

# NatCen

Social Research that works for society

# ELSA Wave 8 Mainstage

## Nurse Project Instructions



The **English Longitudinal Study of Ageing** (ELSA) is a study of people aged 50 and over and their partners.

The aim of the main study is to interview the same group of people every two years to explore **the health, lifestyles and financial situation** of people as they grow older. The field name of the study is 'ELSA 50+ Health & Life'.

**ELSA is run in collaboration with...**



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## How to use these instructions

The nurse instructions give information about what has changed on ELSA wave 8 since the last wave the nurse visit was carried out (wave 6). These instructions should be used in conjunction with the Nurse Protocols Manual and existing Clinical Procedure Guidelines (CPGs).

## Contacts

**If you have a query, your first port of call should be your Nurse Field Performance Manager. They will then pass you on to a Researcher if they cannot answer your question.**

<b>Operations contacts</b>	Switchboard	01277 200600
	Equipment	equipment@natcen.ac.uk
	Nurse Centre	01277 690061 / 01277 690135
<b>Survey doctor</b>	Dr Rob Aldridge	8.00am to 10.00pm
		Monday - Sunday
	Mobile	07790 012159

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# 1 Background

The English Longitudinal Study of Ageing (ELSA) is a study of people aged 50 and over and their partners. The aim of the study is to interview the same group of people every two years to explore the health, lifestyles and financial situation of people as they grow older.

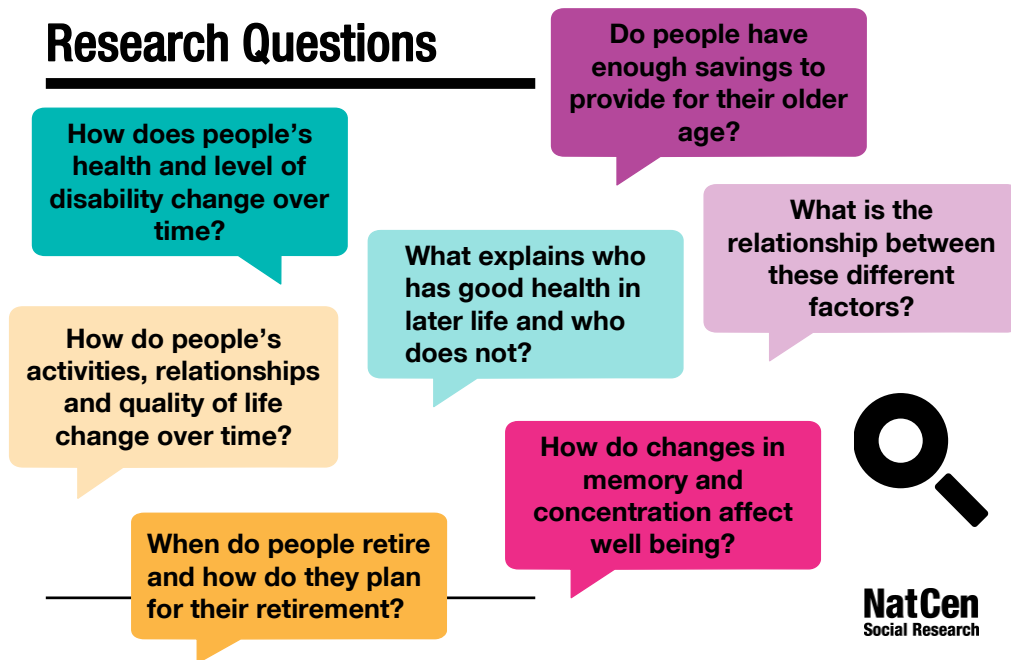
The field name of the study is **'ELSA 50+ Health and Life'**.

ELSA is modelled on the Health and Retirement Study (HRS) which is run in the USA.

## 1.1 ELSA study aims

### ELSA research questions

ELSA aims to answer many different research questions as demonstrated by the questions overleaf.



### International comparisons

ELSA also aims to be able to make international comparisons of the experiences of ageing. Studies that are compared with ELSA include:

- The US Health and Retirement Study (HRS)
- Survey of Health, Ageing and Retirement in Europe (SHARE)
- Northern Ireland Study of Ageing (NICOLA)
- The Irish Longitudinal Study of Ageing (TILDA)
- Brazilian Longitudinal Study of Aging (ELSI-Brazil)
- Chinese Health and Retirement Longitudinal Study (CHARLS)
- Longitudinal Aging Study in India (LASI)

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The various longitudinal studies of ageing around the world are being used to compare experiences across countries and to understand how national policies and contexts can affect people's lives.

## 1.2 Collaborators and funders

### Collaborators

ELSA is carried out by the ELSA team which is made up of NatCen Social Research in collaboration with:



- The Department of Epidemiology and Public Health at University College London (UCL)

Professor Andrew Steptoe  
Director, Institute of Epidemiology and Health Care at UCL.  
The principal investigator in the research team.

