

■ What does the study involve?

- Will I find it uncomfortable or painful to give a sample?
- How many samples will I have to give, and how often?
- Will the arrangements for taking the sample be convenient for me?
- Will my fares or expenses to and from appointments be paid?
- Does the research involve interviews or filling in questionnaires about my or my family's health?

■ What will happen to my blood or other sample?

In law blood and other samples can only be taken with your agreement and you can say what you want done with your sample and how it can be used. You can ask for your sample to be withdrawn from the study, although in practice it is difficult to do.

- Will my samples be kept when the study ends and, if so, what will happen to them?

■ Who is likely to benefit from the research?

Taking part in research may not help you, but you may decide it is worth taking part because it might help other people in the future.

Most genetic research is paid for by charities or the government, but some is paid for by commercial companies. These companies are looking for things that they can patent. If a company gets a patent, it has the official right to be the only company to make and sell it for a certain period of time.

Carrying out research is expensive so patents are granted to researchers to give them time to develop tests or treatments, without competition from other manufacturers.

- Do I mind who sponsors the research?

■ Will I be told the research results?

- Do you want to know the overall results of the research?
- When are the research results likely to be available or published in medical journals or the national press?

This leaflet is also available in Bengali, Cantonese, Somali, Turkish and Vietnamese and on tape in English, Somali and Sylheti.

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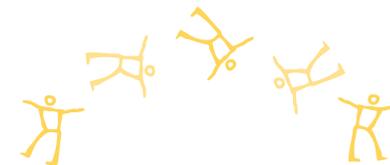
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CONSUMERS
for ethics
IN RESEARCH

GENETIC RESEARCH

GIVING SAMPLES ►►►
FOR LARGE STUDIES



What you need to **think about**



What are genes?

We are all very different from one another: partly because we lead different lives and partly because we inherit characteristics from our parents and grandparents. We inherit characteristics through our genes. We each have a unique set of genes, some of which influence how tall we are or whether, for example, we have curly hair.

Our genes may also make us more or less likely to develop a particular disease. We know that some diseases, such as thalassaemia and sickle cell disorders, are linked to a single gene. However, most diseases have no single cause. They may be caused by several different genes and by the way we live.

Genes may become damaged during our lives by coming into contact with pollution, radiation or a particular virus. Some cancers may also be caused by the way we live, for example, by smoking.

What is genetic research

Genetics is the study of characteristics passed on from parent to child. In the health service, genetic researchers investigate which illnesses can be passed on through our genes. Genetic research is still at an early stage.

Genetic research is not the same as genetic testing. If there is a genetic disease in your family, your doctor may offer you a genetic test as part of their investigations.

There are different kinds of genetic research. Some research looks at the genes of members of families who seem to be more likely to develop a particular disease. This type of research is covered in a separate leaflet.

This leaflet is about research where samples are collected from many people in order to find combinations of genes that may be linked to particular diseases, such as depression or heart disease. In future this research may lead to the development of better tests. It may also help to develop better treatments and medicines. If they understand genetics better, doctors may be able to give you medicines that will help you most and avoid giving you medicines to which you may have a bad reaction. Lots of people take part in this sort of research. No one who takes part in it is told his or her personal results.

What happens in genetic research?

Genetic researchers normally take blood or, sometimes, other samples, such as hair or saliva, from you. If you are having treatment at the moment, the researchers can use the samples that they already have. The researchers then look at the sample to see if you have a particular combination of genes. There is no difference in research on men, women or children.

Deciding whether you want to give a genetic sample

If you are asked to take part in genetic research, the researchers should give you written information to take home. If you agree to take part, the researchers will ask you to sign a form agreeing to the research (a consent form).

Remember you don't have to take part in research.

If you are having treatment, you can refuse and your treatment will not be affected. You don't have to give a reason for refusing, though it may help the researchers if you give a reason.

Think carefully before you decide to take part in genetic research. If you change your mind during the research programme and decide you don't want researchers to use your genetic sample in their research, it may be too late. They may have already carried out their tests or, as your name will not be on your sample, nobody will know it is yours. It may therefore be difficult to withdraw from the programme.

If you speak little or no English, ask for an interpreter or advocate to be with you when you talk to the researchers.

You may want to ask yourself the following questions to help you decide whether or not to give a sample.

