MRC National Survey of Health and Development

UCL

HOME VISIT 2015

NURSE'S MANUAL OF PROCEDURES

TNS

TNS BMRB

MDG Part of Capita plc

Contents

2 MRC NATIONAL SURVEY OF HEALTH AND DEVELOPMENT

Background

The Medical Research Council (MRC) National Survey of Health and Development (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 the seventh decade of 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 MRC National Survey of Health and Development (NSHD). There have been twenty three follow ups so far and contact is maintained with study members through an annual birthday card. The last fieldwork data collection was in 2006-10 when study members were invited to one of 6 Clinical Research Facilities (CRFs) based in Birmingham, Cardiff, Edinburgh, Manchester and London. Study members who were unable or unwilling to visit a clinic were offered home visits. The clinic visit enabled the study members to undergo clinical measures that were not available at the home; this included DEXA and pQCT (bone) scans, an ECG, and an echocardiogram. Previous home visits in adult life have been carried out in 1982, 1989, and 1999.

Postal questionnaires were sent to study members in September – December 2014. The questionnaire collected information on some of the common health problems associated with age (such as sleep disorders, pain, fatigue/exhaustion and urinary incontinence), repeat measures of wellbeing and quality of life, and changes in personal circumstances, including social roles (e.g. retirement transition, loss of or care for significant others) and social and physical activities.

In March 2015, we will begin inviting five hundred randomly selected study members to have a brain scan (PET and MRI scan) and some additional tests of cognitive and motor function, as part of a smaller neuroimaging sub-study. The study will be conducted with colleagues from the Institute of Neurology at UCL. If you have any questions, please contact Dr Michelle Byford (m.byford@ucl.ac.uk) or Prof Marcus Richards (m.richards@ucl.ac.uk).

The MRC NSHD is run by the study team at the MRC Unit for Lifelong Health and Ageing (LHA) at UCL (Director Professor Diana Kuh).

Purpose of the home visit

The ageing population is increasing; the percentage of the UK population aged over 60 years is projected to rise from 20% in 2000 to 27% by 2025, due to the baby boom cohorts and increased longevity. Increasing the proportion of healthy and active older people who remain independent for longer is seen as the main way to relieve the cost of an ageing population, and enhance individual wellbeing. The home visit aims to capture the full spectrum of health as

people age and possibly experience periods of more rapid functional decline. We shall study pathways to ageing by continuing to measure cognitive and physical function (e.g. blood pressure, grip strength, verbal memory) and assess the extent of functional change since previous measures were taken. We are also doing repeat assessments of mental ill-health and collecting reports of health and health care utilisation, behaviours and life circumstances not already captured on the postal questionnaire sent to study members in 2014. A blood sample will also be collected for repeat DNA extraction and biomarker measurements.

A link with study members
Always remember that the research nurse is the vital link with the study members because the nurse:

1. controls the accuracy of the data, and
2. is responsible for re-establishing and maintaining the long standing contact between each individual and the NSHD.

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 MRC NSHD and MDG when you visit a study member.

Throughout the survey the respondents are referred to as **study members** who are familiar with the National Survey team and know them as the **National Survey**. They sometimes call themselves the 'Douglas babies' after James Douglas, the first Director of the study.

The study members are very precious people – most have participated in all past data collections, are knowledgeable about (and committed to) the study; their continued commitment is the most important aspect of the data collection.

Confidentiality
You will be asked, as a condition of work, to sign a form, 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 study members with anyone outside the project team at NSHD and MDG.

If it is necessary to reassure study 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.

3 THE RESEARCH TEAM

The members of the research team:

MRC NSHD
Diana Kuh
Marcus Richards
Rebecca Hardy
Rachel Cooper
Andrew Wong
Maria Popham
Nik Sharma
Daniel Davis

MDG
Carli Lessof
Richard Freeman
David Darrer
Julie Collett
Hayley Cheshire
Judd Norton

Contact details

The Resource Manager at MDG

Julie Collett
0208 416 1302
07725 243 414
jcollett@wearemdg.com

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 related to carrying out the interview and measurements. The nurse supervisor will from time to time accompany you in the field. The supervisors are there to help you do your job to the best of your ability - please consult them whenever you feel you need help. The name of your supervisor is listed in the separate Project Administration notes.

MRC NSHD research team

Andy Wong	**Maria Popham**	**Nik Sharma (study doctor)**
020 7670 5709 0780 1924 791	020 7670 5705	020 7670 5702
andrew.wong@ucl.ac.uk	m.popham@ucl.ac.uk	nikhil.sharma@ucl.ac.uk

The MRC NSHD research team are there to answer more specific queries that study members may ask. If queries should arise please phone a member of the NSHD team on **020 7670 5705. If you have to leave a message, please give an indication of the type of query and the unique identifier** of the study member and your contact telephone number, and the relevant team member will call you back and contact the study member where appropriate.

MDG will be responsible for supplying the equipment, consumables, nurse paperwork and labels for the visit, NSHD will be responsible for preparing the nurse paperwork and labels. If you have any queries, please contact Julie Collett (MDG) or Maria Popham (NSHD) for any additional NSHD supplies or queries.

4 SUMMARY OF STUDY DESIGN

Around 2800 Study Members are eligible to take part in the 2015 home visit, this includes all study members who are still alive, are recorded as living in England, Scotland or Wales and who have not previously refused to participate. For fieldwork purposes the sample has been divided into 9 Waves and there are a total of 35 nurses covering the fieldwork

Fieldwork will take place between March and December 2015. All interviews will be carried out by a qualified research nurse who will conduct the interview using CAPI (Computer Assisted Personal Interviewing). The interviews will last approximately 1 hour 45 minutes and will consist of a variety of questions and cognitive and physical tests.

5 IDENTIFIERS - NTAGS

Each study member is given a unique identity number which allows us to identify which documents relate to which person. This is called the NTAG. The NTAG is made up of a number of different components:

6 digit number picked from a random sample drawn from the address space
+
1 digit sex code
+
1 digit error detection code

The error detection code is computed from the 7 digits composed of the first two items concatenated together. The resulting single digit error detection code is appended to form the NTAG identifier.

The full 8-digit NTAG of the study member must be recorded on all documents for that study member. Great care must be taken to ensure that the correct NTAG 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 NTAGs are entered on documents, there is a danger that the data from one person will be matched with that from someone else.

6 CONTACTING STUDY MEMBERS AND ARRANGING AN INTERVIEW

Sending out the advance invitation letter
Each study member will have been sent an advance letter and information booklet before you telephone to book your appointment with them. These are sent about four weeks before the start of each fieldwork Wave.

TNS telephone unit
The role of the telephone unit will be to follow up study members who do not send their reply slip back. These telephone calls will be conducted by a small experienced team of TNS interviewers. Advance telephone calls will be made at different times of the day (including evening) and on different days of the week (including weekends).

Telephoning to arrange an appointment
It is the nurse's responsibility to telephone study members in advance to set up their own appointments. All contact information is made available via the Nursetrak system. Nurses will follow MDG stand procedure and make their first phone call within two days (of receiving the reply slip) in order to book an appointment for the home visit, calling at different times of the day and on different days of the week.

Procedure for booking an appointment
The nurse should follow MDG's protocol for booking appointments. They must:

- ascertain informed consent.
- ask study members if they have any medical condition that may affect whether a blood sample can be taken. N.B. The blood sample is non-fasting.

  Explain that they will receive a reminder call/text.

Reminder call/text
- Confirm or rearrange a home visit appointment time to suit the study member
- The information will:
  - remind them to have to hand a copy of their repeat prescription card, their glasses for reading and any hearing aids if worn and to wear loose, light clothing and flat shoes.

7 INFORMED CONSENT

Study members are lifelong volunteers who have consented to be part of the study and have been included in over 20 data collections. As the sample is representative of the national population of the same age, there may be a very small number of NSHD cohort members with conditions that impair ability to give informed consent (for example, those with learning difficulties or with head injury), and some conditions (such as stroke or cognitive decline) will become more prevalent as the cohort ages.

Our research has the potential to benefit the study members who have conditions that impair ability to give consent by contributing to better understanding of the causes of these conditions. Our contribution will be limited if such people are excluded from the study. We have obtained MREC approval to include study members in this data collection who may not be able to give consent as long as the following protocol is carried out.

There are three stages when study members unable to give informed consent may be identified:

Stage 1: NSHD review of prior information
The NSHD research team will review relevant information from previous data collections and from the recent postal questionnaire to identify the small number of people who may have trouble giving informed consent. For these study members where there is a recognised problem, the research team will have already identified and approached a 'consultee' who will usually be present during the clinic or home visit (This will be someone who cares for the study member and is interested in his or her welfare other than in a professional capacity or because they are paid to do so; for example, a guardian, welfare attorney or the study member's nearest relative). The NSHD research team will provide any special instructions about the visit and whether the visit needs to be undertaken by a nurse who specialises in this area.

Stage 2: Telephone conversation with study member prior to visit
The MDG nurse for the NSHD study may also identify a few more study members with a recent impairment that affects ability to give informed consent when he/she speaks to the study member on the telephone to arrange the appointment. In this case, the nurse will attempt to identify the appropriate consultee for the NSHD team to approach. The NSHD research team will then give any special instructions about the visit and whether the visit needs to be undertaken by a nurse who specialises in this area.

Stage 3: The consent process
The nurse undertaking the visit must take all reasonable steps to obtain informed consent. This includes:

- reading our the information (when the person may not be literate)
- repeating the information
- talking through the information sheet and telling study members what kind of tests and questions you will be giving them

Where the nurse has followed these procedures but is still not convinced that informed consent has been given they should ask the study member: 'You may find it difficult to do the interview on your own. Would you feel better if a member of your family or a close friend could be with you?' If the answer is 'yes' the nurse should collect the name and contact details of the person the study member wishes to have with them. If that person is available the interview can proceed as long as this is acceptable to the study member, this other person and the nurse. Otherwise the nurse should contact the NSHD team who will assess the situation and, if necessary, approach the appropriate consultee to ascertain whether the study member should remain in the study and, if so, to arrange another visit.

8 THINGS TO DO BEFORE THE HOME VISIT:

- Personalise the paperwork by affixing the correct labels. Each label contains the unique identifier and the name of the form/questionnaire. The following documents that need to be labelled include the:
  - Consent form booklet and each signed consent form
  - Self-completion questionnaire
  - Paper test booklet. The CAPI notes whether word list A or B should be used. Record this on the front of the booklet.
  - Physical activity questionnaire and timesheet

The nurse should have spare copies of all the above documents available in case they are needed.

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 below).

Checklist of materials to take to every visit.

Equipment

- Laptop (Ensure this is fully charged)
- Jamar handgrip dynamometer and spare batteries
- NDD Easy-on PC spirometer and mouth pieces
- Omron 907-HEM, small, medium and large cuffs (Ensure this is fully charged)
- Thermometer to measure room temperature
- Tape measure for anthropometry
- Stadiometer and Frankfort plane card
- Scales
- Wooden board
- Accelerometer and belts
- Measuring tape and masking tape to measure and mark walking distance on floor
- Marker pen for anthropometry measures

Blood equipment

- Centrifuge
- Needle holders
- Alcohol swabs/cotton wool balls/plasters
- Vinyl gloves
- Sharps bin

Per participant:

- You will be provided with a blood kit per participant

Cognitive tests

- Word-list learning test: 2 ring-bound flip-booklets of 15 words, one word per page
- Stopwatch
- Pencil
- iPad (Ensure this is fully charged)
- Finger tapping machine

Paper documents

You will be provided with a pack for each participant

- Informed consent form
- Consent form booklet containing:
    - General consent form (mandatory)
    - Hospital and GP records consent form
    - Clinical advisor consent form (if no GP consent given)
    - Future consent form
- Consultee consent forms (if required)
- Self-completion questionnaire
- Paper test booklet
- Accelerometer questionnaire and timesheet
- Pre-paid envelope for the study member to return the activity monitor and belts, questionnaire and timesheet
- Freepost envelope for sending the consent forms, self-completion questionnaire and paper test booklet to the NSHD
- A set of A4 barcoded labels for each piece of paper work
- A set of small barcoded labels for the blood samples with the 8 digit unique identifier.
- Measurements card

10 INTRODUCING THE INTERVIEW

On arrival at the house
It is important to be aware that although the person you are interviewing has been a study member their entire life, you will be their first personal contact with the study since 2006-10 (or 1999 in a few cases). The date of the last interview is recorded on NurseTrak.

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

Introduction

- Say who you are: "I am a nurse called..."
- Please wear your ID badges
- Say who you work for: "I work for MDG and am carrying out the data collection for the MRC National Survey of Health and Development"
- Remind study members about your appointment: "A few days ago I made an appointment with you over the telephone to see you today about The National Survey".

Most study 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* – MDG 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 2.1
- *what you are going to do* – see Section 2.2
- *how the study 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.

Getting a high response rate
A high response rate is crucial if the data collected are to be worthwhile. Otherwise, we run the risk of getting findings that are biased and unrepresentative, as people who do not take part are likely to have different characteristics from those who do. 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.

"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 worthwhile (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. The measurements are an integral part of the survey data and without them, the interview data, although very useful, cannot be fully representative.

Study 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 contact 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 encourage them to participate.

Some study members 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 MDG 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 Study Member.

Be encouraging
It is essential to encourage reluctant study 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 study member, 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 study members. If you would like to discuss ways of encouraging people to take part, speak to your Nurse Supervisor (or to your Area Manager).

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 re-contact the person and arrange 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.

The number of calls you must make

MDG will advise on the number of call you must make.

11 THE INTERVIEW

Study members will have received information about the measures in the advance letter and accompanying Patient Information Booklet.

Make sure that you are familiar with the content of this home visit and, if necessary reassure study members that every stage is optional.

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

12 SETTING UP THE EQUIPMENT

After introducing yourself, please familiarise yourself with your environment to judge where you can set up and place equipment. For example, are there suitable chairs to use for the chair rises, is there space to conduct the walk test, is there an electrical socket for the centrifuge?

We recommend that you begin by unpacking only a few items, the remainder of the equipment can be set up whilst the participant is resting prior to the blood pressure measurement, or prior to each test.

- Begin by:
    - Unpacking and setting up the stadiometer, match the corresponding symbols together, ensuring the sections are in ascending numerical order. Ask the participant if this can be placed flat against a wall, use the wooden board if necessary
    - Unpack the scales, tape measure and water-based marker pen
    - Unpack the Omron, cuffs and thermometer
    - Unpack the laptop, showcards and iPad

13 THE QUESTIONNAIRE (CAPI)

The interview schedule is on a laptop. Please follow the instructions on the screen, it will guide you through which sections to complete, which questions to ask and which measurements to take. Detailed instructions for individual questions are given in Section 15.

General tips on how to use the computer program

Throughout the CAPI, the modules are separated by headers to indicate when to give instructions "Tell participant" and when to "Ask participant".

Read out the questions in the CAPI **exactly as worded**. This is very important to ensure comparability of answers. You may think you could improve on the wording, but please resist the temptation to do so. Enter the code number beside the response appropriate to the participant, indicating the answer received or the action you took.

Some questions rely on the use of feedforward data and this has been noted in the CAPI. You will be prompted to ask the study member for consent to use this information (see page 19 below).

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

Please speak to Hayley Cheshire/Julie Collett if you have any queries on using the CAPI.

14 OPERATING THE EQUIPMENT

Stopwatch

- Hold the stop-watch with the display facing towards you and the two buttons at the top of the watch
- Check that the stop-watch is in the correct mode (if so it should read 0:00$_{00}$).
- If the stop-watch does not read 0:00$_{00}$ press the left hand (reset) button on the top of the stop-watch.
- If the stop-watch still does not read 0:00$_{00}$ press the mode button on the front of the watch until you obtain the stop-watch display.
- 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.

<u>TO START TIMING:</u>
Check that the stop-watch screen reads 0:00$_{00}$
Press the right hand (start/stop) button on the top of the stop-watch

<u>TO STOP TIMING:</u>
Press the right hand (start/stop) button on the top of the stop-watch

<u>TO RESET TO 0:00$_{00}$:</u>
Press the left hand (reset) button on the top of the watch

Tape measure

- The tape measure works on a press button closure and a slider.
  - Locate and slide the plastic slider to an appropriate length, eg 100cm
  - Locate the “red button” of the tape measure (found at 2cm)
  - Ensure tape is untangled and press this into the back of the plastic slider, indicated by two red arrows.
  - When the tape is positioned around the participant, pull the loose end taut, ensuring the buckle is kept fastened and read off the measurement, as indicated by the red line.
  - Record the measurement, rounding up to the nearest millimetre.

THE HOME VISIT MODULES

The interview consists of a mixture of factual and opinion questions as well as physical and cognitive tests. The CAPI is broken down into a number of *Modules,* the remainder of this manual describes each module in detail, providing a brief introduction and the equipment required. If the module is an interview section, you will be given instructions on how to ask the questions. If the module is a measurement/test, you will be given the protocols, along with the CAPI instruction, on how to accurately and competently conduct the measurement test.

The order of the modules is given below:

- Initial details
- Consents
- Medical conditions and medication
- Blood pressure
- Bloods
- Self-completion
- Addenbrooke's Cognitive Examination (ACEIII) – administered via iPad
- Activity questions
- Anthropometry
- Chair rise test
- Balance test
- Walking test
- Hand grip
- Lung function
- Cognitive function
- Future consent
- Socioeconomic circumstances and parental death
- Health behaviours
- Habitual physical activity

Module: Initial details

Introduction:
This contains information preloaded from Meditrak that should be confirmed at the start of the visit.

START MODULE

Complete the module by checking the following details:

- The participant's name
- Sex
- Date of birth

Check that the:

- "Study member ID" matches the labels you have
- The nurse ID is correct

If the visit has been rescheduled, check/enter:

- Date of visit
- Appointment time

SUBMIT MODULE

Module: Consents

Introduction:
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 the General Consent form (consent to carry out the interview).

Use a pen when completing the booklet and ensure that initials and 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, initial and date, 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.

Equipment:

- Consent booklet (blue cover)
- Pen

START MODULE

Explaining the module:

Explain the purpose of the visit
Ask if the participant has read the patient information sheet
Ask if they have any questions about the study

READ OUT:
"We need to obtain your consent to be interviewed and measured today and to use information collect today and at previous times for research. Even having given consent, you can still decline to do any part of the interview or examination. The results of some tests (blood pressure, lung function, anthropometry and bloods) will be sent within 8 weeks. We will be asking you to consent to send results to your GP which may be useful for your health care and this will be explained at the relevant part of the examination".

Open the consent booklet and turn to the *first* consent form

General consent form - consent to carry out the interview by the study member
We are unable to begin any tests until the study member gives consent.
If the study member does not consent to any sections, please select the relevant box in the CAPI
The sections are listed below:

Read PIS – Has the participant read and understood the patient information sheet?
Access to notes – Consent to validate self-reported medical information (such as cancer, heart attack, diabetes) given by the participant, against their hospital/GP records.
HSCIC – Consent to electronically link to health records such as hospital admissions (Hospital Episodes Statistics)
DNA – Consent to conduct genetic research on the blood samples provide

Data sharing – Consent to share anonymised data with bona fide scientists
Data controller – Consent for UCL to store the data and ensure it is used in accordance with the Data Protection Act
GP results – Consent to send the results of the test and measures to the GP
Take part in study – Consent to participate in the home visit

Clinical advisor consent form - consent to send results to NSHD clinical team if GP consent not provided
If the study member does not consent for their GP to be sent for results to be sent to their GP, then you will need to ask them to sign the clinical advisor consent form. Explain that if this consent is not given, a blood sample cannot be drawn.

