National Centre *for* Social Research

formerly SCPR

MRC

Medical Research Council

MRC National Survey of Health and Development

THE NATIONAL SURVEY OF HEALTH AND DEVELOPMENT - 1999 INTERVIEW

NURSE INSTRUCTIONS

Version: 8 April 1999

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1. MRC NATIONAL SURVEY OF HEALTH AND DEVELOPMENT

1.1 Background

The Medical Research Council National Survey of Health and Development (MRC NSHD) is the longest running birth cohort study of its size in the world and is unique in providing longitudinal information on the health, development and ageing of a nationally representative sample of over 5000 men and women from birth through to mid-life. The study began as a maternity survey in 1946 at a time when there was increasing concern about the birth rate (which had been falling since the 1870s) and about the health and health care of the British population. All the mothers who had a baby between the 3rd and 9th of March 1946 were interviewed by health visitors to find out about the social and economic costs of pregnancy and childbirth and whether the maternity services were responding to the needs of mothers. This original survey showed, for example, that women were not being allowed access to pain relief in labour and the regulations concerning the use of gas and air were changed because of this. It also showed huge variation in infant health among different social groups. Dr James Douglas, the director of the study for thirty years, was keen not to lose an opportunity to observe the health, growth and development of a nationally representative sample of children and he secured funding for a long term follow up - and this came to be called the National Survey of Health and Development. There have been nineteen follow ups so far and contact is maintained with cohort members through an annual birthday card. The last home visit took place in 1989 when cohort members were 43 years old. In addition, women cohort members have been sent a postal questionnaire annually since 1993 to find out about their experience of the menopause.

The MRC NSHD is based at University College London Medical School.

1.2 The 1999 Survey

The purpose of your visit at age 53 years is to collect information from cohort members about changes to their health and life circumstances since we last saw them, to repeat some of our earlier measures, and to add new measures of function, disease and risk status. The data you collect will be valuable immediately as outcome measures to test hypotheses of lifetime precursors of midlife health and in studies of the extent to which predisposition to poor health may be offset by subsequent lifestyle and experience. In the longer term we will use these data as a baseline against which to measure the extent of change with age in physical and mental function, and as midlife precursors of the cohort's health in later life.

1.3 A link with cohort members

Always remember that you will be the vital link with the cohort members. You are vital in two ways.

1. You control the accuracy of the data.

2. You are responsible for re-establishing and maintaining the long standing contact between each individual and the National Survey. You must therefore establish a good relationship with each person you visit, and respect the confidence which he or she has placed in you. You are representing both the National Survey and the National Centre for Survey Research (SCPR) when you visit a cohort member.

Throughout the survey the respondents are referred to as **cohort members** (or **sample members**) who are familiar with the National Survey team and know them as the **National Survey**.

These are very precious people - they have been followed from birth.

1.4 Confidentiality

You will be asked, as a condition of work, to sign a form for the MRC, undertaking to keep the strictest confidence about the work that you do, both on the training sessions and in the interviews. Please take great care to ensure that all the information in your charge is kept securely in your home and transmit your work as soon as you have completed and checked it through. Do not discuss interviews or any aspects of your work that involves contact with cohort members with anyone outside the project team at MRC and the National Centre (SCPR).

If it is necessary to reassure cohort members about confidentiality tell them that the research team regard all information as strictly confidential. It is all kept under lock and key, and all the data that we work with is in statistical form and does not identify individuals.

2. THE RESEARCH TEAM

The members of the research team for the National Survey of Health and Development are:

MRC NSHD	National Centre for Social Research (formerly SCPR)
Michael Wadsworth	*Kavita Deepchand*
Diana Kuh	*Patricia Prescott-Clarke*
Marcus Richards	
Lynn Toon	

The Project Controller is Sandra Dowsett and Kerrie Gemmill (Deputy). They can be contacted between 9.30 and 5.30 weekdays on 01277 200600.

Nurses will be supported by a local fieldwork team consisting of an Area Manager, a nurse supervisor and an interviewer supervisor. The **nurse supervisor** is the person you should consult if you have any queries about your equipment, how to use it in the field or any other problems you might have relating to carrying out the interview and measurements. The nurse supervisor will from time to time accompany you in the field. The supervisor are there to help you do your job to the best of your ability - please consult them whenever you feel you need help. The name of your supervisor is listed in the separate Project Administration notes.

The **MRC NSHD research team** are there to answer more specific queries that cohort members may ask. If queries should arise please phone a member of the NSHD team on 0171 391 1720 giving them the name and telephone number of the cohort member and they will call back.

3. SUMMARY OF SURVEY DESIGN

Around 3200 Cohort Members have been selected to take part in the 1999 survey. For fieldwork purposes the sample has been divided into 5 Waves (each containing around 650 CMs) and also into 233 points each containing an average of 14 addresses/CMs. Each nurse will cover 1 point. However due to the nature of the sample, the point sizes will vary between 10 and 20.

Fieldwork will take place between May and November 1999. All interviews will be carried out by a qualified nurse who will conduct the interview using CAPI (Computer Assisted Personal Interviewing). The interviews will last approximately 2 hours and will consist of a variety of questions, cognitive and physical tests.

4. SERIAL NUMBERS

Each cohort member is given a unique identity number which allows us to distinguish which documents relate to which person. This is called the **Serial Number**. The serial number is made up of a number of different components:

Point number	a three digit number for the postcode sector. This ranges from 001 to 233.
Cohort Member (CM) number	a four digit number for the cohort member. For reasons of confidentiality, this is different to the number that the MRC NSHD team use to store the data.
Check Letter (CKL)	a letter of the alphabet

The full 7-digit serial number of the cohort member must be recorded on all documents for that respondent. Great care must be taken to ensure that the correct serial number has been used. It is vital that the information you collect about someone can be matched to the information that the MRC NSHD team already have for that person. If incorrect serial numbers are entered on documents, there is a danger that the data from one person will be matched with that from someone else.

5. CLINIC VISITS

A minority (400) of CMs will, in addition to the interview by our nurse, be asked to attend a GP clinic in order that further tests can be made. 200 of those selected for a clinic visit will be asked to attend in advance of our nurse calling (pre-interview clinic CM) and 200 will be asked to attend afterwards (post-interview clinic CMs).

CMs have been selected for clinic visits on the basis of their accessibility to one of six clinics.
The ARF information label gives the status of each CM in respect of this. The advance letter to the CM will also vary depending on their clinic status (see Section 5).

Things to be aware of with respect to the clinic visits:

- Those with a PRE-interview clinic status should have already been to a clinic before your visit but may not have done so.
- Those with a POST-interview clinic status are asked an extra question at the end of the CAPI interview, inviting them to attend a clinic.

6. THE ROLE OF THE TELEPHONE UNIT

To save the time of nurses, who are a scarce resource, we have decided that it would be most efficient if appointments were set up in advance by our Telephone Unit.

The Telephone Unit will therefore be making contact with each CM for whom we can obtain a telephone number to arrange a time convenient to both CM and nurse. The Telephone Unit will liaise with you to ascertain times at which they are available for appointments.

Cohort members for whom we are unable to find a telephone number will be issued at the start of each fieldwork period to interviewers (ground tracers).

The ground tracer will visit and make an appointment. The Telephone Unit will be responsible for liaising with the ground tracers (through Operations) about nurse availability.

The Telephone Unit will contact you about 10 days before the start of fieldwork in order to

Wave	TU appt making starts	Fieldwork starts
Wave 1	30th April	17th May
Wave 2	9th June	22nd June
Wave 3	28th July	9th August
Wave 4	1st September	13th September
Wave 5	6th October	18th October

Each Wave will be split into fieldwork point and assignments. Due to the nature of the sample (ie named individuals traced over their lifetime) each nurse assignment will be an average of 14 addresses but will vary depending on the actual number of CMs living in the area.

7. CONTACTING COHORT MEMBERS AND ARRANGING AN INTERVIEW

7.1 The Advance Letter

Each CM will have been sent an advance letter and information pack before your appointment with them. These are sent out about four weeks before the start of each fieldwork Wave and contain:

- an advance letter, giving a brief description of the 1999 interview
- a measurements leaflet, giving more detail about the physical measurements
- a genetics study leaflet, giving further explanation about the DNA genetics study
- a telephone number request slip with a reply paid envelope

In the case of the 200 selected for a pre-interview clinic visit this letter is sent out by a clinic nurse (see attached example). This group will be sent a later letter by the MRC which will mention that the National Centre will be in contact re: the home visit by our nurse.

All other CMs will be sent a letter approximately 10 days before Telephone Unit appointment making starts for that fieldwork wave (see attached examples).

The telephone request slip asks the CM for their telephone number and the times at which it would be best to telephone them. Copies of the measurement leaflet and genes booklet will be in your workpacks.

7.2 Liaison with the Telephone Unit/Field Control Team

The National Centre's Telephone Unit (TU) be making appointments for you wherever possible. It is vital that you keep them informed of all changes to any appointments that are made as these may affect future appointments for you. CMs for whom we have no telephone number will be contacted by a ground tracer (GT) in order to make an appointment.

Please do not phone in to the Telephone asking if any appointments have been made - they will call you. However, please make sure that you inform the TU of any changes to your availability as they will need to update their diaries to prevent double-booking appointments.

To help organise your assignment, you will be sent in your workpack:

- a diary covering the fieldwork period
- a Nurse Sample Sheet showing the addresses to be covered in your assignment

7.2.1 Nurse Sample Sheet (NSS)

The Nurse Sample Sheet (NSS) lists the names, addresses and serial numbers of each cohort member in your assignment. The front cover will have the point, wave number and postcode sector written on together with your name and ID number. The inside pages contain columns for you to complete when key documents are received and sent for each address.

Do not return this document to the office. Keep it in case of queries. An example of a half-completed NSS is shown on Page 9.

