as they need regular blood texts to check that their blood clots slower than average but not dangerously slowly.
- People on anti-platelet drugs do not need blood tests to check they are on the right dose.
- People on anti-platelet drugs, that stop the platelets being so 'sticky' mostly (low dose) aspirin but also drugs like clopidogrel - can have blood taken as normal.

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 essential that respondents consent to ALL parts for you to be able to take blood. 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.

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.

White cell count (WCC) and mean corpuscular haemoglobin (MCH) – When looked at in combination with Ferritin and haemoglobin can indicate anaemia.

Insulin-like growth factor 1 (IGF-1) and dehydroepiandrosterone sulfate (DHEAS) – These are hormones that help control reactions to stress and regulate various body processes including digestion, the immune system, mood, and energy usage.

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 Vacutainer holder Alcohol swabs Vacutainer needles 21G (green with guard) Vacutainer needles 22G (black with guard) Gauze squares Vinvl aloves Butterfly needles 23G (Blue) Adhesive dressing Sharps / needle disposal box Micropore tape Vacutainer plain red tubes Sheet of labels for blood sample tubes Vacutainer citrate blue tubes Royal mail blue 'safebox' / packaging Vacutainer fluoride grev tubes Vacutainer EDTA light purple tubes Antiseptic spray Vacutainer EDTA dark purple 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	6ml plain tube (red)
then	1.8ml citrate tube (blue)
then	2ml fluoride tube (grey)
then	2ml EDTA tube (light purple)
then	4ml EDTA tube (dark purple)
finally	4ml EDTA tube (dark 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.

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 red, blue and first light 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 dark purple tubes. The CAPI programme will instruct you about which tubes you should draw blood for and the order in which you should fill them.

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.

Remember to take the tubes in the correct order, as follows:

- 1. large plain red tube
- 2. blue citrate tube
- 3. grey fluoride tube (if the respondent has fasted)
- 4. light purple EDTA tube
- 5. & 6. TWO dark purple EDTA tubes (if the respondent agreed 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.

Please also refer to the standard NatCen Nurse Protocols for Venepuncture

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 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, 4 and 5. Check that the date of birth is correct and consistent with entry on the nurse schedule and the tube label.
- At item 6 enter your Nurse Number.
- At Item 7 code if the respondent fasted for at least 5 hours before the blood sample was taken.
- At Item 8 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 10 on the front page of the booklet.
- And tick each of the tubes collected (i.e. red, blue, grey, light purple & 2 x dark purple).

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.

For the first batch you will be given **Blue Royal Mail Safeboxes w**hich 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.

Later in the fieldwork period you may be given new **Transparent plastic containers** to despatch the blood tubes instead (when we have run out of the safeboxes!).

- 1. Place the blood tubes in the plastic tray (with the tissue lining) with all the lids up against one side of the tray.
- 2. Push the lid down (it should click) and make sure it is properly closed.
- 3. Put the plastic container and the Newcastle Despatch Note in the plastic envelope and seal the envelope. Make sure you seal the envelope so all the labels (i.e. From and To) can be seen.

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 (or plastic envelopes) 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.

I. PHYSICAL PERFORMANCE MEASURES

These measures are taken in a similar way to the descriptions in the standard NatCen Nurse Protocols – these are **additional** instructions specific to ELSA.

Content of balance measures

The balance measures (including leg raises) evaluate 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.

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 correct stopwatch mode if you have the Quartz Model repeatedly press the MIDDLE button labelled 'Mode' until 'SP' is shown at the bottom of the stopwatch display.
- If you have the TIM Model, press middle button until watch mode is replaced by 0:00:00
- To reset the stopwatch press the **LEFT** button.
- To start the stopwatch press the **RIGHT** button.
- To stop the stopwatch press the **RIGHT** button.

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

- To start the stopwatch press the **RIGHT** button.
- To take the time at the 5th rise press the **LEFT** button.
- To take the time at the 10th rise press the **RIGHT** button.
- 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.
- To reset the stopwatch press the **LEFT** button.

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 <u>10 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 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 respondents from the Wave 4 refreshment sample (i.e. those who are joining ELSA at this wave) will be asked to give a saliva sample. We have also selected 10% of respondents who gave a sample at Wave 2 to give another one this time (although we have excluded anyone who wrote on their Wave 2 saliva logbook that they found giving a sample to be highly unpleasant). The **NRF label** shows who we want to give a saliva sample at Wave 4. It will say 'Sal' if we want the respondent to give a saliva sample or 'NoSal' if we do not.

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 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. It is important that you 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 same 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 Chris Shaw in the pink 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 by ensuring you ask the respondent to
 provide a practice sample to check they are doing it 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.

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
 - Discuss preferred method of making appointments
 - If appropriate, provide availability details
- 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 point out preparation details on this card & tell the respondent the nurse will be contacting them to talk about this 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
- Please note that it would be preferable to arrange visits in the morning in order to collect a fasting blood sample (if applicable), if convenient for the respondent, and does not involve an extra long journey that you wouldn't otherwise incur

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

After interviewer phones - contact respondent ASAP

- Refer to Appointment Record Card
- Either confirm or arrange 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 to fast 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
- If it says on the ARF that you are to collect the respondent's self-completion questionnaire remind the respondent about this.