The clinical advisor will be the NSHD Study doctor, Dr Nik Sharma. If a blood sample is taken, Dr Sharma will give advice on the blood test results.

GP /hospital form
READ OUT:
"We may wish to obtain additional details about your health from your hospital and GP records"

If consent is given for "Access to notes", turn to the next page, Access to GP and hospital records.

How to use the GP look-up
1. Click "Select" box
2. Type in criteria for GP search in "Enter Filter Text" box (e.g. town/postcode) – punctuation is not necessary
3. Wait for list of GP practices displayed below to be updated using your criteria.
4. Move your cursor down to highlight specific GP practice and click on it.
5. The selected GP practice should appear in answer box.

Examples:
Great Lever Health Centre, Rupert Street, Great Lever, Bolton, Lancashire, BL3 6RN.
The Surgery, 187 Gudge Heath Lane, Fareham, Hampshire, PO15 6QA
Roade Medical Centre, 16 London Road, Roade, Northampton, NN7 2NN
The Surgery, The Green, Haddenham, Ely, Cambridgeshire, CB6 3TA
The Surgery, 391 Long Road, Canvey Island, Essex, SS8 0JH

Postcode search
- Start by entering "bl3"
- Refine search by entering full post-code "bl3 6rn"

GP practice name search
- Start by entering "great lever"

NOTE:
If the GP practice is a generic "Health Centre", "The Surgery", "Medical Centre", this will find too many surgeries. Instead, search by address

GP address search
- Start by entering "the green".

- Refine search by entering “the green, haddenham” – Please note the comma.

NOTE:

- *If you select the wrong one, click “Select” and start again*

If the GP practice is NOT in the list:
Select the category "None" at the top of the GP list.
Fill in GP details manually on-screen using questions below:

GP name (Mandatory)
GP address line 1 (Mandatory)
GP address line 2
GP address line 3
GP address line 4
GP postcode
GP phone number

Consultee consent form - consent to carry out the interview by the study member’s consultee

In the case when the study member lacks capacity to provide informed consent, then we need to obtain consent by the consultee. There are a few Study Members who the NSHD have already identified who will need a consultee consent and these have already been flagged. If your telephone conversation of initial conversation with the study member leads you to believe the study member is lacking in capacity, please follow the contact your Nurse Supervisor in the first instance or Dr Nik Sharma at LHA. See section 7 above.

Feedforward consent

Introduction:
In order to reduce the number of questions asked, we have included feed forward data from the recent postal questionnaire or relevant information from the team’s files; please ensure you ask for consent for this information to be used. There is no requirement for a paper consent to be signed.

READ OUT:
“You kindly completed a postal questionnaire recently and provided factual answers to some of the question that I would like to ask you today. Would you be willing for me to use a version of the questionnaire that allows me to see these answers, as this will reduce the amount of information to collect today.”

READ OUT follow up questions

SUBMIT MODULE

Module: Medical Conditions and medication

Introduction:
In order to interpret many of our measurements we need to know what health conditions study members have and what medications they are taking.

Equipment:
- Laminated Showcard A

General: Conditions should have been diagnosed by a doctor.
When a study member says yes they have the condition – an additional set of questions will pop up. These will be different depending on whether the condition is chronic/recurring or an event.

Common cardiovascular conditions and diabetes
We have asked about common cardiovascular conditions and diabetes on the postal questionnaire. For study members who allow feed forward of postal questionnaire information, we just need to record events of diagnoses, which have occurred since they filled in the questionnaire. Note that these will be recent events.

For other study members we ask the same questions that were asked on the postal questionnaire.

For most conditions we ask if they have been diagnosed SINCE 2006 as these conditions have been asked about at the last data collection. The only exception is heart failure where we ask whether they have EVER been diagnosed, as we had not specifically asked about this condition before.

When entering dates of diagnosis or events, try to obtain month and year, but if they are not able to give this provide their age at diagnosis or event.

If the study member provides information for a diagnosis of angina, BP problems of diabetes that is prior to 2006, please do record this information. MI and stroke will only allow you to enter events from 2006 onwards.

START MODULE

READ OUT:
"Have you ever been told by a doctor that you have heart failure" (If necessary explain or use alternative terms)

If yes, ask additional questions.

READ OUT:
"Since 2006, have you been told by a doctor that you have had any of the following conditions…"

For each condition record "Yes" or "No"

READ OUT:
"Angina"

"Heart attack" (if necessary explain or use other terms they may have heard)

"Blood pressure problems" (note this includes low and high BP)

"Stroke" (please exclude TIAs as these will be asked about later)

"Diabetes"

Ask additional questions for all conditions to which the participant has answered "Yes"

Other medical conditions

READ OUT:
"Since 2006 have you had any of the following medical conditions or events? Please only tell us about those which have been diagnosed by a doctor."

Read out each condition in turn and record "Yes" or "No"

Note you may need to explain conditions or use alternative name.

- A transient ischaemic attack and explain that this can be called a mini stroke or a TIA
- Use **Showcard A** for "other conditions affecting the heart or circulation" and explain any conditions if necessary
- Osteoporosis is the thinning of the bones. Do NOT include the milder form of osteopaenia.

Ask additional questions for all conditions to which the participant has answered 'Yes'

Transient ischaemic attack
Click on add for **each** TIA since 2006 and ask additional questions.

Other conditions affecting the heart or circulation
Ask additional questions (allow date of diagnoses even if prior to 2006)

Cancer
Click 'Add' for **each** occurrence of cancer since 2006 and ask additional questions.

Chronic lung disease such as emphysema, bronchitis, COPD
Click 'Add' for each lung disease and ask additional questions.

Asthma
Ask additional questions.

Osteoarthritis
Click 'Add' for each site and ask additional questions.

NOTE:

- *for site just add knees, hands, hips, back/spine rather than left knee, right knee etc.*

Rheumatoid arthritis
Click on add for each site and ask additional questions.

NOTE:

- *for site just add knees, hands, hips, back/spine rather than left knee, right knee etc.*

Osteoporosis

Ask additional questions.

Serious eye trouble such as cataracts, glaucoma or macular generation

Click on add for **each** eye condition and ask additional questions

Depression

Ask additional questions.

Epilepsy

Ask additional questions.

Parkinson's Disease

Ask additional questions.

Memory problems

Ask additional questions about whether the doctor had given these problems a special name and their age at the time but do not prompt with any examples; just record what the participant says. Typical conditions include dementia, Alzheimer's disease, vascular dementia, Lewy body dementia.

Kidney disease

Ask additional questions

Other medical condition not already mentioned

Click **"Add"** for ***each*** medical condition and ask additional questions.

Other health conditions

The next set of questions (up to medication) ask about other health conditions or difficulties over a specific time frame (*in the last week, in the last 12 months*), so please ensure the participant is clear what time period is being considered. These health conditions *do not* have to be diagnosed by a doctor. In some questions, participants will be asked to rate each difficulty in terms of frequency (how often) or degree (how severe).

Health conditions over the last 12 months:

READ OUT:

"In the last 12 months have you suffered from any of the following health conditions?"

Remind participants of the 12 month time frame

Delirium

READ OUT:

"Please think to a time when you have been unwell, for example, perhaps while in hospital. Sometimes a person's memory, thinking and concentration can get worse over hours and days due to an illness, eg. Infection, operation of due to medications. This is called delirium"

"Since 2006, have you ever experienced delirium symptoms?"

If yes, ask additional questions.

NOTE:

- *You may prompt the participant to think about the duration of delirium in days or weeks – record days or weeks first and then enter number of days/weeks in box which pops up. If response is 'a few hours', round this up and record as '1 day'.*

Dizziness
READ OUT:
"How often do you have problems with dizziness when you are walking on a level surface?"

READ OUT the possible responses

Vision and hearing difficulties and hearing aids.
READ OUT:
"Have you had difficulty with the following in the last 12 months?"
READ OUT the possible responses

At the end of the questions about hearing ability, we ask if the study member uses a hearing aid. It may be obvious that they are wearing a hearing aid, but modern devices are often more discreet, so we do need to specifically ask.

Study members may say that they do use an aid, but not necessarily all the time. Please record 'yes' in these cases.

Please remember, if a study member does need a hearing aid, this should be used during the cognitive testing.

Knee and hand symptoms.
Osteoarthritis is very common, especially as study members get older. The previous section asked about medically-diagnosed conditions. The purpose of these questions is to elicit symptoms that may or may not have been formally diagnosed, and whether or not study members say osteoarthritis is the cause of these symptoms. The symptoms of osteoarthritis include pain and stiffness and it will be important to the study member that these are reported for the study.

READ OUT all questions and possible responses
We will ask about symptoms in the knees and hands, left and right, separately. Please record pain and/or stiffness for each of these.

NOTE:

- *The time period in question is on **most** days (i.e. more than 15 days) in any one month in the last year.*
- *The hand refers to any part of the hand, including fingers, knuckles, hand and wrist.*
- *Stiffness may be especially apparent after a period of inactivity, e.g. first thing in the morning on getting out of bed, after sitting for an extended period. When asking about stiffness, it may be useful to ask the participant to think of such situations. For knees, we are interested in stiffness **lasting 30 minutes or more**. This is not asked about separately for the hands.*

Medications
Prescribed medications are a vital source of information when assessing health. When arranging the home visit, study members will have been primed (by you at the telephone call to confirm the visit) to have a copy of any repeat prescriptions to hand and/or medicines.

READ OUT:
"Are you regularly taking any medicines or tablets prescribed by your doctor"
If you, please record the medicine(s)

NOTE:

- *It is likely that most participants will be on at least one prescribed medication. Some participants may take several (more than ten) medications.*
- *It is critical to obtain an accurate list. The default position will be to enter each medication in turn in the CAPI. The text box will access a full dictionary of medications, which will be searched automatically as the first few letters of a given medication are typed. This will be efficient where a few medications need to be entered, but may take substantial time if participants are taking multiple tablets.*
- *You may wish to consider alternative ways to quickly, but accurately, record the medication list. You might consider:*
  - *Jotting down the medications by hand in the paper booklet*
  - *Taking a photograph with the iPad. If you do this, you will need to ensure that the resulting photograph is in focus and all of the printed text can be read. This may or may not be difficult given the green background that many prescriptions are printed on.*
- *Whichever method you use, please enter the medication list into the CAPI in the usual way, either when you are in the participant's home or once you have left.*

Having obtained the list of prescribed medications, please complete the module by asking the two questions about non-prescribed medications:

READ OUT:
"Do you regularly take junior aspirin/low dose aspirin that is NOT prescribed?"
This refers to the aspirin 75mg that is available over the counter. It may be apparent from the prescribed medication list that the participant is already taking aspirin 75mg, in which case you should NOT include it here as a non-prescribed medicine.

READ OUT:
"Do you regularly take any other non-prescribed/over the counter medication or supplements?"
This may refer to any supplements, vitamins, painkillers, herbal remedies, decongestants etc. Please note you do NOT need to write these down.

SUBMIT MODULE

Module: Blood pressure

Introduction:
This is the 5th time we have measured adult blood pressure and it is important for assessing change over time that we follow the protocol.

Equipment:
- Omron HEM-907 automated digital oscillometric sphygmomanometer.
- Normal, large and extra-large cuff
- Thermometer
- Stethoscope (used for manual recordings)
- Measurement card

NOTE:
- *If needed, you can enter the readings on the measurement card, but please remember to enter these onto CAPI before moving onto the next test.*

START MODULE

READ OUT:
"I would now like to take your blood pressure"
Explain briefly how this will be done.

READ OUT:
"Would you be willing to have your blood pressure taken?"

If the participant is unwilling or unable to do this test please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can.

If the participant is willing, please select 'Yes'. Enter air temperature in Celsius to the nearest degree and proceed with test.

Feel the right radial pulse
1. If heart rate is regular proceed with automated measurement
2. If heart rate is not regular proceed with manual measurement

Preparation

1. Ask the participant to sit with legs uncrossed at the end of a table near the front right-hand corner with the right arm resting comfortably, palm up, on the table.
2. Position the Omron so that the readings cannot be seen by the participant.
3. Sit at the front of the table close to the right-hand end, facing the machine.
4. Ask the participant to remove any watch and expose the upper right arm
5. Make sure that the rolled up sleeve does not constrict the arm.
6. Select the appropriate cuff
7. Locate the brachial pulse just medial to the biceps tendon

8. 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.
9. Connect the cuff to the sphygmomanometer.
10. Explain that the machine will take blood pressure three times and that the participant can request to stop at any time.
11. Ask the participant not to move his/her arm while the measurement is being taken. The instrument is sensitive to movement while deflating, and may fail to take a reading.
12. Explain to the participant that before you measure their blood pressure, it is necessary to sit quietly for at least two more minutes with legs uncrossed to rest.
13. Keep conversation to a minimum until after blood pressure measurements.

<u>Automated</u> Measurement

1. When first set up the display should be blank.
2. Press the green 'On/Off' button to prepare the machine to take a reading.
3. Set the MODE Selector to "AVG."
4. The display will show a zero and a heart symbol.
5. Preset should be set to 180.
6. Press the blue 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.
7. The Omron will automatically perform the next two reading, at 1 minute intervals.
8. At the end of the measurements, average values are displayed. DO NOT enter this reading. Press the grey deflation button to cycle through the 1st, 2nd and 3rd readings.
9. Record value of the pulse, systolic, and diastolic measurements in the relevant boxes in the CAPI.

Occasionally the machine will be unable to give a reading and display an error message; this may be due an arrhythmia and you will need to do a **"MANUAL"** blood pressure reading. If this occurs explain to the participant that you will need to do the readings again, but manually, because the machine is very sensitive. Please switch the Omron off and follow the manual measurement protocol below. **Do not just start doing a manual reading as this may cause the participant to become concerned.**

<u>Manual</u> measurement protocol

1. When first set up the display should be blank.
2. Press the green 'On/Off' button to prepare the machine to take a reading.
3. Set the MODE Selector to "MANU.".
4. The display will show a zero and a heart symbol.
5. Preset should be set to 180.
6. Press the blue start button. The cuff will automatically inflate and slowly deflate.
7. Using the stethoscope, listen for the Korotkov sounds against the numbers counting down on the blood pressure machine and **write** the readings down on the measurement card

NOTE:

- *The Omron does not display the results when taking a manual reading; you will need to write down the reading as it is deflating the cuff.*

8. Once you have written down the results, start the stop watch for one minute
9. During this minute you can do the manual pulse reading and record this.
10. Once the minute is up, repeat steps 6-9, twice more so that three measurements are recorded in total.

NOTE:

- *Occasionally participants 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 participant a chance to recover before repeating the measurements, as long as the participant is willing.*
- *Enter into CAPI which protocol was followed (automated or manual) and why.*

Answering queries about the participant's blood pressure

Three blood pressure measurements are taken. The first reading can be high because people are nervous about having their pressure taken. Base the feedback on the lowest measure. The CAPI programme will provide the relevant instructions below:

- Tell the participant if the blood pressure is normal

- If the blood pressure is mildly raised (systolic 140-159 or diastolic 85-99 mmHg) please 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 if this is a once-off finding or not."

- If the blood pressure is moderately raised (systolic 160-179 or diastolic 100-114mmHg) please 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 if this is a once-off finding or not."

- If the blood pressure is severely raised (systolic >/= 180 or diastolic >/= 115mmHg) please 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 if this is a once-off finding or not."

SUBMIT MODULE

Module: Blood sample

Introduction:
The blood sample is being taken to obtain indicators of blood function, liver function, kidney function, risk factors for cardiovascular disease and diabetes, nutrition, and other measures of health. The blood will be analysed in the first instance for blood tests requiring duty of care, including haematology measures (white blood count, haemoglobin, platelets etc.), HbA1c, serum lipids (cholesterol, triglycerides). These results will be fed back to the participant and their GP (if consent is given).

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

The blood will be used to study indicators of genetic predisposition to some illnesses, since DNA can be obtained. This will allow us to look at genetic characteristics to understand why some people seem to be unaffected by some known health risks, for example smoking, while others are affected. We will be distributing the blood into a number of tubes for different compounds and will be storing for future biomarker analysis.

Equipment:
- Alcohol swabs/cotton wool balls/plasters
- Micropore tape
- Vinyl gloves
- Needle disposal box
- Labels for sample tubes

Per Participant:
- 5.0ml SST BD Vacutainer x 3
- 4.0 ml EDTA BD Vacutainer x 2
- 2.7ml Sodium Citrate Vacutainer x 1
- VACUTAINER NEEDLE HOLDER, SINGLE USE
- Butterfly (Safety-Lok Blood collection set)
- ALCOHOL WIPE
- Plaster
- TDL MEDIUM SPECIMEN BAG WITH POUCHES
- TDL Request Form
- PROTOCOL LABEL / EXPIRY DATE x1 on request form & x1 on specimen bag
- Barcodes - x1 on request form & x1 on specimen bag
- Prepaid Address Label (Therapak to stick on the Smartbox Env)
- Smartbox Corrugated Envelope - Ref 885088
- 95kPA Biohazard bags
- 4 Bay Aqui-Pak EDTA BD Vacutainer

START MODULE

READ OUT:
"Have you given a blood sample before?"

READ OUT the follow up questions

READ OUT:
"I would like to take some blood samples from you?"

Explain the purpose and procedure for taking blood

READ OUT:
"Would you be willing to have a blood sample taken?"

NOTE:
***Exclusion criteria**:*

All participants are eligible to provide a blood sample except those

- *who volunteer information that they are HIV positive or have hepatitis C (the participant must not be asked about these).*
- *are not willing to give their consent for a GP or clinical advisor to contact them if necessary*

We are not excluding participants on anticoagulants. However, if the participant is on warfarin or other anticoagulant, it will affect the clotting time for serum in the laboratory. You will know from the list of medications whether or not the participant is on warfarin or other anticoagulant. Please enter this information on the TDL request form.

If the participant is unwilling or unable to do this test please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can.

If the participant is willing, please select 'Yes' and proceed to take the blood sample.

Taking of the blood samples

1. Ask the participant to remove their jacket and roll up their sleeve of the arm to be used and rest their arm.
2. Wash or cleanse your hands; wear gloves is required
3. Select a suitable vein and then apply the tourniquet around the participant's arm. Ask the participant to keep their arm as still as possible during the procedure. Clean the venpuncture site gently with a mediswab. Allow the area to dry completely before the sample is drawn.
4. Venepuncture should be performed with the appropriate gauge vacutainer needle or butterfly. The blood bottles should be taken in the order below as indicated below. The blood bottles should only be labelled after all the blood has been taken.

1 x 4ml EDTA blood tube	(dark purple)	Label with "**E N1"**
1 x 4ml EDTA blood tube	(dark purple)	Label with "**E N2"**
1 x 5ml serum separator	(gold top)	Label with "**SE N1"**
1 x 5ml serum separator	(gold top)	Label with "**SE N2"**
1 x 5ml serum separator	(gold top)	Label with **"SE N3"**
1 x 2.7ml Citrate blood tube	(blue top)	Label with "**CI N1"**

PLEASE REFER TO THE COLOUR CHART SHOWING ORDER OF DRAW AND LABELS

5. Release the tourniquet (if not already loosened), remove the needle and place a cotton wool ball firmly over the venepuncture site. Ask the participant to hold the gauze swab on their arm firmly for one minute.
6. Take a plaster or piece of micropore and attach it over the piece of gauze swab on puncture site and explain to the participant they may remove it after a period.
7. Attach the labels for that participant onto the blood bottles you have just filled, checking that the labels are for the correct participant and correct tube.

