



Understanding Society Nurse visit

Nurse Project Instructions

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1 HOW TO USE THESE INSTRUCTIONS

This manual sets out the survey procedures for nurse assignments for *Understanding Society*.

The instructions are divided into sections explaining:

- Background information about *Understanding Society*
- Overview of the fieldwork structure and sample design
- Content and procedures of the various stages of the interviewer and nurse visits
- Tips about your initial contact and achieving high response
- Introducing your measurement task and carrying out the interview

This manual must be used in conjunction with the Nurse Protocols Manual and existing Clinical Procedure Guidelines (CPGs).

2 BACKGROUND & AIMS

2.1 Key features of Understanding Society nurse visits

Aims	Understanding Society is a major household panel study involving 40,000 households in Britain. It is about people's lives, experiences, behaviours and beliefs, and will enable an unprecedented understanding of diversity within the population.
Lead Research Organisation	Institute of Social and Economic Research (ISER), University of Essex
Sponsor	Economic and Social Research Council (ESRC)
Eligibility	A sample of adults (aged 16+) with a fully productive <i>Understanding Society</i> stage 1 interview
Sample size	9,500 issued households
Fieldwork period	12 months
Data collection method	Face-to-face CAPI interview, objective measurements

2.2 The purpose of *Understanding Society*

Understanding Society is a major household panel study which has been commissioned by the Economic and Social Research Council (ESRC). Taken as a whole, it is the largest study of its type in the world interviewing a total of 40,000 households across the UK. It is led by the Institute for Social and Economic Research (ISER) at the University of Essex. The survey will also be known as the UK Household Longitudinal Study (UKHLS) among the academic community, but we will only refer to it as *Understanding Society*.

Understanding Society will provide valuable new evidence about people throughout the UK, their lives, experiences, behaviours and beliefs, and will enable an unprecedented understanding of diversity within the population. The survey will assist with understanding the long-term effects of social and economic change, as well as policy interventions designed to impact upon the general well-being of the UK population. The data will be used by academic researchers and policy-makers within government departments, feeding into policy debates and influencing the outcome of those debates.

The survey will collect data from all household members aged 10 and above on an annual basis. Annual interviewing will allow us to track relatively short-term or frequent changes in people's lives, and the factors that are associated with them. As the years of the survey build up we will be able to look at longer-term outcomes for people in the sample.

Each respondent will be contacted annually, but because of the large sample size, each wave of interviewer fieldwork will last for two years. In W2 an additional stage of fieldwork carried out by qualified nurses was introduces to the study. During the first year of W2, a selected sub-sample of around 11,900 household were offered the nurse visit. This year there will be a continuation of the nurse fieldwork with a different sub-sample of around 9,500 house holds. The nurse visits will occur approximately five months after the respondents have taken part in a face to face interview in stage 1. (See figure 1).

Jan10

W1

W2

Nurse visits

W3

Nurse visits

W4

Figure 1: Understanding Society fieldwork outline

2.3 Data collected

The wave 2 *Understanding Society* interview focuses on the following topics:

- Family, relationships, fertility, child-birth history;
- Educational aspirations; future plans; retirement expectations
- Health, physical activity, nutrition, disability and caring;
- Leisure, culture, transport, voluntary work and charitable giving;
- Employment, work conditions, finance and personal consumption; and
- Ethnicity, religion, politics and political engagement.

The wave 3 *Understanding Society* interview focuses on the following topics:

- Ethnicity and religion; Neighbourhood and social networks; Relationships;
- Health; Cognitive ability;
- Annual events; Employment; Finances;
- Family networks and childcare;
- Politics;
- Neighbourhood belonging; Satisfaction; (self-completion)
- How they see themselves as a person; Sexual orientation; (self-completion)
- Future intentions (for young adults); and Friendships and partner relationships. (self-completion)

The nurse visits will involve collecting the following measures:

- Height
- Weight
- Bioelectrical impedance (body fat)
- Waist circumference
- Blood pressure
- Grip strength
- Lung function
- Blood sample

Information about the survey, its objectives and design has been submitted to Integrated Research Application System (IRAS), which approves the ethical aspects of medical research. Committee members represent medical, professional and patient interests. They have approved the nurse visits for *Understanding Society* 2011-2012.

2.4 How will the data be used?

Understanding Society is a relatively new research study, but it's predecessor *Living in Britain* was carried out for 18 years. The data is put on the UK Data Archive and is available for researchers to download for analysis.

Some recent examples of research carried out using Living in Britain data:

- The well-being of older persons with disabilities (Katrin Gasior, 2009)
- Dynamics of household joblessness in Australia and UK (Rezida Zakirova, 2009)
- Life course influences on inequality and poverty in old age (Rachel Stuchbury, 2009)
- Transition from school to work (Masahiko Sano, 2008)
- Recurrent poverty (Mark Tomlinson, 2008)
- Health over the life course (Christiaan Monden, 2008)

2.5 Further information about *Understanding Society*

If you would like more information about *Understanding Society*: http://www.understandingsociety.org.uk/

3 THE TEAM

3.1 The Research Team

Understanding Society is led by The Institute for Social and Economic Research (ISER) at the University of Essex. NatCen has been commissioned to conduct the first five waves of fieldwork.

3.2 The Survey Doctor

Dr. XXX is the 'Survey Doctor'. He is responsible for providing nurses with medical support and for liaising with respondents in relation to blood pressure abnormalities that are detected as a result of this survey.

In cases where respondents have considerably raised blood pressure (systolic at or greater than 180 mmHg or Diastolic at or greater than 115 mmHg) nurses will need to contact the Survey Doctor after leaving the respondent's home.

The survey doctor is available most of the time. If the doctor is not immediately available, leave a message saying that you wish to pass on details of a considerably raised blood pressure case and the doctor will get back to you in good time.

