



## **Donating biological samples for medical research**

### **Introduction**

Medical research is necessary to improve our understanding of what keeps us healthy and how diseases start and progress. It also means scientists can develop new and improved treatments.

Body fluid (such as blood, saliva, urine) and human tissue (such as fat, cancer tumours or muscle) are often used in scientific and medical research. Types of research that need body fluid and human tissue include:

- Looking at how the body works to fight disease.
- Testing new treatments for conditions such as heart disease and diabetes.
- Developing tests for different types of cancer.
- Researching how certain types of cells could be used to treat conditions like Parkinson's disease, Alzheimer's disease and multiple sclerosis.

Many of the tests and treatments used today resulted from people donating body fluid and human tissue (often called 'samples') for research years ago.

### **How are human samples collected?**

There are a number of ways that human samples can be collected:

- Samples may be left over after surgery. Tissue may be removed during surgery so tests can be done on the tissue or to stop the diseased tissue spreading to other parts of the body. After any necessary tests have been done on the tissue, there may be some left over. This left over tissue may be destroyed or used for medical research.
- Samples may be left over from a medical test such as a blood test.
- Samples might be donated specifically for medical research.
- A person may give permission (known as 'consent' or 'authorisation') for a sample to be taken and used for research in the event of their death.
- A person's family may give permission for the person's organs, which would have been donated for transplant, to be used for research if they are not suitable for transplant or a suitable recipient is not available.

The collection and use of samples is tightly governed by law in the UK. The removal of samples from a person is always done with the donor's permission, and any research first has to be approved by a research ethics committee. This committee is usually made up of doctors, scientist, patients and the general public, and ensures any research allowed to be done is for the benefit of patients. In specific circumstances the law allows samples that have already been collected to be used for another purpose, as long as the donor cannot be identified and the use has been approved by an ethics committee.

### **What is done with the sample once it is collected?**

Samples may be collected by a researcher and used immediately, or they may be collected for research purposes and kept. This may be in a researcher's laboratory or it may be in a storage place specifically for samples, known as a biobank.

The biobank keeps the samples so they can be used by scientists for research. In other words, biobanks are a little like libraries of samples, and only a research team can use them if they have the appropriate approval. A biobank has to follow regulations and have a licence, granted by the Human Tissue Authority (a UK Government organisation), to be able to store human tissue samples for research.



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These systems ensure that any research respects the privacy of the people who donated the samples and that the research is of benefit to society. In many cases, it can be very important to have a patient's medical records along with their sample so that scientists can make sense of the results of their research. Any identifying information, such as names or addresses, is removed and not included with the sample.

**How long is the biological sample kept?**

A sample may be used all at once. However, it is often the case that it won't all be used in one go. Therefore the sample may be stored and used over many years so that research can be done on it well into the future.

**What are the benefits from donating biological samples to medical research?**

The person donating the sample is unlikely to benefit directly from the research, as it can take many years for the research on samples to produce new treatments or cures for diseases. Nevertheless, donors often see a benefit from knowing that they have personally helped medical research.

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**The following information was used during the making of this leaflet:**

"Donating samples for research; Patient information" – Central England Haemato-Oncology Research Biobank

"Donating your tissue for research"- Human Tissue Authority

"Active choice but not too active: Public perspectives on biobank consent models" Simon et al. 2011; Genetics in Medicine