NOTE:

- *If venepuncture is unsuccessful on the first attempt, a second attempt should be made on the other arm. Do not make more than **3** attempts.*
- *You will have leftover labels after labelling the blood tubes, please keep them.*

After taking the bloods

1. Needs are discarded in the sharps bin. Sharps bins should not be allowed to become overfull as they present a potential hazard to the nurse.
2. If the participant looks or feels faint during the procedure, it should be discontinued and the participant should be asked to place their head between their knees. They should be subsequently be asked to lie down, or placed in the recovery position if feeling faint. If they are happy for the test to be continued, after a suitable length of time, it should be done with the participant supine.
3. Ensure that if a participant has fainted during the procedure to document everything that happened in the CAPI and whether the participant continued the test or finished early.
4. If wearing gloves, these can be removed but otherwise please wash or cleanse your hands.
5. In CAPI, please indicate whether you were able to collect all, some of none of the blood samples.
6. Complete the follow up questions
7. After taking the sample, invite the participant to have something to eat or drink if needed and you will be prompted to set an alarm for 30 minutes.

SUBMIT MODULE

Processing of the samples

1. Once all the samples have been taken, the 3 serum separator (gold top) blood bottles need to be centrifuged. If taken, place the EDTA and citrate plasma tubes in the postal pack.
2. Place the yellow top serum (SST) blood tubesin the centrifuge, ensuring they are balanced.
3. The SST should be left to stand for a minimum of 30mins and a maximum of 3 hours to allow for clotting prior to centrifuging. Where possible the blood bottles need to be placed in an area that is not too warm, so not near direct heat or in a very warm room. Ideally the room should be kept at a temperature no greater than 22^{o}C. Perhaps an area in the kitchen would be suitable but use your judgment when doing this.
4. After the 30 minutes has elapsed, please ensure the sample has clotted. If so, please centrifuge at 3000 rpm for 10 minutes, to separate the serum from the cells.
5. Once the centrifuge stops, place the SST tubes in the sample bag together with the rest of the samples and the TDL request form.

Request form and posting samples

1. Once the blood samples have been collected and the serum separator gold top) blood bottles have been centrifuges, all the samples can be placed back into the postal pack for mailing to the blood laboratory (TDL).
2. Ensure you place the leftover labels into the postal pack. These are the labels with a 2D barcode and ID number on, and blood number on them. This is for TDL to label up the samples when they are processing the blood
3. Complete the carbon request form and attach the barcode label to both the white and pink parts of the form. Enter:
   - Time the blood was taken
   - Date when the blood was taken
   - Whether blood was successfully obtained for each tube
   - Nurse ID
4. Separate the 2 forms and place the white copy in with the blood samples to be posted to TDL. The pink copy is to be sent back to UCL together with the rest of the paperwork.
5. The postal packs can be posted in any post box to TDL.

NOTE:

- *At the end of the visit, ensure all the labelled blood bottles, leftover labels and TDL request form are in the pre-paid postal pack. Seal the pack and post samples back to TDL the same day.*

Module: Self-completion (GHQ-28)

Introduction:
The GHQ28 is a series of questions about how participants have been feeling recently, and has been administered at the last two data collections.

Equipment:
- Self completion questionnaire
- Back pen

START MODULE

READ OUT:
"I would like to give you this questionnaire to fill in by yourself. The questions are about how you have been feeling recently. Please check with me if any of the questions are unclear"

READ OUT:
"Are you willing to do this test?"

If the participant is unwilling or unable to do complete the questionnaire, please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can. This is the end of the module for these participants.

If the participant is willing, please select 'Yes' and give the questionnaire and pen to the participant

It is best not to monitor while they complete this, unless someone requires help with reading or understanding. While the participant completes the questionnaire you prepare the bloods for centrifuging.

When the participant has completed the questionnaire, please check they have answered all questions and point out any that are missed (but don't press if this is because of refusal).

NOTE:
- *If the participant has answered*
  - *'much more than usual' to the questions on the GHQ 'Have you recently found yourself wishing you were dead and away from it all? ' (Q27)* or
  - *'Definitely has' to the question on the GHQ 'Have you recently found that the idea of taking your life kept coming into your mind? (Q28),* or
  - *has a strong emotional reaction to any of the questions, you may wish to suggest to the participant that they discuss these feelings with their GP.*
  - *If the participant does not want to involve the GP for whatever reason, you can leave them a leaflet summarising relevant care services. Use your judgement about what is the best approach and be guided by how upset the participant appears to be. If a leaflet was given to the participant, please tick the box.*

You will be asked to confirm that you have checked the responses and whether the booklet was completed independently or with assistance.

SUBMIT MODULE

Module: Addenbrooke's cognitive examination (ACEIIII)

Introduction:
The ACEIII is one of the most popular and commonly used clinical cognitive tests. Although used in clinical practice, we will not be using the ACEIII as a diagnosis tool. It includes the mini-mental state examination (MMSE) and includes five subdomains – attention and orientation, memory, verbal fluency, language and visual spatial skills. The ACEIII will be administered using an iPad.

It is assumed that you have watched the following videos.
http://acemobile.org/ACEm_Ax_Tut.html

Equipment:
- iPad
- Paper test booklet
- Pencil

START MODULE

READ OUT:
"Do you feel that you have more difficulties with your memory than other people of a similar age?"

Explain the test:
"This assessment will explore your thinking skills such as memory. Some of the questions are basic whereas others are more difficult. It is entirely normal to find some questions hard or to even make mistakes."

READ OUT:
"Would you be willing to carry out a short test using the iPad?"

If the participant is unwilling or unable to do this test please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can. This is the end of the module for these participants.

If the participant is willing, please select 'Yes' and proceed with test.

Protocol:
The app contains prompts for each action, please read the exact sentences to the participants. You will need to use the blank pages in the paper test booklet to capture drawings/writing that the participant is asked to do, and for you to jot down participant verbal responses.

Launching the ACEMobile App
Login details: XXXX PIN: 1471

Recording a subjects response
On a number of occasions you will need to record the participants response i.e. drawings, sentence or word list.
You will need to take photographs of these later on, therefore we recommend each drawing, sentence, word list is spread out (max of 3 per A4 page of the paper test booklet).

Entering subjects details (Standard version of the App)

1. Click on Assessment.
2. Click on generate ID
3. Fill in details.

General

There are a number of key features that you will find on each page.

1

On every page is a sequence of red numbers, these guide you through the steps required on each page.

Instructions

Tap each word as said.

Each question begins with an instruction to you in black.

Say to the Patient

What is the day?

Where you see a speech bubble, this indicates what you should say to the patient (verbatim).

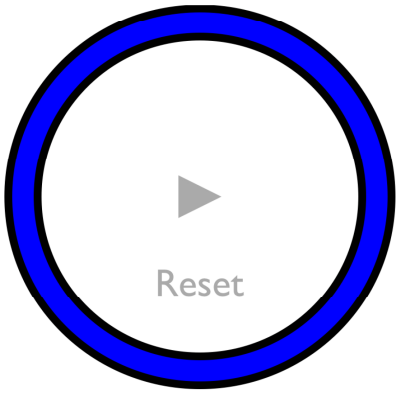
Lemon | Key | Ball

Many of the questions are presented in a multiple-choice format. For these types of question, tap on the patient's response which will then become highlighted blue.

Once all questions or tasks have been completed on a page a Next button will appear in the bottom right hand corner. You will need to tap this to move onto the next screen.

ACEmobile has an inbuilt timer for some of the subtests.

This can be paused or reset at any time.



Within the App

On each page of the ACEmobile assessment you will see three buttons. Tap these to:

 Open the tutorial.

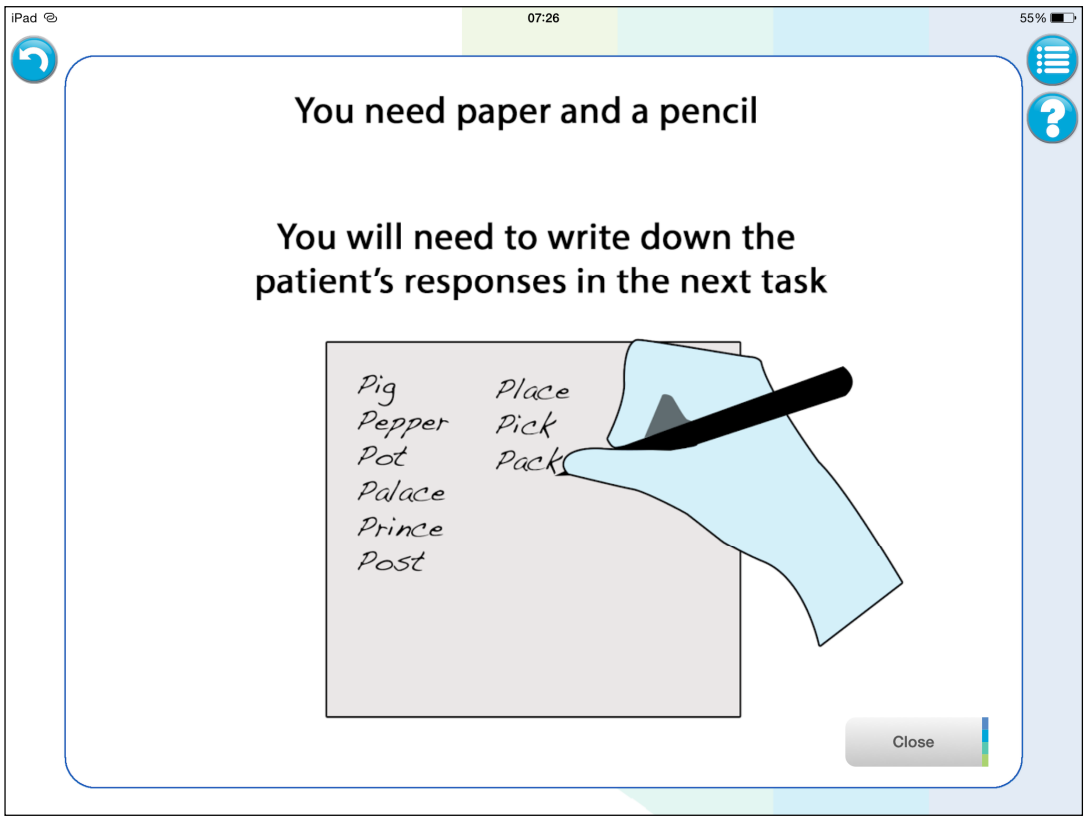
 Move back to the previous page.

 Open the in-assessment menu.

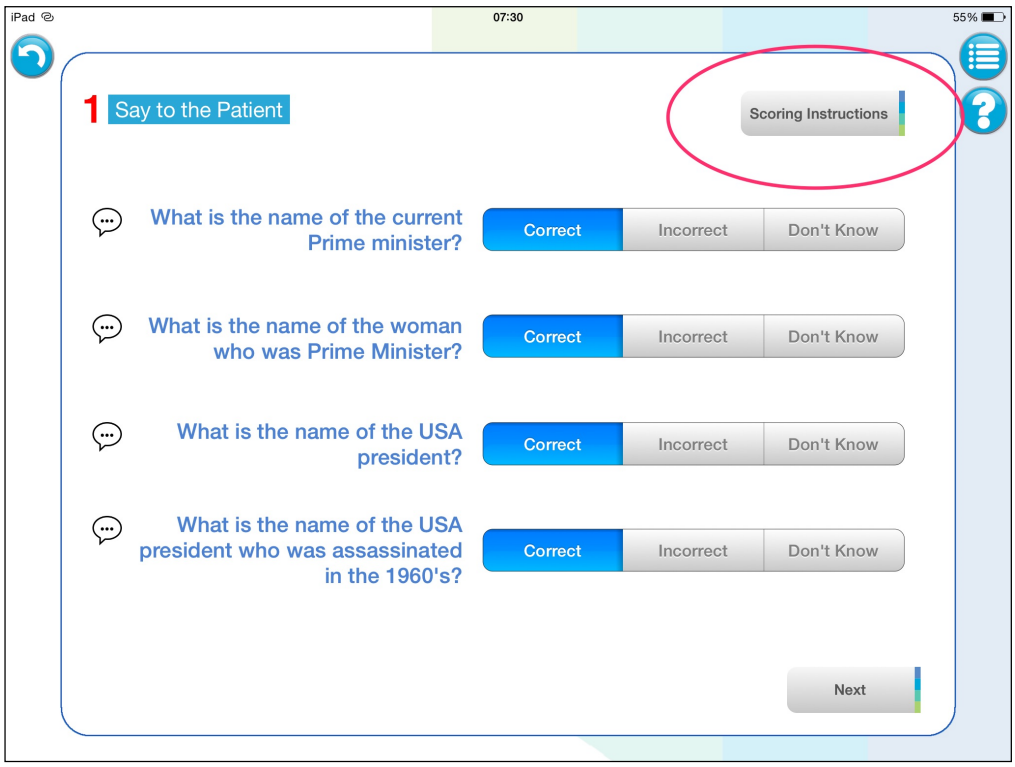
Within the in-assessment menu  there are 4 options:

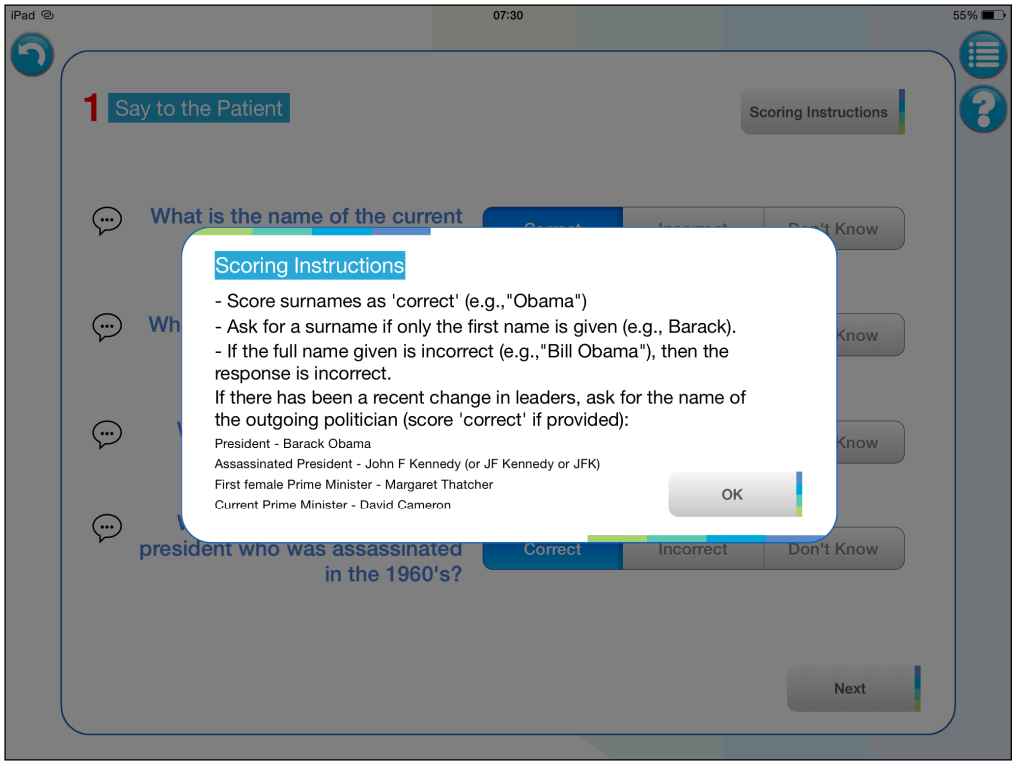
Abandon Assessment	End the current assessment (you will be asked to note a reason for this action).
Restart Task	Restart the current task.
Skip Task	End the current task (you will be asked to note a reason for this action).
Add note for Task	Add a note to self, for later review.

Where necessary the App will give you instructions on equipment

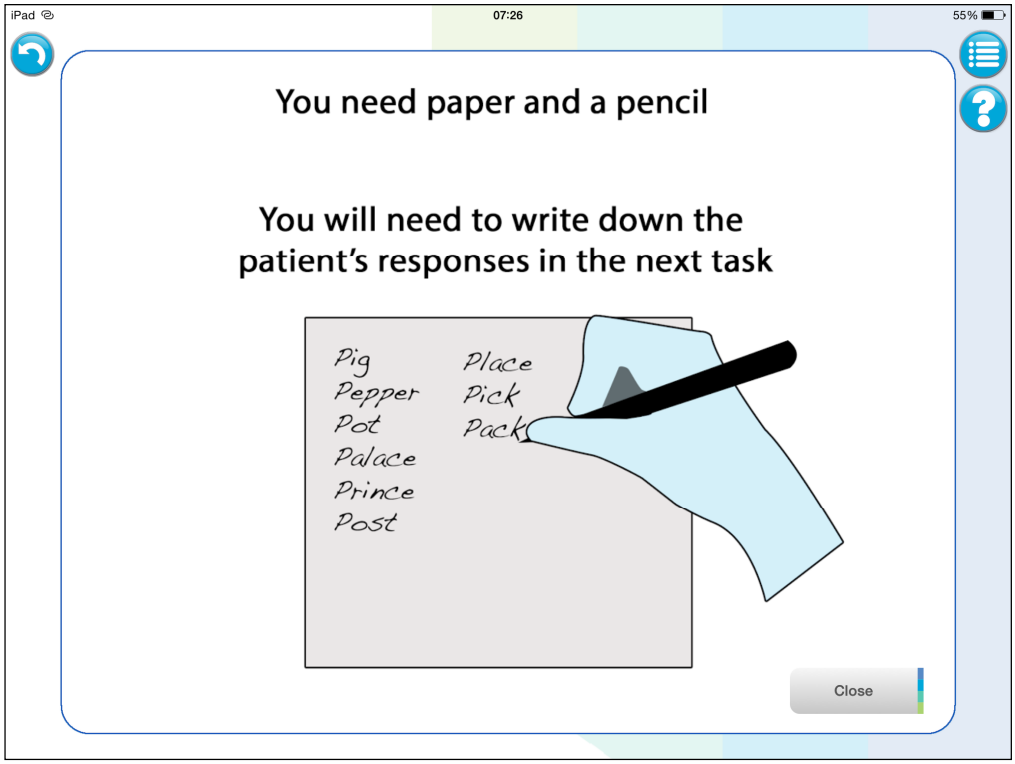


Where necessary the app will give instructions on scoring





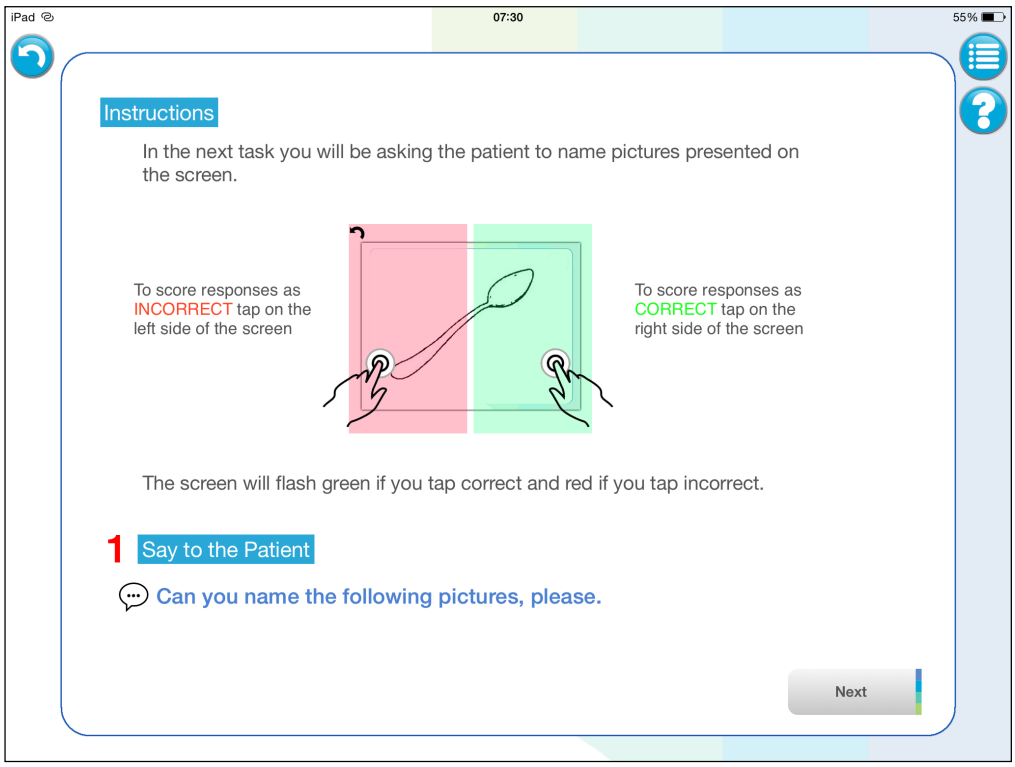
Sometimes you need to write down the participant's responses.
Please use the first few pages within the paper test booklet



When you are recording the subject's response it is important to note down the each response i.e. it is the **number** that is important.