- The Institute for Fiscal Studies (IFS)
- The University of Manchester

The ELSA Research team also has close links with researchers from the University of East Anglia.

### Funders

The funding for ELSA is shared between:

- the ESRC;
- the US National Institute on Aging (NIA) - which also funds the Health and Retirement Study;
- and a consortium of UK government departments (including the Department for Work and Pensions and the Department of Health).

## 1.3 Ethical clearance

ELSA wave 8 has gained ethical clearance from the NHS Berkshire Research Ethics Committee.

## 2 Fieldwork overview

### 2.1 The ELSA interview

The wave 8 ELSA interview has several components:

<b>Household questionnaire</b>	Checks who is still living with the ELSA sample members. Collects basic facts about them and the household.
<b>Individual questionnaire</b>	Covers a range of topics including physical health, mental health, and economic circumstances and includes objective measures of a timed walk and weight measurements.
<b>Nurse visit</b>	The nurse visit is introduced for some participants at the end of the interview. The interviewer either arranges an appointment for you to visit a few days later or tells the participant that you will telephone them to arrange the visit (depending on the method you agree with your interviewer).
<b>Collection of self completions</b>	<p>During the interview participants will be asked to complete two self completion questionnaires:</p> <ol style="list-style-type: none"><li>1. Core self completion</li><li>2. Male or female sexual relationships questionnaire</li></ol> <p>These are completed before, during or after their interview. If any of the questionnaires are left behind with the participant, the interviewer will arrange with the participant for you to collect it when you do your visit (for nurse sample households only).</p>

### 2.2 Nurse visit

#### Structure of the nurse visit

An overview of the content of the nurse visit is outlined below:

ELSA Wave 8 Nurse Visit Content	
<i>Module</i>	<i>Last included</i>
Prescribed medications and drug coding	Wave 6
Blood pressure	Wave 6
Cognitive function assessment – fluid intelligence	Wave 6 interviewer CAPI
Grip strength	Wave 6
Blood sample (fasting)	Wave 6





## What's new for wave 8?

Some changes to the wave 8 nurse visit include:

### a. Shorter visit

- The nurse visit will be shorter in length than in previous waves with fewer measurements and samples – average length of around 30 minutes.
- In previous waves the nurse visit included hair samples, saliva samples, a waist measurement, balance tests and a lung function measurement. These will NOT be included in wave 8. The weight measurement has moved to the interviewer visit to allow weight to be collected from the full ELSA sample.

### b. Nurse sub-sample

- The nurse visit will be offered to around half of the wave 8 sample. These include participants who have had at least one or more productive nurse visit in past waves.

### c. New blood analyte

- An extra tube of blood (PAXgene) for all eligible participants will be taken to look at the expressions of a number of genes.

### d. Cognitive assessment

- Fluid intelligence is the ability to use abstract thought to solve novel problems and it is typically assessed via logic puzzles (See section 7.5).
- The fluid intelligence test has been moved from the interviewer CAPI to the nurse interview.

## 2.3 Measurements and protocols

Please refer to the Nurse Protocols Manual for instructions on:

- Blood pressure measurement
- Grip strength measurement

The protocols for the fasting blood sample are in Appendix A.

## 2.4 Fieldwork period

Field is due to start at the end of May 2016 and will continue until May 2017.

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## 3 The ELSA sample

ELSA participants were initially recruited via the Health Survey for England (HSE) and the aim is to interview them every two years (i.e. each **wave** of the study) until the participant or the study itself comes to an end! Until now, nurse visits have taken place on every other wave, waves 2, 4, 6 and now 8 (so, every four years). Most ELSA sample members would have had a nurse visit at HSE, as well as at ELSA wave 2, 4 or 6. There are two main types of participant:

### 3.1 Core members

Participants who joined ELSA after being selected from people who had participated in the HSE study are known as '**core**' members. Core members may have joined ELSA at different times, as the original ELSA sample was taken from HSE for Wave 1 and then was refreshed in Waves 3, 4 and 6 by including more participants from HSE as new core members. This made sure that the sample continued to include the full range of age groups. There were no new core members added for Wave 8, so all of the participants will be drawn from the existing sample.

### 3.2 Partners

ELSA is interested in the households that the core members live in, and this means that partners of core members are also included in the main interview. In some households, both people in a couple are core members of ELSA because both originally took part in the HSE study that ELSA core members are selected from. In other households, however, the core member's partner did not originally take part in HSE, or is too young to count as part of the ELSA sample, and so they are not a core member of ELSA. These partners are eligible to be interviewed for ELSA, but not to receive a nurse visit (see below).

### 3.3 Who is included in the nurse sub-sample for wave 8

In wave 8, the ELSA nurse sample includes:



- Core members who have completed a nurse visit every time they were offered one – that is, if they were in the sample from the start,
- they had a nurse visit in waves 2, 4 and 6;
  - if they joined in waves 3 or 4 they had a nurse visit in waves 4 and 6;
  - and if they joined in wave 6 they had a nurse visit in wave 6.