7.2.2 Appointment diary

About 10 - 14 days after the advance letters have been posted, the Telephone Unit at Brentwood will contact each nurse working in that Wave to establish availability. The Telephone Unit are given an identical appointment to the one sent in your workpack. Go through with the diary with the Telephone Unit interviewer so that they are aware of when you are available for appointments. When establishing availability with the Telephone Unit please remember:

a) each interview will last approximately 2 ¼ hours in-house

b) you will need to take the blood samples to a Post Office for posting

c) the Telephone Unit are not familiar with the area you are working in. Please advise them how much time you will need to travel between addresses, and which addresses cluster most effectively together. They will do their best to make the most effective appointments for you, although this will not always be possible.

d) to tell the Telephone Unit whether you wear a uniform. (The cohort member may ask the TU)

e) to tell the Telephone Unit the make and colour of your car. (The cohort member may ask).

7.2.3 Office refusals

For completeness, Operations will also send you the ARFs for office refusals. That way you will receive an ARF for each address in your assignment, regardless of whether you will be making a visit to each address. For unproductive ARFS:

1. Record on your NSS the date you receive the ARF.
2. Go into the interview schedule to that address on your laptop, complete the Admin and enter the final outcome code from the top left hand corner of the ARF. This will be written in by Operations before sending it onto you.
3. Fill in the SLOT NAME and RETURN NUMBER on the ARF.
4. Post the ARF back to Operations together with the next batch of paper work.

Example of Nurse Sample Sheet

Serial number Name Address	Date of appoint-ment	Date received ARF	Date ARF and paper documents returned to HO	Dates Samples Posted	Notes
SN: 0013726 X MR ALAN STURGIS 15 MOUNT VIEW ROAD LONDON EC1 6QR	6/5/99 15.30	Int ~~Appt~~ 3/5/99 ARF 7/5/99	7/5/99	6/5/99	
SN: 0019365 A MRS JENNIFER FARADAY 12 LONGFIELD AVENUE LONDON EC2A 4AT	6/5/99 9.00	5/5/99	8/5/99	6/5/99	
SN: 0014977 R MR THOMAS GREEN THE VILLA, CASTLE MANSIONS ISLINGTON LONDON N1 7RD	15/5/99 10.00	10/5/99			Broken appt new appt 30/5/99 11.30
SN: 001 2302 X MRS MARGARET JONES 35 NORTHAMPTON SQUARE LONDON EC1V OAX	24/5/99 16.30	16/5/99			
SN: 0015583 X MRS HELEN JOHNSTON 20 LONGTON AVENUE WHITEFIELD MANCHESTER M46 6JR	Office	retnsal 6/5/99	N/A	N/A	

7.2.4 Interim Appointment Record Form

You will receive from Operations an ARF for ALL addresses in your assignment including for refusals made directly to the Telephone Unit.

A few days before fieldwork is due to start you will be sent the ARFs for all appointments made during the lead-in time. After that you ARFs will be posted to you as soon as an appointment has been made.

Although Operations will post all ARFs immediately, they will also telephone you to tell you when they have made appointments for you. That way you will know immediately (just in case the ARF gets delayed in the post) and also this helps you to keep track of how many ARFs you should be receiving.

The Interim Appointment Record Form is a one page yellow document which provides space for you to write in the address details and the date and time of the interview. Please make sure you have all the correct details (including the correct address) as you may not receive your ARF before your appointment with the CM.

An example of the Interim Appointment Record Form is shown overleaf.

National Centre *for* Social Research

P1846

MRC NATIONAL SURVEY OF HEALTH AND DEVELOPMENT

INTERIM APPOINTMENT RECORD FORM

(to be completed by nurse when appointment details are initially transmitted by telephone)

An appointment has been made at:

	POINT	CM No. 4 DIGIT	CKL
Serial Number :	0 0 1	2 3 0 2	X

CM's full name: MRS MARGARET JONES
Address: 16A UPPER STREET
ISLINGTON
LONDON N1 4LG

Other useful information from information label:
2nd floor flat above 'Sevenseas' fish+chip shop

Telephone number: (inc STD code) 0171 609 4093

1. Date details telephoned through: 21 (Day) 05 (Month) 1999 (Year)

2. Date of interview: 24 (Day) 05 (Month) 1999 (Year)

3. Time of interview (24 hour clock): 16.30

4. Office refusal Yes ☐ No ☑

8. THE ADDRESS RECORD FORM (ARF)

This document records the outcome at each stage of the survey for each cohort member selected for interview, regardless of whether or not the cohort agrees to a nurse visit. The ARF is designed to be used by not only yourselves but also the Telephone Unit (and Ground Tracers).

Although there may be nothing for you to do at some of the addresses (see below), you will be sent an ARF for each address in your assignment so that you can check that they have all been dealt with by the Telephone Unit, and that none have been missed or lost in the post.

If you do not receive an ARF for each cohort member by the second week of fieldwork, please phone the Telephone Unit to check that nothing has been lost in the post.

Pages 1 - 4 of the ARF are completed by the Telephone Unit (and interviewer ground tracer). The Telephone Unit will then post the ARF on to you to complete page 5. (Page 6 is for reference purposes and additional notes.) Once you have completed page 5 and entered the final outcome code on page 1, you will then post the ARF back to the office. It is vital that you receive an ARF for each cohort member in your assignment. For office refusals, the Project Control team in Brentwood will assign the appropriate outcome code on the ARF before sending it to you.

Page 1

Page 1 of the ARF contains two labels. The label at the top left hand corner of the page contains:

- the serial number (7 digits plus a check letter)
- the full name and address of the cohort member

The label at the top right hand corner of the page contains:

- the serial number
- the telephone number for the Cohort Member (if known)
- the clinic status (PRE, POST or NO clinic)
- any special circumstances the MRC NSHD feel it may be useful to know before the interview:

Hlp	someone helped CM with their last interview
MH	CM mentally handicapped
INS	CM living in an institution at last contact
RD	CM may have reading difficulties
SP	MRC has some special information about the CM. In these cases, the MRC will speak individually to the nurse responsible for that interview during the briefing.

Example label 1:

```
SN 001 2302 X                    FA: 0

MRS MARGARET JONES
35 NORTHAMPTON SQUARE
LONDON
EC1V OAX
```

Example label 2:

```
SN 001 2302 X

Tel: 0171 250 1866
Clinic status: no clinic
Date of last int: 08/1989
Word List: A
Background information:
```

If not already done so by Operations, write in your own name and nurse number in the space provided at the top of the Address label.

The appointment details will be written in the box at the bottom of Page 1. **Please note the address number (1,2 or 3) as this is the address you will need to interview at. It will not always be the same as the one on the printed address label.** If the cohort is traced to a new address, the new address, telephone number and appointment details will be written on page 2.

Pages 2-4

These are used by the Telephone Unit/Ground Tracer. If the appointment is made for Address 2 or 3 you will need to refer to Page 2 for the correct address.

Page 5

Q9. Record all calls to the cohort member whether by telephone or in person.

Q10. Write in any relevant notes, new appointment times etc. Also check the back page for any additional notes made by the TU/GT

Q11. Circle or write in ONE outcome code and copy this number onto the box on the front page marked FINAL OUTCOME CODE. The outcome codes most commonly used by nurses will be:

Code 51	Productive interview at Address 1 (original address)
Code 52	Productive interview at Address 2 or 3 (new address)
Code 72	Appointment made but CM phoned the office to refuse
Code 73	Appointment made but CM refused to nurse
Code 75	Someone else refuses on behalf of CM
Code 76	Broken appointment, no new appointment made
Code 77	CM too ill to be interviewed
Code 78	CM away (write in date of return on Page 6)
Code 79	Other unproductive

For a full list of all outcome codes, see Page 6.

Q12. Circle the status of each of the listed survey documents used throughout the interview.

Q13. Code whether the CM accepted the orange diet diary.

Page 6

Page 6 gives a full listing of all the outcome codes.

The Telephone Unit/Ground Tracers have been asked to write down details of finding the address. If you are unsure of how to find the address, phone the CM.

8.1 Summary of contact procedures

- **Telephone Unit**
  - To ascertain nurse availability
  - To inform nurses of appointments made by telephone
  - Nurse to inform TU of new appointments made to replace broken ones

- **Ground Tracers**
  - Inform nurses of appointments made. Operations will send nurse the ARFs Nurse to fill in Interim Appointment Record Form

- **Operations**
  - Forward to nurses, the ARFs for which appointments have been made by TU
  - Forward to the GTs, the ARFs for which no telephone number or no contact possible by phone
  - Forward to nurse unproductive ARFs eg office refusals, no trace ever established etc. (Nurse - do Admin on laptop, fill in slot name, return number and mail back ARF)

9. BEFORE YOU ARRIVE AT THE HOUSE

- Make sure you have the correct address details.
- Check that you have the correct materials and equipment (including spares) to conduct the interview. (see checklist)
- NEVER fill in the front cover on the paper documents or blood labels in advance. There is time allowed for this in the interview.

9.1 CHECKLIST OF MATERIALS TO TAKE TO EVERY VISIT

<u>In pilot bag:</u>
Handgrip dynamometer, leads and handset with small and large large handles
Micromedical spirometer
Spirometer mouth pieces and filter
Omron
Thermometer to measure room temperature
Blood equipment
Vacutainer Needle holders
Alcohol swabs/cotton wool balls/plasters
Vacutainer needles (green)
Butterfly needles (green)
Vinyl gloves
Needle disposal box
Per Respondent:
6 Labels for sample tubes
3 Postal containers (plastic)
3 Postal boxes with pre-paid postage/address label
Buccal cell collection tube
Buccal cell collection swabs
2 x 3ml EDTA vacutainer blood tubes
2ml EDTA vacutainer blood tube

6ml ACD vacutainer blood tube
4ml Lithium Heparin vacutainer blood tube
The tubes are labelled 1- 6.