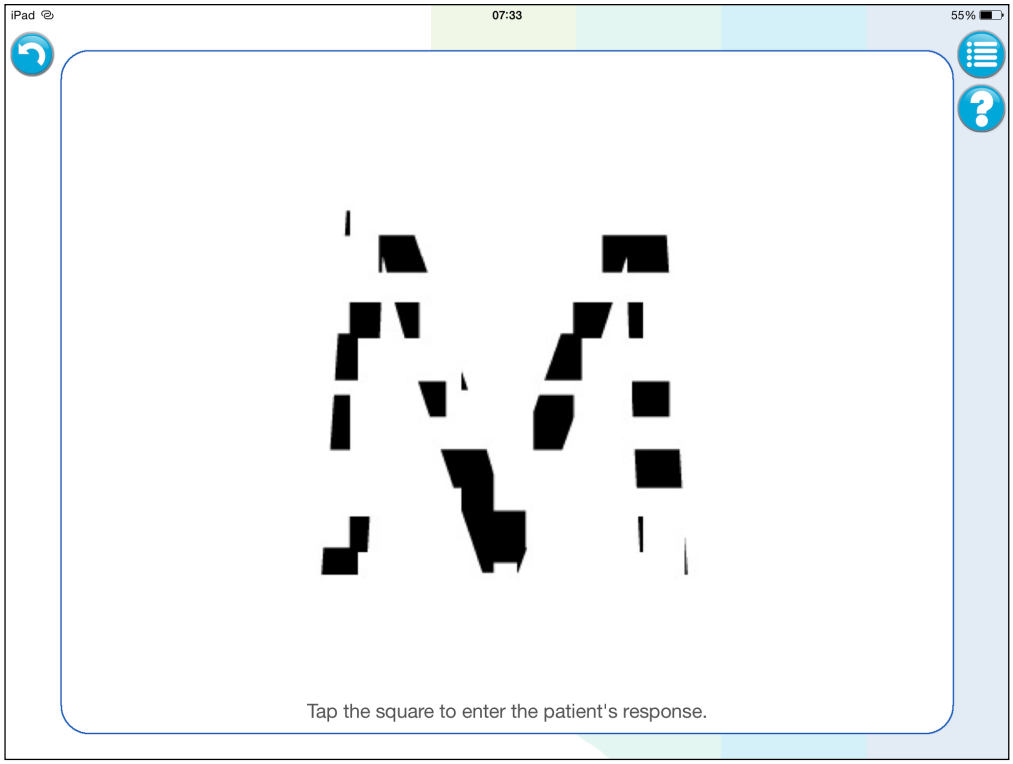
- If the responses are very quick it is acceptable to use a short stem i.e. 'hippo ' rather than 'hippopotamus'.
- If a subject repeats a word you a can place a dash next to the word i.e. III if repeated three times

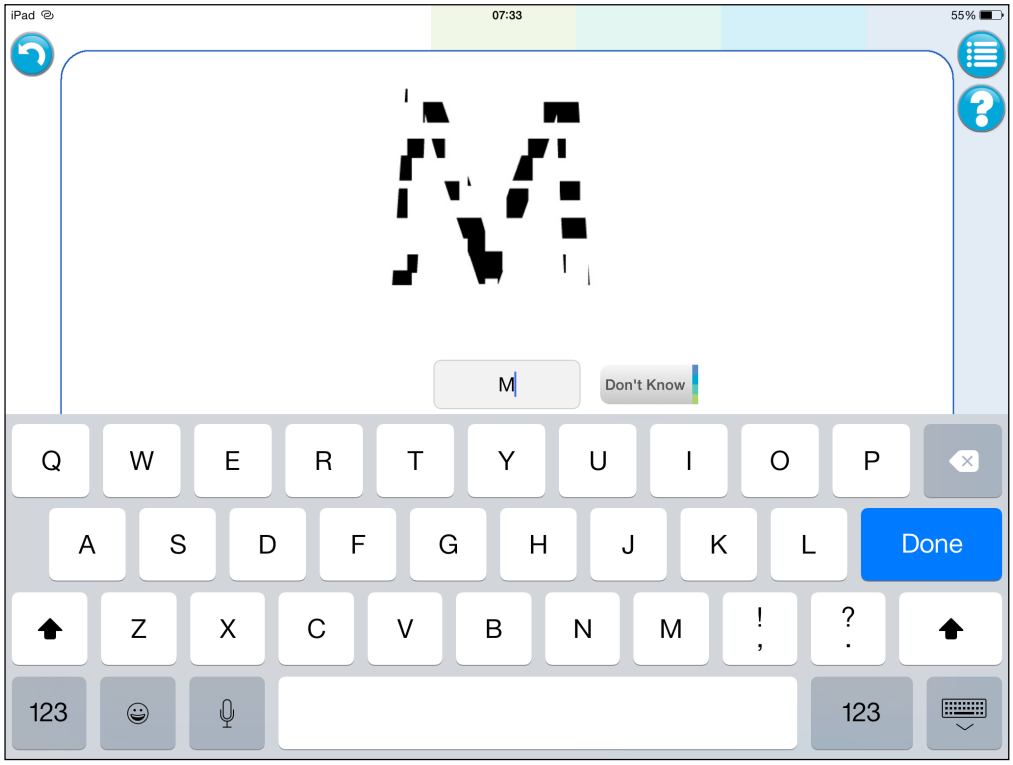
Sometimes you need to tap the screen to record the participant's answer



On a few occasions you will need to enter values such as below.

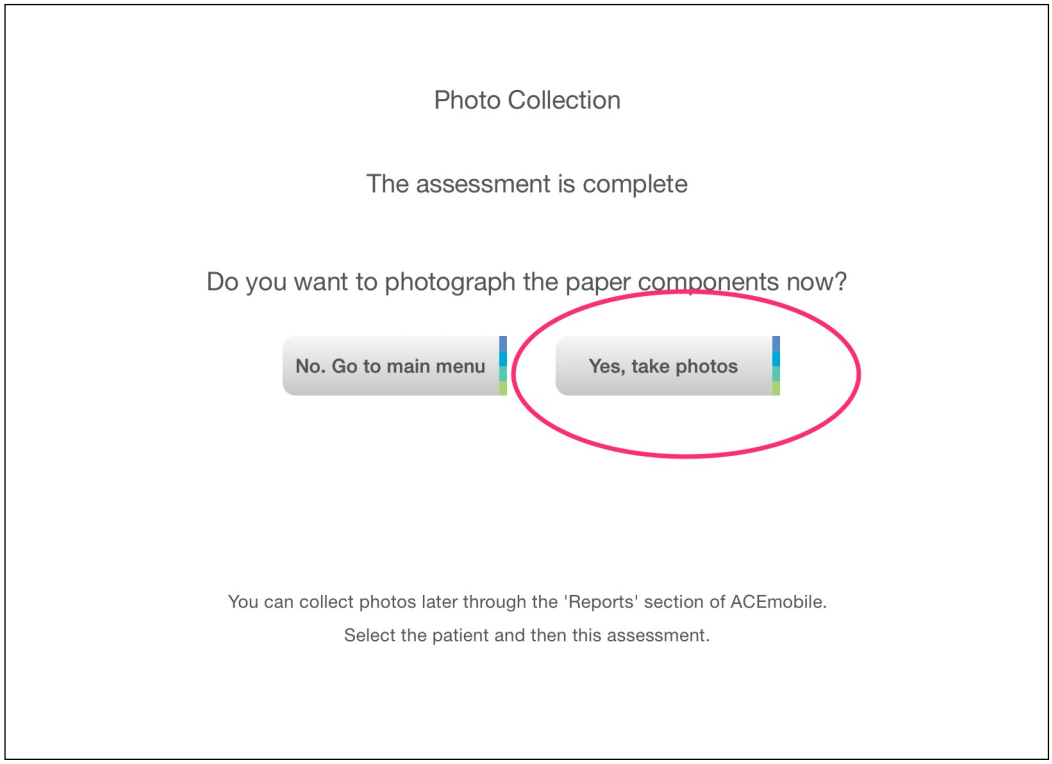
We recommend that you **turn the Ipad towards you** for a brief moment and enter the value and then turn the ipad back to the participant.





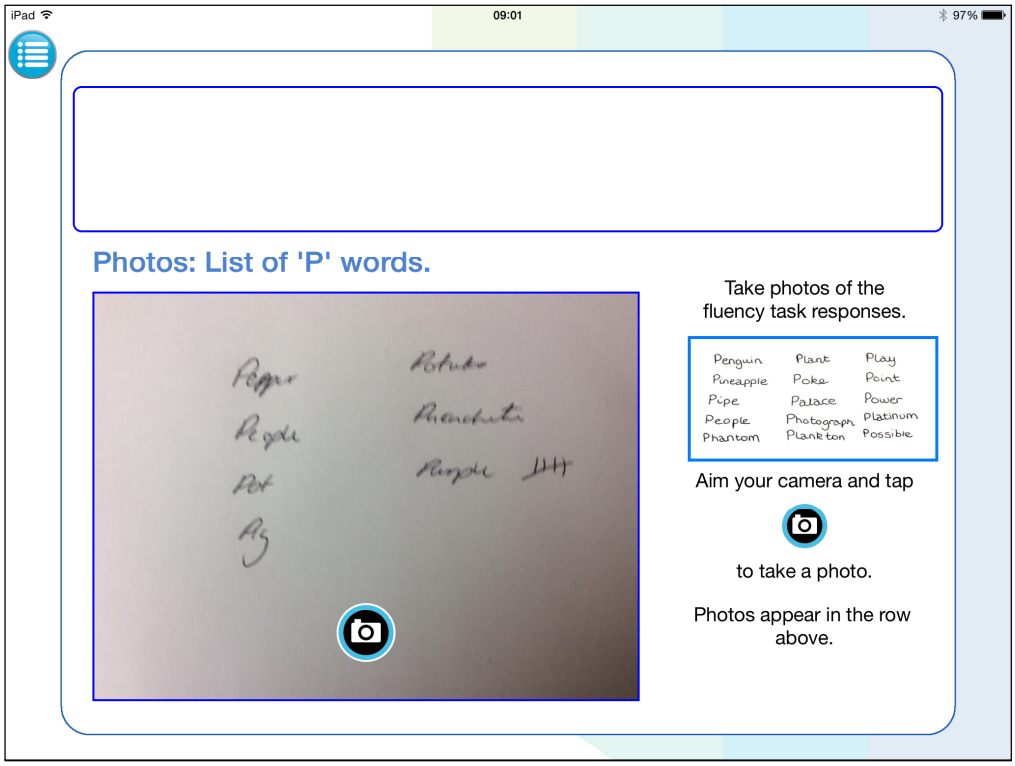
At the end of the test, you will need to take photographs of the participant's response.

- This can be done off-line and after you leave the participant's home



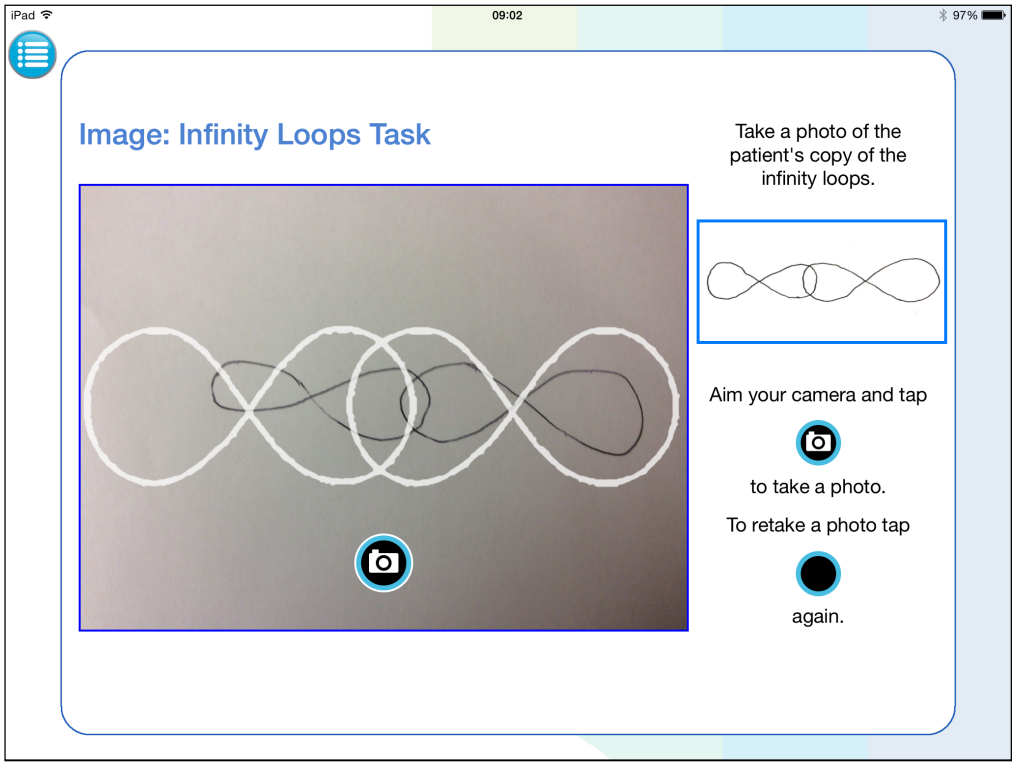
Taking a Photo of the different word lists.

- Remember to include of the words and that the repetitions are marked (in this case the person said “people” 5 times)

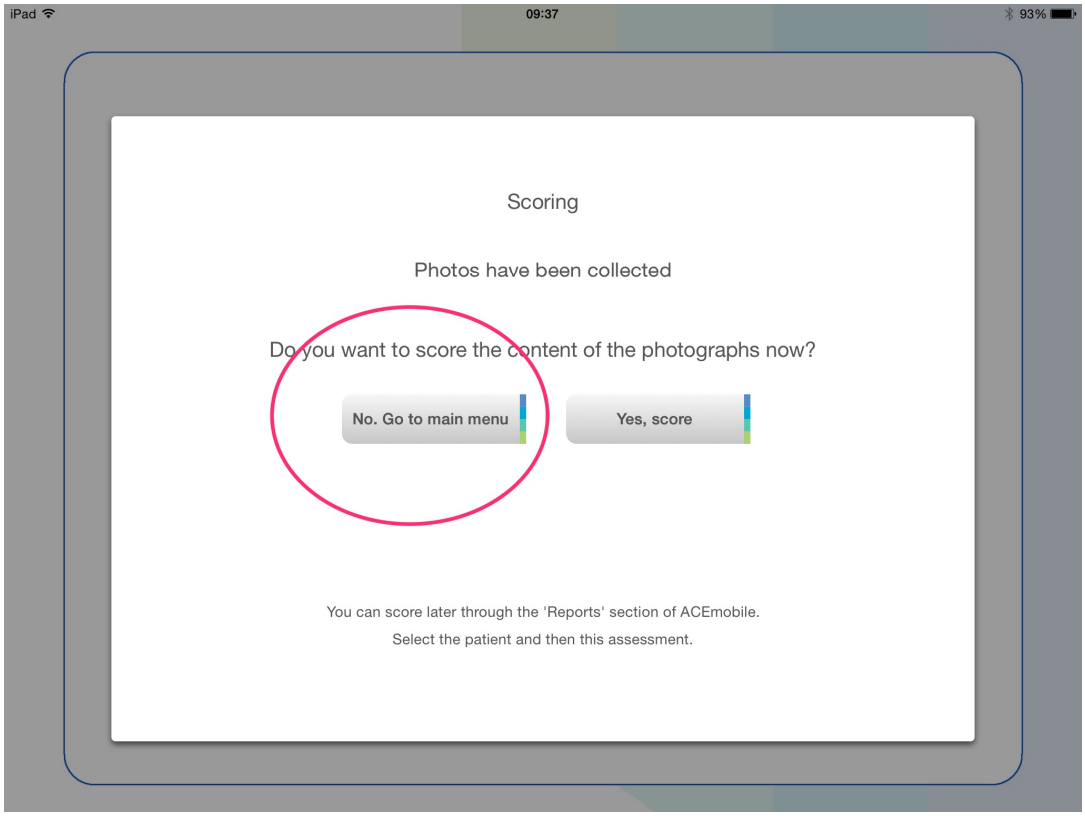


Taking a Photo of the different diagrams.

- The app will present you with a guide.



After taking all of the photos the app will ask whether you want to score these: <u>you do not need to.</u>



SUBMIT MODULE

Module: Performance questions, ADLs and IADLs

Introduction:
To complement the physical and cognitive tests that we ask study members to perform, we also want to collect information on difficulties study members may have performing functional tasks such as gripping, walking and climbing stairs. We also want to ascertain whether study members have difficulties with basic and instrumental activities of daily living (i.e. ADLs and IADLs). ADLs consist of essential self-care tasks such as bathing, dressing, eating and using the toilet. Instrumental ADLs (IADLs) such as managing medications and shopping are not as fundamental as basic ADLs but do allow individuals to live independently in the community. If someone is experiencing difficulties undertaking functional tasks, ADLs or IADLs, this is likely to impact on their quality of life and wellbeing and participation in social activities.

This modules includes a series of questions about the difficulties study members may have with a range of tasks. If a study member reports difficulty there will be follow-up questions on this so please just carefully follow CAPI. All study members whether they have difficulty or not will be asked follow-up questions on some questions (e.g. balancing and climbing stairs).

Equipment:
- Laminated Showcards B-G

START MODULE

READ OUT:
"These next questions are about difficulties you may have carrying out different daily activities, because of long term health problems."
"Do you have any long-term illness, health problems or disability that limits the activities or the work you can do?

READ OUT word for word each question in turn and select the appropriate response on CAPI.

NOTE:
- *It is important to read each question out word for word.*
- *Please pay attention to the response options.*
- *If a participant reports difficulty with a task please clarify, if shown on CAPI, if that is "**some difficulty**" or "**a lot of difficulty**" (for physical perform module).*
- *If a participant reports difficulty with an ADL, you will then need to ask the follow-up questions about their use of aids and personal help with this task, which will appear on CAPI.*
- *If a participant reports the use of personal help with any of these tasks there will also be follow-up questions to ask about **who** helps them and **how often**.*

We are interested in difficulties experienced even if the participant says these difficulties are just because they are getting older rather than because of specific health problems.

