

Life in Your Early 60s

NURSE VISIT GUIDE



Your nurse's name is

THE NURSE VISIT

Thank you for taking part in the interview. We would also like to arrange for a registered nurse to visit you and take some health measurements. We hope that you will agree to the nurse visit, as it is an extremely valuable part of the survey, and will help provide a fuller picture of health in people your age.

This leaflet provides you with information about all the measurements we would like to take during the nurse visit. The nurse visit is entirely voluntary and you can skip any measurement you do not wish to take part in.

The nurse can give you a note of some of these measures to keep for your own records if you would like. The visit will take just over an hour to complete.



MEASUREMENTS

WEIGHT, BODY FAT, WAIST & HIP MEASUREMENTS

Being overweight or obese is a growing health concern in today's society. Having excess weight is linked with a wide range of health conditions including type 2 diabetes. Special scales will be used which will also measure your body fat. This is useful since people of the same weight can differ in how much fat they have. We will also measure your waist and hip circumference since there is evidence that the distribution of fat in the body is important for health too.

BLOOD PRESSURE AND HEART RATE

High blood pressure (also known as hypertension) is one of the biggest risk factors for health conditions such as heart disease and stroke. Collecting data on blood pressure, especially alongside the other types of

information collected in NCDS, is therefore extremely valuable in helping us to get a better understanding of what factors are linked to high blood pressure.

Blood pressure is measured using an inflatable cuff that goes around the upper arm.

We will ask to measure your blood pressure first while you are seated and rested, and then again while you are standing up.

The nurse can tell you your seated blood pressure, along with an indication of its meaning, if you would like. Whilst a diagnosis cannot be made on measurements taken on a single occasion, we can send your blood pressure results to your GP (if you give us permission to do so), as they are best placed to interpret the results in light of your medical history.



GRIP STRENGTH

We would like to measure how strong a grip you have. Grip strength is an indicator of people's general health and it has also been shown to be linked to people's future health. Some studies have shown that grip strength is also linked to what people eat.

In order to measure your grip strength we will ask you to grip and squeeze a handle on a small device for a few seconds.

BALANCE

Measuring your ability to balance involves asking you to perform a few simple movements. This measurement can be an indicator of overall health and some studies show there is a link between balance and future health. The nurse will explain what we would like you to do when they visit.

TIMED WALK

A walking speed test, or timed walk, involves measuring how long it takes you to walk a short distance (8 feet, or 244cm) at your normal pace. The timed walk is designed to find out whether people find walking difficult and we can link this to other aspects of people's health and lifestyle. The nurse will find a suitable space and place a measuring tape alongside the space where the walk would take place.



BLOOD SAMPLE COLLECTION

The nurse will ask you if you are willing to provide us with a blood sample. This is an important part of the survey, as blood samples will tell us a lot about the health of your generation.

With your written permission, the nurse will take a small amount of blood from a vein in your arm. This will be no more than 25ml – just over four teaspoons.

Some of the blood samples we are taking need to be separated into their different components as soon as possible after the blood is taken. This is done by spinning the tubes using a portable centrifuge which the nurse will do during the visit.

WHAT WILL THE BLOOD BE TESTED FOR?

Part of the sample will be sent to a laboratory to be tested for the following:

- ***Total Cholesterol and High Density Lipoprotein (HDL) Cholesterol.***

Cholesterol is a type of fat present in the blood, related to diet. Too much cholesterol in the blood increases the risk of heart disease. However, there are two types of cholesterol; HDL is the 'healthy' type, which helps to keep 'bad' cholesterol levels lower.

- ***Glycated haemoglobin.***

This is an indicator of long term blood sugar levels and is linked with the risk of developing diabetes.

- ***Triglycerides.***

Triglyceride levels are associated with cardiovascular disease, and are also important to help us work out how much low-density lipoprotein (LDL) is in your blood. LDL is the 'bad' type of cholesterol.

- ***C-reactive protein (CRP)***

This is a measure of inflammation in the body, and can help predict the risk of developing diseases such as cardiovascular disease, diabetes and cancer, as well as mental health issues.

We would also like to store some of your blood sample for future analysis. This part of your sample will be sent to a specialist storage facility at the University of Bristol.

WHY DO WE WANT A DNA SAMPLE?

We will ask for your written permission to extract, analyse and store DNA from your blood sample for research purposes. Research shows that an increasing number of illnesses have a genetic component. For example, previous research using DNA from the blood samples given by NCDS participants has led to important breakthroughs in our understanding of the role of genetics in common medical conditions such as diabetes, rheumatoid arthritis and coronary heart disease. Combining information about your genes with all of the other information we have collected about your health and your lifestyle will help researchers to identify which genes are linked to certain conditions. This will help with understanding who is most at risk, which may in turn lead to improved diagnosis, treatment and disease prevention.

Many of you gave permission for us to extract DNA from the blood sample you provided in 2002-4. A second DNA sample will give us a unique opportunity to do 'epigenetic' research. This involves investigating how genes are expressed (switched on and off) and the effect this may have on health and other aspects of life.

WHAT WILL THE STORED SAMPLES BE USED FOR?

The samples will be used for research purposes only. They cannot be accessed by lawyers or insurance companies and will not be used for cloning. Any future analysis will be done at the specialist storage facility or at another laboratory, which may be outside the UK. This could include research by the commercial sector. We will not sell or make any profit from the samples you donate and they will only be used in research which meets ethical guidelines.