Word-list learning test: 2 ring-bound flip-booklets of 15 words, one word per page
National Adult Reading Test: 1 showcard of words
Prospective memory test: 1 brown envelope per cohort member
Stopwatch
Pencil
Mini stapler

Paper documents (plastic wallet supplied to keep papers together)
ARF/Interim Appointment Record Form
Jump card
Self completion questionnaire (yellow)
General health questionnaire
Diet diary (orange)
Envelope to post diet diary back in (postage paid return to MRC NSHD)
Hand examination and paper test booklet (green)
Consent Booklet (blue)
Frankfort plane cards
Showcards
Cigarette Coding Booklet (grey)
National Centre for Survey Research leaflet (A5)

(Should also carry with you:
Project Instructions
Genes booklet
Measurement leaflet
Broken appointment card
Abnormal BP sheet
In tennis bag:
scales
stadiometer

Laptop Computer

9.2 Personal safety

Let someone know where you are going and when you expect to return before you leave for an interview.

10. INTRODUCING THE INTERVIEW

10.1 On arrival at the house

It is important to be aware that although the person you are interviewing has been a study participant their entire life, you will be their first personal contact with the study since 1989 (or 1982 in a few cases). The date of the last interview is printed on the Information Label on the front cover of the ARF.

The general rule is to keep your initial introduction short, simple, clear and to the immediate point:

Introduction

* Show your identity card
* Say who you are: "I am a nurse called..."
* Say who you work for: "I work for The National Centre for Social Research and am carrying out the National Survey of Health and Development "
* Remind cohort members about your appointment: "A few days ago you made an appointment over the telephone (or in person with an interviewer from The National Centre) about The National Survey and they made an appointment for me to see you today."

Most cohort members will be looking forward to your visit and will be keen to help. But some may have become reluctant to co-operate, perhaps because they have become nervous. You will need to use your powers of persuasion to reassure and re-motivate such people, as it is vital that they take part.

Use the points in the box below when necessary.

* *who you are working for* - SCPR on behalf of the MRC National Survey
* *who the survey is for* - for the Medical Research Council National Survey of Health and Development
* *why the survey is being carried out* - see Section 1.1
* *what you are going to do* - see Section 1.2
* *how the cohort member was selected for the survey* - the sample was drawn from all people born between 3rd and 9th March 1946 and started off as an investigation of health in childhood. Since then the National Survey have carried out regular interviews either in person or by post.
* *the confidential nature of the survey* - individual information is not released to anyone outside the research team.
* *how much time you need* - this varies a bit but it is best to allow about 2 hours plus 15 minutes to put equipment away and so on..

10.2 Getting a high response rate

A high response rate is crucial if the data collected is 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. Also because the survey aims to collect information on the same person over a number of years, if they are lost from the survey in one year, it is much harder to gain their co-operation in future years.

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

Some people think that they are not typical (they are ill, they are healthy, and so on) and that it is therefore not worth while (from both your and their point of view) to take part in the survey. You will have to explain how important they are, and that our interest is in health and how people stay healthy. So we need information from all types of people, whatever their situation.

Our target is to interview and take measurements from everyone selected. The measurements are an integral part of the survey data and without them, the interview data, although very useful, cannot be fully utilised.

10.3 Cohort members are not patients

Your previous contact with the public as a nurse up until now may have only 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 - or can agree, but can 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.

Some respondents may have forgotten what the Telephone Unit told them about the survey's purpose or what your visit involves. You should therefore be prepared to explain again the purpose of the survey. You may also need to answer questions about who The National Centre are. Some points you might need to cover are shown on the previous page.

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

10.4 Being persuasive

It is essential to persuade reluctant cohort members to take part, if at all possible. However, please remember that these are very special people who cannot be replaced in the sample if they drop out. The NSHD have data on each person dating back to 1946 and wish to go back to these people in the future.

You will need to tailor your arguments to the particular respondent, meeting his or her 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 to your Area Manager).

10.5 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 on an urgent errand.

In any case, make every effort to recontact 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 try to phone them to arrange another appointment.

Don't forget to notify the Telephone Unit of the new appointment day and time so they don't double book an appointment.

10.6 The number of calls you must make

You are asked to keep a full account of each call you make to an address at Q9 on page 5 of the **Address Record Form**. Complete a column for each call you make, telephone calls as well as personal visits. Note the exact time (using the 24 hour clock) you made the call, and the date on which you made it. In the notes section keep a record of the outcome of each call - label your notes with the call number.

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

11. THE INTERVIEW

As well as receiving information about the measurements in the advance letter and accompanying leaflets, the Telephone Unit will have introduced your visit, but has been told to give only a brief outline of what it is about. They will have also told cohort members that you are the best person to explain what your visit is about.

Make sure that you are familiar with the content of the survey and, if necessary reassure nervous respondents that every stage is optional.

The MRC National Survey team will be informing the cohort member's GP of their results if they give their consent to do so.

12. THE QUESTIONNAIRE

The interview schedule is on computer. Rather than you having to work out which sections to complete, once it knows the cohort member's serial number it will tell you which questions to ask and which measurements to take. Detailed instructions for individual questions are given in Section 14.

12.1 General tips on how to use the computer program

Read out the questions in the Nurse Schedule **exactly as worded.** This is very important to ensure comparability of answers. You may think you could improve on the wording. Resist the temptation to do so. Enter the code number beside the response appropriate to that respondent, indicating the answers received or the action you took (eg. at the question called *HOU,* you enter the number corresponding to the total number of people living in the household).

Some questions take the form of a "CHECK" - see *Inst* for an example. This is an instruction to you to enter something without needing to ask the respondent a question. If a question appears in capital letters, do not read it out, it is for you to read to yourself only.

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

12.1.1 Making notes

There is a NotePad facility that allows you to type in any comments you feel are necessary to make. To open the NotePad type **Ctrl+M**, type in your note and press **Ctrl+M** again to close the NotePad. You

will notice that a black square appears next to the question name, alerting the Office that a note was made at that question.

12.2 The content of the interview

The interview consists of a mixture of factual and opinion questions as well as physical and cognitive tests. The interview contains questions about:

Household composition	number of people in the household etc
Marital history	updating the information already given in previous interviews
Children	updating the information already given in previous interviews
Hospital admissions (day patient and out patient visits)	collecting information about illnesses resulting in hospital care
General health, prescribed medicines	more detailed questions about general and specific illnesses
Phlegm, breathlessness and wheezing	questions on respiratory problems
Smoking	Cigarette, pipe and cigars
Parental history	updating the information already given in previous interviews
Mammograms (women only)	Mammograms and consultations about breast lumps
Muscles and joints	hand examination and questions about knee injuries
Balance and coordination	leg raises and chair stands
Exercise	physical exercise
Social support	social life
Work	Job details for CM (and spouse). Questions about spells of unemployment
Memory and recall	Word Lists, visual search, envelope test, NART, animal naming
Self-completion booklet	Questions about diet, feelings, social support, men and women's section
MEDICAL EXAMINATION	Blood Pressure, Lung Function, Height (standing and sitting), Weight, Mid upperarm circumference, Chest circumference (at rest and expanded), Waist circumference, Hip circumference, Air temperature, Grip strength, Knee examination, Buccal sample, Blood sample
Diet diary	Handing over of diary
(Introduction to clinic visit)	For around 200 CMs

12.3 Moving around the questionnaire

The questionnaire is divided into a number of modules, preceded by 'Jump to' questions:
To jump to a particular question use <Shift + F9> and type the 2-digit number corresponding to the module you want to jump to.

01 Household grid
02 Marital history
03 Children
04 Hospital admissions
05 General health
06 Smoking
07 Parental history
08 Mammograms
09 Muscles and joints
10 Balance and coordination
11 Social life
12 Work

13 Memory and recall
14 Blood Pressure
15 Lung Function
16 Body circumference
17 Grip strength
18 Knee examination
19 Buccal sample
20 Blood sample
21 Diet diary

NB You can only use the "Jump to" facility on completed (fully or partially) questionnaires.

12.4 Saving work

It is a good idea to save your work regularly while in the interview, especially as you will be having to get up and leave the computer to take measurements etc. It has been known for children or pets to interfere with the computer and cause nurses to lose their work. A good habit to get into is to save the schedule every time you stand up to do a measurement or test.
TO SAVE YOUR WORK PRESS 'SHIFT+F2'

12.5 Practice slots

12 practice slots have been set up on your laptop. You can access these by typing the number corresponding to the title **P1846 PRACTICE**.

Each slot has a unique serial number containing certain background information which has already been programmed into the computer. The information you will need for each slot outlined below:

serial number	check letter	sex	day of birth	serial number	check letter	sex	day of birth
001 1874	G	M	4	001 4199	J	F	6
001 2173	G	M	5	001 4901	X	M	8
001 2302	X	F	8	001 5400	P	M	3
001 3528	E	F	9	001 6241	D	M	8
001 3726	V	M	6	102 1040	B	M	9
001 4053	A	M	5	102 1165	F	F	6

13. THE CONSENT BOOKLET

This is an essential part of the interview and is used throughout.

After verifying you are in the correct interview schedule, the computer prompts you to obtain a signature for Form 1 or Form 2 (consent to carry out the interview). Before doing this, complete the front page of the Consent Booklet (excluding Q3, Q5-7 which you will complete later).

Never do this in advance of your visit to the household.

Do NOT prepare this or any other documents in advance of your visit, as there is a serious danger that you will use the wrong set of documents for the wrong person. It is all too easy to do in the stress of the moment. Check carefully that you have entered the Cohort Member's correct serial number.

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

The information on the front cover links the consents to the correct interview information. Make sure you write in clearly and accurately.

Write the address at which you are interviewing in the box at the top of the Consent Booklet. Write in the Survey Wave (1,2,3,4 or 5), and then fill in the serial number boxes.
Q1 Write in your Nurse Number
Q2 Write in the date of the interview
Q3 Record the **full** name of the respondent. The MRC NSHD will be using this to write to their GP (with their permission) to give him/her their test results. The name by which the GP knows the respondent and any other names the respondent is known by should be checked and recorded during the interview. This may, for example, be a maiden name.
Q4 Code the cohort member's sex.

You will be prompted to enter details for Q 5 and 6 during the course of the interview.
Q5. Write in the name and address of the CM's GP, if they give consent for their blood pressure, lung function and/or blood test results to be sent to their GP. Write as clearly and legibly as possible as this information is not keyed by nurses as part of the Admin but by the MRC NSHD at the end of fieldwork.