We are interested in difficulties people have doing activities for themselves. If they have found ways to lessen those difficulties (e.g. using a medicine box to help them remember when to take medications or making lists) then they should rate the difficulty when using these methods.

Personal help received for ADLs and IADLs
At the end of the ADL questions, study members who have said they need personal help to do any of these tasks are asked to look at **Showcard B** and tell you all the people that have helped

them do these tasks in the last month and to look at **Showcard C** how many hours of help they received in the last week. This is repeated for the IADL tasks using **Showcard D** and **E**.

Providing help to other people.
Introduction:
These questions relate to care provided for someone with long-term physical or mental ill-health or disabilities or who are frail. They do not include help given in a professional capacity or as part of paid help, and they do not include more general help, such as looking after healthy grandchildren (which was asked about on the postal questionnaire). The questions are split into care provided for people who live with the study member and for people who do not live in the same household.

Participants are asked whether they provide special help to anyone **living with them** who is sick, frail or has a disability, and if so, *who they provide help to* and *how many hours a week* they spend helping these people (**Showcard F**).

NOTE:
- *Only include children or grandchildren if they have special care needs.*

The questions are then repeated to find out what help they may give to people who **do not** live with them.

Personal help in the future.
Using **Showcard G**, participants are asked to say who would be most likely to help them [and their spouse/partner] with daily activities if they became sick, frail or had a disability.

NOTE:
- *Choosing spouse/partner is not an option. If they do this say 'who do you think would help if both you and your spouse/partner needed help with daily activities?' More than one option can be chosen.*

SUBMIT MODULE

Module: Anthropometry

Introduction:
Using previous anthropometric measures in childhood and adult life we have described lifetime weight and height trajectories in this representative cohort and shown how they relate to many aspects of adult health, such as cardiovascular risk and physical and cognitive performance. It is important for assessing change in these measures over time that the protocol is followed.

Equipment:

- Stadiometer
- Tanita weighing scales
- Frankfort plane card
- Tape measure
- Water based felt tip marker
- Wooden board
- Measurement card

NOTE:

- *If needed, you can enter the readings on the measurement card, but please remember to enter these onto CAPI before moving onto the next test.*

START MODULE

Weight change questions:
We are asking questions about weight change because as people get older, weight loss, particularly if it is unintentional, has been shown to be related to poor health outcomes.

Explain you are first going to ask a few questions and then take the measurements.
READ OUT:
"Has your weight increased, decreased, or not changed, in the last year?"
If increased or decreased ask additional questions

Measurements
READ OUT:
"I would now like to take different types of measurements."

Explain that these measurements will be height, weight, waist and hip circumference. If necessary explain that the participant can consent to some measures and not others.

READ OUT:
"Would you be willing to be measured and weighed?"

NOTE:

- *There are no exclusion criteria unless the participant is unable to stand to have his/her height measured*

If the participant is unwilling or unable to do this test please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can. This is the end of the module for these participants.

If the participant is willing, please select 'Yes' and proceed with measurements.

Height

Preparation

- Explain that you will first measure height
- Place the stadiometer against a flat wall, using a wooden board as necessary
- Ask the participant to remove shoes (they should keep their socks/tights on)

Protocol

1. Ask participant 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.
2. Arms should be held loosely at the side.
3. 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).
4. Check the position by holding the Frankfort plane card beside the participant's face.
5. Ask the participant to take a deep breath in, re-check the Frankfort plane position and bring the headpiece down on the centre of the participant's head.
6. Take measurement **rounding up** to the higher mm if the pointer is between 2 marks
7. Record height in cms (e.g. 140.3cm) in CAPI.
8. Record in CAPI if you were unable to take measurement.

Weight

Preparation

- Explain that you will now measure weight
- Place the scales on a hard floor.
- If there isn't a hard surface easily available, place the scales onto the wooden board, on the floor.
- Ask participant to take off any jacket or jersey. The participant should wear a skirt or trousers and shirt, and socks but no jacket or jersey and no shoes.

Protocol

1. Reset the zero button
2. If necessary, check that the scales measure in kgs
3. When the zero shows ask the participant to step on looking straight ahead (and not downwards), without hesitation.
4. Read off the flashing answer
5. Enter the measurement in **kg** in CAPI.
6. Record in CAPI if you were unable to take measurement.

Waist (abdominal) circumference

Preparation

- Ask the participant to face you and to stand straight with feet together and looking straight ahead.
- Stand to the right of the participant and 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 participant to hold it whilst you retrieve the end of the tape from his/her left hand.
- This should leave you standing slightly to the participant's left when you click the tape together.

Protocol

1. Ask the participant to lift their top so that the waist is exposed.
2. Make a mark with a waterproof pen at the costal margin and another at the iliac crest.
3. Apply tape at a point midway between these two points, in line with the mid axilla.
4. Ensure that the tape is level all the way around and not twisted.
5. Ask the participant to breathe 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).
6. Pull tape taut
7. Take measurement **rounding up** to the highest mm at the end of a normal expiration and
8. Record measurement in cm (e.g. 140.3cm) in CAPI.
9. If participant is tense, repeat the measurement and record the new reading if it is higher.
10. If it is not possible to measure on the skin, measure over light clothing using same protocol without marking with pen
11. Record in CAPI if you were unable to take measurement.
12. Record if the measurement was on skin or over clothes in CAPI.

Hip circumference

Preparation

- If tape is still around participant make tape loser and slide down to hips
- If tape is undone, follow procedure for preparation again

Protocol

1. Measure to be taken over light clothing.
2. Locate the greater trochanter (this will be at the widest part of the hips, at the level of the buttock line).
3. To check the levels you have to position the tape on the right flank and peer round the participant's back from their left flank to check that it is level.
4. If the greater trochanter is difficult to locate, the largest gluteal circumference should be measured.
5. Ensure that the tape is level all the way around and not twisted.
6. Ask the participant to breathe 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).
7. Pull tape taut
8. Take measurement, **rounding up** to the highest mm in mid-expiration when the abdominal muscles are maximally relaxed.
9. Record measurement in mm in CAPI
10. If participant is tense, repeat the measurement and take the new reading if it is higher.
11. Record in CAPI if you were unable to take measurement.

NOTE:

- *If measurements were taken, record whether waist circumference was measured on skin or over clothes*
- *If one or more measurement could not be taken, record in box in CAPI reasons why.*

SUBMIT MODULE

Module: Physical Performance tests

Introduction:
We are asking study members to undertake four physical performance tests: chair rises; standing balance; walking speed; grip strength. Most study members have performed some of these tests at least once before. Using previous scores on these tests we have shown that midlife physical performance is influenced by a range of factors across life including childhood motor and cognitive development, lifetime weight trajectories and social circumstances, and exercise. We have also shown that these measures are useful markers of ageing.

It is important to repeat these tests using exactly the same protocols so that we can assess what affects age-related changes in these measures.

NOTE:

- *The test below require the use of a stopwatch, please pay special attention when entering the times onto CAPI*
- *If needed, you can enter the times on the measurement card, but please remember to enter these onto CAPI before moving onto the next test.*

Chair rises

Introduction:
Chair rises require power in the leg muscles, balance and coordination. These physical attributes are needed for climbing stairs, walking and running etc. You will be prompted to ask the study members if they are willing to attempt 10 chair rises. If they are unable, you will be prompted to ask if they would be willing to attempt 5 chair rises

Equipment:
- 2 standard straight-backed chairs, with solid legs and no arms (one acts as a support against the wall and stops people banging their head on the wall as they sit down)
- Stop-watch (instructions for use on page 14)

START MODULE

PROCEDURE

READ OUT:
"I would now like you to do 10 chair rises. First I will ask you to fold your arms and, after I say, 'And Go', stand up from your chair and sit down again 10 times, as quickly as possible. Like this…'

DEMONSTRATE THE TEST

READ OUT:
"Are you willing to do this test?"

NOTE:
Exclusion criteria:
- *Inability to stand.*
- *Severe cardiorespiratory disease or untreated hypertension (≥200mmHg systolic or ≥102mmHg diastolic).*
- *Hip or knee replacement; severe hip or knee problem.*

If the participant is unwilling or unable to do this test please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can.

If the participant is willing and able to do the test of 10 chair rises please select 'Yes' and perform the test as follows:

IF THE PARTICIPANT IS WILLING TO DO THE TEST OF 10 CHAIR RISES:
PROTOCOL FOR 10 CHAIR RISES
1. Ensure that shoes with heels more than 1.5" high are removed.
2. Seat the participant in an upright **armless** chair of normal height (seat surface approximately 18" from the floor).
3. Ask the participant to fold their arms
4. Remind them again that after you say 'And go', you want them to stand up from their chair and sit down again ten times as fast as they can
5. Make sure that the participant knows that they need to stand up fully and sit back down fully in the chair each time.

6. Allow the participant to practice performing one or two chair rises
7. Check that the stop-watch reads 0:00$_{00}$ and that the participant is seated in the chair with their arms crossed
8. Say 'And go!', and start the stop watch
9. Count each chair rise out loud
10. **Stop** the stop-watch as soon as the participant **sits down fully for the tenth time**.
11. Record the time on the stop-watch to 1/100th second on CAPI
12. Confirm that 10 chair rises were completed
13. If 10 chair rises were NOT completed record the time and how many rises were completed
14. For participants who attempted 10 chair rises this is the end of the test/module.

IF THE PARTICIPANT IS UNWILLING OR UNABLE TO DO THE TEST OF 10 CHAIR RISES:

READ OUT:
"Although you are unable to do 10 chair rises, would you be willing to do a test of 5 rises instead?"

If the participant is unwilling please select 'No'. This is the end of the test/module for these participants.

If the participant is willing please select 'Yes' and perform the test as follows:

PROTOCOL FOR 5 CHAIR RISES
1. Ensure that shoes with heels more than 1.5" high are removed.
2. Seat the participant in an upright **armless** chair of normal height (seat surface approximately 18" from the floor).
3. Ask the participant to fold their arms
4. Remind them again that after you say 'And go', you want them to stand up from their chair and sit down again five times as fast as they can
5. Make sure that the participant knows that they need to stand up fully and sit back down fully in the chair each time.
6. Allow the participant to practice performing one or two chair rises
7. Check that the stop-watch reads 0:00$_{00}$ and that the participant is seated in the chair with their arms crossed
8. Say 'And go!', and start the stop-watch
9. Count each chair rise out loud
10. **Stop** the stop-watch as soon as the participant **sits down fully for the fifth time.**
11. Record the time on the stop-watch to 1/100th second on CAPI
12. Confirm that 5 chair rises were completed
13. If 5 chair rises were NOT completed record the time and how many rises were completed
14. This is the end of the test/module for these participants.

SUBMIT MODULE

Standing balance

Introduction:
Balance and coordination are necessary to carry out every day physical tasks at reasonable speeds. Poor balance will be a major cause of falls and fractures as the cohort gets older. You will be prompted to ask the study members if they are willing to attempt two standing balance tests. This involves standing on one leg, up to a maximum of 30 seconds, once with eyes open and once with eyes closed.

Equipment:
- Stop-watch (instruction for use on page 14).

START MODULE

PROCEDURE

READ OUT:
"I would now like to assess your balance and coordination. First I will ask you to fold your arms and, after I say *'And Go'*, stand on your preferred leg and raise your other foot off the floor like this…."

DEMONSTRATE THE TEST

READ OUT:
"I will ask you to hold this position for as long as you can or until I tell you to stop. Then I want to repeat the test with your eyes closed. Are you willing to do this test with your eyes open?"

NOTE:
Exclusion criteria:
- *Inability to stand or walk unaided without zimmer frame or crutches*

If the participant is unwilling or unable to do this test please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can. This is the end of the test for these participants.

If the participant is willing and able to do the test please select 'Yes' and perform the test, with eyes open as follows:

PROTOCOL (EYES OPEN):
1. Make sure there is a firm support nearby.
2. Shoes should be removed unless they have flat heels.
3. Ask the participant to fold their arms
4. Remind them again that after you say 'And go', you want them to stand on their preferred leg and raise the other leg off the ground a few inches keeping their foot parallel to the floor
5. Allow the participant to practice
6. Check that the stop-watch reads 0:00$_{00}$ and that the participant is stood near a firm support with their arms folded
7. Say '**And go**!', and start the stop-watch as the participant raises one leg off the ground

8. Stop the stop-watch either a) when the raised leg touches the floor as the participant loses their balance or b) after 30 seconds, whichever happens first.
9. Record the time on the stop-watch to 1/100th second on CAPI
10. If the participant falls over straight away and you are unable to record a time please select 'Fell over straight away'

After completing the test with eyes open,

READ OUT:
"Are you willing to do this test again with your eyes closed?"

If the participant is unwilling or unable to do this test with their eyes closed please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can. This is the end of the test for these participants.

If the participant is willing and able to do the test please select 'Yes' and perform the test, with eyes closed, using the same protocol as above, as follows:

PROTOCOL (EYES CLOSED):

1. Remind the participant again that after you say 'And go', you want them to stand on their preferred leg, close their eyes and raise the other leg off the ground a few inches keeping their foot parallel to the floor
2. Allow the participant to practice
3. Check that the stop-watch reads 0:00$_{00}$ and that the participant is stood near a firm support with their arms folded
4. Say 'And go!', and start the stop-watch as the participants raises one leg off the ground (and closes their eyes)
5. Stop the stop-watch either a) when the raised leg touches the floor as the participant loses their balance or b) after 30 seconds, whichever happens first.
6. Record the time on the stop-watch to 1/100th second on CAPI
7. If the participant falls over straight away and you are unable to record a time please select 'Fell over straight away'
8. End of test

SUBMIT MODULE

Walking speed

Introduction:
Walking speed in older people has been shown to predict level of disability, future use of health care and mortality. You will be prompted to ask the study member if they are willing to walk 2.44 m (8 feet) at their usual pace while you time them. This test will performed twice.

Equipment:
- Stop-watch (instructions for use on page 14)
- Tape measure to measure out 8ft (2.44m)
- Floor tape to mark out 8ft (2.44m)

START MODULE

PROCEDURE

READ OUT:
"I would now like to time you while you walk a short distance at your usual walking pace, just as if you were walking down the street to go the shops. Walking aids are permitted but help from another person is not."

DEMONSTRATE THE TEST

READ OUT:
"Are you willing to do this test?"

NOTE:
Exclusion criteria:
- *Inability to walk without assistance from another person*

If the participant is unwilling or unable to do this test please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can.

If the participant is willing to perform the test but you are unable to find sufficient space in the home please record this as unable, other and record the reason as lack of space.

If the participant is willing and able to do the test please select 'Yes'.

READ OUT:
"Are you able to walk without another person's help?"

If the participant is **not able** to walk without another person's help this is the end of the module.

If the participant is able to walk without another person's help please ask about the use of walking aids. Participants can use their walking aids to complete this test, if required.

PROTOCOL:
1. Ensure that the participant is wearing their normal footwear.
2. Measure out 2.44m on the floor (a line of tape is placed on the floor and another line of tape is placed 2.44m away).

3. Explain to the subject that they will need to stand positioned with their toes resting directly behind the marked line. When you say 'And Go' they will walk at their normal pace until they have crossed the other line. They will be asked to do this twice. Also explain that you will be timing them with the stopwatch, but it's not a race!!
4. Do not encourage the subject to walk faster, allow them to walk at a pace that is comfortable and normal to them.
5. The subject should use any walking aid that they require i.e. stick, frame etc. for the walk but no physical assistance should be given.
6. Demonstrate the test
7. Allow the participant to practice
8. Check that the stop-watch reads 0:00$_{00}$
9. Ensure that the subject is standing with both feet together at the start of the course with their feet positioned behind the starting line.
10. Say 'And go!' and start the stop-watch when either foot is placed down on the floor across the start line. The whole foot must be across the line before the test is started, so if the participant is shuffling, or puts their foot down so that it straddles the line, start the stopwatch when the whole foot has crossed the line.
11. Stop the stop-watch when either foot is placed down on the floor across the finish line. The whole foot must be across the line before the test is complete, so if the participant is shuffling, or puts their foot down so that it straddles the line, stop the stopwatch when the whole foot has crossed the line.
12. Record the time on the stop-watch to 1/100th second on CAPI
13. Reset the stop-watch and ask the participant to repeat the test a second time.

NOTE:

- *If space permits walk behind and to the side of the participant as he/she walks.*

SUBMIT MODULE

Grip strength

Introduction:
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 hand-grip dynamometer which consists of a gripping handle (with a strain-gauge transducer) and an amplifier with digital displays.

Please note that the participants will be familiar with this test but we are using a different type of dynamometer than they are used to.

Equipment:
- Jamar dynamometer
- A standard straight backed chair with solid arms

START MODULE

PROCEDURE

READ OUT:
"Now I would like to assess the strength of your hand in a gripping action. After I say *'And Go'* I want you to squeeze this handle as hard as you can, just for a couple of seconds and then let go"

READ OUT:
"Are you willing to do this test?"

NOTE:
Exclusion criteria:
- *swelling or inflammation, severe pain or recent injury in their hands*
- *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)*
- *blood pressure over ≥200mmHg for systolic or ≥120mmHg for diastolic*.

If the participant is unwilling or unable to do this test please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can. This is the end of the module for these participants.

If the participant is willing to do the test, please select 'Yes' and proceed with the test.

READ OUT:
"If possible I would like to take 2 measurements from each hand. Do you have use of both hands?"

NOTE:
- *If the participant has use of both hands please perform all four measurements (two in each hand (left, right, left, right))*
- *If the participant only has use of one hand please record this and perform the two measurements in that hand.*

- *If the participant is unable to use either hand please change the response option to the previous question (Are you willing to do this test?) and provide a reason that the participant is unable to use either hand.*

If the participant is willing to do the test and has use of at least one hand.

READ OUT:
"Which is your dominant hand?"

Proceed with the tests (if participant has use of both hands the order of the tests will be: Left hand, Right hand, Left hand, Right hand)

PROTOCOL:

1. Sit the participant comfortably in a standard chair with legs, back support and fixed arms. Use the same chair for every measurement.
2. Take the dynamometer out of the box and turn it on by pressing the [On / Off] button
3. Check that the dynamometer settings are correct – the display panel should show **KG** on the right hand side and **LR 5** in the top left hand corner (if the settings are not correct, follow instruction 4 for resetting the dynamometer)
4. **Setting the dynamometer display to "LR 5"**
    - Press **[SELECT TEST]** until it reads "LR1" in the top left hand corner of the display panel
    - Then press **[# OF TRIALS]** until the number "5" is displayed on the panel
5. Adjust the grip position so that it is the correct size for the participant's hands. The grip handle may be placed in any of five positions to accommodate the size of the participant's hand. This is done as follows:
    a. Push the lower end of the handle so that the slotted portion rotates away from the lower shaft.
    b. Making sure not to drop the handle allow it to separate from the top shaft.
    c. Determine the appropriate grip position and replace the top part of the handle on the top shaft.
    d. Rotate the lower part of the handle onto the lower shaft until it clicks into place. (see detailed instructions for how to do this below)

The following instructions are for those participants who have use of both hands, please amend accordingly if participant only has use of one hand

LEFT HAND MEASURE

1. Ask the participant to rest their left forearm on the arm of the chair in the mid-prone position (i.e. with the thumb facing upwards) and their wrist just over the end of the arm of the chair in a neutral but slightly extended position.
2. Carefully place the wrist strap around the participant's left wrist. Then place the dynamometer in their left hand.
3. Position the hand so that the thumb is round one side of the handle and the four fingers are around the other side. The instrument should feel comfortable in the hand. Alter the position of the handle if necessary. Large rings may need to be removed.
4. Remind the participant that when you say 'And Go' you want them to squeeze as hard as possible for a couple of seconds, until you tell them to stop. Make it clear that gripping very tightly registers the best score.
5. Once you are happy that the participant's arm is positioned correctly and **just before you start the test press the [TEST] key** (and check that a number in the left hand

corner of the display is flashing and that the display reads 0.0). You are then ready to take the measure.