Those **not** included in the ELSA nurse sample are:



- Core members who may have missed one or more nurse visits across the ELSA nurse waves.
- Core members who have asked not to be contacted again.
- Partners of core members.

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## 3.4 Who is eligible for the nurse visit

- ✓ **Eligible Core members, including those in institutions** The interviewer will attempt to interview all eligible core members and their partners.  
Core members who have completed the maximum number of nurse visits that have been offered to them will be eligible to have a nurse visit in wave 8. These include people in institutions.

Those who are not eligible for a nurse visit:

- ✗ **Partners** Partners are **not eligible** for a nurse visit and we **do not** want you to carry out a nurse visit with the partners.
- ✗ **Proxy interviews** Participants who have completed a proxy interview are **not eligible** to have a nurse visit.
- ✗ **Core members who refused a previous visit** Core members who have refused a nurse visit at a previous wave are **not eligible** to have a nurse visit at wave 8.

### Rules for carrying out a nurse visit with partners

Nurse visits **should not** routinely be offered to partners. They should only be carried out in **extremely rare situations** where you feel you would lose the core member if the partner did not take part. From past experience we know that some partners are unhappy that they were not allowed a nurse visit at Wave 4 or Wave 6.

You may take all the measurements and samples for partners that they wish, including blood samples. You will be provided with separate blood labels for partners. For new partners you will need to write the participants details clearly on blank labels.

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## 4 The 'Nurse Link' and eNRF

### 4.1 The Nurse Link

All the information you need for each address is recorded by the interviewers in their admin block and is then transmitted to you within 24 hours of the interviewer transmitting their productive and completed work via the 'Nurse Link'. Your address menu is updated via the Nurse Link each time you connect to the host. You should use your sample cover sheet (see Section 4.2) to log your progress at each address. Updated information about each address will come through to you via the Nurse Link and will show up in your address menu.

At the start of fieldwork your address menu will be blank. When the interviewer has completed work at a household and transmitted it back to the office, the address will be transferred to your laptop. This means that at the start of a point you will not see a slot for that point on your laptop until the interviewer transmits the first household to you (which may be a No Nurse Visit or a Nurse Visit. Further addresses will then appear as the fieldwork goes on and as the interviewer transmits more households.

When you connect to the host machine, all the information you need about the household will automatically be picked up by your laptop. You will not be required to carry out a nurse visit at some addresses e.g. households who refused to take part. You should monitor your address menu closely and use your sample cover sheet to map your progress and update our Nurse Field Performance Manager in regards your progress.

Participants' addresses transmitted via the nurse link may be different to the issued addresses on the sample coversheet – this is because participants may have moved. If the interviewer finds that participants in a household have split up – instead of receiving one serial number you will receive two (e.g. 299991111 and 299991112).



**NOTE** – Always use the address and participant details which have been transmitted via the nurse link as this is the most up to date address for the respondent.

If the participant has moved address then you will need to notify your Nurse Field Performance Manager. You can continue to carry out a nurse visit if the participant is in/near your point of work. Otherwise, it may need reallocating to another nurse.

It is essential to pick up the 'Nurse Link' prior to going out on a visit as it 'brings forward' information from the interviewer CAPI to the nurse CAPI. In order to access the 'Nurse Link' and the most up to date information, you must connect to the host regularly to pick up your work. We recommend that you do this **every 2-3 days**. This should help you to plan your work effectively and inform you as soon as possible if there is any work to do at the addresses on your sample cover sheet.

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## 4.2 Nurse sample cover sheet

You will have a nurse sample cover sheet detailing all the serial numbers you will receive from your interviewers via the nurse link. The sample cover sheet helps you keep track of all the addresses in your point.

During the assignment, keep in regular contact with your interviewer partner. If there are any households which you have not received via the nurse link, please call the interviewer to check what the outcome was on those addresses – it is likely that they were not covered by the interviewer or there may have been a problem with the nurse link.

The nurse sample cover sheet has the following information:

- Tranche
- Field area
- Nurse name and number
- Nurse interviewer name and number (per point)
- Serial number and address of each household

For each household you will need to enter:

- The outcome for the household:
  - A – at least one person agree to the nurse visit
  - B – no nurse visit was required
- Number of blood samples taken, refused or were not possible
- The final outcome for that household
- The date(s) you posted the documents back and transmitted the data.

## 4.3 The eNRF

On ELSA all the information you need for each address is recorded by the interviewers in their admin block and is then transmitted to you within 24 hours of the interviewer transmitting their productive and completed work via the 'Nurse Link'. Once you have a household in the address menu you can enter this serial number. Here you will find the 'eNRF' (Electronic Nurse Record Form).

The eNRF is made up of two screens and contains all the information you need about the household.

The information on the household will include:

- Date of interview
- Telephone number(s) – mobile and landlines
- Person number(s)
- Name – title, first name, surname(s)
- Sex
- Age
- Nurse – nurse visit needed? Answers could be 1. Yes: CM (core member); 2. No: CM; 3. Partner; 4. Not elig: No int (not eligible, no interview, not eligible this wave)
- Need to collect interview self completion yes/no
- Appointment date and time (if available) if appointment was made by the interviewer for the nurse.