Do <u>not</u> encourage the Cohort Members to spend time during the interview looking for the postcode or telephone number of their GP - the MRC HSHD can access this information easily.

Q6 **Summary of consents.** You record here the outcome of your requests for permission for all the consents required by the MRC NSHD and the ethics committees.
By the end of the interview every cohort member should have **THIRTEEN** codes ringed at Item 7.

There are eight Consent forms contained in the booklet:

Form 1/Form 2	Consent to carry out the interview by the cohort member or the cohort member's carer
Form 3	Consent to consult hospital records.
Form 4	Consent to obtain copy of cohort member's mammogram (women only).
Form 5	Consent for nurse to take physical measurements.
Form	Consent to give mouth cell sample.
Form 7	Consent to give blood sample and take part in the genetics study and to store blood sample.
Form 8	Consent to send results to GP.

The last three pages of this booklet are despatch notes for blood samples. These are perforated sheets which are to be completed and sent to the appropriate laboratories:
Despatch 1 is to go with tubes 1,2 and 3 to the MRC Human Biochemical Genetics Unit.
Despatch 2 is to go with tube 4 to the European Collection of Cell Cultures (ECACC)
Despatch 3 is to go with tubes 5 and 6 to the Royal Victoria Infirmary (RVI).
Despatch 4 is to remain with pages 1-9 and returned with your ARF.

14. NOTES ON INDIVIDUAL QUESTIONS

14.1 Household Grid

Definition of a household: HOU

A "household" is defined as a person living alone, or a group of individuals who live at the same address, having that as their main residence and regularly sharing at least one main meal a day. Having joint or common housekeeping also counts as constituting a household.

Individuals who are absent temporarily should be included e.g. someone working away or a child who is a student. Make a note of their absence on the questionnaire.

Rel1: Partners

A partner must be part of the household.

14.2 Children

Chiln, Chs: Children

These refer to all cohort member's natural, biological children. Exclude other 'non-biological' children. Also exclude stillbirths and miscarriages.

14.3 Hospital admissions

Reason: reason for in-patient stay

Please give as much detail as you can about reasons for admissions to hospital. Only include overnight stays in hospital.

HD: day patient treatment

This is about courses of treatment as day patients at a hospital. By day patient we mean someone is admitted to hospital for treatment but does not stay overnight. Do not include visits to outpatients for tests or consultations, or treatment at a GP clinic or health centre

14.4 General Health

Angin - ChPrl

If a response is equivocal - such as "do you get it when you walk uphill or hurry?" and the response is something like "I don't know, I think I might but I am not really sure" - the answer should be recorded as "no". The only exception to this is in question Q11b and c, and if in doubt here go on with the question.

Gum

Trouble with gums and mouth includes teeth.

14.5 Parental History

Mliv, Fliv

These refer to the natural (biological) mother and father.

14.6 Muscles and Joints

Hand: Clinical examination of hands

When prompted to do so, conduct the examination of the CM's hands and enter the observations on Page 2 or the green Hand and Paper Test booklet.

Please remember to:

- Enter the full 7 digit serial number, your nurse ID number the date of interview on the front cover of the booklet.
- When making the physical examination of the CM's hands, remember to place the paper diagram in the same rotation as the CM's hands.

- Mark the observations on the paper diagram. If there is time, you will be prompted to enter the data into the computer when the CM is completing their self-completion booklet.
- If there is only possible (not definite) evidence of boney swelling or tenderness or squaring (of the thumb) enter S and/or T and/or SQ on the computer but write '?S' and/or '?T' and/or ?SQ on the paper diagram

There are 15 areas to look at on each hand: finger DIP joints (4), finger PIP joints (4), finger MCP joints (4), thumb IP joint (1), thumb MCP (1), and thumb CMC (1). (See figure 1)

1. Examine each of the joints for:
   (a) visible cool bony swelling of the joint (S) and
   (b) tenderness (T) (pain, reproduced on moderate, not heavy, palpations)
   and ask whether the cohort member
   (c) suffers pain in that joint (P).

   Record S,T and/or P as appropriate on the picture of the hands in the test booklet.

2. Examine the base of the thumb (CMC) for evidence of:
   (a) squaring (SQ) (a squared edge to the normal curve where the thumb meets the wrist)
   (b) visible cool bony swelling in the base of the thumb (S)
   (c) tenderness (T) (pain, reproduced on moderate, not heavy, palpations)
   and ask whether the cohort member
   (d) suffers pain in that joint (P).

   Record S,T,P and/or SQ as appropriate on the picture of the thumbs in the test booklet. Degenenerative changes at the thumb base (first carpmetacarpal joint) can cause adduction of the first metacarpal and wasting of the nearby small muscles to give the appearance of the 'square hand'.

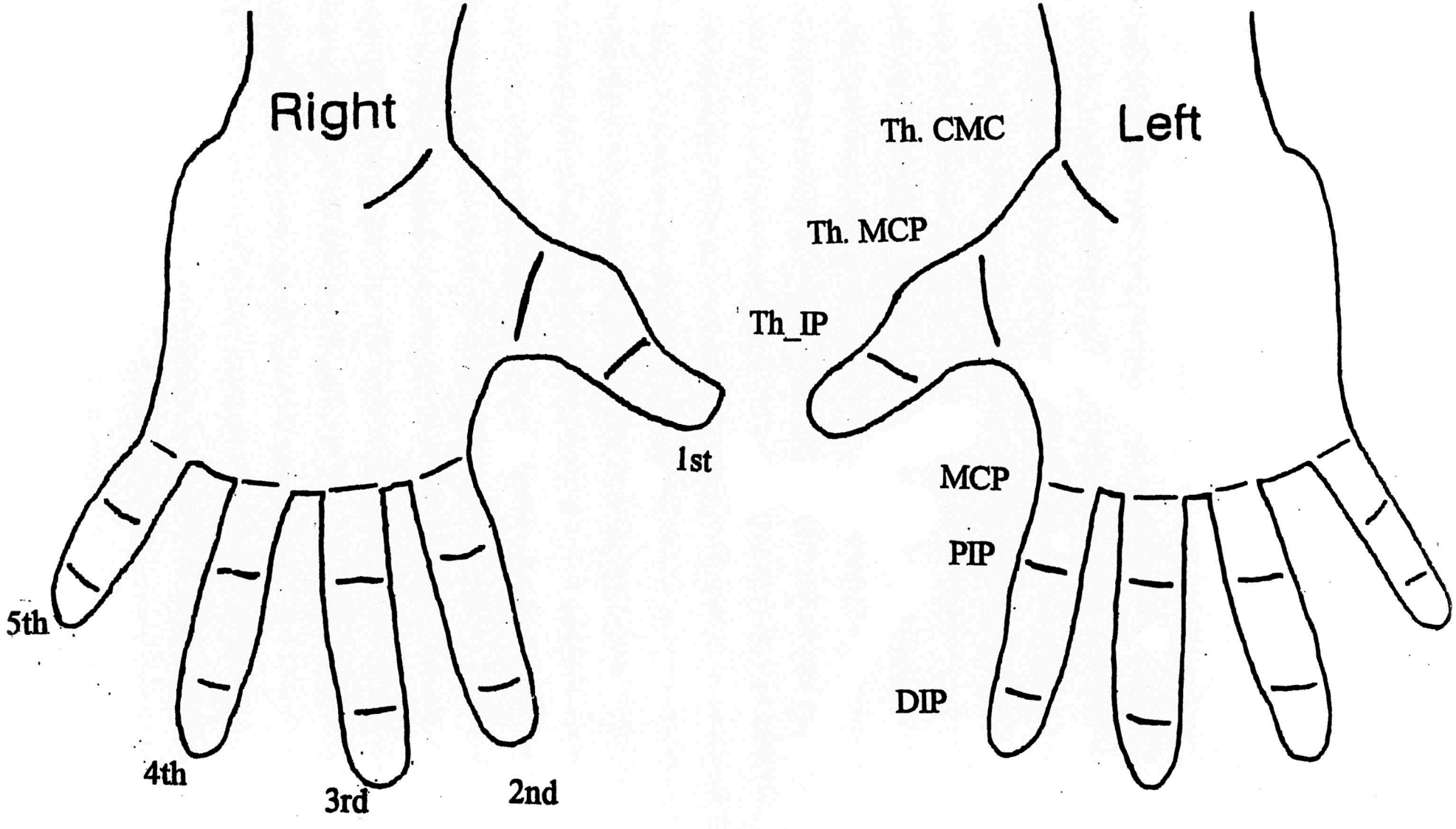
3. Examine both hands for evidence of:
   (a) Heberden's nodes and
   (b) Bouchard's nodes.
   Ring the area marked on the diagram where there are definite Heberden's nodes (HN) or possible Heberden's nodes (?HN) on the DIP joints and thumb IP joint and Bouchard's nodes (BN) or possible Bouchard's nodes (?BN) on the PIP joints. Mark on the hand diagram where there is deviation (DEV) of the distal phalanx (end of the finger). Heberden's nodes are still recorded as present even if there are no bony swellings but there is deviation (displacement) of the joint. Nodes found on the MCP (metacarpal phalangeal) joints - 'knuckles' - are not included. Heberden's nodes (DIP joints) are the most common manifestation of OA in the hands. These bony swellings eventually stabilise in size, although there may still be progressive change with the deviation of the distal phalanx (end of finger). The bony swellings of nodal OA are called Bouchard's nodes when they affect the PIP joints. The PIP joints are less commonly affected than the DIP joints in hand OA.

IF THERE IS NOTHING TO MARK ON THE HAND DIAGRAM WRITE 'NO PROBLEMS' TO CONFIRM THIS.

Hand 2

HAND EXAMINATION

Mark T (tenderness), S (boney swelling) or P (reported pain) for each of the three joints in each finger and each of the two joints in each thumb.
Mark evidence of squaring (SQ) for each thumb
Mark location of definite Heberden nodes (HN) and Bouchard nodes (BN). Mark any deviation (DEV) of the distal phalanx (end of the finger)



14.7 Balance and Coordination

Balance and coordination are needed to carry out successfully every day locomotor functions at reasonable speeds and to prevent falls. Poor balance will be a major cause of falls and fractures as the cohort ages.

