

# THE NEWCASTLE



## STUDY

### 10 YEAR FOLLOW UP (Phase 5)

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



**Please take the time to read this  
participant information booklet. It  
contains all you need to know about the  
10 year follow up stage of this study.**

You have previously taken part in the Newcastle 85+ study and we are now inviting you to take part in the next stage of the study – the 10 year follow up. We last met you 5 years ago and now wish to study people as they approach the age of 95 years old.

Before you decide whether to take part, we feel it is important to go over the reasons why you were chosen, why this research is being carried out and what this study of the study involves. Please take the 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, researchers and scientists from the Institute of Health and Society 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 95<sup>th</sup> year, and we would like to find out more about the secret of your success. In 2006 we invited all people who were born in 1921 and who were living in Newcastle or North Tyneside to take part in The Newcastle 85+ Study. We are very grateful that you were one of the people who agreed to take part and who helped to make the study a great success and we would now like to invite you take part in the 10 year follow up stage of the study.

### **Do I have to take part in the 10 year follow up?**

It is up to you to decide whether or not to continue to take part in this study. You do not have to do so; however any information 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 the current or future medical care in any way.

### **What will happen to me if I take part in the 10 year follow up?**

If you do agree to take part, a researcher will come and talk to you in your home at a time convenient to you. They will explain about this stage of the study in more detail and answer any questions you may have. The visit will last for approximately 75 minutes and will involve answering questions about your health.

The researcher will also request your approval for the research team to review your medical records (general practice, community health services, dental and hospital records). They will also ask for approval to review the records held by social services about use of their services. It should be acknowledged that some individuals will die during the course of the study and that permission is asked to review records in the event of death.

### **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 any questions on your behalf

In other cases a person who consented to take part in a stage of the study is now having memory problems and unable to fully understand the implications of continuing in the study. In all cases such as these we have a legal duty to seek an opinion from another individual known as a consultee, who will represent your best interest and be involved in the whole research process on your behalf. Consultees can also withdraw you from the study if they feel it is causing you distress, or no longer appropriate for you to continue.

### **How is a consultee chosen?**

Where possible consultees are chosen by you, the person taking part in the research. The researcher will ask you directly for these details should you agree to consent.

A consultee may be 'personal' or 'nominated'. A personal consultee is usually a spouse, partner, close relative or friend. A nominated consultee is usually an individual who is a paid carer or healthcare professional, who has knowledge of you but no connection with the research study. An individual may be approached to be a nominated consultee in situations where:

- Where there are no relatives or close friends willing and able to act as a consultee
- Where family or friends live a long distance away and are not in frequent contact with the person

### **What about my usual medical care?**

Taking part in this study will not affect usual medical care. If treatment is currently received from a doctor or hospital, this will continue unchanged. This study does not involve taking any extra treatments (tablets/medication). We would like to keep your doctor informed about your involvement in this study.

### **What are the possible benefits of taking part?**

While there are no immediate personal benefits in taking part in this study, we believe the information gained will improve what is known of the health and needs of individuals in older 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 at any time.

### **What if I change my mind and want to withdraw from the study?**

You are free to withdraw from the whole or part of the study at any time without having to give a reason. You are also free to request that all information and or samples donated are destroyed by the study team (although it may not be possible to trace all distributed sample remnants). Such a withdrawal would prevent information about people from contributing to further analyses, but it would not be possible to remove data from analyses that have already been done. Situations where memory problems make it difficult for individuals to fully understand the implications of continuing in the study will be discussed with the consultee. Consultees have equal freedom to withdraw from all or any part of the study if they feel it would cause any distress, or there is any change in circumstances where they feel it is no longer appropriate for the research to continue. Again, they are able to request that all information and or samples donated by you are destroyed by the study team (although it may not be possible to trace all distributed sample remnants). Such a withdrawal would prevent information about people from contributing to further analyses, but it would not be possible to remove data from analyses that have already been done.

### **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 interview questions and medical tests will be kept separate from personal information (such as 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 is sponsored by Newcastle University. The 10 year follow up is funded by the National Institute for Health Research School for Primary Care.

### **Who has reviewed the study?**

The study has been reviewed by the National Research Ethics Service (reference number .....

### **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 a member of our 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.**

## Newcastle 85+ Study Team for the 10 year follow up

Principle Investigator – Dr Rachel Duncan

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