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In addition, you will also see any comments or notes from your interviewer about the household, such as useful tips about finding and accessing the address or household availability (planned holidays or times when participant not available). You can navigate between the screens by holding down '1' and pressing 'Enter'.

Where an appointment has not been made by your interviewer, you must contact the household to arrange your visit. Please do this as soon as possible – we know that participants are more likely to have a nurse visit if there is a shorter gap between the interview ending and your contact.

When you receive an eNRF, you know who is eligible for a visit, whether you need to contact them to make an appointment and if you have a contact number. This means you can get straight on to contacting the participants and arranging a visit.

## 4.4 The NRF pad

Once you have received an address via the 'Nurse Link', it is important that you transfer the relevant information from the eNRF onto a blank sheet from your NRF pad. This is a pad of printed sheets. You will be sent address labels, so stick the appropriate one onto the sheet. You must take down the details of those in the household and their contact details. There is also space for you to write any relevant notes the interviewer has made for you. You can then tear off the sheet and use this as your working field document for that household, recording all relevant information for that household and any notes you may find helpful as the fieldwork progresses.

Once the nurse visit has been completed you will then need to transfer information from the NRF pad to the admin block and transmit the serial number back. It is important that all relevant information is transferred from the NRF pad to the admin block. After your assignment is complete and you have received your pay, you should shred the completed sheets in the NRF pad.

### **IMPORTANT**

It is vital that you connect to the host machine regularly to pick up the Nurse Link data as this will tell you where nurse visits are to be conducted.

Before you go to a household, you should check that the Nurse Link information is on your laptop, by entering that household serial number.

You should also make sure you have filled the NRF pad for that household before you leave.

If the Nurse Link has not worked because of a technical problem you will need to contact the IT help desk for assistance. Please also inform your Nurse Field Performance Manager.

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## 5 What the participant already knows about your visit

### 5.1 Pre-visit information

#### Appointment record card

At the end of the interviewer visit, the interviewer will give each eligible participant an appointment record card. This confirms the appointment time (if appropriate) of your visit.

Since we are asking some participants to fast for the blood samples, the card also gives information about what they can eat on the day of their appointment.

<b>Appointment before 1pm</b>	Participants are asked not eat or drink anything (apart from water) on the day of their appointment.
<b>Appointment between 1pm and 6pm</b>	Participants 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.
<b>Appointment after 6pm</b>	Participants can have a usual breakfast and a light lunch of items listed on the appointment record card before 1pm. Requested not to eat or drink anything (except water) after 1pm.



**NOTE** – Let participants know that you will contact them again the night before the visit to encourage them and remind them of the fasting rules. Also, to emphasise the importance of drinking water if they are fasting.

#### Nurse survey leaflet

All participants who have agreed to a nurse visit will be given a nurse survey leaflet by the interviewer at the end of their visit. The nurse survey leaflet contains comprehensive information about the different samples, storing of bloods and possible insurance implications for the respondent.

We have stressed the importance of leaving the nurse survey leaflet with the participant but you will have spare copies in your work pack should you need them.



**NOTE** – Please ensure that you ask participants if they have had the nurse leaflet from the interviewer. If they haven't, give them a copy to read over. If they are unable to read it please go through the information with them. There is a check in CAPI at the start of the nurse visit about this.



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## 6 What to do on initial contact

### 6.1 Telephoning participants before the visit



**NOTE** – Your initial contact with participants should be by telephone and should be within the first week of being fed forward the information by the interviewer via the eNRF. The general rule is keep your introduction short, simple, clear and to the point.

### 6.2 Go through the appointment record card

If the participant is willing for you to carry out your visit you will need to go through the appointment record card.

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 – if they are not fasting.
3. Remind them to drink a good amount of water - if they are fasting.
4. Find out if they are eligible to have a blood sample taken. They are NOT eligible to have a blood sample taken if they:
  - ✘ • have a clotting or bleeding disorder
  - have had a fit/convulsion in the last five years. Ensure they DO NOT give blood if they have suffered a fit in the last five years
  - are taking anticoagulant drugs (such as Warfarin, protamine or acenocoumarol)
  - are pregnant (not very likely with ELSA respondents)
5. If they are eligible to have a blood sample taken you will need to determine if they are eligible to fast. Participants 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 (if interviewer has mentioned that the participant is 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.

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## 6.3 Approaching participants in institutions

There may be some participants who are eligible for a nurse visit who have moved into an institution (i.e. a nursing or a care home). Participants who are in an institution are still eligible for a nurse visit as long as they have had a core interview in person (not via proxy).

If any of your participants have moved into an institution you must ensure that your interviewer has provided you with the details of the contact person at the institution, such as the Care Home Manager. Your interviewer would have given the Care Home Manager a letter explaining the purpose of the study, which you also have copies to give out. Please contact the Care Home Manager and explain the content of the nurse visit and measurements that are involved. Check whether it is safe to carry out the measurements with the participant.