BalInt: Protocol for Leg raises

Procedure:

1. Explain and demonstrate the procedure. Make sure there is a firm support nearby and allow the cohort member to have a practice.
2. Shoes should be removed unless they have flat heels.
3. Ask the cohort member to fold their arms and, after a count of three, to stand on their preferred, dominant leg and raise the other leg off the ground a few inches (*see questionnaire for instructions to give*).
4. Set the stopwatch as soon as the cohort member raises one leg off the ground.
5. Stop the stopwatch either a) when the raised leg touches the floor as the cohort member loses their balance or b)after 30 seconds, whichever happens first. Record the time in seconds.
6. Ask the cohort member to repeat the procedure (3-5) one more time with eyes closed. Record the time in seconds.

Exclusion criteria: Inability to stand or walk unaided without zimmer frame or crutches.

ChairInt: Protocol for Chair stands

Chair stands require power in the leg muscles, balance and coordination. These physical attributes are also needed for climbing stairs, walking and running etc. The rate of deterioration as the cohort ages will depend on health and levels of activity.

Procedure:

1. Explain and demonstrate the procedure
2. Shoes should be removed, unless the heels are flat.
3. Seat the cohort member in an upright chair of normal height (seat surface approximately 46cm (18") from the floor). Preferably, it should have a hard flat seat that is parallel to the floor and not one with a seat that slopes back.
4. Ask them to fold their arms and, after a count of three, to stand up from their chair and sit down again ten times as fast as they can (*see questionnaire for instructions to give*).
5. Make sure that the cohort member knows to rise up fully from the chair, to a position where legs and back are both straight.
6. Set the stopwatch on 'go!', count the movements and stop the watch as soon as the cohort member sits down for the tenth time. Record the time in seconds.

Exclusion criteria: Inability to stand. Severe cardiorespiratory disease. Hip or knee replacement; severe hip or knee problem.

14.8 Social support

Rob

Robbery means theft from the person. It does not include having their house burgled unless they were present at the time.

14.9 Work

Inch: Income

Deductions other than tax and national insurance, such as superannuation or the employee's contribution towards a company car, should be included. Do not forget child benefit. The income bands at the lower

end of the scale are narrower than the upper bands as it is more important to be precise in households with less income. Give time for cohort members to provide an answer. Type Ctrl+K if they refuse to answer the question. An estimate is much betterthan a don't know. At least try to record an answer such as "well, at least as much as ...." or "no more than ...."

Job descriptions for SOC coding
SPSOC, SPSOC2, SOCR, SOCR2
Information on jobs must be clear and unambiguous. Write down the full job title (indicating professional status if applicable). Use precise terms such as radio mechanic, woodworking machinist, primary schoolteacher, district surveyor, production engineer, chartered accountant rather than terms like mechanic, machinist, teacher, surveyor, engineer, accountant. If the occupation is known in the trade or profession by a special name, record that name. For those in H.M. Forces record rank. For civil servants and government officials record grade, and check for professional activity. If the person has more than one paid job give the details of the job in which they spend most of their time. If the job is obscure, type in a description of the main activity in the job and what the firm makes or does.

SPESR1, ESR1
The size of the firm is the number of employees in the actual establishment where the cohort member works. By manager we mean someone whose primary function is to plan, organise, co-ordinate and control work resources on a long term basis. They may directly supervise staff but it is not essential that they do this. By supervisor we mean someone whose primary function is the immediate day to day control of the basic production of work and the supervision of workers carrying out that particular work. If there is any doubt as to which code applies indicate possible options by ringing more than one rather than specifying unknown.

EARN, EARNX
This question applies to all cohort members with a current paid job, including the self employed. Give cohort members time to provide their earnings. If they do not know how much they earn encourage them to give an estimate. If they still cannot provide an answer indicate whether they do not know or have refused (Ctrl+K or Ctrl+R)

JOBN
A job change is counted where there has been a definite change in the type of work or the employer or where the job has changed from full-time to part-time (or vice versa).

14.10 Cognitive Tests

Purpose: Cognition, i.e. activities such as thinking, memory and attention, is an important aspect of health and daily function, and has been frequently assessed in the cohort using pencil and paper tests, most recently at age 43 years. Among other things we wish to investigate the extent to which early influences on cognitive development, such as family background, are still evident in mid-life, or are overshadowed by adult attainment.

Equipment:
Word-list learning test: 2 ring-bound flip-booklets of 15 words, one word per page
National Adult Reading Test: 1 showcard of words
Prospective memory test: 1 brown envelope per cohort member
Stopwatch (see Annex for instructions)
Paper test booklet
Black pen

14.11 INSTRUCTIONS FOR THE STOPWATCH

Hold stopwatch with the display facing towards you and the three buttons at the top of the watch. Press the middle button to obtain the stopwatch display (it should read 0:0000). If the stopwatch is still running, press the right hand button to stop and then the left hand button to reset. If the stopwatch is displaying a time, press the left hand button to reset.

To start timing: press the right hand button.
To stop timing: press the right hand button.
To reset to 0:0000: press the left hand button.

Preliminary considerations: Good cognitive testing assumes that the optimum performance of the respondent has been obtained. At minimum this means that if a participant normally uses reading glasses or hearing aids, these must be used during testing, and that the setting should be as free as possible from interruption or disturbance. Participants should also be motivated, although you should exercise judgement here, since people sometimes complain of having an "off day" in the face of poor (but representative) performance. Record any circumstances which significantly interfere with test performance.

Considerations during testing: Encouragement should be given to the cohort member during testing, but do not coach or prompt.

Please note that it is particularly important to adhere to each test protocol, including delivering each test instruction verbatim, since even subtle departures from the formal procedure can influence responding.

De-briefing the cohort member: Following testing some cohort members may seek reassurance or request further information. The following two points should be born in mind. First, cognitive testing in this project is for research only, and is *not* used for clinical evaluation. Second, and related to this, cohort members should not be encouraged to dwell on their performance in terms of good, average or poor. For example, it is not unusual for people to be concerned about poor verbal memory performance when in fact their scores are quite normal. Say that there's a wide range of scores that are usual at this time of life. If they are worried, refer them to their GP.

Procedure:

WrdLst, RepTrial, WrdLst4: **Word-list memory**

Instructions to the cohort member:

"I want to see how well you remember a list of 15 words. I will show you one word at a time and when I reach the end of the list you have one minute to write down as many words as you can. Write them here (*show place*) in any order you like. At the end of the minute turn over to the next page. It is best not to talk to me/anyone while you are doing this."

Administration:

Provide cohort member with the test booklet showing word list 1 and a pencil. Show the words at 2 second intervals using the appropriate word list (A or B), as prompted by CAPI.. Make sure the last word is shown for 2 seconds. At the end of the list indicate to the cohort member that they should start writing. Try not to distract or interrupt the cohort member when doing this. At the end of one minute ask the cohort member to turn the page, and repeat the administration. The third presentation is the same, and uses the following page. It is crucial

that no hint is given at any point during the administration of this test that cohort members will be asked to recall these words again after the visual search test.

WrSrch: Visual search

This is a test of attention and speed of working. The cohort member uses the sheet of letters. The test is timed for 1 minute, and the task is for the cohort member to cross out as many letter "P"s and "W"s as possible in that time. Make sure the cohort member understands the instructions.

Instructions to the cohort member:
Point to the page of letters in the test booklet. Say:
"I want to see how quickly you can work through this list crossing out the "P"s and "W"s. Start at the top left where the arrow is and work along the row from left to right then go to the beginning of the next row and work from left to right again, like reading a page. Carry on this way crossing out any "P"s and "W"s with one mark of the pencil, like this (*demonstrate*). **Work as quickly and as accurately as you can."**

Administration:
After exactly 1 minute ask the survey member to stop. A small number of survey members may come to the end of the letters before this time.

WrdLst4: Delayed word recall

This is to see whether cohort members have retained their memory for the words learned in word list memory test. As already noted, it is crucial that the request to remember the words comes as a surprise.

Instructions to the cohort member:
"Do you remember that list of words I showed you earlier? I want you to write down as many of those words as you can remember"

Administration as per the initial learning trials.

***Env:* Prospective memory I**

Sometimes referred to as "remembering to remember", prospective memory concerns future activities and events, in this case remembering to carry out a task following a pre-specified signal.

Instructions to the cohort member:
Hold up the brown envelope. Say: **"Later on I'm going to give you a name and address to write on this envelope. When you have finished doing that I'd like you to do the following: turn it over, seal it, and write your initials on the back. Could you remember to do that then, without me reminding you?"**

Now put the brown envelope out of sight.

Anin: Animal naming

This is a test of verbal fluency. The cohort member is required to name as many animals as possible within one minute.
Instructions to the cohort member:
"Now I'd like you to tell me as many different animals you can in one minute"

Administration:

Explain that animals include birds, insects, humans, etc. If the cohort member gets stuck, encourage with "Can you think of any more?" Write the responses on page 8 of the test booklet. If a cohort member generate names faster than you can write legibly, you may use a more simple system of marking (e.g. one tick per name). If so, however, you must remember not to tick repetitions and redundancies (see below).

Scoring:
You will be prompted to score the total number of different animal named when the CM is filling in their self-completion booklet. Anything that is not a vegetable or a mineral is an animal. Species (e.g. dog, terrier, poodle, etc.), gender and generation-specific names (e.g. bull, cow, steer, heifer, calf) all count as different names. However, do not give credit for repetitions, or for redundancies (e.g. black cow, brown cow, etc.).

NAAD1: Prospective memory II

Instructions to the cohort member:
Give the cohort member the brown envelope shown earlier. Say:
"Please write the following name and address on this envelope: 'JOHN BROWN, 42 WEST STREET, BEDFORD'. Please go on remembering this name and address and I will ask you about it later"

Here the cohort member should remember your earlier request to seal the envelope and write their initials on the back. If neither are done spontaneously, say: "Were you going to do something else with the envelope?". If only one action is carried out, say: "Was there something else you were going to do?". If the initials are still not written, say: "You may remember I asked you to write something special on the back of the envelope". When this part of the test is finished take back the envelope and put it out of sight.