3.3 The Fieldwork Team

Each nurse will be supported in her/his area by a local fieldwork team consisting of the Area Manager, a Nurse Supervisor, and a team leader. The Nurse Supervisor is the person you should consult if:

- You have any queries about your equipment and how to use it in field,
- You have other problems about carrying out the interview and measurements.

The nurse supervisor will from time to time accompany you in the field.

The team leader supervises interview work on *Understanding Society* within each field area (including allocation of work to interviewers and fieldwork progress), and will work with the Nurse Supervisor to oversee nurse progress. The supervisors are there to help you do your job to the best of your ability. Please consult them whenever you feel you need help. The names of your supervisors are listed on page 4 of the instructions.

4 FIELDWORK OVERVIEW

4.1 Research Stages

Main Interview

The first stage of *Understanding Society* involves an interview visit with the following elements:

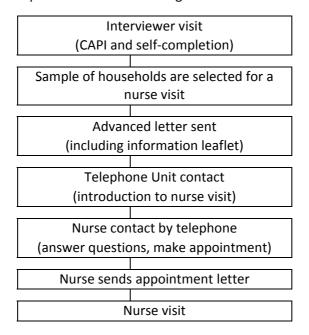
- 15 min Computer-Assisted Personal Interviewing (CAPI) Household questionnaire;
- 25-32.5 min (average) Individual Adult CAPI questionnaire for all aged 16+;
- 10-15 min (average) Adult Self-Completion questionnaire;
- 10-15 min (average) Youth Self-Completion questionnaire for all aged 10-15;
- 11.5 min cognitive testing element for all aged 16+ (introduced in W3 only).

Nurse Visit

A qualified nurse carries out the second stage of fieldwork with some of the people interviewed in the first stage. The nurse visit will occur approximately five months after the original interview.

It is estimated that the measurements and CAPI will take approximately 1 hour for each respondent. Nurses are responsible for making their own appointments for this study.

The diagram below outlines the process between the stage 1 interview and the stage 2 nurse visit:



5 THE SAMPLE

5.1 Sample design

The total sample for *Understanding Society* is around 40,000 households. This includes the following sample groups:

- General Population sample
- Ethnic minority boost sample
- British Household Panel sample
- Innovation Panel sample

The nurse visits for 2011-2012 will be carried out with the **British Household Panel sample** and a sub sample of the **General Population** in England only. This is a named sample of people who have been interviewed in the most recent wave of interviews. We have liaised with area managers and clustered the sample to reflect geographical areas.

The nurse visit fieldwork period will start around the 17th of each month. You will receive information on your sample each month around the beginning of fieldwork. You will have six weeks from receipt of the sample information in which to complete your assignment. If you identify any movers/split households you should begin tracing immediately. Workload will vary from point to point, but it is expected that one month's work for a nurse will be approximately 10 households.

5.2 Who to visit

Not all people in the household are necessarily eligible for the nurse visit.

Eligible	Not eligible	
Full individual stage 1 interview	Refused stage 1 interview	
	Proxy stage 1 interview	
Stage 1 interview in English	Stage 1 interview translated	
Aged 16 or over at the time of the stage 1 interview	Turned 16 since stage 1 interview	

Only the eligible respondents will be listed on the contact information sheet on the back page of the NRF (more details in section 6.4).

Respondents who are known to you

We do not want you to visit anyone you know personally, such as a friend, a neighbour, son or daughter of a friend. In addition, you should not interview anyone you know in a professional capacity such as a colleague at work, a teacher at night school etc. Refer such cases back to your team leader immediately and the case will be re-allocated.

Whom to interview and where

In the main interview, we are following people who have moved into most institutions (e.g., hospitals, nursing homes/Old Peoples Homes, Army Camps, halls of residence but not prisons). We will not be interviewing those who are judged by other sample members/guardians to be "too frail or mentally impaired".

Whole household moves

If everyone in the household has moved to a new address then you should attempt to obtain their new address as quickly as possible. You can do this by:

- Calling households members using any of the telephone numbers on the contact information sheet (back page of the NRF)
- Asking the current residents

If you find a new address and it is within your fieldwork area, you may carry out the nurse schedules at the new address. Record the new address in the admin block. If the new address is outside your fieldwork area please code 96 and return the case to the office. If you can't find a new address you should code the case as 97 and return to the office.

Split households

You may find that some respondents are no longer resident at the issued address. If this is the case, you can carry out the nurse schedule with the remaining household members and attempt to obtain a new address for the split-off mover(s).

5.3 Fieldwork design

The interviewer fieldwork for each wave of *Understanding Society* lasts for two years, and is split into 24 monthly samples. Sample members will remain in the same monthly sample that they were allocated to in the first wave. There can be no swapping of addresses to a different monthly sample.

The 24 monthly samples are named:

- JA1, FE1, MR1, AP1, MY1, JE1, JL1, AU1, SE1, OC1, NV1, DE1
- JA2, FE2, MR2, AP2, MY2, JE2, JL2, AU2, SE2, OC2, NV2, DE2

The nurse visits will follow the same pattern as the stage 1 interviews, with a five month lag after the interview. Nurses will cover the British Household Panel sample who will be interviewed in the first 12 months

of wave 3 fieldwork (P8023) and a sub sample of the General Population who will be interviewed in the second year of wave 2 fieldwork (P8821) (both running between January 2011 and December 2011). Therefore the British Household Panel sample will be issued under sample months JA1 to DE1 and the General Population sample will be issued under sample months JA2 to DE2:

BHPS Sample month	General Population Sample month	Interviewer cases issued	Nurse visit cases issued
JA1	JA2	Jan 2011	Jun 2011
FE1	FE2	Feb 2011	Jul 2011
MR1	MR2	Mar 2011	Aug 2011
AP1	AP2	Apr 2011	Sep 2011
MY1	MY2	May 2011	Oct 2011
JE1	JE2	Jun 2011	Nov 2011
JU1	JU2	Jul 2011	Dec 2011
AU1	AU2	Aug 2011	Jan 2012
SE1	SE2	Sep 2011	Feb 2012
OC1	OC2	Oct 2011	Mar 2012
NV1	NV2	Nov 2011	Apr 2012
DE1	DE2	Dec 2011	May 2012

5.4 Nurse Record Form (NRF) and Sample Cover Sheet

At the start of each assignment you will receive a **sample cover sheet** which tells you the postcode sector or area in which you will be working and the point number and lists the addresses in your sample. There is room on the sample cover sheet to record your own progress, and at the end of your assignment period you should be able to account for all addresses on your sheet.