If the institutional contact agrees to the nurse visit you will need to check that the participant is contactable by phone, so you can explain the nurse visit, and if so, check that you have the right details for them. If you are unable to contact the participant by telephone you will need to visit them in person to explain the nurse interview and preparation for it (e.g. fasting) in detail.



**NOTE** – When visiting participants in institutions, although they have all been capable of completing the 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.

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## 6 The consent booklet

### 6.4 Completing the consent booklet

A consent booklet will need to be completed for every participant who has a nurse visit, regardless of whether measurements requiring consents are to be taken. This is because it provides an important check in the office. Every piece on the front is important. It will form the basis of the blood pressure (BP) and blood sample result letters which are sent to the GPs, if the participant consents to this. Please complete all sections fully.

The consent booklet is in a carbonised booklet format. Ask the participant to write on a firm surface, so that their initials come through to the carbon copy. The structure of the booklet is as follows.

#### Front cover

The respondent's name and address should be accurately recorded. Stick the serial number bar code in the appropriate box. Please ensure you use the correct bar code for the participant – check their name and date of birth on the sheet of bar code labels. Accuracy is vital.

Complete items 1 to 6 before you start using the computer to collect information from the respondent. Items 7 to 9 are completed during your interview (you will be prompted by CAPI).

Please try to get as many contact details about the respondent's GP as possible. These are important to ensure that the GP letters are sent to the correct address. Fill in the full name and complete address of the GP on every consent booklet for a household, even when all members have the same GP. Each individual is treated separately once the booklets reach the office. If a participant is unable to give you complete GP details, please look up the GP details using the internet at <http://www.nhs.uk/Service-Search/GP/LocationSearch/4>



**NOTE** – Always use this site when looking up GP details.

During your visit you will need to record the outcome of the respondent's consent for the various samples or measurements. There is space to do this in the grid on the front page of the consent booklet. By the end of the nurse visit every participant should have **six** codes circled.

SUMMARY OF CONSENTS RING CODE FOR EACH ITEM	YES	NO
a) Blood pressure to <b>GP</b>	01	02
b) Sample of blood to be taken	03	04
c) Blood sample results to <b>GP</b>	05	06
d) Blood sample results to <b>participant</b>	07	08
e) Blood sample for <b>storage</b>	09	10
f) Blood sample for PAXgene extraction and storage	11	12

CAPI will prompt you to complete these different consent forms as you go through the schedule.

### Inside front cover

The inside front cover contains the office despatch note. This should remain in the booklet and be returned to the office. You will need to enter the number of tubes of blood you have collected from each respondent.

### Inside coloured pages

The coloured pages are the office copies of the signed consents. These pages should remain in the booklet. Ask the participant to **initial** each box next to each sample/procedure they consent to. **As soon as a participant has initialled one box, please ensure that they sign and date the booklet at the bottom.** You will also need to sign the booklet at this point. Without the initials in the boxes and signature at the bottom of the booklet there is no consent. If a participant does not consent to a section in the booklet, CAPI will prompt you to cross a line through that section to make it clear in the office that no consent was gained for that part.

Please ensure you record the serial number in the boxes at the top of the first page so that it is transferred onto the carbon copy.

### Carbonised white pages

The inside white pages are the respondent's copies of the signed consents. These are perforated. Once the booklet has been completed, carefully remove these pages and leave them with the respondent.

### Inside back cover

The inside back cover is the laboratory dispatch note. It is essential that the information your record here is accurate. This page is perforated and is to be removed from the booklet and packaged with the sample(s) and sent to the lab (see Appendix A Section 1.8).

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## 6.5 Participant signatures

Use black pen when completing the booklets, and ensure that initials/signatures are always in pen and not pencil. Each participant must **initial** (not tick) each box if they have consented to the measurement or sample to be taken. The participant must also sign and print their name at the end of the booklet. You should also sign and date the booklet as a witness to the consent. If you make an error, do not erase any of the information. If necessary, cross out errors and rewrite so that any corrections can be seen.



**NOTE** – Always give the participant the white copies of consents and leave the original, coloured ones attached in the booklet to send back to the office.

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## 7 The nurse schedule

### 7.1 Prescribed medications

In the nurse CAPI there is a module of questions about prescribed medications which are currently taken by the respondent. Where a participant is taking prescribed medications you will need to take down the name of the medication and code the medication using the coding and prescribed medications booklet and the BNF. All nurse surveys use the same version of the BNF and coding booklet.

### 7.2 Drug coding

Drugs are coded using their BNF classification codes to the third level of classification. Use the six-digit format, using a leading zero where appropriate. You should have a copy of the BNF. You also have a 'Coding prescribed medications' booklet which lists the 400 (or so) most commonly used drugs in alphabetical order and gives their BNF classification codes.