Scoring: You score this according to whether they complete both actions correctly (i.e. sealing the envelope and writing their intials on the back) and whether either action had to be prompted.

NARTInt: National Adult Reading Test (NART)

This is a word-reading test, which provides a sensitive measure of familiarity with words. Place the word show-card in front of the cohort member.

Instructions to the cohort member:
"I want you to read slowly down this list of words, starting here (*point to* CHORD*).* **Continue down this column and onto the next. I must warn you that there are many words that you probably won't recognise. In fact most people don't know them, so just guess at these. OK, go ahead"**

Administration:
Mark each word as the cohort member pronounces them putting in tick in the correct (C) or not correct (NC) column. In general, cohort members should attempt all words. However, you may terminate the test if 14 out of 15 consecutive responses are incorrect, although testing should continue if there is any doubt about whether a cohort member has reached her/his limit. If a cohort member seems anxious about words not recognised, reassure that he/she is certainly not expected to know all the words. An admission that you yourself did not know them all at first (if true) will often allay anxiety and improve rapport.

Scoring:

Words are correct or incorrect according to the pronunciation guide. Note that alternative pronunciations are given for some words. If there is any doubt whether a word is correct (e.g. the effect of an accent) mark with a '?' and note the way the word was pronounced, using phonetic spelling or other cues (e.g. "rhymes with ...").

NAADTA: Memory for address

Instructions to the cohort member:

"What was the name and address I asked you to remember a short while ago?"

Enter the number corresponding the parts of the address correctly recalled.

SEET, HET: Scoring for sensory difficulty

It is important to know whether the cohort member was having hearing or visual difficulties DURING TESTING, e.g. undiagnosed/untreated impairment, or adequate reading glasses/hearing aid not available. Do not give a positive rating for difficulty if there was impairment which was adequately corrected or controlled at the time of testing.

14.12 SELF COMPLETION QUESTIONNAIRE

You will be prompted to hand over the self-completion booklet, and, depending on the sex of the CM and further background information (some women do not need to be asked the women only questions) you will be prompted to cross out certain pages of the booklet before handing it over.

If the cohort member asks why she is not being asked to complete this section explain it is because she has previously given us the information we need on the annual postal women's health questionnaires. If the cohort member is unsure about how to fill the questionnaire in provide assistance.

You are then instructed to :

a) score the animal naming test (for instruction refer to test protocol)

b) unpack the equipment so that you are ready to take the physical measures once they have completed the questionnaire then

c) if the CM has not yet finished the self-completion booklet, you will be prompted to enter the results of the hand examination in the computer.

If the CM refuses to complete the self-completion booklet, you must still score the Animal naming test and set up your equipment before progressing on the physical measurements.

DO NOT ENTER THE HAND EXAMINATION RESULTS IF THE COHORT MEMBER HAS ALREADY COMPLETED THEIR BOOKLET.

15. GUIDANCE NOTES FOR PHYSICAL MEASURES

15.1 BLOOD PRESSURE

The OMRON instructions are at the end of this manual.

Ask the cohort member to remove any watch and expose the upper left arm for the blood pressure cuff, and to sit at the end of a table near the corner with the left arm resting comfortably, palm up, on the table. You should sit on the other side of the corner of the table, facing the OMRON, which is positioned so that the readings cannot be seen by the cohort member.

When the shirtsleeve is rolled or slid up to allow sufficient room to place the cuff, make sure that it does not constrict the arm (if it does, ask the cohort member to slip their sleeve off). Locate the brachial pulse just medial to the biceps tendon, wrap the cuff round the arm like a tape measure and position the cuff so that the centre of the inflation bag (marked on the pocket) lies over the brachial artery. The lower edge should be 2 to 3 finger-breadths (about 1 inch) above the cubital fossa. Connect the cuff to the OMRON.

Then explain to the cohort member that before you measure their blood pressure, which you will do twice, it is necessary to sit quietly for a few minutes with legs uncrossed to rest. Keep conversation to a minimum whilst you then unpack the rest of your measuring equipment and until after blood pressure measurements.

When first set up the display is likely to be showing the time. Press the red 'sphyg/clock' button to prepare the machine to take a reading. The display will show a zero and a heart symbol. Normally the pressure valve pre-set should be set to 170.

Warn the cohort member not to move his/her arm while the measurement is being taken and that the cuff may feel a little tight. The instrument is sensitive to movement while deflating, and may fail to take a reading.

To take a reading simply press the grey start button. The cuff will automatically inflate and slowly deflate. When the reading is complete the machine will alternate between showing systolic and diastolic BP and showing pulse.

In a few cases, with the pressure valve set to 170, the sphyg will fail to inflate sufficiently. In these cases repeat the measurement with the pressure valve set higher.

During the measurement of reactivity we expect that the stressor (P.S.A.T.) will elevate some cohort members' BP by 10 to 20 mmHg. If the baseline systolic measurement is within this margin of the selected pressure valve setting you should select a higher setting before beginning the test. The maximum preset pressure is 200 mmHg. If you expect the systolic reading to exceed this figure you can manually drive the instrument beyond 200 mmHg by holding down the start button.

Store the results in the OMRON's memory by pressing the red 'memory set' button. (This may vary depending on OMRON model). Enter value of the pulse, systolic, diastolic pulse measurements.

Now repeat this procedure once more. Write the person's serial number on the paper print outs and staple it to the inside of the green hand and test booklet.

15.1.1 Answering queries about the cohort member's blood pressure

It is VERY IMPORTANT to remember that it is **not** the purpose of the survey to provide respondents with medical advice, nor are you in a position to do so as you do not have the cohort member's full medical history. But if a cohort member has a raised blood pressure, you will need to say something. This will be calculated by the computer and will appear on the screen for you to **read out exactly as written**. The computer will decide which advice is appropriate based on the following guidelines.

Two blood pressure measurements are taken. The first reading can be high because people are nervous of having their pressure taken.

Definitions of raised blood pressure differ slightly. It has been decided to adopt the ones given overleaf for this survey.

If the blood pressure is **Normal,** you will be prompted to say, 'Your blood pressure is normal'.

If the blood pressure is **Mildly raised,** you will be prompted to say, 'Your blood pressure is a bit high today. Blood pressure can vary from day to day and throughout the day so that one high reading does not necessarily mean that you suffer from high blood pressure. You are advised to visit your GP within 3 months to have a further blood pressure reading to see whether this is a once-off finding or not.'

If blood pressure is **Moderately raised,** you will be prompted to say, 'Your blood pressure is a bit high today. Blood pressure can vary from day to day and throughout the day so that one high reading does not necessarily mean that you suffer from high blood pressure. You are advised to visit your GP within 2-3 weeks to have a further blood pressure reading to see whether this is a once-off finding or not.'

If blood pressure is **Severely raised,** you will be prompted to say, 'Your blood pressure is high today. Blood pressure can vary from day to day and throughout the day so that one high reading does not necessarily mean that you suffer from high blood pressure. You are strongly advised to visit your GP within 5 days to have a further blood pressure reading to see whether this is a once-off finding or not.'

For systolic readings above 180mm Hg or diastolic reading above 115mm Hg, fill in the **Abnormal Blood Pressure Sheet** and send it immediately to Operations.

N.B. Occasionally people become faint during blood pressure measurement: this is usually evident from the very low pressure readings and slow pulse. If this is happening disconnect the cuff and give the cohort member a chance to recover before repeating the measurements. They may need to lie down and, if they do faint, make sure they are placed in the recovery position.

SURVEY DEFINITION OF BLOOD PRESSURE RATINGS

Women

Rating	Systolic		Diastolic
Normal	< 140	and	< 85
Mildly raised	140 - 159	or	85 - 99
Moderately raised	160-179	or	100 - 114
Severely raised	180 or higher	or	115 or higher

Men

Normal	< 160	and	< 95
Mildly raised	160 - 169	or	96 - 104
Moderately raised	170 - 179	or	105 - 114
Severely raised	180 or higher	or	115 or higher

NB: < means 'less than'

15.2 Lung Function

Explain to the cohort member that you are going to measure breathing capacity. Use a cardboard mouthpiece on its own to demonstrate how this is to be done, by filling the lungs to capacity, making a tight seal with the lips around the tube, and then blowing as hard and as fast as possible until the lungs are empty.

Follow these instructions:

1. Attach the plastic filter to the spirometer. It slides on one way only with printing on the filter next to the spirometer. Attach an unused cardboard mouthpiece to the filter.

2. Move the switch from the 'off' to the 'blow' position.

3. Ask the cohort member to stand up and to take as deep a breath as possible, place their lips around the mouthpiece to make an airtight seal, and then blow out the air into the mouthpiece **quickly, as hard and for as long as possible**. Warn the cohort member that they may feel slightly light-headed doing this. Try to encourage them to improve their performance at each go. The results are strongly affected by how the respondent blows, emphasise they must blow **as hard as possible** and for **as long as possible**, a shallow extended blow will give a false reading, although respondents suffering from respiratory problems may only be able to blow like this.

4. Give verbal encouragement.
   Give the cohort member a practice go, then two recorded attempts. If the cohort member is distressed or has bad problems after any of the attempts, and does not want to continue, DO NOT INSIST. Enter values for any attempts they did complete and write why you did not complete this measure on the schedule.

5. The machine will initially show a value for FEV1. Record this in the appropriate place on the schedule and then move the switch to the 'view' position. The machine will cycle through four measurements, FEV1, FVC, FER (%) and PEF displaying each in turn.

6. Give adequate time in between attempts for the cohort member to get their breath back. Repeat steps 3 and 4 once more and record values again.

7. Holding onto the machine firmly, ask the cohort member to remove the filter and the cardboard mouthpiece and to throw it away for you.

