



85+

Were you born in 1921?

**If so, please take a few
minutes to read through
this information pack**



**With your support we
hope to help people
stay healthy and
active in older age**

You are being invited to participate in a research study called The Newcastle 85+ Study. Before you decide whether to take part, it is important that you understand why you have been chosen, why this research is being carried out and what it involves. Please take time to read this information booklet carefully and discuss it with your relatives and carers. If there is anything that is not clear, or you need more information, please ask. You will find our contact details at the back of the booklet. This leaflet is yours to keep.

What is the purpose of this study?

It is becoming more common for people to live to age 85 and beyond. Previously little attention has been paid to the health and needs of individuals in this age group. We are a team of doctors, nurses and scientists from the Institute for Ageing and Health at Newcastle University who are interested in the health and needs of older people. We want to find out what health, or other problems, older people have in their lives and what helps some individuals stay healthy and independent whilst others are not doing so well. We are also interested in finding out more about the scientific processes that happen with ageing. We hope to use the information from this research to find ways to help people stay healthy, independent and active in old age and to improve medical and social services for older people.

Why have I been chosen to take part in this study?

You are a very important person; you have survived to your 85th year, and we would like to find out more about the secret of your success. We are inviting all people who were born in 1921 and who live in Newcastle or certain parts of North Tyneside to take part in this study. We have learned your name and contact details through the list of people registered with general practitioners in Newcastle and North Tyneside Primary Care Trusts.

Do I have to take part?

It is up to you to decide whether or not to take part in this study. You do not have to do so; however your help is extremely valuable to us.

If you do decide to participate, you will be asked to sign a consent form, a copy of which you will be given to keep. You can still change your mind and withdraw at any time without having to give a reason. Deciding not to participate, or withdrawal from the study, will not affect your current or future medical care in any way.

What will happen to me if I take part?

If you do agree to help us, a nurse will come and talk to you in your own home at your convenience. They will explain about the study in more detail and answer any questions you might have. They will arrange to visit you 4 times over a period of a few weeks. 3 of the visits will last about one hour and forty minutes each and involve answering questions about yourself and your health together with some medical tests e.g. blood pressure, weight, heart tracing, breathing test. The 4th visit will be to take blood samples. There is a full list and explanation of each of these tests at the end of this booklet. You may decline to have some or all of these tests if you wish.

The nurse will request your permission for the research team to review your medical records (general practice, community health services and hospital records). The nurse will also ask for permission to review the records held by social services about use of their services.

We would very much like to keep in touch with you in the future and to visit you again every year to find out how you are getting on and to repeat some of the medical tests. Each year, we will contact you again to see if you still want to be involved and to let you know in more detail about the questions and tests we would like to do. With your permission, we will use the information held by the NHS and records maintained by the General Register Office to keep in touch with you and follow up your health status.

You are free to withdraw from the whole or any part of the study at anytime without having to give a reason. You are also free to request that all information and or samples donated by you are destroyed by the study team.

What if I have health or memory problems?

The research team have a lot of experience of working with people in your age group. We understand that some individuals may have health or memory problems and might feel anxious about taking part in a research project. It is important that we find out about the needs of all older people. We can adapt the interview to suit your individual needs e.g. with shorter visits and/or a family member or carer can be present at the interview to help or to answer questions on your behalf.

What about my usual medical care?

Taking part in this study will not affect your usual medical care. If you currently receive treatment from your doctor or the hospital, this will continue unchanged. This study does not involve taking any extra treatments (tablets/medication).

We would like to keep your own doctor informed about your involvement in this study. The nurse will ask your permission to contact your doctor with the results of those medical tests that are particularly important for your health.

What are the possible benefits of taking part?

While there are no immediate benefits in taking part in this study to you personally, we believe the information gained will improve what is known of the health and needs of individuals in your age group. We also hope that you enjoy taking part.

What are the possible disadvantages of taking part?

It is very unlikely that you will experience any harm by taking part in this study. If you do find that taking part causes you any distress or concern, you are free to withdraw.

Will my taking part in this study be kept confidential?

All the information that you provide during the course of this research will be securely stored in either locked files or a secure computer database and kept strictly confidential. The answers to your interview and medical tests will be kept separate from your personal information

(such as your name or address) and will only be identified by a special code number.