**NOTE** – Try to see the medication packets to record the names accurately.

### 7.3 Blood pressure measurement

All sample members who give consent are 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 blood pressure readings.

### 7.4 Grip strength measurement

All participants will be asked to take part in this measurement. This measurement is carried out with the isometric handgrip strength measure. Three measurements of grip strength are taken on both the dominant and non-dominant hand.

### 7.5 Cognitive assessment – fluid intelligence

ELSA has asked a variety of questions to assess cognitive function as a measure of early cognitive impairment. In past waves these questions have been included as part of the interviewer visit. In wave 8, a sub-set of questions measuring fluid intelligence will be included in the nurse visit.

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## Cognitive tests over time

Some participants will have completed this test at earlier waves and some may be surprised to meet the same questions again but in the nurse visit. It is important that you reassure participants that it is a deliberate part of the study to ask people to repeat certain activities so that we can understand how and when people's circumstances change.

## Considerations prior to cognitive testing

Good cognitive testing assumes that the optimal performance of the participant has been obtained. As a minimum, this means that if a participant normally uses reading glasses or hearing aids, these must be used during testing. It also means that the tests are performed in private i.e. only the nurse and the participant should be in the room at the time and that the settings should be as free as possible from interruption or disturbance. At the end of the CAPI module you will be asked to record whether or not these conditions were observed. If there are any circumstances which you feel interfered with test performance, please record this information.

## Numerical problem solving: Fluid intelligence

Fluid intelligence is the ability to use abstract thought to solve novel problems and it is typically assessed via logic puzzles. The tests are currently used on the Understanding Society and ELSA's sister study in the US, the Health and Retirement Study (HRS). When describing the tasks to participants it would be better not to refer to them as fluid intelligence tasks, but numerical problem solving tasks.

For this task, **participants should use a pencil and paper** to write down the number sequences as you read them out. The number series will consist of several numbers with a blank number in the series. The participant will be asked which number goes in the blank. For example:

*2...4...6...Blank?*

First, you will give a simple example to the participant so they understand how the task works. In the example, you are able to tell the participant if they give an incorrect response and inform them of the correct answer. If the participant does not understand the instructions, or answered 'Don't know' in the example, a further example is provided. If they answer incorrectly a second time, CAPI will instruct you to inform them of the correct response and explain how the sequence works. If the participant still does not understand, or seems confused, code this and move on to the next element. However, if the participant understands the task, code this and move on to the number series.

After the example number series questions have been completed, feedback should not be provided – the correct answer should not be given and participants should not be told if their answer is correct. If the participant says they do not know the answer, this should be coded as 'Don't know'. If the participant is unable to do the test, for example because of severe speech or hearing problems, or because they do not understand the instructions, this should be coded as 'Unable to do'. Prompts should not be given after the number series has been written down by the respondent. Based on the number of correct responses given, the computer will select further series for the participant to answer.

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## Considerations during testing

The participants should be given encouragement during the testing, but do not give any specific feedback or assistance beyond what is specified in the instructions. Please be sure to administer the test exactly as specified. This includes delivering the test instruction precisely as written. Even subtle departures from the written instructions and procedure can influence the participant's performance. It is crucial that the test is performed in a standardised way by all nurses so that we can compare the performance of different participant's in this study and compare our findings with other studies.

## Debriefing participants

Following testing, some participants may request feedback about their performance. Participants should not be encouraged to dwell on their performance in terms of good, average or poor. For participants who need reassurance, it may be helpful to reiterate that the test is designed to be difficult. In rare cases where the participant feels genuinely concerned about their performance, they may be advised to discuss their concerns with their general practitioner.



Specific feedback should not be given. Do not say exactly how well they have performed, and never provide the correct answers.



You can say "Everybody finds it difficult, you have done fine".

## Scoring fluid intelligence tests

Note that for the fluid intelligence test a 'don't know' answer should be coded as incorrect. This is because experience shows that such responses are usually associated with inability or difficulty in doing the task. Try to encourage participants to "Just have a go".

## 7.6 Blood samples – the PAXgene test

The PAXgene is a new test in ELSA measuring gene expression or Ribonucleic acid (RNA). The test measures a range of substances to help our understanding of the health risks and protective health factors in later life.

The PAXgene tube is a special test tube that allows us to stabilize and store cells in blood for a long time. These cells will then be used in the future to measure new molecules that will help our understanding of health risks in later life.



## 7 Other nurse documents & equipment

### 7.1 Nurse documents

The following is a list of documents you will need for ELSA wave 8.

