

Information for patients and the public about the benefits of taking part in genetic research

- *Genetic research offers the possibility of developing cures for many serious, and sometimes fatal, diseases*
- *The development of these cures depends on the donation of biological samples from affected people to be used in research*
- *If you participate in genetic research, you will be helping many people in the future who are affected by genetic disease*
- *Sometimes researchers will offer benefits of different kinds to research participants, in recognition of their investment*
- *Participating in genetic research is not dangerous or painful!*

Access and Benefit Sharing: Why should I take part in genetic research?

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What is Benefit Sharing?

Benefit sharing is the result of collaboration between researchers, and members of the public (for example, people such as you, your family or friends) who helped the research to go ahead by donating biological samples

- DNA research is carried out in order to develop treatments and cures for diseases
- Where research is successful and these advances are made, 'benefit sharing' is way in which the lives of affected communities are improved by these developments
- In this way, those who donate their DNA for research get a 'return' on the investment of their biological material, the return being benefits to health of affected communities and individuals

Why is it important?

Genetic research has the potential to transform lives by developing new treatments for serious and debilitating genetic disorders

- If you agree to participate in research by donating biological samples, it may be important to you to know that the developments and advances resulting from research can reach the people who need them the most
- It might not be obvious how research in a laboratory is turned into real health benefits, as there is usually a delay between research beginning, and drugs or treatments being developed and brought to the market

- Those doing the research feed back the outcomes of their work in a number of ways to show patients and patient groups how valuable their contribution to the research has been, and how their lives could be improved by further investigations
- In this way, 'benefit sharing' helps to foster and maintain good relationships between researchers and those who, by donating DNA samples, enabled the research to go ahead. Benefit sharing helps to ensure that research continues to be done to develop new treatments, and to ensure that the pace of improvements to health is maintained

Benefit sharing and patient groups

Close links between patient groups and researchers are essential to ensuring that progress in curing genetic disease can continue

If you belong to a patient group, such links may enable you to find out about new therapies and treatments, and information about future ones that may otherwise be difficult to find out about

Patient groups also play a crucial role in passing the benefits of research back to those affected by genetic conditions

By mediating between the interests of the pharmaceutical industry and patients, patient groups act as a way of transferring benefits and resources between them, ensuring that treatments can be developed in the most useful and appropriate way

Equal distribution of benefits

Benefit sharing schemes help to make sure that advances made by genetic research are shared out equally between those who could benefit from them

Good benefit sharing schemes attempt to direct resources and knowledge to communities affected by a disease so that all those affected can benefit. Benefit sharing can take a number of forms and handled by a number of different agencies and bodies

What forms can benefit sharing take?

[Direct financial return](#)

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Direct financial return

- If you donate biological samples for use in research into how to treat a disorder, the research team or organisation may sometimes offer you a financial incentive in return for your participation
- These incentives such as this may take the form of a one-off payment, though more frequently a benefit sharing scheme can be done by offering you as a participant a share in the profits derived from the patenting and sale of the drugs developed
- As drugs are developed using samples that you donate for research, donors such as yourself should therefore be entitled to share in the same financial benefits. In order to achieve this, the research team can offer you and other research participants a financial return on the basis of a percentage

Technology Transfer

- 'Technology Transfer' describes how scientific research using biological samples is turned into benefits to health

- Drugs developed are the outcomes of the 'technology transfer'. The technology is been turned into therapies which can treat people with genetic conditions
- If you participate in research, drug manufacturers carrying out the work may offer a subsidy to you and other DNA donors on therapies that they develop. Alternatively, they may channel the outcomes of the research to patients and affected communities via patient groups and healthcare providers

Health promotion and training

Benefits like these are important and useful, because there are inequalities in good health information throughout Europe at all levels from the local to the international

- You may live somewhere where specialist health information about genetics is limited or unavailable, and where such information is needed by yourself and others
- Investment in health education could benefit directly yourself and others in your area, or who are in a similar situation to you. If you are considering participating in research, you should ask whether incentives such as investment into health education can be provided in return for your involvement

Improvements to infrastructure

The drug company or research organisation carrying out the work that you are participating in may invest in practical improvements to health provision, in return for your involvement.

- Payments for improvements in health infrastructure may be made to a number of bodies which might include local healthcare providers or patient organisations
- Some examples of what these financial incentives could be spent on might be improved disabled access to buildings, or public provision for those who are hard of sight or hearing. There are many ways in which you or those which impairments caused by genetic disease may benefit from investment into new or additional medical machinery or equipment

Honesty

Benefits and incentives offered by research bodies in return for patient participation should be deliverable in practice. The claims made about these incentives should be realistic and achievable

- Laboratory research cannot be turned instantly into new treatments and therapies, so not all studies which use biological samples that you donate and which investigate how to treat a genetic condition will necessarily bring about a cure straight away
- However, the research body should offer some commitment to ensuring that affected communities, which may include yourself, will benefit, in the event that the research has the type of results that are hoped for

Scale

If a research organisation offers incentives to you as a potential research participant, it is important that these benefits are proportional to your involvement in it

- No organisation can compel you to become involved if you don't want to be. You are under no obligation to participate if you do not wish to, however large the incentive

Access to the outcomes of research

In order that genetic research can continue to develop new therapies at the current pace, the scientific community needs a degree of open access to the results of previous research programs

- This means that some sharing of personal genetic data donated for research is necessary
- Whether or not you agree to participate in research in which your DNA samples may be accessible by other research teams afterwards is a decision for each individual participant. A researcher, doctor, or other health professional involved should take

you through an appropriate informed consent procedure prior to you making any decision

- Biobanks and genetic research are supervised and externally audited, to make sure that researchers are using data appropriately. The ability of researchers to be able to continue with research in future depends on them adhering to high standards of data privacy

NB: *Disclosure of your identity can be prevented in some cases by anonymising or encrypting data samples (for full explanation of this, see the sections on Informed Consent and Biobanking). This is not carried out in all studies however as it is not appropriate for the aims of the research in every case*