No individual will be identified or identifiable in any publication arising from the research.

Who is organising and funding the research?

The research study is organised by the doctors, nurses and scientists listed at the end of this information booklet. The study has the agreement of the appropriate authorities in the NHS and in Newcastle University. The study is funded for the next 5 years by the Medical Research Council.

Who has reviewed the study?

The study has been reviewed by the Newcastle and North Tyneside Medical Research Ethics Committee.

Whom can I contact for further information?

We will be happy to answer any questions you, your family or your carers may have about any aspect of this research study. Please call the number at the end of this booklet and ask to speak to our Research Nurse Manager: Karen Davies or one of the 85+ Research Nurse Team. If no-one is available, please leave your details on the answer machine and we will return your call. Alternatively you can write to us at the address at the end of the booklet.

Your help is very important to us; we very much hope you will agree to take part.

Thank you for reading this.

Now please read the **‘Information about Tests’** section of this booklet.

INFORMATION ABOUT TESTS

All tests will be carried out within your own home. They will involve minimal inconvenience and, apart from some mild discomfort when taking a blood test, are quite painless. The research team are very experienced in collecting this type of information and realise that not everyone has the same level of ability. All of the following tests will only be carried out with your permission and to your level of ability.

- **Weight and body composition**

The research nurse will weigh you in your own clothes (with bare feet) using specialised electric scales. These scales will also calculate the amount of fat and water in your body.

- **Demi-span**

The research nurse will use a tape measure to measure the distance between your breastbone and finger tips. This measurement is used to calculate your height.

- **Waist and hip measurement**

The nurse will use a tape measure to measure round your waist and hips.

- **Blood pressure**

The research nurse will measure your blood pressure whilst you are sitting using an automatic blood pressure machine by placing an inflatable cuff on the top of your arm.

- **Hand-grip strength**

The research nurse will measure how strong your hand grip is by asking you to squeeze a lever as tightly as possible on a special machine which measures the force of your grip.

- **Dietary Assessment**

The research nurse will ask you in detail about the food and drink you had during the day before their visit. They will do this on 2 separate occasions.

- **Tooth count**

The research nurse will count your teeth.

- **Up and go test**

The research nurse will time how long it takes you to get up from a chair and walk a short distance within your home.

- **Memory and concentration tests**

The research nurse will do some tests of your memory and concentration using a computer. Please do not worry if you have no experience of using computers; you will still be able to do the test and most people find these tests quite enjoyable!

- **Spirometry**

The research nurse will ask you to blow into a special machine to measure how strong your lungs are.

- **Oximetry**

The research nurse will measure the oxygen level in your blood stream by attaching a monitor to your finger tip.

- **ECG**

The research nurse will perform a heart tracing. This test involves attaching stickers to your chest and limbs which are then connected to a monitor to record your heart trace.

- **Blood tests**

The research nurse will take samples of your blood.

If possible, they will call first thing in the morning before you have had anything to eat or drink. If this would be a problem for you, please let the nurse know and they will call at another time.

The samples will be used for the following tests:

- blood count
- liver, kidney, heart and bone function
- sugar level

- cortisol level
- lipid level (e.g. cholesterol)
- thyroid function
- vitamin and mineral levels
- markers of inflammation
- markers of immune function (how the body tackles infection)
- markers of ageing

Some of your blood samples will also be used to investigate whether there are certain genetic or other factors which help some people live longer and more healthily than others.

We would like to store these samples for a long time; this is because new and important tests may become available over the coming years. We would then ask an ethics committee for permission to use your samples.

At any time you have the option to request withdrawal of your blood samples and they will be destroyed.

THE NEWCASTLE 85+ STUDY TEAM

Research Nurse Manager: Karen Barrass

Research Nurse Team

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Julie Burrows
Julie Ferguson
Julie Kimber

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Telephone: 0191 2481116

(If no-one is available please leave your details on the answer machine
and we will return your call)

RESEARCH NURSE TEAM:



Karen Davies – Research Nurse Manager



Sally Barker



June Edwards



Joan Hughes



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No permission to include photograph on website:

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