Reassure the cohort member that a degree of 'wheeze' is normal if the test is done properly, with maximum effort.

15.3 Measurement of standing height

Ask the cohort member to remove shoes and to stand with feet together, flat on the base plate and with heels against the back of the plate, and to stand as tall as possible. Arms should be held loosely at the side. Tilt the head to the Frankfort plane position, so that an imaginary line passing through the external ear canal and across the top of the lower bone of the eye socket immediately under the eye would be parallel to the floor (i.e. horizontal). Check the position by holding the Frankfort Plane card beside the CM's face. Ask the CM to take a deep breath in, re-check the Frankfort Plane position and bring the head piece down on the centre of the cohort member's head and check the level using the spirit level. Take the reading to the nearest 0.5cm and enter the value.

15.4 Measurement of sitting height

Use the bottom 2 or 3 sections of the column part of the stadiometer (the bottom one has one mark on the back, the next has 2 marks, and so on) to make this measurement.

To measure sitting height you will need a hard, dining or kitchen type chair with as flat a seat as you can find. If there isn't a flat surface easily available, ask the person to sit on the floor.

Place the column of the height measure so that the cohort member is sitting upright with his/her back to it, and with feet on the floor. Make sure that the back is straight and the head in the Frankfort plane, (check using Frankfort Plane card), and then place the headpiece on the centre of the cohort member's head, and check the level using the spirit level. Take the reading to the nearest 0.5cm as before and enter the value.

15.5 Measurement of weight

Measure weight with the cohort member wearing skirt or trousers and shirt, but no jacket or jersey and no shoes.

Place the scales, if possible, on a hard floor. Reset the zero button, be sure the scales measure in Kgs. When the zero shows ask the cohort member to step on, without hesitation, and then read off the flashing answer, and enter the value.

15.6 Measurement of right upper arm circumference

Ask the cohort member to bend the right arm to a right angle and measure the right mid-arm level halfway between tip of acromion and tip of olecranon. Ask him/her to let the arm hang loosely semi-pronated at the elbow (with palm facing side of thigh). Measure the mid-arm circumference at the level marked. Tape measure should be just tight enough to take up slack but not to compress the skin. Take a reading to the nearest 1mm and enter the value.

15.7 Measurement of chest circumference and expanded chest circumference

Measure chest circumference underneath the shirt, or with shirt removed, in men at nipple level, and in women immediately below the breasts at the end of a normal expiration. Take a reading to the nearest 1mm and enter the value. Ask the cohort member to take a deep breath and hold it while you remeasure their circumference with the chest expanded. Take a reading to the nearest 1mm and enter the value.

15.8 Measurement of waist (abdominal) and hip circumferences

Ask the cohort member to face you and to stand straight with feet together and looking straight ahead. Stand to the right of the cohort member. Hold the tape in your right hand with the side of the tape where the scale begins facing you. Pass the other end of the tape round the back flank with your left hand and ask the cohort member to hold it whilst you retrieve the end of the tape from his/her left hand.

This should leave you standing slightly to the cohort member's left when you draw the tape taut.

Waist circumference

Apply tape at a point midway between costal margin and iliac crest and in line with the mid axilla. Only measure the waist circumference over a waistband if the waistband is at the correct waist level and is very thin.

Ensure that the tape is horizontal.

Ask the cohort member to breathe out gently and to look straight ahead (to prevent them from contracting their muscles or holding their breath). Pull tape taut and measure to the nearest 1mm below and record value. Take the measurement to the nearest 1mm at the end of a normal expiration. Enter value. If cohort member is tense, repeat the measurement.

Hip circumference

Locate the greater trochanter (this will be the widest part of hips, at the level of the buttock line. Take the measurement to the nearest 1mm and enter the value.

To check the levels you have to position the tape on the right flank and peer round the cohort member's back from their left flank to check that it is level.

While measuring ask cohort member to breath out gently, to let arms hang loosely by their sides and to look straight ahead (to prevent them from contracting their muscles or holding their breath). Pull tape taut and measure to the nearest 0.1 cm and record. Try to take the measurement in mid-expiration when the abdominal muscles are maximally relaxed. If cohort member is tense, repeat the measurement.

15.9 Room temperature

Read the temperature (in centigrade) to nearest whole degree and enter the value.

15.10 Measurement of isometric hand-grip strength

Hand-grip strength affects every day function (such as raising the body weight or holding heavy objects) and declines with age. It is measured with a strain-gauge hand-grip dynamometer which consists of a gripping handle (with a strain-gauge transducer) and an amplifier with digital displays.

Setting up the handgrip dynamometer

Do this before starting the questionnaire. The machine needs at least 20 minutes to warm up. Identify a convenient power socket and table. Unpack the dynamometer. Connect the handset lead to the input socket on the front and set range knob to zero. Connect the power cable to the back, and plug into the mains. Do not hold the leads and allow the transducer (the handset) to dangle as this may damage the connection.

Switch on

1. at the wall,
2. at the back of the dynamometer (a green light should come on),
3. at the front of the dynamometer (the display should light up).

If it does not, check that all the cables are pressed fully into their sockets.

When you are ready to begin the measurement set the zero and range as described below.

Procedure

1. Explain and demonstrate the procedure
2. The cohort member should sit in an upright chair with arms facing the dynamometer display.
3. As you turn the 'set zero' knob slowly in either direction, the dot moves into three different positions (left (.000), centre (0.00) and right (00.0). Using the 'set zero' knob, adjust the display so that the black dot is in the centre of the display panel (0.00*)*. Set the range switch to 'hold' and to '0-200kg' (the black dot will move to the right (00.0) when you do this), unless the subject is small or frail when '0-20kg' should be used.
4. Ask the cohort member to rest their preferred/dominant arm on the arm of the chair in the mid-prone position (i.e. with the thumb up) and wrist slightly extended.
5. Place the transducer in the preferred/dominant hand (unless injured), large rings may need to be removed. If the hands are very large you may need to use the larger handles on the transducer. To do this, simply prise off the smaller plastic handle which has the pins in the same location as the larger handle and replace with the larger handle.
6. Allow the Cohort Member a practice with both hands then ask them to squeeze as hard as they can for a couple of seconds and then release quickly *(see questionnaire for instructions to give)*. Record the value held on the digital meter to the nearest 0.1kg. In most of the dynamometers the value will remain displayed for 10 seconds and then reset automatically. For the rest, reset by setting the range knob to zero and then back to hold. Repeat the procedure with the other hand (unless injured).

7. Take 2 measurements for the right hand and 2 for the left hand. Do not include measurements carried out incorrectly.

   Exclusion criteria: Those with swelling or inflammation, severe pain or recent injury, and those with surgery to the hand in the last 6 months (if there is a problem with one hand only use just take measurements on the other hand.

15.11 Clinical examination of knees

Ask the cohort member to be seated in a comfortable chair with their legs stretched out in front resting on another chair. The examination can be done over leggings, tights or most trousers. If the trousers are wide they can be rolled up above the knee as long as this does not restrict movement. Examine the knee for evidence of (a) crepitus (b) joint margin tenderness, (c) bony swelling and (d) using the following procedures:

(a) Crepitus

Place the left hand over the knee cap and the right hand holding the ankle at the front, flex the knee from full extension to 90° flexion. With the left hand feel for a grating sensation during the movement, and as the knee is straightened again to full extension. Any palpated grating is designated crepitus. Record.

(b) Joint margin tenderness

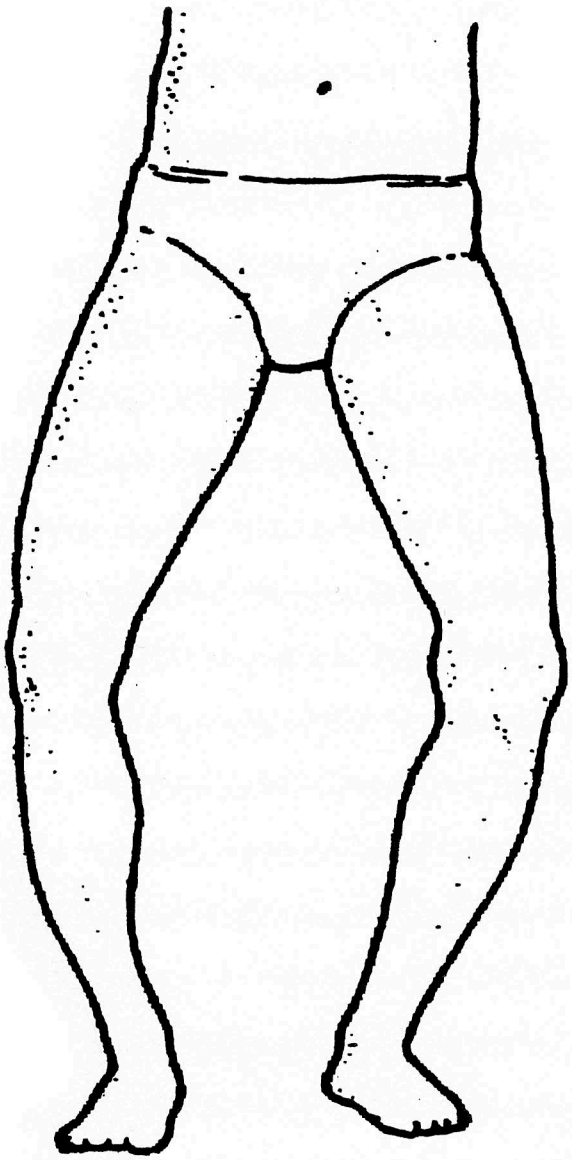
With the knee flexed at 90°, palpate the antero-medial and antero-lateral joint margins with the left and right thumbs. At uniform pressure, tenderness of the joint margin at the level of the patella but medial or lateral to it is recorded. The tenderness is assigned by the patient wincing. Record

