

## **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.

## **What is the name of the Data Controller?**

The Data Controller for this study is Newcastle University. Contact details for the Data Protection Officer can be found at the following link:

<https://www.ncl.ac.uk/data.protection/>

## **What is the lawful basis for processing your data?**

The lawful basis for carrying out this study under GDPR is Task in the Public Interest, (Article 6,1e) as research is cited as part of the University's duties. As we are collecting special categories of personal data the second lawful basis is Scientific Research (Article 9, 2j).

## **How long will my data be kept?**

Your data has to be kept from the end date of the study for a period of 20 years. This includes electronic and paper copies of the information. When data is archived the data will be completely anonymized.

## **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 may still be happy for your data to be retained and processed for research. However you are also free to request that data and samples donated are no longer processed (contribute to further analyses) and are destroyed by the study team (although it may not be possible to trace all distributed sample remnants). Nevertheless, in the case of such a withdrawal 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 understand fully 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 data and 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.

To withdraw consent please contact the study research team (details below).

### **Who will you share data with?**

Personal Identifiable data (name, address, NHS number) was shared with NHS Digital which allows them to flag your records as being part of the 85+ Study cohort. This happened when you first enrolled on the 85+ study in 2006/2007. Using this information, NHS Digital provide the study with regular updates of date and cause of death. No more Personal information needs to be shared with NHS Digital.

### **Types of data we store**

Personal data held by the study falls into three categories

- (i) Identifiable data collected at the start of the study (name, address, NHS number);
- (ii) Data from interviews, medical tests and blood samples (de-identified);
- (iii) Date and cause of death from NHS Digital (linked then de-identified).

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. Month and year of death and cause are linked to other data, and then identified only by a special code number. No individual will be identified or identifiable in any output that arises from the research.

ONLY de-identified data is shared with approved collaborators whose research aims match or further the goals of this study. De-identified data is data which has had identifiable information removed.

### **Will my data be looked after safely?**

Your personal data in the consent forms, names and addresses, and data supplied by NHS Digital, are stored in a secure location within Newcastle University with restricted access given only to the Principal Investigator Professor Dame Louise Robinson, and the Research Nurse who has carried out the interview.

All electronic data is stored securely and access is restricted to only those members of staff with a clearly defined need. When data is shared, information is restricted only to that needed to answer a specific research question.

**Who do I complain to?**

You have a right under law to raise a complaint with the Information Commissioner's Office (ICO) <https://ico.org.uk/concerns/> The ICO is the UK's independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals.

**Contact details of Newcastle University Study team:**

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Principal Investigator Newcastle 85+ Study

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