

ELSA

English
Longitudinal
Study of
Ageing



 **NatCen**
National Centre for Social Research
 **IFS** Institute for
Fiscal Studies

Health and lifestyles of people aged 50 and over

A study of the population aged 50 and over in England

Information about donating a blood sample for genetic (DNA) studies

This leaflet tells you about the collection of
genetic material as part of the study and
why it is being done

Introduction

In a room full of people it's obvious that individuals differ: some are taller, some are shorter, some have darker hair, some have fairer hair. The characteristics that make us unique individuals are influenced by our genes.

It is thought that we each have about 30,000 genes. Genes are made of a substance called DNA. Variations in DNA result in slightly different versions of genes. As a result, no two persons (apart from identical twins) have exactly the same genes.

Research shows that genes have a role in the development of common diseases, including diabetes, asthma and heart conditions. A person's genes can contribute, with other factors such as smoking, to the development of these diseases. For example, sometimes two people may have the same genetic risk for a

particular illness, but only one person actually experiences any symptoms of it.

Understanding how these processes work involves looking at the genes from a large number of people to study the differences between genes, how they interact with the environment and other risk factors and how they relate to health. Answers to these questions could eventually lead to new ways of preventing disease, or new treatments.

How will the DNA be collected?

An ordinary blood sample can be used to prepare suitable DNA for our scientific work. We shall ask for your written consent to take a normal blood sample from which we will extract, analyse and store the DNA.

What type of genetic studies will be done in ELSA?

ELSA focuses on understanding how genes influence ageing, disabilities and common chronic diseases. We also want to understand how these genes interact with social and economic factors.

In studying how people age, we are interested in how the functions of the different body systems change. For example, we are interested in how genes influence the functioning of muscles, or the brain.

We will also look at the role genes play in the development of chronic diseases including heart disease, diabetes and Alzheimer's disease. In the future we may also be able to study other chronic diseases.

Of course there must always be safeguards on the research done. Only research that has been approved by both the ELSA team and by an independent NHS Multi-centre Research Ethics Committee (MREC) will be allowed. All data and samples will be coded before being provided to researchers (see details below).

Will I be told the results of the genetic tests on my samples?

The study cannot provide participants with their personal genetic information, because:

- Most of the information will not be meaningful in terms of individual people's health.
- As the research will be carried out on groups of people, the clinical importance of the findings for individuals will only become clear over a long time.

We will include information on the general findings from genetic studies in our newsletters and websites, as well as in the scientific journals.

How will the information be stored, protected and used?

Each blood sample will be given its own number. Only this new number, and not your name, will appear on the prepared DNA samples and the stored materials. This new number will also be different to your survey number, which appears on the consent form.

Only the National Centre for Social Research will be able to link your name to your results and this will be kept separately and securely and used only to allow the further collection of information for the study. Your name will not be in information supplied to researchers who want to do scientific analyses.

The data and samples will remain confidential and will be coded.

The study collaborates with leading scientists in this country and abroad. Anonymised samples and data may be shared with these outside scientists, but this will only be done with approval of the genetics data committee, and only if the scientists can guarantee at least the same level of safeguards as we have described in this information leaflet. The details linking your name to the samples will never be released.

Can I withdraw my consent?

Initial consent to the collection, storage and use of the samples in the genetic project is given by you. It is not possible to “opt in” to certain genetic studies and “opt out” of others, but you can opt out of the whole genetic project at any time, without giving any reason and without penalty.

After initially taking part, you may stop further participation, or completely withdraw. If you completely withdraw from the project, then the samples, your study database record and any linkages would be destroyed. However, we can't destroy data already circulated to researchers in anonymised datasets or already placed in the public domain in anonymised form. It may also not be possible to trace and destroy all of the genetic sample.

What will the study do in the future?

The sample and information you donate will remain very valuable for science for many years to come. In the event of your death we need to continue to include your information and DNA in the research. This would also apply if you ever became unable to make your own decisions. If we didn't include such data then we could get misleading results.

Who will own the specimens and data?

The specimens and data will be legally owned by University College London, and overseen by the study Principal Investigator, Prof Sir Michael Marmot. The study will not sell specimens or data.

If the research leads to a test or treatment, intellectual property rights from this would belong to the Universities.

All the project resources will be maintained for the public good.

Will the DNA samples be used for other things?

The DNA samples will only be made available in the future for studies of the health topics identified above, i.e:

- Genes related to ageing and functioning, including those influencing disability.
- Genes influencing common chronic diseases.
- How these genes interact with social and economic factors.

Future projects will only go ahead if the study team and an NHS ethics committee approves them.

The information will **not** be available for life insurance, mortgage applications, or AIDS/HIV testing.

Access to the resource by the police or other law enforcement agencies will be acceded to **only** under court order.

The research team

The study is a collaboration between four of Europe's leading research groups in the fields of health, economics and social statistics:

- University College London
- The Institute for Fiscal Studies
- The University of Cambridge
- The National Centre for Social Research

We hope that this leaflet answers your questions. If you have others, please contact the medical investigators at the address below. Thank you very much for helping with the development of this study.

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You can find out more about the study, or contact us, via the ELSA web site:

<http://www.natcen.ac.uk/elsa/>