You will receive a **Nurse Record Form (NRF)** for each household where there is work for you to do. It includes key information about the members of the household who are eligible for the nurse visit. to help you identify each sample type in your monthly assignment, the NRF for the **Living in Britain** sample will be white and the RF for the **General Population** sample will be yellow.

The NRF has two functions:

- it tells you the outcome at the household of the Telephone Unit's attempts to contact the household
- it is the form on which you report to the office how successful you have been at those households.

You must complete all sections of the NRF:

Page One – Information and calls records
At the top of the page enter the date of the initial appointment and the date you received the NRF.
The top section of page 1 will be completed with the address details (incl. co-ordinates), information about the stage 1 interview and information about the Telephone Unit contact.
Record all telephone calls and personal visits.
Page Two – Household outcome codes
Ring the appropriate household code outcome and write on the top hand corner of page 1.
Write in the total number of consent booklets obtained for the household

Page Three - Individual outcome codes

Write in the individual outcome code for each selected respondent.

Indicate if a blood sample has been sent to the lab (Y/N).

Write in the date of the nurse visit.

Record codes for any refusals

Page Four – Respondent information

Contains person numbers, age, sex and contact details for every eligible member in the household

Shows telephone unit outcome for each eligible individual

You must not take measurements or samples from any household member who is not listed on page four of the NRF.

Occasionally you may find someone in a household who has refused the nurse visit when contacted by the telephone unit (code 2) and then decides to take part. You **can** take the measurements as these people are eligible.

The address co-ordinates are provided for the address. This is to help those in rural areas to locate addresses. You will be sent a map with all the addresses selected for the assignment you are working in marked on it. If this is not clear, the postcode can also be used to locate addresses and to obtain a map using one of the following web pages: www.multimap.co.uk or www.streetmap.co.uk. If you cannot search these yourself, please contact the office in Brentwood who will be happy to help. If the (MMU/interviewer) made any notes about useful ways of locating the house, these will be recorded on the first page of the NRF under 'Location Details'.

6 SECURING AN APPOINTMENT FOR A NURSE VISIT

6.1 What do respondents know about your visit?

Advanced letter and leaflet

Understanding Society respondents who have been selected for a nurse visit will be sent an advance letter giving details about the nurse visit. The advance mailing will include a leaflet which gives a brief overview of the measurements and samples that will be collected in the nurse visit. The letter and leaflet will also inform participants that they will receive a £10 voucher as a token of appreciation for taking part in the nurse visit.

Contact from the telephone interviewer

An interviewer from NatCen's Multi Mode Unit will then make contact with one of the selected adults within a household. They will explain the nurse visit to the respondent and answer any non-medical questions about the study.

The telephone interviewer will then explain that a nurse will be in contact to set up an appointment. In households where **all** the selected respondents refuse the case will not be issued to a nurse. The telephone interviews (approx 5 mins) will then cover the following:

- (a) establish contact with at least one selected adult per household
- (b) introduce the nurse visit and answer any (non-medical) queries
- (c) get agreement from one person per selected HH for the nurse to make contact with the HH
- (d) confirm the current address for all selected adults within the household

6.2 Making initial contact

The contact information sheet (back page of the NRF) contains contact telephone numbers for all eligible individuals in the household. The Telephone Unit outcome code is also listed, showing who has agreed, refused or not yet been engaged with regarding further contact with a nurse. When phoning a household to book appointments it is preferable to begin with the individual who has a TU outcome code of 1 (agreed to nurse contact) and attempt to book further interviews for the household through this individual.

Keep the call short, simple, clear and to the immediate point. The purpose of the call is to book an appointment and whilst respondents may have queries or concerns, you will be much better placed to explain what your visit will cover and address any concerns face-to-face when you visit for the appointment.

An example of how to introduce yourself over the telephone is given below. Before calling be clear in your mind whether a respondent has said 'yes' to the Telephone Unit to a nurse contacting them or that they have not yet been engaged with regarding nurse contact. This is essential so that you can tailor your introduction.

Introducing yourself to respondents on the phone:				
Say who you are:	"I am a nurse called"			
Say what you're calling about:	"I work on the <i>Understanding Society</i> survey"			
If this respondent has agreed to nurse contact at TU stage, remind them of this:	"A few weeks ago, someone from phoned you regarding the survey and you kindly agreed that I could contact you."			
OR				
If TU has not engaged with this respondent, remind them of the stage 1 interview:	"Several months ago, one of our interviewers (NAME) visited you for the <i>Understanding Society</i> survey. We recently wrote to you about the next stage of the study which involves a qualified nurse coming to visit you. This is to get a more detailed understanding of people's health. I'm calling to try and arrange an appointment time to visit you."			
	IF NECESSARYADD:			
	The visit involves:			
	- some questions about your health			
	- some measurements such as blood pressure, height and weight			
	- with your consent, I will take a blood sample			
	- All elements of the nurse visit are optional			
Book the appointment:	I'd now like to make an appointment to come and see you. Would (DATE/TIME) be convenient for you?"			

If the suggested date is not convenient for the household, then you can negotiate an alternative that is convenient to you both.

6.2.1 Being persuasive

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

You will need to tailor your response 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. The most important thing is to find out what are the respondent's concern, or reason for being reluctant about the nurse visit (is it the time taken? / the content of the visit? / the purpose of the study?) and then answer this question only.