6. Say '**And Go**!' at which point the participant should squeeze as hard as they can for a couple of seconds and then release quickly. You should provide verbal encouragement by telling the participant to '**Squeeze, squeeze, squeeze'** and then you should tell them after a few seconds to stop.
7. During the test please make sure that the participant's arm remains in position resting on the arm of the chair.
8. Record the value on the display to the nearest 0.1kg on CAPI.
9. Once the value for the left hand is recorded on CAPI carefully take the dynamometer from the participant.
10. You are now going to repeat the test in the participant's right hand.

RIGHT HAND MEASURE

1. Ask the participant to rest their right forearm on the arm of the chair in the mid-prone position (i.e. with the thumb facing upwards) and their wrist just over the end of the arm of the chair in a neutral but slightly extended position.
2. Carefully place the wrist strap around the participant's right wrist. Then place the dynamometer in their right hand.
3. Once you are happy that the participant's arm is positioned correctly and **just before you start the test press the [TEST] key** (and check that a number in the left hand corner of the display is flashing and that the display reads 0.0). You are then ready to take the measure.
4. Say '**And Go**!' at which point the participant should squeeze as hard as they can for a couple of seconds and then release quickly. You should provide verbal encouragement by telling the participant to **'Squeeze, Squeeze, squeeze'** and then you should tell them after a few seconds to stop.
5. During the test please make sure that the participant's arm remains in position i.e. resting on the arm of the chair.
6. Record the value on the display to the nearest 0.1kg on CAPI.
7. Once the value for the right hand is recorded on CAPI carefully take the dynamometer from the participant.

NOW REPEAT THE INSTRUCTIONS ABOVE AND TAKE A SECOND MEASUREMENT IN THE LEFT HAND, FOLLOWED BY A SECOND MEASUREMENT IN THE RIGHT HAND

Once all four measures (or two measures if the participant only has use of one hand) are recorded turn the dynamometer off by pressing the [On / Off] button

Adjust the grip position and place the dynamometer back in the box.

NOTE:

- *If for any reason a chair with arms is not available please consider whether it is possible to conduct the test with the participant resting their arm on the edge of a table*

SUBMIT MODULE

Module: Lung function

Introduction:
Lung function is a marker of general health status as well as respiratory health and affects every day activities. Lung function declines with age and with the measures we have taken previously at younger ages we can investigate the rate of decline. Lung function will be measured using a spirometer and you will need to get the study member will be asked to blow as hard as they can, as fast as they can and for as long as they can. It is important to ensure that the study member uses the correct technique.

Equipment:
- Laptop with Easy on-PC software
- Easy on-PC sensor (spirometer)
- Spirettes
- Water for participants

START MODULE

READ OUT:
"Now I would like to measure your lung function."

READ OUT the exclusion criteria questions.
If exclusion criteria reached module will end.
Explain to the participant that they cannot do the lung function test as it would not be safe

NOTE:
Exclusion criteria:
- *Abdominal or chest surgery in the past three weeks*
- *Admission into hospital for a heart complaint or stroke in the past six weeks*

READ OUT:
"Are you willing to do this test?"

If the participant is unwilling or unable to do this test please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can. This is the end of the module for these participants.

If the participant is willing to do the test, please select yes. Ask the follow up questions and proceed with the test.

Explaining the test:

Explain:
"You will need to stand up for this test. First you will need to take as full and as deep a breath as you can so as to fill your lungs to capacity. Then make a tight seal, with your lips, around the tube, place your tongue under the mouthpiece, and blow out as hard, as fast and as long as you can, until no more air can come out and you are instructed to stop. You will be doing this at least three times 3 times in order to make sure that we obtain similar results. You may feel slightly lightheaded whilst doing this. Remember you need to blow as hard as you can, as fast as you can and for as long as you can. I will also be encouraging you to blow for as long as possible."

While providing this verbal demonstration, it is helpful for you to demonstrate the procedure to the participant, using your own spirette.

The participant needs to be standing to perform this test in order to get the best result. However, should they be unable to stand then perform the test seated.

Opening the participant's spirette:

1. To open the spirette, tear along the dotted line of the plastic cover until the black mark.
2. Insert the spirette into the sensor by lining up the triangle on the spirette with the triangle of the sensor.
3. Remember to hold the plastic cover over the mouthpiece until the spirette is inserted completely.

Performing a practice blow:

Explain to the participant that they are going to do a practice blow first to ensure that they perform the test correctly. This will not count towards the number of blows they do.
Allow the participant to do a practice but do not let them blow for the full time, stop them mid blow.
The practice is done to make sure they have understood the technique. If they have not understood, explain again. If necessary you may need to perform another practice blow.

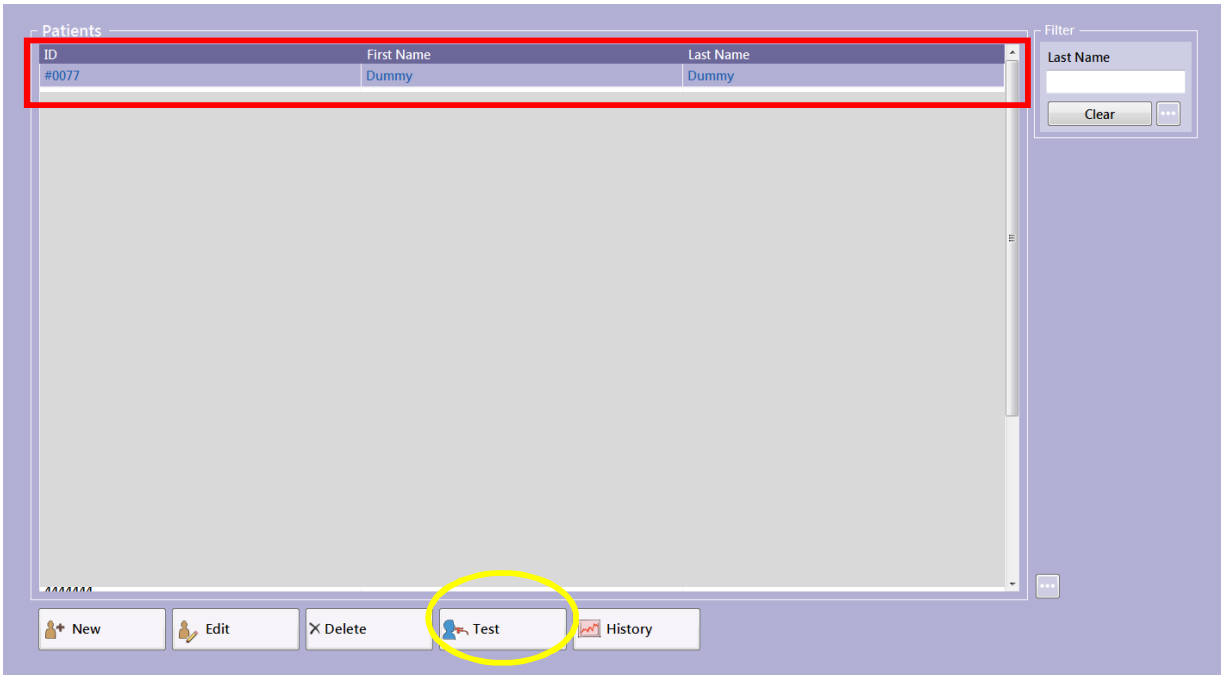
Preparation

- Plug the spirometer into the USB port before launching the software.
- Click on **'Launch Application.**

Selecting a participant:

1. When you are happy they have the technique correct, click on the icon **'Patients'**

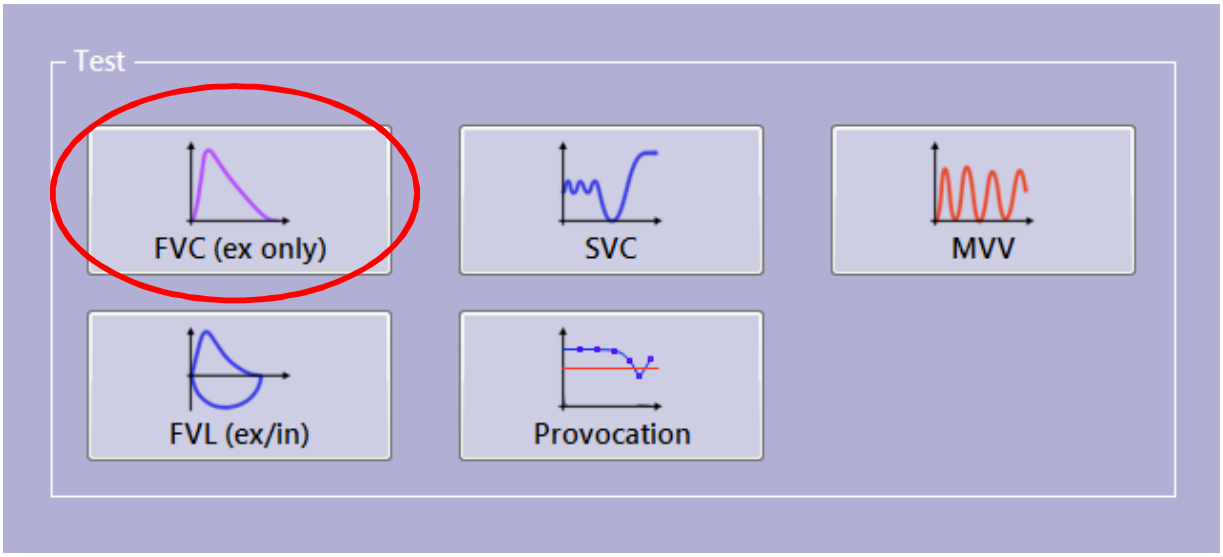
2. You will now see the following page:



3. For all participants you will be doing the test with the name of **'Dummy; Dummy',** outlined in red above. Click on **'Dummy; Dummy'.** Make sure that this row is now highlighted in purple on your screen.

4. Then click on **TEST** at the bottom of the screen, circled in yellow above.

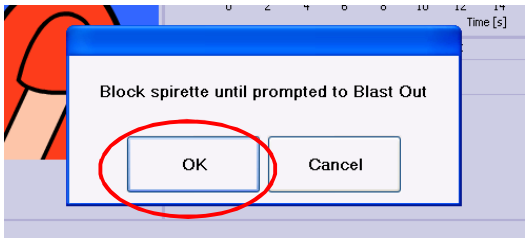
5. Now click on **FVC (ex only)** as circled in red below.



6. Once you have clicked on **FVC (ex only)** you will be able to perform the test.

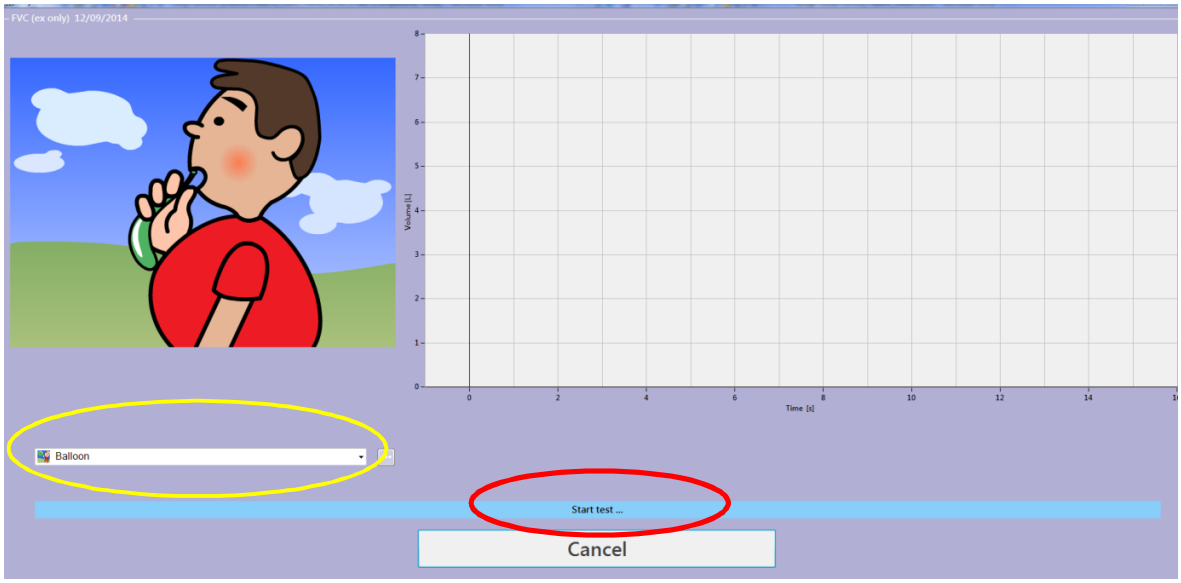
Performing the test:

7. A screen will appear and a pop up will ask you to **Block spirette until prompted to Blast Out.**



8. Cover the BACK of the spirette the participant used for the practice, with the palm of your hand and **click on OK.**

9. The programme will set the baseline and when it has done this you will see the programme say **START TEST**



10. Ensure that when this screen appears you see the boy with the balloon. This is the incentive to encourage the participant to blow for as long as they can. If this picture does not appear, change it by using the drop down menu, outlined in yellow above.

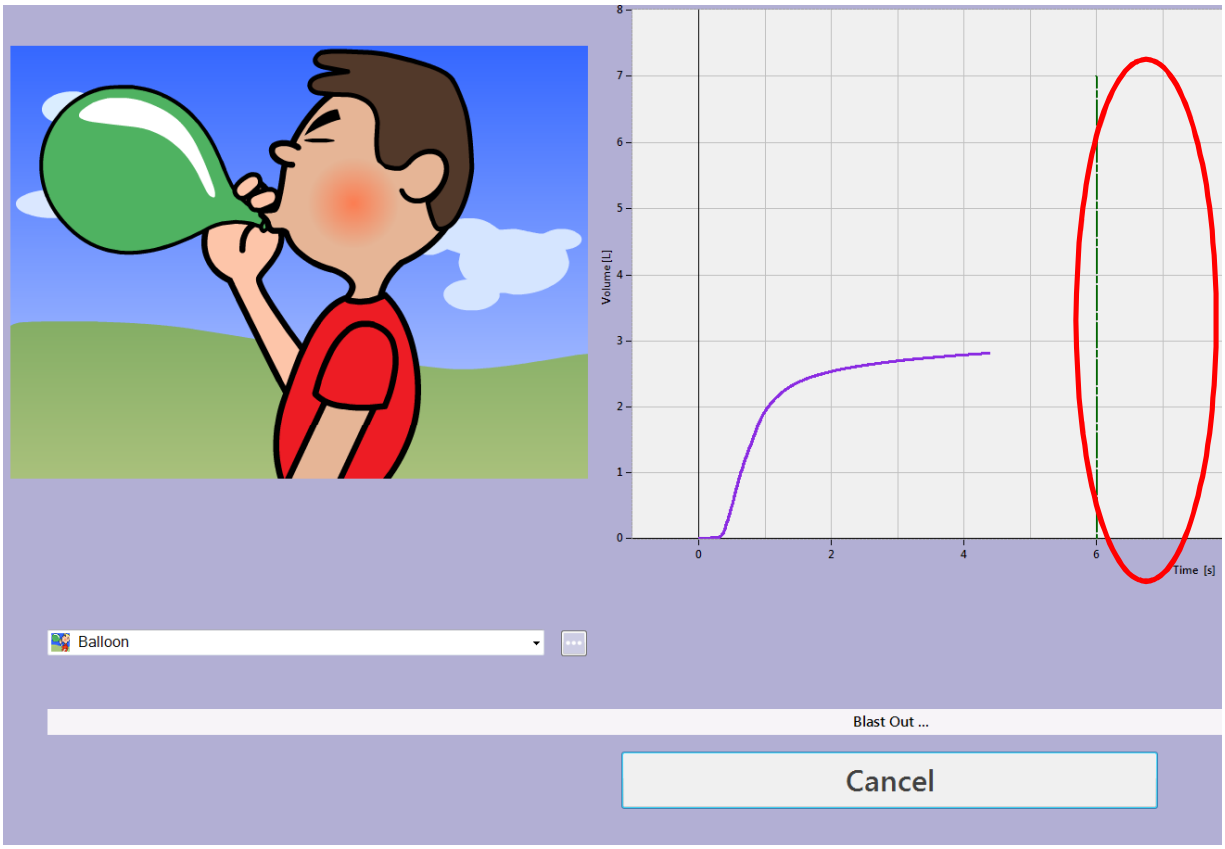
11. Ask the participant to stand up and hand them the spirometer. When they are ready say: **"Ready, Begin"**

    It is important to visibly observe the participant perform the maneuverer, making sure that he/she appears to have taken a deep breath, correctly placed the mouthpiece and they are tolerating the test. Do not stand in front of the participant when they are blowing, keep observing aside.

12 Give the participant enthusiastic verbal encouragement whilst they are blowing by saying:

“Keep blowing, keep blowing”

13 Encourage the participant to keep blowing until they feel that there is no more air in their lungs. If the participant is facing the screen they will be able to see the boy blowing the balloon up and the participant needs to keep blowing until the balloon pops and the program says **‘Analyzing data’**. This is usually until the 6 second line circled in red below, but not always. Some participants are able to blow longer.

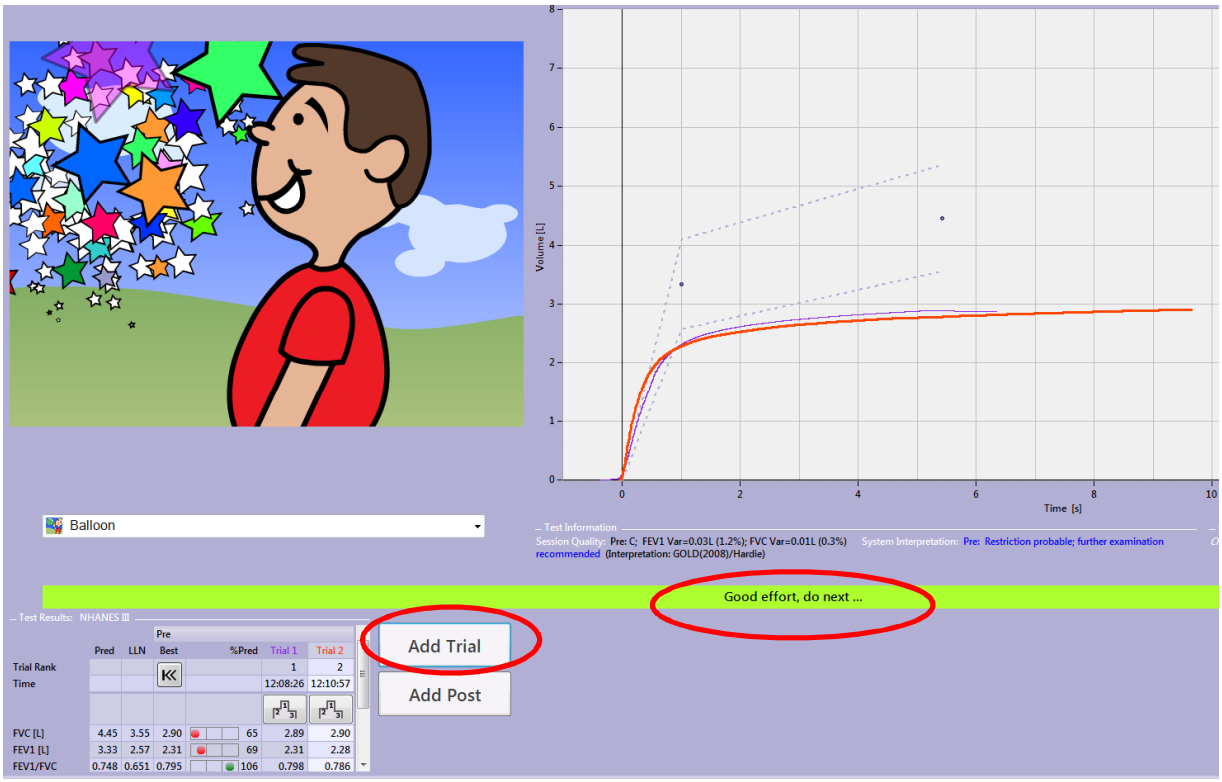


14 If the participant feels they cannot continue blowing or feels dizzy etc, stop the test. Check if they are happy to continue and if you feel they are able to continue, complete the rest of the test.