Researchers who want to use your blood sample or DNA will have to apply for permission to an independent committee which oversees access to the samples and resulting data. Permission to use the samples and resulting data is only given to genuine researchers who can explain the potential impact of the research and its wider value for society.

The anonymised samples will be treated in strict confidence in accordance with the General Data Protection Regulations (GDPR).

CAN YOU FIND OUT THE RESULTS?

We can only send you your *total and HDL cholesterol*, and *glycated haemoglobin* results. If you wish, we can also send these results to your GP. We will need your permission to do this. The letter with your results will also say whether or not they are in the normal range. **It will not be possible to routinely feedback any results from genetic testing.**

WHAT HAPPENS TO YOUR BLOOD SAMPLE AFTER THE TESTS?

If you give your permission, the blood sample and DNA will be stored securely and labelled with a unique ID number so we can link your blood tests to the other data we hold about you. Your name and address will not be attached to the blood sample when it is sent to the lab nor will it be stored with your samples. Researchers using your sample will not have access to your name and address.

WHAT IF YOU CHANGE YOUR MIND AFTER YOU HAVE GIVEN A SAMPLE?

You can withdraw your consent for the use of your samples at any time, without giving any reasons, by writing to the Centre for Longitudinal Studies (see details at the end of this booklet). They will inform the laboratory and any remaining stocks of your samples will be destroyed.



WHAT ABOUT HYGIENE STANDARDS?

The nurses maintain the highest hygiene standards to reduce any risk of infection. We use a new, unused, sterile needle and tubes for every person.

IS ANY SPECIAL EQUIPMENT NEEDED?

Before a needle is inserted into your vein, the nurse will apply a tourniquet (a band put round your arm to control your blood flow). This keeps more blood in the vein, making it easier for the nurse to see and access the vein.

WHAT IF YOU FEEL FAINT?

You might feel faint during or immediately after giving a blood sample, although most people don't. If you begin to feel faint at all, tell the nurse as soon as possible, if you can. The nurse will be watching you for any signs of fainting, and if necessary will stop taking the blood sample.

If you experience any of the following after the nurse has left, you should seek further help, for instance from your GP or dialling the NHS 111 service (for England and Scotland) or NHS Direct Wales on 0845 46 47:

- severe pain
- numbness or persistent 'pins and needles' in the arm, hand or fingers
- a large swelling or swelling which is getting bigger
- painful redness or inflammation.

FINDING OUT WHAT YOU EAT AND DRINK

We would like to collect information about your eating habits. The links between diet and health are well established, and information about what we eat and drink is an important part of helping understand health and illness. This information will be collected using an online questionnaire which we will ask you to complete on two days after the nurse visit. The nurse will let you know on which days we would like you to complete the questionnaire. Completing the questionnaire will take 10-20 minutes on each of the two days.



MORE INFORMATION

CONFIDENTIALITY AND DATA SECURITY

The information you provide will be treated in strict confidence in accordance with the General Data Protection Regulations (GDPR), and used for research purposes only. This means that the data we collect from you is always kept separately from information which could identify you (such as your name and address). When reports based on the data are published, care is taken to ensure that no information which could identify an individual is included.

The data controller for this project is University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at: **data-protection@ucl.ac.uk**.

The legal basis used to process your personal data is performance of a task in the public interest.

If you are concerned about how your personal data is being processed, please contact the UCL Data Protection Office in the first instance using the email address above. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: **ico.org.uk**

Your data will be stored securely and retained until it is no longer required by the Centre for Longitudinal Studies.

Participation in this research is not compulsory and you have the right to withdraw at any stage.

More information about privacy and confidentiality is available on the NCDS website: **ncds.info/faqs/#privacy-and-data-protection**

ETHICAL APPROVAL

This year's survey has been approved by an independent group of people called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity.

INSURANCE COVER

If you agree to your blood pressure or blood sample results being sent to your GP, then they may use them in medical reports about you. For example, if you apply for a new life assurance policy, or for a new job. When people apply for new policies, insurance companies may ask if they can obtain a medical report from your GP. But they cannot do this without your permission.

Having given your permission, you then have the right to see the report before your GP sends it to the insurance company, and you can ask for the report to be amended if you consider it to be incorrect or misleading.

WHO TO CONTACT IF YOU NEED MORE INFORMATION

We hope this booklet answers any questions you may have. Your nurse will also be able to answer any further questions you might have when they contact you to make your appointment, but if you need more information or need to make a complaint please contact NatCen:

 ncds@natcen.ac.uk


 0800 652 4574


For information about the National Child Development Study, you can visit:

 ncds.info

or contact the NCDS team:

 ncds@ucl.ac.uk

 0800 035 5761

 National Child Development Study, Centre for Longitudinal Studies, UCL Social Research Institute, 20 Bedford Way, London, WC1H 0AL.

PREPARING FOR THE NURSE VISIT

If possible please do the following:

- for **30 minutes before the nurse arrives**, DO NOT:
 - eat
 - drink alcohol or caffeine
 - smoke
 - exercise vigorously
- **wear light, non-restrictive clothing** and avoid tight clothing (e.g. lycra, tight jeans) and thick belts and very long garments
- wear trainers if you have them, otherwise please **wear shoes you can comfortably walk** in without slipping or tripping
- have your GP details to hand as the nurse will ask you for these
- please have to hand any medication you take, as your nurse will ask about any medication you are currently on
- **if you have not already given them back, please have ready:**
 - the 'Your Life Now' questionnaire
 - the 'Childhood' questionnaire