What you might mention when persuading someone to take part in the survey:

If the respondent is unsure about the measurements:

- · You will explain each measurement/sample and check before proceeding with each one
- The respondent does not have to do anything they don't want to perhaps you could just ask the questions about medicines, and take the blood pressure? (once inside, you may find that the respondent then agrees to more measurements)

Why Understanding Society is important:

- It is carried out annually
- It is the largest study of its type in the world, interviewing a total of 40,000 households across the UK
- It is a national survey funded by the Economic and Social Research Council
- It provides valuable information about people throughout the UK, their lives, experiences, behaviours and beliefs, and will enable an unprecedented understanding of diversity within the population
- It will assist with understanding the long-term effects of social and economic change, as well as policy interventions designed to impact upon the general well-being of the UK population

Why we want to include everyone:

- The survey covers the whole population
- To get an accurate picture, we **must** talk to all the sorts of people who make up the population the young and the old, the healthy and the unhealthy, and those who like the current government's policies and those who do not.
- Each person selected to take part in the survey is **vital** to the success of the survey. Their address has been selected not the one next door. No one else can be substituted for them.

If they have concerns about confidentiality

No-one outside the research team will know who has been interviewed, or will be able to identify an
individual's results.

6.2.2 Number of calls you must make

You must make at least **six phone calls per eligible individual** before you can give up. Each of these calls must be at different times of the day and on different days of the week, including evenings and weekends. However, we hope you will make a lot more than six calls or visits to the household to get respondents that are difficult to contact. If you fail to make contact you should try again but let the office know as someone may be able to help you.

You are asked to keep a full account of each telephone call or personal visit you make at a household on page one of the **Nurse Record Form** (see Section 6.4). Complete a row for each call/visit you make. 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.

Once you have agreed a suitable appointment time with a respondent send the appointment letter to the respondent with the date and time and your name filled in. #

6.2.3 No answer

If you are consistently getting no answer when you telephone it may be because the respondent doesn't pick up phone calls from numbers they don't recognise or withheld numbers. You may be able to overcome this by leaving a message saying who you are and saying that you're planning to call back at [day, time]. Respondent's sometime pick up the next time you call.

6.3 Broken appointments

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

In any case, make every effort to re-contact the person and fix another appointment. Start by leaving a **Broken Appointment Card** at the house saying that you are sorry that you missed them and that you will call back when you are next in the area. Add a personal note to the card. Try telephoning them and find out what the problem is. Try to dismiss any misconceptions and fears respondents might have. Make them feel they are important to the success of the survey.

7 ACHIEVING HIGH RESPONSE RATES

In most cases respondents will be looking forward to your visit. They have all participated in an interview a few months ago. The Living in Britain sample have taken part in the survey for 20 years and the General Population sample have been involved in *Understanding Society* for two years now. Having completed the interview they have already invested time in our survey, and most will be willing to complete the nurse stage. However, some may need persuading.

7.1 The importance of high response

A high response rate at all stages of the survey is crucial if the data collected are to be worthwhile. Otherwise, we run the risk of getting findings that are biased and unrepresentative, as people who do not take part are likely to have different characteristics from those who do. Keeping respondent co-operation high at this important stage of the survey is therefore vital to its success.

7.2 Keep your introduction short

While you will need to answer queries that respondents may have, you should keep your introduction short and concise. As already noted, 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 to keep your initial introduction short, simple, clear and to the immediate point. Points to remember about your doorstep introduction:

- Show your identity card
- Say who you are
- Say who you work for
- Remind respondents about your appointment:

"A few days ago I spoke to you on the phone regarding Understanding Society and we made an appointment for me to see you today."

For most people this will be enough. They will invite you in 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 and be prepared to answer questions about the survey. Some respondents may have forgotten the purpose of this stage of the survey or what your visit involves. You may also need to answer questions about how the household was sampled and why in some households not all individuals are eligible for the nurse visit.

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

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

7.3 "You won't want to test me..."

Some people think that they are not typical (they are old, they are ill, they are young and healthy, and so on) and that it is therefore not worthwhile (from both your and their point of view) to take part in the survey. You will have to explain how important they are. The survey must reflect the *whole* population, young and old, well and ill. We need information from all types of people, whatever their situation. If someone suggests that you see someone else instead of them, explain that you cannot do this as it would distort the results.

Our target is to interview <u>and</u> measure all eligible respondents. The measurements carried out by the nurse are an integral part of the survey data and without them the interview data, although very useful, cannot be fully utilised.

7.4 Respondents are not patients

Your previous contact with the public as a nurse will normally have been in a clinical capacity. In that relationship, the patient needs the help of the professional. Your contacts with people in the course of this survey will be quite different. Instead of being patients, they will be people who are giving up their leisure time to help us with this survey. You need their help to complete your task. The way you deal with them should reflect this difference.

They are under no obligation to take part, and can decline to do so. They can also agree, but then decline to answer particular questions or provide particular measurements. But of course we want as few as possible to decline, and we rely on your skills to persuade them to participate.

8 CARRYING OUT THE INTERVIEW

8.1 The interview documents

The nurse questionnaire is on computer CAPI. As well as the computer schedule, you will use other documents during the interview itself. These include:

- the consent booklet
- the visit information leaflet
- the blood information leaflet
- the coding prescribed medications booklet
- measurement record card

The CAPI will prompt you when to use them (see APPENDIX A for a list of all nurse documents).

8.2 General tips on how to use the documents/CAPI

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 a 'CHECK'. This is an instruction to you to enter something without needing to ask the respondent a question. The convention is that, if a question appears with "NURSE:" before it, you do not read it out. You shouldn't read out any instructions that have been CAPITALISED.

If 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.

8.3 Preparing the documents & CAPI

At the start of the fieldwork period you should connect your computer to the modem (separate instructions about this are provided) and pick up the households that have been allocated to you.

Check that the information from the interviewer is on your laptop BEFORE you leave home for the appointment. The computer will show you the information about the eligible members of that household.

When you arrive at the household, you should go into the nurse schedule and check that it is the right one by looking at the serial number and/or viewing the information about the household members.