15 If after having performed the test standing, the participant feels that they are able to continue but would feel safer performing the test seated, indicate this in CAPI and allow the participant to perform the test seated. This applies to both the Clinic & Home Visit setting.

16 If the participant or you feel they should not continue, stop the test. You will then need to enter discontinued and continue to the next test.

17 After each blow the programme will provide you with a result. If the participant has been able to blow well and performs a satisfactory blow it will appear with the wording **‘Good Effort, do next…’**



18 If the participant is happy to continue with the next blow, click on ADD TRIAL, wait for **Start test** and say:

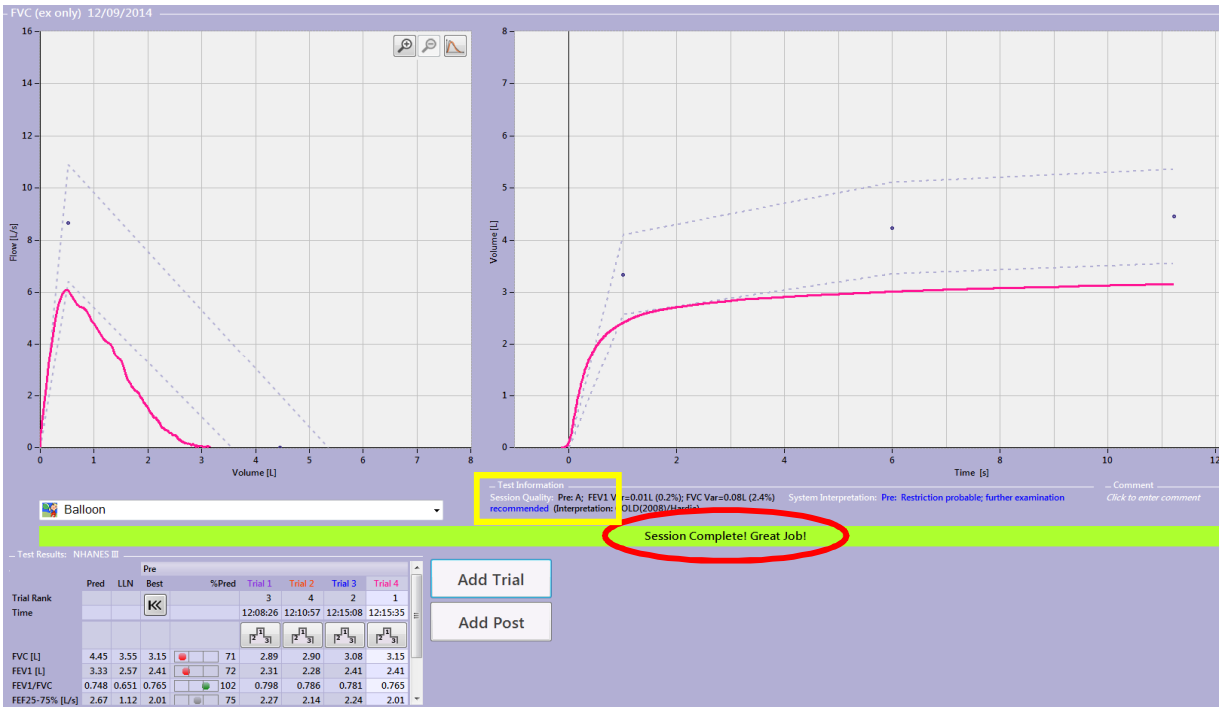
“Ready, Begin”

19 Repeat points 10 - 17 for all subsequent readings. You will not need to set the baseline for the subsequent tests.

20 You need to achieve 3 readings of similar values. The programme will advise you when you have these by displaying the wording:

‘Session Complete! Great Job!’

This is circled in red in the screen shot below.



21 You will now not need to perform any further readings.

22 If however you have not achieved 3 readings of similar values, the programme will give you information as to where the problem was, e.g. 'Deeper breath'. Please see the list below of instructions given by the program following an unsatisfactory manoeuvre (blow) and how these should be interpreted.

23 You must only ever perform a **maximum of 5 blows.**

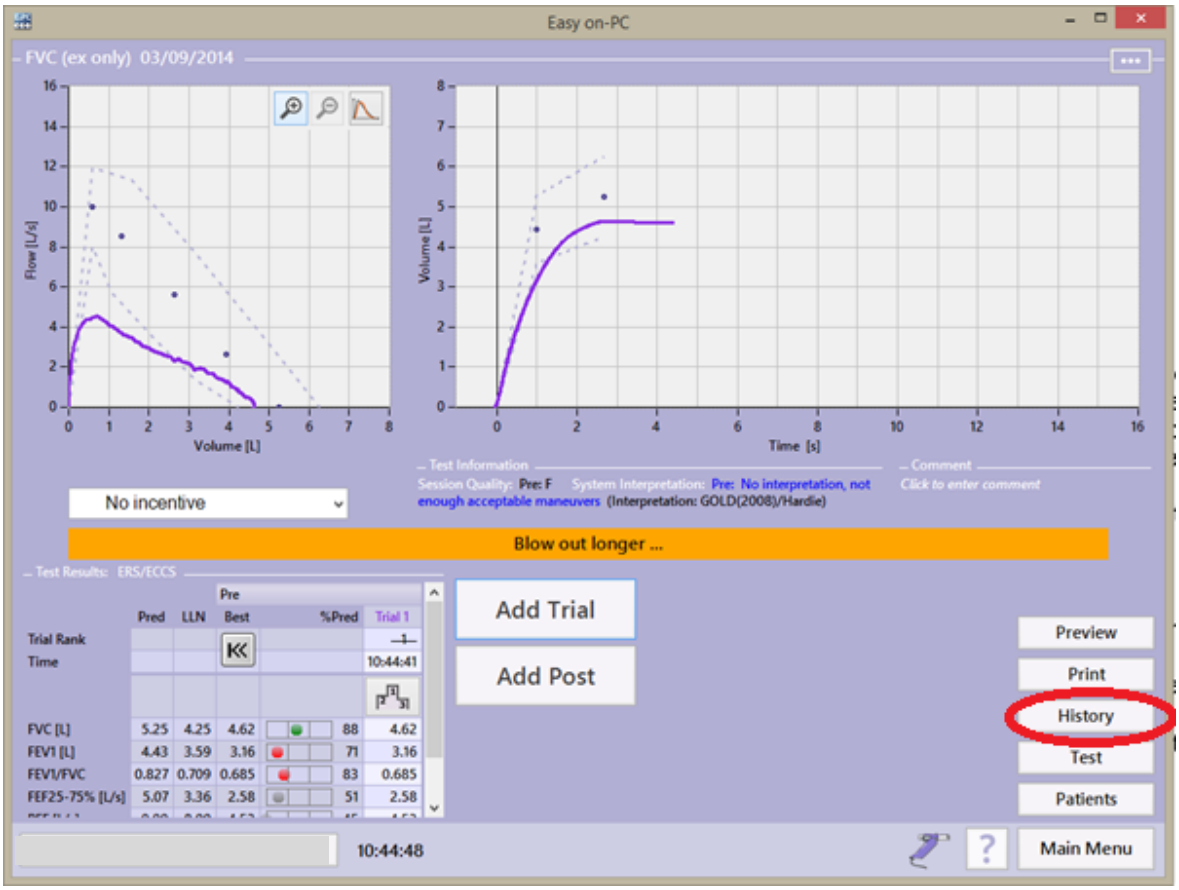
24 If the participant reaches the 5th blow without achieving 3 readings of similar values, do not do any more. Explain to the participant that is the end of the test and continue to the next measure.

25 In CAPI you will need to enter the **'Session Quality'.** This can be found just above where **'Session Complete! Great Job!'** appears. It is outlined in yellow in the screen shot above.

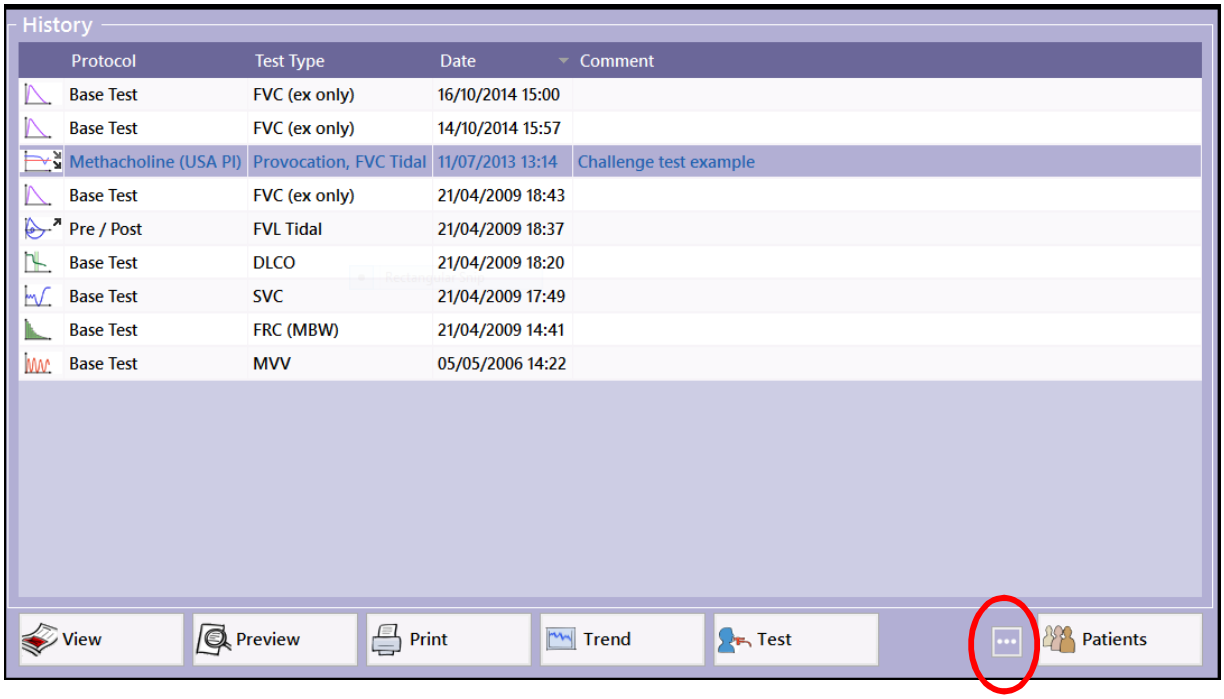
26 You will also need to record, in CAPI, the number of attempts and whether the test was discontinued or not.

27 The readings are all automatically saved but need to be sent to **EMR.**

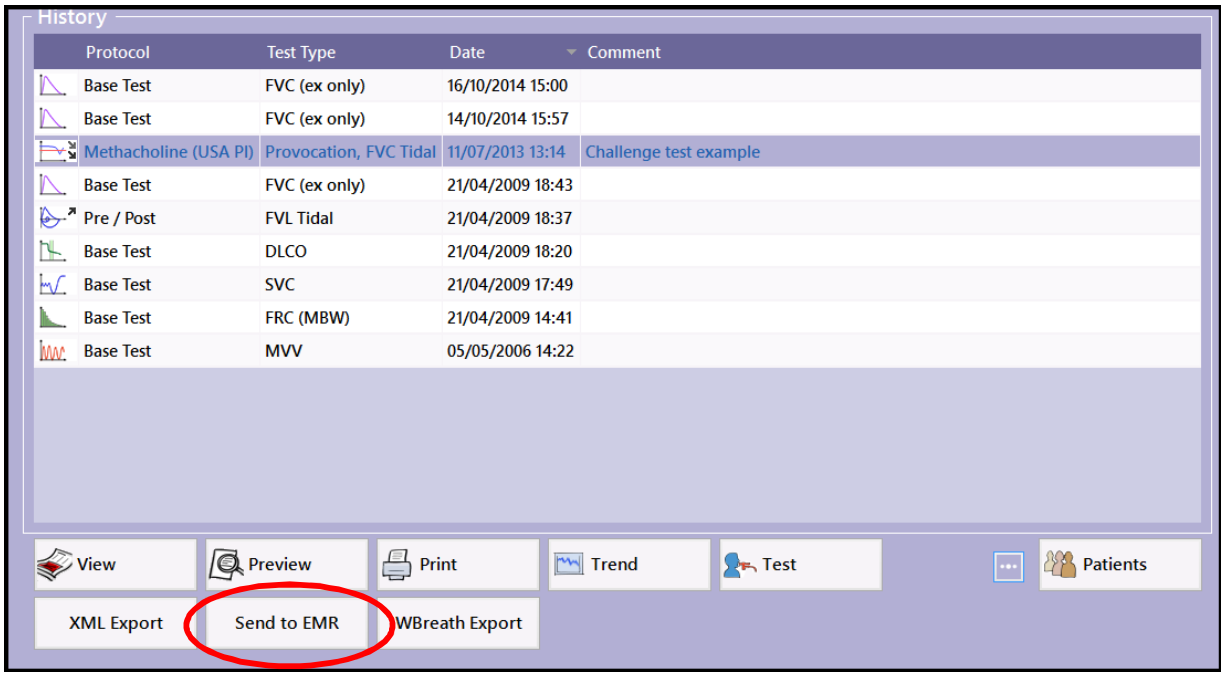
28 To do this you need to click on **'History',** circled in red in the screen shot below.



29 Once you have clicked on 'History' the screen below will appear and you need to then click on the 3 dots next to the Patients button, circled in red.

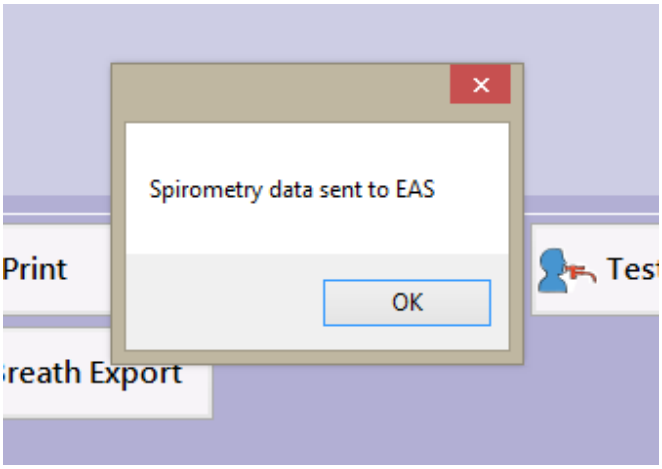


30 Once you have clicked on these 3 dots, the screen below will appear and you then need to click on ‘Send to EMR’, circled in red.



31 When you click on ‘Send to EMR’ the lung function data is sent to the EMR. Only the data highlighted in purple on the screen will be sent.

32 Once the data has been sent you will see a pop up informing you of this.



33 Click on **OK** and then close the Lung Function software.

34 You will then be taken back to CAPI.

35 Record in CAPI whether you were able to take any readings, the session quality as per lung function software and the number of blows attempted and saved (include all blows except the practice even if technically not acceptable.

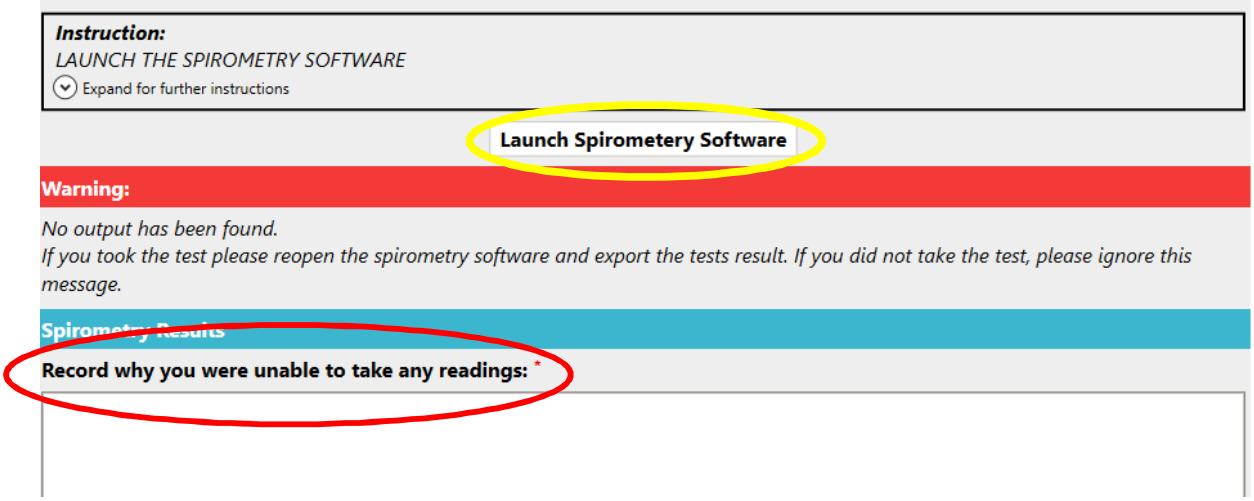
36 Record whether the session was stopped prior to seeing the 'Session Complete!' message and whether the participant stood or sat to carry out the test.

37 If you have either:

1. Closed the Lung Function Software before saving the data file
2. Opened the Lung Function software but then the participant or the nurse decided not to continue so there are no attempts to save.

CAPI will pick up if the lung function data has not been sent to EMR.

38 If this is the case you will see the following message appearing:



39 If you have closed the Lung Function Software before saving the data file you need to reopen the software by clicking on **'Launch Spirometry Software',** circled in yellow above.

40 You will then need to find that participant's record and then export the file.

41 If you did not obtain a reading and will not be obtaining a reading, then enter a comment as to why you were unable to obtain any readings in the box provided, circled in red above.

SUBMIT MODULE

Technically unsatisfactory blows and program advice

A technically unsatisfactory blow can occur for many reasons. Below is a list of the instructions given by the program following an unsatisfactory manoeuvre (blow) and how these should be interpreted.

Messages following unsatisfactory blows

Message	Reason	Advice
Don't hesitate…	The participant exhaled air in short bursts	Participant must breathe out (blast out) all the air at once, not in short bursts
Blast out faster…	The participant did not blast the air out fast enough	The participant must breathe out the air as fast as hard and as fast as possible
Blow out longer…	The participant did not breathe out for long enough OR stopped when they still had air in their lungs	The participant needs to breathe out for longer OR they need to force out as much air from their lungs as possible
Test abrupt end!	The blow stopped sooner than was expected	The participant needs to breathe out for longer OR they need to force out as much air from their lungs as possible
Good effort, do next…	The blow was acceptable	This is an acceptable blow. They need a two more of these for the overall session to be complete
Do not start too early!	The participant was breathing through the spirette before the program was ready	The participant needs to wait until the screen reads 'Start manoeuvre' until they breathe through the spirette
Cough detected. Try again…	The participant coughed while blowing	The participant needs to avoid coughing if possible.