(c) Bony swelling

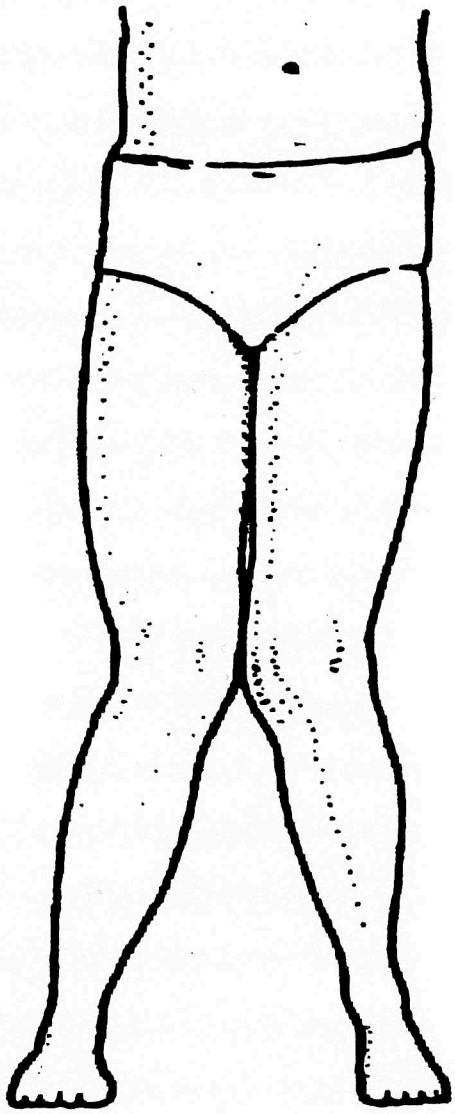
During palpation for joint margin tenderness, palpation should also be made around the circumference of the knee joint margin for evidence of craggy cold hard swelling representing osteophyte from the femoral condyles or tibule plateau. Record.

(d) Varus and valgus

Look down the leg towards the feet and observe if the feet turn inwards (varus) or outwards (valgus) in an obvious way (see diagram overleaf). Record.



Varus



Valgus

15.12 Buccal and Blood samples

The blood sample is being taken to obtain indicators of risk factors for cardiovascular disease and other measures of health and nutrition. The blood will be analysed for cholesterol, (raised levels are associated with an increased risk of heart disease), ferritin, (an indicator of the body's iron stores), vitamin B12, glycosylated haemoglobin, (an indicator of blood sugar), folate, (which shows folic acid levels) and white and red blood cell counts (which give basic indicators of health, such as the oxygen carrying capacity of the blood).

The samples will **not** be tested for any viruses, such as HIV/AIDS.

The blood and buccal cells will be used to study indicators of predisposition to some illnesses as DNA can be obtained from both. This will allow us to look at genetic characteristics so we shall be able to begin to understand why some people seem not to be affected by some known health risks, for example smoking, while it is harmful to others. The immediate tests will be done using the samples in tubes 1, 2 and 3. If the cohort member agrees some of the blood will be stored for future cell culture.

Equipment: All nurses will have the following equipment.

Vacutainer Needle holders
Alcohol swabs/cotton wool balls/plasters
Vacutainer needles (green)
Butterfly needles (green)
Vinyl gloves
Needle disposal box
Per Respondent:
6 Labels for sample tubes
3 Postal containers (plastic)
3 Postal boxes with pre-paid postage/address label to different addressses
Buccal cell collection tube
Buccal cell collection swabs
2ml EDTA vacutainer blood tube
2 x 3ml EDTA vacutainer blood tube
6ml ACD vacutainer blood tube
4ml Lithium Heparin vacutainer blood tube

The tubes are labelled 1- 6.

15.12.1 Buccal sample

Consent form 6 corresponds to tube 1 with BLUE cap (destination MRC-HBGU)

The buccal cell swabs should be given to the CM while they hold the tube and explain. The mouth should be free of food before taking the sample. Each of the 10 swabs should be taken in turn and rubbed around the inside of the cheeks, around the gums and inside the lips for about 20 seconds. All the swabs (used and unused) should then be placed into the blue capped tube with the swab end in the liquid.

15.12.2 Blood sample

Eligibility for blood sample

All cohort members are eligible to provide a blood sample except those who are:

a) pregnant

b) have a clotting or bleeding disorder. By clotting or bleeding disorders we mean conditions such as haemophilia, low platelets or thrombocytopenia. There are many different types of bleeding/clotting disorders but they are all quite rare. These respondents are excluded from blood sampling because the

integrity of their veins is extremely precious and we do not wish to cause prolonged blood loss. For purposes of blood sampling, those who have had, for example, a past history of thrombophlebitis, a deep venous thrombosis, a stroke caused by a clot, a myocardial infarction an embolus are **not** considered to have clotting disorders.
c) Not willing to give their consent in writing
d) Anyone who has had a fit in the last 3 years.

Consent form 7 point 1 corresponds to tubes 5 and 6 (destination RVI)
Consent form 7 point 2 corresponds to tubes 1, 2 and 3 (destination MRC-HBGU)
Consent form 7 point 3 corresponds to tubes 4 (destination ECACC)

Preparing the cohort member

1. Explain the procedure. The cohort member should be seated comfortably in a chair, or if they wish , lying down on a bed or sofa. Cover any furniture with kitchen roll.

2. Ask the cohort member to roll up their left sleeve and rest their arm on a suitable surface. Ask them to remove their jacket or any thick clothing, or to slip their arm out of their sleeve, if it is difficult for them to roll up their sleeve.

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

3. Apply the tourniquet around the subject's arm. Ask the cohort member to clench and unclench their fist 3 or 4 times. Select a suitable vein and ask them to relax their fist. Blood may <u>not</u> be collected from the respondent's wrist. It is desirable to use the tourniquet applying minimal minimal pressure and for the shortest duration of time. Do not leave the tourniquet in place for longer than 2 minutes.

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

4. Put on your rubber gloves at this point. You are required to wear rubber gloves when collecting blood for the survey.

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

<u>Taking the sample</u>

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

2. Grasp the respondent's arm firmly at the elbow to control the natural tendency for the respondent to pull the arm away when the skin is punctured.

3. Place your thumb an inch or two below the vein and pull gently to make the skin a little taut. This will anchor the vein and make it more visible.

4. Ensure the needle is bevelled upwards. Do **not** bend needles for venepuncture. Enter the vein in a smooth continuous motion.

5. Remember to fill the blood tubes in the following order.
Tube number 2. 3ml EDTA
Tube number 3. 2ml EDTA tube
Tube number 4. 6ml ACD tube
Tube number 5. 4ml Lithium Heparin tube
Tube number 6. 3ml EDTA tube

6. The vacutainers should be filled to capacity in turn and inverted gently on removal to ensure complete mixing of blood and preservative.

Dispatch of blood samples
To ensure the blood tubes reach the correct destinations, the tubes should be packaged as follows:

Remove the inner wadding from the plastic postal container, insert the appropriate blood tubes and then put the wadding back inside the plastic container.
(NB: Tube 1 does not fit inside the wadding pouch but is placed into the plastic container alongside the blood tubes and wadding.)
Tubes 1, 2 and 3 are placed into the container labelled 123,
Tube 4 is placed into the container labelled 4,
and tubes 5 and 6 are placed inside container 56.
Replace the lids of the plastic containers and ensure that each one is put inside the cardboard box bearing the same number.

Fainting respondents
If a respondent looks or feels faint during the procedure, it should be discontinued. The respondent should be asked to lie down. If fainting occurs place the cohort member in the recovery position.

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

Disposal of needles and other materials
Place the used cotton wool balls, gloves, etc. in the self-seal disposal bag. This bag, together with the needle disposable box, should be taken to your local hospital for incineration. Telephone them beforehand, if you are not sure where to go.

Needle stick injuries
Any nurse who sustains such an injury should seek immediate advice from their GP. The nurse should inform his/her nurse supervisor of the incident.

15.13 Diet
Read as instructed. Please do not get into detailed discussion about the diary. If the Cohort Member needs further information or help with the diary, ask them to telephone the number on the front of the diary.

Do not forget to
- fill in the serial, your nurse number and the interview date on the front of the diary
- give the CM a reply paid envelope to return the diary.

15.14 POST CLINIC INVITATION
If the CM is one of the 200 selected for a post interview clinic visit, one further question will appear, inviting them to attend a clinic.

16. FINISHING THE INTERVIEW

Ensure that you have thirteen ringed codes on the front of the Consent Booklet. If any results are to go the GP check that you have details written in the GP details clearly on the front.

At the end of the interview, thank the cohort member for all their help.

17. THE ADMIN BLOCK

The computerised interview schedule consists of two main components:

1. The interview
2. The admin block

Each component is known as a 'parallel block'. This means that you can enter each component at any time, no matter where you are in the schedule. The way to move between parallel blocks is by pressing 'Ctrl+Enter', which brings up a screen called 'Goto parallel blocks'. This screen is the gateway to the other components of the schedule.

18. RETURNING YOUR WORK TO THE OFFICE

Before returning your work, check that you have completed everything you have to do at an address and have all the documents you should have and that they are properly serial numbered and so on. Check that they match Page 5 of the ARF and that the Omron printout is stapled securely to Paper Test Booklet.

Post the ARF and Consent Booklet back to the office (in the same envelope) the same day as you take the blood samples to the Post Office. In a second envelope post the Omron printout, the paper Test Booklet and the Self-completion booklet.
Do not entrust other people to post your envelopes - always post them yourself.

Before returning CAPI work:

- Make sure you have a Backup disk of your most recent work
- Connect up to the modem
- Select 'T' for 'Transmit/Return data to HQ' **from the Action menu**, and follow the instructions on the screen.

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.

18.1 Unproductive addresses

Before being able to do your 'End of assignment clear-out' you must remember to transmit the addresses for any unproductive serial numbers. To do this,

- Highlight the serial appropriate serial number at the Address Menu.
- Go into the Admin block by pressing 'Ctrl+Enter' at the parallel blocks screen.
- Complete the Admin and enter the appropriate outcome code. (If the ARF was unproductive when it was sent to you by Operations, the outcome code will already have been entered on the front cover of ARF. If not, please remember to write it in).

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

- Make sure that you have taken a Backup of your most recent work

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

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