What does the biobank do with my samples and data?

Samples may be used immediately or stored securely with restricted access in the biobank for future research. When a sample is first collected, the name of the patient and medical record number is recorded, so that the healthcare team can link the samples to the patient. Your sample will not be labelled with any information that can identify you. Instead, it will be given a unique biobank number or code.

Your healthcare data will be stored on a secure password-protected computer and only the investigating healthcare team will have access to information that identifies you. Your sample and healthcare data may be shared with other researchers, however, your identity will never be shared. Researchers very often work with other universities, hospitals or health-related companies (businesses involved in the development of new tests, treatments, medicines, medical devices) in Ireland and abroad, so that their work will have a wider impact and they can avail of other technologies that will lead to better tests andtreatments.

The biobank does not benefit financially from sharing your samples and healthcare data. The healthcare team will discuss this in more detail with you if you decide to participate in the biobank.

How does the biobank protect my confidentiality?

The biobank has very strict governance procedures in place to ensure your healthcare data is treated with privacy and confidentiality, according to EU and Irish data protection laws. All research studies need ethical approval to ensure they are carried out ethically and safely, that your rights are protected and that the study complies with data protection regulations. If your coded sample and data is being shared with other researchers, a legal agreement is put in place to ensure that these are used as agreed.

How do I get involved?

To contribute to the biobank, please speak to a member of your medical team. For more information on biobanks and associated research studies, please see www.stjames.ie/cancer/research/biobanknetwork/

Email: cancerbiobanks@stjames.ie

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

ST JAMES'S HOSPITAL

Trinity St James's Cancer Institute

OECI CANCER CENTRE

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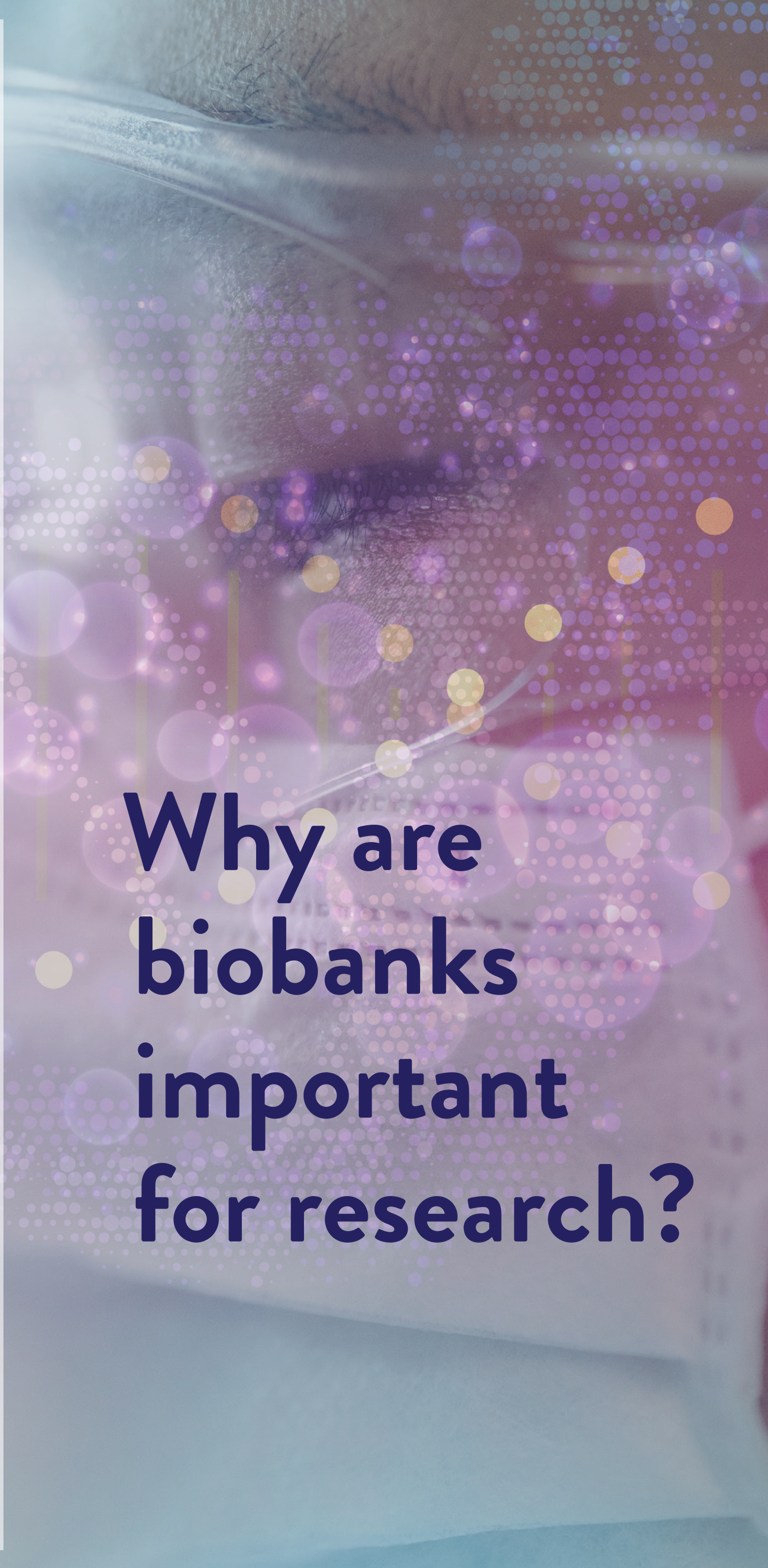