<b>ELSA Wave 8 Nurse Documents</b>	
<i>Document</i>	<i>Colour</i>
NRF Pad	Green
Consent booklet	Pink
Nurse visit leaflet	Green
Appointment letter	Headed paper
Re-contact letter	Headed paper
Measurement record card	Yellow
Venepuncture leaflet	White
Sharps disposal letter	Headed paper
Coding prescribed medications booklet	Nurses to use existing booklets which matches the BNF
Barcode labels	White
Blood draw card	White laminated
Address labels for NRFs	White

### 7.2 Nurse equipment

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

<b>ELSA Wave 8 Nurse Equipment</b>
<b><i>Drug Coding</i></b>
British National Formulary (BNF 69)
<b><i>Blood pressure</i></b>
Thermometer and probe
Omron (small, medium and large cuffs)
<b><i>Blood Sample</i></b>
Blood labels and tubes (blue, red EDTA, grey, lilac, PAXgene tube); related blood sampling equipment; sharps bin and dispatch packaging.
<b><i>Grip Strength</i></b>
Dynamometer

# Appendix A.

# Blood samples (fasting)

## 1.1 Eligibility

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



**1. 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).

**2. People who have had a fit in the last 5 years**

**3. People who are not willing to give their consent in writing.**

**4. People who are currently on anticoagulant drugs, eg Warfarin therapy.**

Some participants 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 tests 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.

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

## 1.2 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 participant **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 PAXgene RNA. You should seek to obtain all these consents before you take any blood. However, it is not essential that participants 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 for storage. Even if there is no consent given for specimen storage, we would still like to collect blood for immediate analysis, provided of course the participant 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) by 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 participant if they would be willing to have a **blood sample taken**. Try to reassure participants about the process, and be prepared to answer their concerns. You will need to explain to the participant the need for written consent and how important it is.
- b. Obtain written consents in the appropriate **Blood Sample Consent section**.
- c. Obtain consent to **store blood**.
- d. Obtain consent to send laboratory **results to the respondent**
- e. Obtain consent to send laboratory **results to GP**
- f. Obtain consent to take additional blood sample for **PAXgene extraction and storage**.
- g. Check that you have circled the correct consent codes on the front of the consent booklet.

Having checked that you have: all the appropriate initials; the respondent's signature in the appropriate section on page 5; and circled the appropriate codes, you are ready to take the blood sample. If you obtain a sample, note down any problems in CAPI. If you do not manage to get any blood, again code as appropriate in CAPI.

## 1.3 Purpose

A blood sample will be collected from participants who give consent. The blood will be analysed for the following and participants and GPs will be sent results if consent has been given .

<b>Total cholesterol</b>	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.
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<b>HDL cholesterol</b>	This is 'good' cholesterol which is protective for heart disease.
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\*Not measured but calculated using a formula involving total cholesterol, HDL cholesterol and triglyceride concentration:

<b>*LDL cholesterol</b>	This is 'good' cholesterol which is protective for heart disease.
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Blood will also be analysed for the following but results will not be provided to the participant.

<b>Fibrinogen</b>	A protein necessary for blood clotting. High levels are also associated with a higher risk of heart disease.
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<b>Triglycerides</b>	Together with total and HDL cholesterol, they provide a lipid profile which can give information on the risk of cardiovascular disease.
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<b>Ferritin and Haemoglobin</b>	These are measures of iron levels in the body and are related to diet and other factors.
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<b>C-reactive protein</b>	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.
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<b>Fasting glucose and Glycated haemoglobin</b>	Both indicate the presence or risk of type 2 diabetes, which is associated with an increased risk of heart disease.
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<b>White cell count (WCC) and mean corpuscular haemoglobin (MCH)</b>	When looked at in combination with Ferritin and haemoglobin, can indicate anaemia.
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<b>Vitamin D</b>	Obtained from the diet and from sunshine, we need Vitamin D for healthy bones. The only way we know if someone has enough Vitamin D for the body's needs is to measure it in the blood.
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<b>PAXgene</b>	Genetic factors are associated with some common diseases, such as diabetes and heart disease, and relate to general biological aspects of the ageing process.
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The blood will **not** be tested for any viruses, such as HIV (AIDS).

## 1.4 Equipment

Tourniquet	
Alcohol & non alcohol swabs	Vacutainer safety needles 21G (green)
Gauze squares	Vacutainer safety needles 22G (black)
Vinyl gloves	Butterfly safety needles 23G (blue)
Adhesive dressing (spot plaster)	Sharps / needle disposal box
Micropore tape	Vacutainer blood tubes
Sheet of labels for blood sample tubes	Sharps bin
5 slot plastic dispatch packaging	Vacutainer fluoride grey tubes
Antiseptic hand gel / antibacterial hand wipes	Vacutainer EDTA light purple tubes
	PAXgene

## 1.5 The blood tubes

If the participant has fasted and has given consent for PAXgene extraction and storage, then **FIVE** tubes need to be filled. They should be filled in the following order of draw to maintain the highest priority of analysis.