Immediately before you start to carry out measurements on a respondent, complete the first half of page 1 of both Consent Booklets. **Never do this before your visit to the household.**

8.4 Organising the interview

When you arrive at the household, check whether any of the people you have come to see have eaten, smoked, drunk alcohol or done any vigorous exercise in the last 30 minutes. This could affect their measurements. If someone has done any of these things, arrange to see other members of the household first in order to give time for the effects to wear off. 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 the order of interviews 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.

8.5 Introducing the measurements

The telephone interviewer may have introduced your visit, but will have given only a brief outline of what is involved. He/she will have told respondents that you are the best person to explain what your visit is about.

Before you begin you will need to explain what you hope to do during your visit and to reassure nervous respondents that every stage is optional. After you have explained what you are going to do and the order in which you wish to see the respondents, you should provide each respondent with the **Information for Participants** leaflet and ask them to read it before you start. It describes what you will be doing and details that the survey is voluntary and has been approved by an NRES (National Research Ethics Service) ethics committee. It is particularly important that respondents read this leaflet as it forms part of the informed consent for taking part in the survey.

If a respondent is willing to have a blood sample taken it is advisable that they have read the **Giving a Blood Sample: Frequently Asked Questions** leaflet as it outlines what they are agreeing to when they sign the different components of the blood sample consents.

9 THE NURSE SCHEDULE AND ADMIN BLOCK

9.1 Getting into the nurse schedule

Practice cases

If you want to practice at home before 'going live' then you can use a practice case. 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 *Understanding Society* nurse practice interview, at the **MAIN MENU** you can select **WORKING AT HOME** and **PRACTICE INTERVIEW** and then select the project **P8821** or **P8023**. The screen displays all the 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.

Checking your cases at home

You should check that the information about a household is on your laptop BEFORE you leave home for the appointment. After logging on to CMS you will come to the **MAIN MENU** screen. To access *Understanding Society* nurse work from home, you will need to select **VIEW/AMEND LOADED WORK.** This displays the projects/slots by survey month that have been loaded on to your laptop.

Live interviewing

When you are actually in a respondent's house then from the MAIN MENU you should select LIVE INTERVIEW.

To get into the *Understanding Society* nurse schedule, select **P8821** (for the General Population sample; yellow NRF) or P8023 (for the Living in Britain sample; white NRF) and the relevant survey month you are working on. This will then display a screen with the 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.

9.2 Household information

The household information should be checked **before** making the visit. The information about who is in the household will already be in the CAPI program. This information includes name, sex, DOB, date of their main interview, and their eligibility for the nurse visit.

The question *Elig* provides an overview of the household members and whether they are eligible for the nurse visit or not. Individual schedules are only available for eligible respondents.

9.3 Parallel blocks

The computerised nurse schedule consists of three main components:

- the household information
- the individual schedule
- 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 (after you have reached *Elig*). For example, you can enter the drugcoding block at any convenient moment in the individual schedule.

The way to move between parallel blocks is by pressing <Ctrl+Enter>, which brings up a screen called 'Parallel Blocks'.

This screen is the 'gateway' to the other components of the schedule. It lists all the possible blocks you could go into, and looks like this:



The list of blocks will vary depending on the number of people in the household and the extent to which you have completed the drug coding. There will always be a 'P8821' or 'P8023' and an 'Admin' for each household. In addition, there will be a 'Schedule:' for each eligible individual in the household (in the above example, there are two eligible individuals). As soon as you tell the computer that an individual has some prescribed drugs, it will create a 'Drugs' block for that individual. Thus, you may have fewer 'Drugs' blocks than 'Schedule' blocks.

Each nurse schedule has the person's name listed after it. The drug-coding block also lists the person's name, so that you can be sure you are interviewing the correct person and coding their drugs correctly. If someone doesn't take any prescription medicine then a 'Drugs' block will not appear for them.

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 drug coding for Brain, but none of the other blocks yet.

9.4 Individual information

The individual information should be collected when you are in the household. This section includes the protocols for measurements, as well as some background and CAPI information on each measurement. This section aims to deal only with CAPI questions, which are particularly problematic or important. If you have another problem you can usually solve it in one of these ways:

- If someone does not understand the question, repeat it, before trying to rephrase
- If you are given an answer we have not provided for, open a note by pressing <Ctrl+M>, to write in the nature of the query.

9.5 Prescribed medications (all respondents)

This is about <u>prescribed medicines currently used</u> only. Ignore anything else. Medicines should be being taken now, or be current prescriptions for use "as required".

Make sure you get details of all medicines by checking "Are you taking any other medicines, pills, ointments or injections prescribed for you by a doctor?" Try to see the containers for the medicines. Respondents should be prepared for this, but if they are not ask early on in your visit for the containers to be fetched. Check the name of the medicine very carefully and type it in accurately. Record the brand name or generic name so that you can code it.

Do not probe for contraceptive pills, as this may be embarrassing or awkward for some respondents. If it is mentioned, record it. Pills for hormone replacement therapy should also be included. Include suppositories, injections, eye drops, and hormone implants if they are on prescription.

One of your tasks is to enter a six-digit code for the drug. You do not have to do this as soon as you enter the names of the drugs, but the computer will not let you leave the schedule until it is done as it will give you the chance to query any hard-to-find drugs and to ask a respondent what a drug is used for if it has several uses. There are also one or two follow-up questions to ask if the drug is one commonly prescribed for CVD conditions to find out whether or not it has been prescribed for one or more of these conditions.

You can do the drug coding whenever you wish by pressing <Crtl+Enter> and selecting 'Drugs'. If you are doing more than one interview in a household, you will be given the choice of several drug-coding blocks. You should choose the one which matches the individual schedule, e.g. if you are completing 'Schedule 1: Sally' that person's drug coding block will be called 'Drugs: Sally'. If you go into the wrong drug-coding block by mistake, just press <Ctrl+Enter>, then select the right one.

