ELSA English Longitudinal Study of Ageing

Health and lifestyles of people aged 50 and over

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.

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Introduction

Research shows that an increasing number of illnesses have a genetic element. Diabetes, asthma and certain heart conditions are now thought to have a genetic component.

Often genes do not actually give rise to a specific illness but may pre-dispose to one. Two people may both be pre-disposed to a particular illness, but only one person actually suffers from it. Why? What triggers the onset of the illness? Is it something to do with the environment? Or is it other genes?

This is the type of question that we hope to try to answer, through a variety of genetic studies. We need to look at the genes from a large number of people so that we can study the differences between genes, and how they relate to health.

What are genes?

In a room full of people, individuals differ: some are tall, some are short, some have dark hair, some have fair. The characteristics that make us unique individuals are influenced by our genes. Following the recently published "working map" of the human genome, it is thought that we each have about 30,000 genes. We have genes that determine many things about us such as our height, our hair and eye colour and also the likelihood that we may develop certain diseases, that tend to run in families.

There may be several forms of the same gene. For example, the genes for eye colour have several different forms so there is a range of different eye colour – blue, green, brown, etc. The form of the eye colour gene does not appear to have any effect on health. Because there are a number of variations of each gene, no two persons (apart from identical twins) have exactly the same combination of genes, although we all have the same number.

What is DNA?

DNA is the substance of which genes are composed. Genes are found on structures called chromosomes. There are 23 pairs of chromosomes (46 in total) present in each of the cells of our bodies.

Each chromosome contains a long thin tightly packed thread. This is the DNA. The DNA strand is divided up, along its length, into the genes. One chromosome contains hundreds or thousands of genes. Each gene lies at an exact place on a specific chromosome. Pairs of chromosomes contain the same set of genes in the same order, but they may carry a different form of the same gene.

It is this genetic variation in the DNA that will be studied in the genetic part of the project.

How will the DNA be collected?

DNA can be obtained from any cell in the body.

Since we wish to take a blood sample anyway for your biochemical tests we would like to use this to prepare DNA. We shall seek your written consent to do this.

What type of genetic studies will be done?

Some studies will simply find out how many people have a certain type of gene. In the future, if a certain gene is found to be associated with a certain illness, then knowing how common that gene is will help to plan and develop health care.

Other studies will see if there is a link between certain genes, the environment and health among members. Genetic results will be compared with information in your interview, and your physiological and biochemical test results, to see if there are common underlying factors.

No names of individuals will ever be revealed or identified in the presentation of the results.

Will the DNA samples be used for other things?

If you agree, the DNA sample will be made available for future studies relating to health which have received ethical approval.The information will not be available for life insurance, mortgage applications, police records or AIDS/HIV testing.

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?

Each blood sample in the project will be given its own number. This number will be different to your survey number, which appears on the consent form. Only this number, and not your name, will appear on the prepared DNA samples and the stored materials. The 'paperwork' which links you to your results will be kept on a secure computer at NatCen Social Research.

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.

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
- NatCen Social Research
- The University of Manchester

We hope that this leaflet answers your questions. If you have others, please contact one of the research team at the addresses below. Thank you very much for helping us with the development of this important survey.

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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/

22/59_Genetics leaflet (I&N)