<i>First</i>	1.8ml citrate tube (blue)
<i>then</i>	6ml plain tube (red)
<i>then</i>	2ml fluoride tube (grey) (if fasted)
<i>then</i>	2ml EDTA tube (light purple / lavender)
<i>finally</i>	2.5ml PAXgene tube (clear with orange line)

CAPI will guide you as to which tubes will be drawn and order of the draw. You will also have a credit card sized 'order of blood draw' card as a reminder. **If the participant has not fasted, the grey tube will not be taken.**

## 1.6 Taking the sample

You will be taking a maximum of five tubes. Everyone who is eligible and willing to have their blood taken should give **at least three** tubes of blood (the blue, red and

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first light purple tubes). If the participant has fasted they will also give blood for the grey tube (you cannot return for a second visit to take a fasting blood sample). 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 participant forgot 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 participant that they have not eaten or drunk anything (except water) **in the last five hours**. Participants who have taken medication with water in the last five hours are eligible to give a fasting blood sample and you do not need to make a note.

If the participant 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. blue citrate tube (invert 4 times)
2. large plain red tube (invert 8 times)
3. grey fluoride tube (if the participant has fasted) (invert 8 times)
4. light purple EDTA tube (invert 8 times)
5. PAXgene tube (clear top with orange line on top of tube) (invert 8-10 times) – **MUST BE THE LAST DRAW**

The vacutainers should be filled to capacity in turn and inverted gently as appropriate for the tube (as above) on removal to ensure complete mixing of blood and preservative.

**Please also refer to the standard NatCen Nurse Protocols for Venepuncture and Blood Sampling.**

## Taking the PAXgene sample

The PAXgene tube should be the last sample of blood you take. It is important that the PAXgene tube draws the full 2.5mls of blood required, and that once drawn the tube is inverted 8-10 times. Partially filled samples will not be useful for any future analysis of RNA.

If you are unable to draw a full PAXgene sample (2.5mls) on your first attempt and the PAXgene sample is then the only tube to fill, you **should not** make a second attempt to draw the sample.

If you are unable to draw a full PAXgene sample **and** you still have at least one other tube to fill, in the order of draw **then you can** make a second attempt to draw the remaining sample. This is to reduce the risk of any PAXgene additive back-flowing into the participant's vein, if it was the only tube being filled.

## 1.7 Labelling tubes

- |    |   |
|----|---|
| 1. | Label the tubes after you have completed the procedure. |
|----|---|

2.	Use the set of serial number barcode labels to label the vacutainer tubes.
3.	You have one sheet of labels per participant – check the serial number, person number, full name and date of birth printed in the top left of each one.
4.	Attach one serial number barcode label to every tube that you send to the lab.
5.	Do <b>not</b> write any information (such as date of birth) on the labels.



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!

## 1.8 Completing the despatch note

### Completing the lab copy blood despatch note

1.	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.
2.	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.
3.	At item 6 enter your Nurse Number.
4.	At item 7 code if the participant fasted for at least 5 hours before the blood sample was taken.
5.	At item 8 state the number of tubes collected
6.	At item 9 circle 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 9 on the front page of the booklet.

### Completing the office (Brentwood) copy blood despatch note

1.	At item 6, affix a serial number barcode label that corresponds to those used on the Newcastle Dispatch Note, the tubes, and the front of the consent form.
2.	State the numbers of tubes you sent to the lab at item 1. This indicates what we should expect back from the laboratory. Note if any of the samples were incomplete.
3.	Code the respondent's sex at item 2.
4.	Write in their date of birth at item 3 (check this corresponds with the barcode

	labels, NRF etc.).
5.	Write in the date the blood is taken at item 4.
6.	Write in the date the blood is dispatched at item 5. This tells us the date you sent the samples to the labs.
7.	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 dispatch note and give the reason.

## 1.9 Packaging the blood samples

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

You will be given **5 slot plastic dispatch packets (to fit the larger PAXgene tube)**

1.	Insert the blood sample tubes in the slots of one side of the dispatch packet.
2.	Fit the other half of the packet onto the first – clicking the corners to ensure it has fastened together.
3.	Place the Newcastle Dispatch Note in the striped posting polybag addressed to RVI in Newcastle; along with the sealed blood packet.
4.	Seal the striped polybag by removing the self seal strip. Post the sample in a post box with same day collection.

## 1.10 Posting the blood samples

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

### IMPORTANT

- The samples should be posted **AS SOON AS POSSIBLE**, within 24 hours of being taken.

This is vital as the PAXgene samples must be received and processed by the lab within a 72 hour period (3 days).

- Try to avoid taking a sample if you think that you will be unable to post it within 24 hours and if you feel the sample will not reach lab within the 72 hour period.
- The lab is closed over the weekend and will not process any samples during this period.
- Samples cannot be taken Saturday afternoon unless you are able to get it into a post collection box that afternoon. If samples are taken on Saturday afternoon and the post is missed then the next post collection won't be until the Monday (48 hours later) and it may not get to the lab in time for processing.
- Please avoid taking samples where you feel that you will not be able to post the samples in time to be received and processed by the lab within 72 hour period.



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When you have posted the samples, fill in **the time and date** of posting on the Office Copy of the Dispatch Notes and return this to Brentwood with the Consent Forms. We will be closely monitoring PAXgene blood collection dates/times and dates/times the samples were received and processed by the lab.