To get out of the drug-coding block, press <Ctrl+Enter> and select whichever 'Schedule:' you are currently completing. This will take you back to the start of that individual schedule, so you will have to press <End> to get back to where you were before.

The ideal time to code the drugs is while the respondent is resting with the cuff on prior to the blood pressure measurement. With practice, you will get to know the more common drugs and will be able to code them quickly.

Drugs are to be coded using their British National Formulary (BNF) classification codes - down to the third level of classification. These should be recorded in a six-digit format, using a leading zero where appropriate and with no full-stops. You have a copy of the BNF (make sure it is the March 2011 edition), in your nurse bag. You also have a coding prescribed medicines booklet which lists the 400 (or so) most commonly used drugs in alphabetical order and gives their BNF classification code.

Taking *Premarin* tablets as an example, the alphabetic listing gives the entry 06 04 01. Enter this as a continuous string of numbers, i.e. 060401 (no spaces, dashes or full stops). Alternatively, if you had looked up *Premarin* (tablets) in the BNF itself, you would have found it listed in section 6.4.1.1. It is classified down to a fourth level. For our purposes we are only interested in the reference 6.4.1. With leading zeros, this becomes 060401.

If you are unable to find the correct code, enter '999999'.

If you cannot find a drug in the BNF, or if it has more than one reference and you are not sure how to deal with it, record its full name clearly and what it is being taken for.

If the respondent takes aspirin, record the dosage as this can vary.

Please note: there has been some small changes to how lipid lowering drugs and drugs to treat dependence as well as antihypertensive and antidiabetic medications are being coded. These changes are outlined in your drug coding booklet. You do not need to remember these changes but just be aware of them should you notice a discrepancy between the drug code assigned to them in the BNF and the coding booklet. As a result of these changes, all of the drugs listed under sections 2.12, 4.10, 2.5.5 and 6.1.2 are listed in the coding booklet under either the generic or brand name.

10 THE CONSENT BOOKLET

10.1 Completing the consent booklet

The consent booklet contains a form that the respondent has to sign to give written consent for:

- blood sample to be taken
- blood sample to be stored
- blood sample for DNA

It is a yellow A4 booklet and must be filled out for every respondent 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 of information on the front is important. You are asked to record the date of birth again. This is an important identity check, along with your nurse number and the date of interview.

The consent booklet is in a carbonised booklet format. Ask the respondent to write on a firm surface, so that their initial/signatures come through to the carbon copy. Use a black or blue biro when completing the booklets, and ensure that signatures are always in pen, not pencil. Each respondent must initial each box if they have consented to the measurement or sample to be taken. The respondent must also sign and print their name and write the date at the end of the booklet. You should also sign and date the booklet youself. Do not erase any of the personal information. If necessary, cross out errors and rewrite so that any corrections can be seen.

You must get the respondent to sign and **personally** date the form. You should not date them yourself as this falls outside the requirement of informed consent.

The structure of the booklet is as follows:

Inside cover

All details on the inside must be completed. Complete items 1 to 6 before you start using the computer to collect information from the respondent. The respondent's address can be recorded by writing down the house/ flat number (or name) and their postcode. Item 7 is completed during your interview, and you will be prompted by CAPI. You will record, in a box similar to the one below, the outcome of the respondent's consent for the various aspects of the blood sample. By the end of the nurse visit every respondent should have three codes circled.

	SUMMARY OF CONSENTS - RING CODE FOR EACH ITEM	YES	NO
7	a) Sample of blood to be taken	01	02
	b) Blood sample for storage	03	04
	c) Blood sample for DNA	05	06

Where a blood sample has been collected, please record the date of despatch at Item 8.

Centre pages (carbonised)

Blood sample consent form. The respondent is to initial in the box next to each procedure they consent to. As soon as a respondent 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. It is the initials and signature in the consent booklet that are important. Without these there is no consent. Leave the original YELLOW copy in the booklet to be returned to the office. Tear off the CARBONISED copy and leave with the respondent.

Dispatch note. This is to be completed in full. It is essential that the information is accurate (more information about completing the note can be found in Section 14.4). Tear off the original YELLOW copy and send with the blood samples to the storage facility, leave the CARBONISED copy in the booklet to be returned to the office.

Inside back cover

The inside back cover contains a space to note any problems with venepuncture. This is to remain in the booklet and to be returned to the office.

10.2 Questions about the use of blood samples

Respondents may have some queries about the use of blood samples. Analysis will not be carried out immediately and it is not yet clear what analytes will be tested. There are a list of FAQs on the back page of the leaflet called "The Nurse Visit: Information for Participants". These cover questions about the blood sample in detail.

What will happen to the blood sample I give?

The blood sample will be stored at a secure facility, your name and address will not be attached to the sample and so your sample will remain confidential. Your blood will not be analysed immediately, but will be available for scientific analysis. Any analysis will have to be approved by an independent committee set up by the ESRC. The stored blood will not be available for commercial purposes.

Before being used in future research, some of the information we have collected in this survey (but not any details which would identify you) may be attached to the sample. You can withdraw your consent to store your blood at any time, without giving any reason, by asking the investigators in writing for your blood to be removed from storage and destroyed.

When the sample is tested for research, it will no longer be possible to link it to you, so you will not be told the results of the testing. It will not be possible to remove your results from reports, as the results cannot be linked to you.

Will any genetic tests be made?

The anonymous samples may, in the future, be tested for DNA or genetics. Any analysis like this could not be linked to you and no names of individuals will ever be revealed or identified in the presentation of the results. The blood samples will not be tested for the HIV (AIDS) virus and will not be available for paternity testing, life insurance, mortgage applications or police records.

10.3 Gaining informed consent from special groups

A signature on a consent form is only valid where the respondent is properly informed and capable of understanding. It is important that you allow respondents ample time to read the consent forms and that you check that they understand what they are agreeing to. You should also be prepared to answer any questions they might have.