DISCONTINUED PROTOCOL

Lung function can be discontinued for various reasons and at any point during the testing.

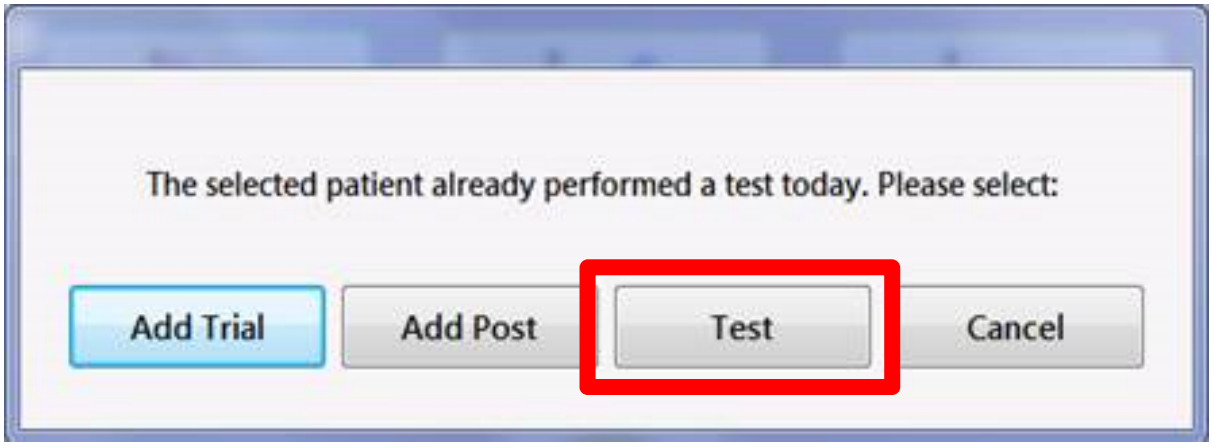
Please refer to the table below for further information.

Scenario/Software interpretation	**Action**
1st attempt – Good effort (Green) 2nd attempt – Good effort (Green) 3rd attempt – Good effort (Green) **SESSION COMPLETED**	No further attempts required. DISCONTINUED is entered as N
1st attempt – Good effort (Green) 2nd attempt – Deeper breathe (Orange) 3rd attempt – Don't hesitate (Orange) **SESSION COMPLETED**	No further attempts required. DISCONTINUED is entered as N
1st attempt – Good effort (Green) 2nd attempt – Deeper breathe (Orange) 3rd attempt – Don't hesitate (Orange) **OR** 1st attempt – Deeper breathe (Orange) 2nd attempt – Deeper breathe (Orange) 3rd attempt – Don't hesitate (Orange)	If the **you or the participant** feel it is okay to continue – continue to do a further one or two attempts to achieve the 5 attempts. **OR** If **you or the participant** do not want to or feel able to continue – DO NOT do any further attempts. Enter DISCONTINUED as Y and enter a comment in CAPI to indicate why the test was discontinued.
1st attempt – Deeper breathe (Orange) 2nd attempt – Deeper breathe (Orange) 3rd attempt – Don't hesitate (Orange)	If after 3 attempts you feel that the participant is not able to understand the technique required to obtain a satisfactory blow, DO NOT do any further attempts. Enter DISCONTINUED as Y and enter a comment in CAPI to indicate why the test was discontinued.

Instructions if seeing more than one participant per day

If you are seeing your second or third participants of the day, when you click on **'Launch Application'**, the software will think this is the same person as the previous one and

The message below will appear:



IF THE MESSAGE APPEARS BEFORE PERFORMING LUNG FUNCTION, PLEASE SELECT **TEST**.

This creates a new record for that participant.

DO NOT click on 'Add trial', as it attaches the blows to the previous participant.

Module: Cognitive performance

Introduction:
Cognitive function concerns how we engage mentally; for example how we understand the world around us, learn and retain information, and manage our attention so that we can focus on one thing or multitask. It is an important aspect of our general health, and indeed changes along with many other aspects of health.

Equipment:
- Stopwatch
- Paper test booklet
- Pencil

START MODULE

Explain the test:
"Now I'm going to give you some mental tasks. They are designed so that no-one gets the maximum score on all of them. So please just do the best that you can; as long as you do your best that is what we want you to do.

Word-list memory

READ OUT:
"Now 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. Please write the words in any order you like. It is best not to talk to anyone while you are doing this"

READ OUT:
"Are you willing to do this test?"

If the participant is unwilling or unable to do this test please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can.

If the participant is willing, please select 'Yes' and proceed with the test.

Protocol:
1. Show the words at 2 second intervals using the appropriate word list (A or B).
2. Make sure the last word is shown for 2 seconds.
3. At the end of the list indicate to the participant that they should start writing.
4. Try not to distract or interrupt the participant when doing this.
5. At the end of one minute ask the participant to turn the page, and repeat the administration. The third presentation is the same, and uses the following page.

Visual search

Introduction:
This is a test of attention and speed of working. The study member uses the sheets of letters in the paper test booklet. The test is timed for 1 minute, and the task is for the study

member to cross out as many letter "P"s and "W"s as possible in that time. Make sure the study member understands the instructions.

Equipment:

- Stopwatch
- Paper test booklet
- Pencil

Explain the test:
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."

READ OUT:
"Are you willing to do this test?"

If the participant is unwilling or unable to do this test please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can.

If the participant is willing, please select 'Yes' and proceed with the test.

Protocol:

1. After exactly **1 minute** ask the survey member to stop and ask them to underline the letter on which they finished.
2. A small number of survey members may come to the end of the letters before this time.

Rating for sensory difficulty:
It is important to know whether the participant 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 that was adequately corrected or controlled at the time of testing.

Finger tapping

Introduction:
We previously collected finger tapping at age 15 years. It is a sensitive measure of motor system efficiency.

Equipment:

- Finger tapping machine

Explain the test:
"Now I am going to ask you to tap your finger as fast as you can for 10 seconds. Use firstly your RIGHT hand with palm down and fingers extended. Please keep your hand and arm stationary and tap the lever with your index finger (demonstrate). You will then do this with your LEFT hand."

READ OUT:
"Are you willing to do this test?"

If the participant is unwilling or unable to do this test please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can.

If the participant is willing, please select 'Yes' and proceed with the test.

Protocol:

1. Ask the participant to place their right hand on the table palm down and fingers extended.
2. Tell the participant to keep their hand and arm stationary and tap their index finger as fast as they can for 15 second.
3. Record the number of taps.
4. Repeat with their left hand.

SUBMIT MODULE

Module: Future consent

Introduction:
It is good research practice in a longitudinal study to obtain future consent from study members and update this at each data collection. The future consent form asks for the name and address of the person that the research team should contact (the 'consultee') in the event that the study member becomes unable to give informed consent in the future. It provides information to the research team and the consultee about whether the study member would like to remain in the study if they lost capacity.

Equipment:

- Consent booklet (blue cover)
- Pen

START MODULE

Open the consent booklet and turn to the *Future consent* form

NOTE:

- *If in England/Wales, turn to the England/Wales future consent form*
- *If in Scotland, turn to the Scotland future consent form*

READ OUT:
"In the future when we wish to contact you again, if we found that we were unable to contact you personally, for example if you had a long-term illness or were unable to speak to us, would you be prepared for us to collect information about your circumstances from your husband/wife/partner or from a close friend?"
"If you were, we would not intentionally approach someone if you were on holiday or temporarily ill. We would only approach them if you were too sick, either physically or mentally, to make a decision for yourself."

Write down the name and address of the consultee.

Remember to turn over the consent form to ask about their wish to remain in the study.

Make sure you and the participant signs this form.

NOTE:

- *In Scotland, you will need to refer to their nearest relative, welfare guardian or welfare attorney.*

SUBMIT MODULE

Module: Socioeconomic circumstances and parental death

Introduction: The next set of questions on economic circumstances. Explain that this study and others have shown that factors like income, wealth, and the level of financial security can affect health in a number of ways.

Equipment:

- Laminated Showcard H & I

START MODULE

READ OUT:
"The next few questions are about your economic circumstances as this study and others show that things like income and your level of financial security can affect health in a number of ways."

Net household income.
Hand the participant **Showcard H** listing income amounts and READ OUT:
"Which of the letters on Showcard H represents your total net household income? Please include your own and your partner's earned income (after deduction for income tax and national insurance), any state benefits and any other sources of income such as pension, interest and rental income. Please also include contributions from other members of your household (such as children). Please choose the period (annual, monthly or weekly) that is most convenient for you to use. Then, find the amount in pounds which represents your net household income and state the corresponding letter."

NOTE:

- *If you know there is only a spouse or partner in the household, or that they are living on their own, please reduce the instructions accordingly.*

Give participants time to provide their net income. If they do not know their household income, encourage them to give an estimate. If they still cannot provide an answer, indicate on the CAPI whether they do not know or have refused.

Enter the letter that represents their net household income into CAPI.

Financial hardship.
The next set of questions refer to financial hardship.

READ OUT these questions and the possible responses.

NOTE:

- *The question 'Have you and your family had to go without things you really needed…' relates to the household – that is the participant, any spouse or partner, and any dependent children (i.e. aged under 16 or aged 16-18 and in full-time education).*

Household wealth.
Hand the participant **Showcard I** and READ OUT:
"If you sold all the assets you own in your household, for example, your house, car, caravan, boat, and jewellery, cashed in your savings and investments, and paid off any debts you have (including your mortgage), how much money do you think you would have? Please find the amount in pounds which represents the total amount and state the corresponding letter**.**"

Enter the letter that represents their total household assets into CAPI.

Parental deaths if not known

Introduction:
We have asked each study member about their parents throughout the study. By now, many parents have died, and this information will have been fed-forward so that only those for whom we do not have information on parental death will be asked these questions.

The questions ask about the study member's mother and father in turn. If the mother or father has died study members will be asked:

- how old their parent was when they died.
- date of death (with the option to record 'details unknown').
- cause of death (with a prompt to think about what was recorded on the death certificate, though it is not required that the study member recalls this exactly) (free text).

NOTE:

- *These questions refer to the biological mother and father.*

Please be sensitive to any comments made by the participant with regards to parental deaths, especially recent deaths.

SUBMIT MODULE

Module: Health behaviour

Introduction:
Evidence suggests that alcohol consumption, physical activity and sedentary behaviour are important modifiable determinants of adult health, including physical and mental function.

START MODULE

Alcohol.
Alcohol use has a significant influence on many dimensions of health amongst older people. It has been collected in NSHD using diet diaries, questionnaires and recall of alcohol for the last seven days. On the postal questionnaire in 2014, we asked about whether the participant drinks and the amount they drank in a week. The set of questions on alcohol asked here are taken from the AUDIT, a simple method of screening for alcohol abuse and identifying behaviours associated with harmful or hazardous drinking.

READ OUT the instructions, the questions and the possible responses.

Physical activity.
Participation in leisure time physical activity, sports and exercise was captured in the postal questionnaire in 2014. If the participant did not complete the postal questionnaire this question will automatically appear.

READ OUT the two questions and the possible responses

Sedentary behaviour.
We also want to capture information on the time participants spend sitting down watching TV, using a computer and reading. These are important sedentary behaviours.

READ OUT the three questions and the possible responses.

NOTES:
- *For watching TV, if the participant queries this, please ask them to include time spent watching DVDs, streaming movies etc.*
- *For using a computer please include time spent sitting down using a computer or tablet*
- *If the participant is unsure how much time they spend please encourage them to provide their best guess/estimate for an average day.*

Going outside the home:
READ OUT the question and possible responses.

SUBMIT MODULE

Module: Habitual physical activity

Introduction:
Habitual physical activity can be objectively measured by impact and movement using a combined sensor in daily living. We previously asked study members to wear an actiheart monitor around the chest using electrodes; some study members reported skin irritation. Please reassure study members that this is a different monitor and should be worn around the hips for 7 consecutive days, taking off when sleeping or when it is likely to get wet.

Equipment:
- Accelerometer
- Elasticated Belt
- Questionnaire and timesheet
- White pre-paid return envelope and brown Jiffy bag

NOTE:
- When affixing ID label onto time sheet please ensure the barcode is centred within the box, without obstructing the black square in the corner.

START MODULE

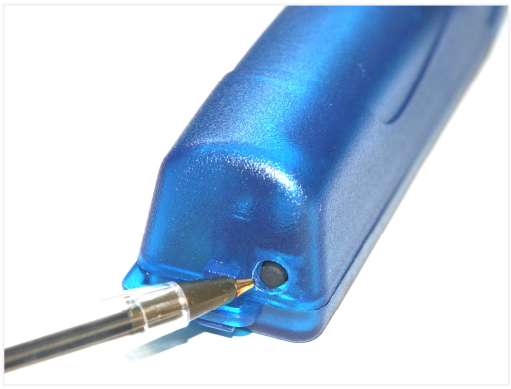
READ OUT:
"We would like you to wear a small activity monitor, worn on a belt on the hip, for the next 7 days while you carry out your normal activities."

Explain the test:
"The monitor will record how often movements are made and how forceful your movements are. The monitor should be taken off when you wash and go to sleep. You will be given instructions, a short questionnaire and a box and pre-paid envelope for posting it back to us. If you want, we can send you information about your results."

READ OUT:
'Would you be willing to wear the activity monitor for 7 days?"

If the participant is unwilling or unable to do this test please select the appropriate response option AND then record the reason in the text box. Please provide as much information as you can.

If the participant is willing, please select 'Yes' and READ OUT:
"**Would you like us to send you information about your results?"**



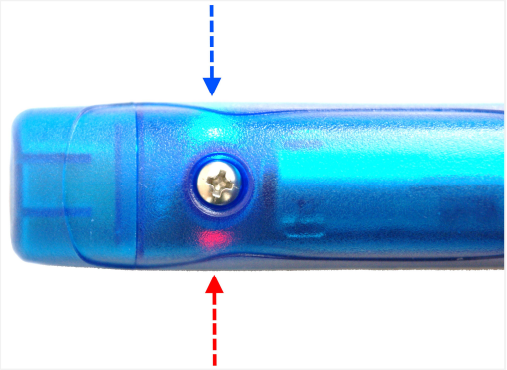
Preparation

- The monitors will be supplied ready for you to use, but will be switched off to save the battery life. Therefore, if the participant agrees to wear the monitor, you will need to initialise the device (switch on).

Turning the monitor on:

- Briefly press in and release the small black button at the back of the monitor with the tip of a ballpoint pen or similar.

- The blue and red lights will come on for a second. When activated/recording, the monitor's blue light will be flashing approx. every second (with the red light coming on briefly when a movement is recorded).
- If the button is pressed in for too long (5 sec) both lights will flash and the monitor will turn off, with no lights flashing – try again with a shorter press.
- Enter the activity monitor number onto CAPI and also write it down on the time sheet.



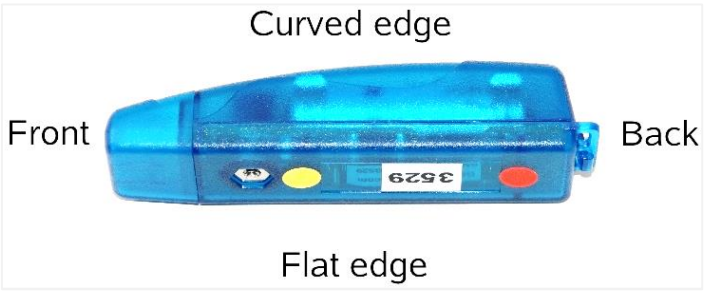
NOTE:

- *Please, make sure the button is pressed and released once only. If the button is pressed twice, please switch the device off (see above) and then switch it on again.*

Selecting the belt:

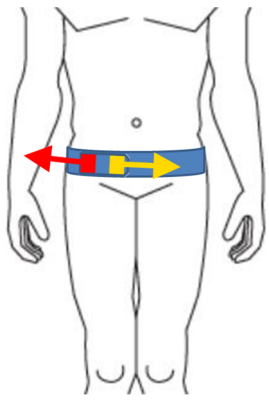
- Select either Small, Medium or Large belt.
- If the participant wishes, they can wash the belt at 40ºC before wearing it.
- However, they must remove the monitor from the belt, before washing.

- **Inserting the monitor in the belt:**
- Once the monitor is switched on, place it in the lengthwise pocket on the elastic belt.
- The monitor should be placed in the pocket with the flat edge upwards with the coloured dots matching the coloured pockets, as shown below.



Placing the belt on the participant:

- The monitor should ideally be worn under clothes (either against the skin or over a thin base layer, e.g. T-shirt), under trousers/skirt and below the participant's belt if they are wearing one.
- Place the belt, with the pocket (and the monitor in it) facing towards the body**,** so that the monitor's flat edge is pressed against the body. It should be placed low under tummy and next to right hip bone.



NOTE:

- *It is preferable that the participant wears the belt placed on them by you during the home visit. The monitor should ideally be worn as outlined in this document for the 7 days. If the participant realises they have worn the monitor upside down, they should put it on correctly the next day.*

Points to remember:

- *When inserting the monitor.* The coloured dots on the monitor should match the coloured pockets on the belt. The monitor should be placed into the pocket, so that the flat edge with the 4-digit ID label is visible.
- *When putting the belt on.* The belt should be put on with its pocket (and the monitor's flat edge) against the body, under tummy and next to right hip bone. The yellow end should point towards the participant's tummy button and the red end should point away from it.
- *If asked how to store the monitor during night or when having bath or shower.* When not in use, the belt with the monitor in should be stored as stationary as possible, ideally in a safe place, free from any movement and vibration.

Final checks:

Always double check the following:

1. The accelerometer number is entered on CAPI and on the timesheet
2. The participant ID label (barcode & number) is on the front page of the questionnaire as well as on the time sheet.
3. The monitor has a blue flashing light on.
4. Inside the pre-paid envelope is:
    a) Physical activity questionnaire
    b) Participant instruction sheet
    c) Time sheet
    d) 1 Jiffy bag
    e) 1 monitor and 1 belt

NOTE:

- *Please ask the Participant to put the monitor and belt in the Jiffy bag first and then place the Jiffy bag, the completed Activity questionnaire and Time sheet in the white freepost envelope provided.*

SUBMIT MODULE

Thank the participant.

Inform the participant they and their GP (if consent is given) will receive a results letter within 8 weeks. The letter will contain their heights and weight, blood pressure, lung function measurements and, if taken, their blood results (cholesterols, HbA1C and full blood count).

15 AFTER THE INTERVIEW

Before leaving the home

- Ensure you have removed the blood samples from the centrifuge
- Ensure all the blood bottles are labelled and the remaining labels are placed in the TDL pre-paid envelope
- Ensure you have all the documents and they are all properly labelled, ie all labelled with the same ID number.

Postage

- Post the consent booklet and the pink blood TDL request form back to NSHD using the pre-paid envelope.
- In a second envelope, post the paper test booklet and self completion booklet.
- Post the blood samples and the white blood TDL request form to TDL using the pre-paid envelope.

Do not entrust other people to post your envelopes – always post them yourself.

Please follow MDG protocol for returning the CAPI work.

16 TROUBLESHOOTING

Dynamometer

Changing the display from LB to KG

- If the machine is set on LB, turn the machine off by pressing the [On / Off] button.
- Open the battery compartment at the back of the machine
- Move the small button to KG
- Close the battery compartment and turn on