From time to time you may meet respondents who are fully capable of meaningful consent but who are blind or have poor eyesight or literacy difficulties. In all such cases it is essential that you carefully explain the required consent to the respondent by going through the information leaflet and then read the consent form aloud in full, verbally checking it has been understood. Where possible you should do this (having first sought the respondent's agreement) in the presence of a family member or third party. If you have to read out the form, you should make a note at the bottom, and sign the form yourself, as follows:

For a respondent who is blind and/or cannot read:

Add at the bottom of the consent form

For the respondent:

"This form has been read to me and I confirm that I understand the information and give consent to allow a qualified nurse to take a sample of my blood /that my blood can be stored and used for scientific research / that DNA can be taken from my blood and used for scientific research."

Respondent's signature

(write in their name if they cannot sign)

For yourself:

"I confirm that I read this consent form word for word to [insert name] who understood the information and gave informed consent."

Interviewer signature and date

If someone else is available as a witness:

"I confirm that the interviewer read out the form and explained it to [insert name], and that [name] understood and agreed to allow a qualified nurse to take a sample of my blood /that my blood can be stored and used for scientific research / that DNA can be taken from my blood and used for scientific research"

Witness signature and date

11 INTERVIEWING MINORS AND VULNERABLE PEOPLE

11.1 Interviewing minors (aged 16/17)

For this age group you need to get consent from the respondent but you do not need parental consent to interview someone of this age. If the respondent lives with their parent(s), out of courtesy advise the parents what you will be doing.

The term 'parent' means the minor's natural or adoptive parent. All other people who claim parental status have been classified on the NRF as having legal parental responsibility.

If disagreement arises between parents and/or parent and minor about whether or not to co-operate, always respect the wishes of the non co-operator.

11.2 Interviewing vulnerable respondents

When interviewing 'vulnerable' respondents special considerations may need to be taken. According to the Mental Capacity Act (MCA) people can make a decision (for accepting medical treatment or participating in research) if they are able to:

- understand the information relevant to the decision
- retain that information
- use or weigh that information as part of the process of making the decision, or
- communicate the decision

You should not conduct a visit with respondents who you don't believe are able to do these things.

12 PROTOCOLS MANUAL

There is a protocols manual to be used on all NatCen Surveys involving nurse work. You should refer to the manual and follow the protocols for all 2011 measurements and samples. These include:

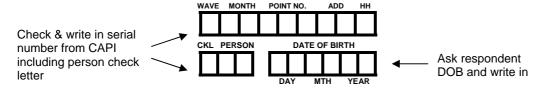
- Height measurement
- Weight and body fat measurement
- Waist circumference
- Lung function
- Blood pressure
- Grip strength
- Spirometry
- Blood sampling (non-fasting)

13 LABELLING & DISPATCH OF SAMPLES

The samples are sent to the Fisher BioServices secure storage facility in Bishop Stortford, Hertfordshire. It is important that all samples are sent correctly labelled and safely packaged and that they are dispatched immediately after they have been taken.

13.1 Labelling tubes

Label the tubes as you take the blood samples. It is vital that you do not confuse blood samples within a household.



Use the set of serial number and date of birth labels (black) to label the vacutainer tubes. Attach a serial number label to <u>every</u> tube that you send to the lab. Enter the serial number and date of birth very **clearly** on each label. Make sure you use a **biro** (**blue or black**) - it will not run if it gets damp. Check the Date of Birth with the respondent **again verbally**.

Stick the label over the label already on the tube. For blood samples the laboratory needs to see on receipt how much blood there is on the tube. 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.

13.2 Packaging the blood samples

You have been provided with a despatch container which will hold up to six blood samples. The maximum number of tubes per container in this study is **five tubes**.

IMPORTANT

Each respondent must have their samples dispatched separately. Do not use the same packaging for more than one household member. This is because in the past the laboratory has received wrongly labelled samples. This has resulted in all samples in that box being discarded, as the laboratory cannot reliably identify which samples belong to which respondent.

13.2.1 The dispatch transporter

All samples should be packaged in a 6-vial transporter:

- 1. Lay the collected sample(s) in the indentation in the transparent side of the transporter. It should fit securely but not have to be forced into place.
- 2. Once you have finished collecting samples for a respondent, fold the white side of the packaging over the transparent side.
- 3. Securely close the packaging by pressing together down on each of the corners until you hear it 'click' closed. It is closed securely once you have heard it 'click' on either side of the packaging.
- 4. Insert the transporter into the **yellow** plastic sample envelope.
- 5. Once the lab dispatch note has been completed, tear off the **yellow** copy from the respondent's consent booklet and place in the envelope with the transporter.
- 6. Remove the backing strip from the flap on the envelope.
- 7. Fold the flap over onto the envelope ensuring that the envelope is securely closed.

THERE MUST ONLY BE ONE TRANSPORTER PER ENVELOPE. PLEASE MAKE SURE THAT THE NECESSARY LAB DISPATCH NOTES HAVE ALSO BEEN PUT INSIDE THE ENVELOPE.

13.3 Posting samples

The size of the packaging means that the samples can be posted in a standard letterbox.

The samples should be posted AS SOON AS POSSIBLE, within 24 hours of the sample been taken at the latest. Try to avoid taking samples if you think that you will unable to post them within 24 hours. As usual, the office will notify you of any laboratory closures.

Weekend posting

If you miss the Saturday post collection, the sample must be posted on the following Monday morning. Please put the samples in a letterbox as soon as possible after collecting the blood sample.

When you have posted the samples, fill in the date of posting on the front of the consent booklet.

13.4 Completing the dispatch note

The Consent Booklet contains a carbonised dispatch note which should be filled in with a blue or black ballpoint pen. The original yellow copy must be sent to the storage facility with the blood samples and the carbon copy must remain in the booklet to be returned to the office.

- 1. Enter the respondent's serial number very carefully. This should correspond to your entry on the front page of the consent booklet and to the serial numbers you have recorded on the blood tube labels.
- 2. Circle the sex of the respondent.
- 3. Check that the date of birth is correct and consistent with your entry on the nurse schedule and the tube label.
- 4. Tick the blood samples obtained.
- 5. Complete the date the samples were taken.
- 6. Ring a code to tell the laboratory whether or not permission has been obtained to extract DNA from the sample. Your entry here should correspond to your entry at item 7 (c) on the front page of the consent booklet and item 3 on the consent form.
- 7. Enter your nurse number.

Tear off the yellow copy of the dispatch note and send it with the respondent's samples to the storage facility. Leave the carbon copy in the booklet to return to the office.

14 RETURN OF WORK

14.1 Nurse Record Form

Recording the outcome of your attempts to interview and measure:

On *Understanding Society* the Nurse Record Form (NRF) is not returned to the office. On pages 1 to 3 of the NRF there is space to record the outcome of your attempts to interview persons in the households in your sample. Record outcomes here for your own information only. Any information recorded on the NRF should also be entered into CAPI.

14.2 Returning work to the office

If you are measuring all respondents in a household at one time, post the Consent Booklets back to the office using the pre-paid envelopes supplied on the same day as you send the blood samples to the storage facility (or in time the following day to catch that day's post). **Special Delivery is NOT required on this project.** Transmit the nurse schedules on the same day as you post the paper materials.

If you do need to make more than one visit to the household and there is a gap between visits, keep all the paperwork to be returned together for that household. But post it back immediately you have completed your task there. Do not wait to post blood samples.

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 an Office Consent Booklet for each person with a productive outcome (11 or 12), even if they did not consent to give a blood sample.

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

- Please send ALL office consent booklets back to the office. We must receive the signed consent in order to be able to use the blood samples.
- 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.

At the end of your assignment, check that you have accounted for all the serial numbers on the Sample Cover Sheet (SCS). Keep this SCS. It will help sort out queries, should there be any, about work done by you.

APPENDIX A SUMMARY OF NURSE MEASUREMENTS & SAMPLES

Measure	What the measurement is testing	Consent	Exclusion criteria	Equipment
Height	In conjunction with other measurements (such as weight) height can predict, the nutritional status, performance, and health of a population.	Verbal	 If respondent is pregnant Too stooped to obtain reliable measurement Too unsteady on feet If respondent is in a wheelchair Too painful to stand up straight 	Portable Stadiometer Frankfort Plane card
Weight and body fat	Weight and body fat measurements are measured to estimate prevalence of obesity	Verbal	 If respondent is pregnant If respondent is wearing a pacemaker Someone weighs over 23½ stone. Too unsteady on feet. 	Tanita scales
Waist	Measure of distribution of body fat. Important indicator of CVD risk	Verbal	If respondent is pregnantIf respondent is in a wheelchairHas a colostomy/ileostomy	Insertion tape (with press button and slider)
Grip strength	A test of physical ability, usually declines with age	Verbal	 If respondent is pregnant Swelling, severe pain or recent injury to the hand Surgery on the hand in the last 6 months 	Dynamometer
Blood pressure	High blood pressure risk factor for cardiovascular disease	Verbal	□ If respondent is pregnant	OMRON HEM BP monitor Child/small adult cuff (17-22cm) Standard adult cuff (22-32cm) Large adult cuff (32-42cm) AC adapter
Lung function	Objectively tests respiratory function. Used in clinical settings to diagnose respiratory diseases	Verbal	 If respondent is pregnant Abdominal or chest surgery in last 3 weeks Admitted to hospital with heart complaint in last 6 weeks Eye surgery in the last four weeks Have a tracheostomy 	In England and Wales: ndd easy-on spirometer In Scotland: Vitalograph Escort spirometer Mouthpieces / spirettes Calibration cylinder
Blood sample	Samples to be stored for future analysis	Written: Blood samples to be taken Stored for future analysis DNA extraction	 If respondent is pregnant Clotting or bleeding disorder Taking anticoagulant drugs If ever had a fit Not willing to give written consent Respondents who are HIV positive, have Hep B/C 	Blood collection materials – 1 red vacutainer (plain) 1 blue vacutainer (citrated plasma) 3 purple vacutainers (EDTA) See Nurse Protocols Manual and CPG

APPENDIX B NURSE DOCUMENTS & EQUIPMENT

Name of Document	Colour	Use
Sample cover sheet	White	The list of addresses in a nurses sample point.
Nurse visit leaflet White		Provides information about the nurse visit such as what measurements will be taken. Nurses will ensure that respondents have a copy of the leaflet and will explain in more detail.
Venepuncture leaflet	White	Provides information about the blood sample.
Consent booklet	Yellow	Before blood samples are taken nurses <u>must</u> obtain written consent in the consent booklet. You should leave a carbon copy for the respondents records. The booklet includes despatch notes for the storage facility and office. This needs to be returned to the purple team.
Nurse Record Form (NRF)	White / Yellow	Nurse Record Form for the nurse to record details of visits made to an address and the outcome of the visits.
Measurement record card (MRC)	White	You will get MRCs to write in nurse measurements.
Coding prescribed medicines booklet	Blue	Used for the coding of prescribed medicines. You will be asked to enter a drug code.
Blood tube labels	White / black	To be used to label blood samples. Ensure that correct serial numbers and date of births are recorded for each respondent.
Broken appointment card	White	Used for missed appointments – can write message and time of next visit.
Promissory note	White	To be left with respondents who will be sent a voucher.
Incident report sheet	White	To be filled in should any serious incident occur during a nurse visit.

NURSE EQUIPMENT
Pilot bag
Stadiometer
Tanita weight / body-fat scales
Dynamometer
Spirometer
OMRON HEM-907, thermometer and probe
Waist and hip tape
British National Formulary (BNF 61), March 2011 version
Blood collection materials:
1 x plain (red) tube
1 x citrate (blue) tube
3 x EDTA (purple) tube

The equipment is described in more detail in the relevant section of the Nurse Protocols Manual.