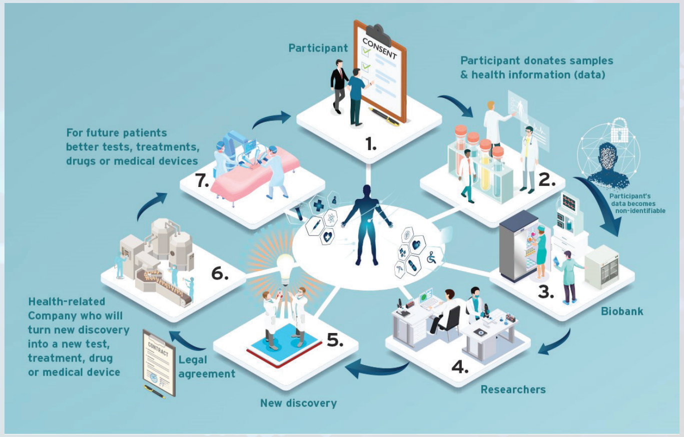
Why are biobanks important for research?

About Us

St James's Hospital is a University teaching hospital of Trinity College Dublin. Research and education are important aspects of a teaching hospital. We are constantly learning and researching in order to get the best treatments for patients and to improve patient care. You may be asked to contribute to a biobank as part of the research.

What is a biobank?

A biobank is a collection of biological samples and healthcare data donated by people for health research. Biological samples may include tissue, blood or other specimens. Healthcare data includes information in your medical records about your condition, for example medical history, blood tests and scan results.



Why are biobanks important?

Collecting samples and healthcare data, also known as biobanking, allows us to answer important research questions. It helps us understand more about the human body in health and disease and to find new and improved ways to treat certain medical conditions. Health research can take many years and large numbers of people are required to donate their samples and healthcare data to get the best results. Biobanks can speed up research by having samples and healthcare data ready to use when researchers need them.

What are the benefits to me?

It is well reported that hospitals that are active in research have better outcomes for all patients. Research has resulted in new tests for diagnosing diseases, improved treatments, and better quality of life for people living with illnesses. Treatments currently available were developed as a result of past research studies. An example of this is Herceptin, a drug used to treat breast cancer. Herceptin was developed with the use of a health research biobank. Biobanks collect and store samples and healthcare data to answer future research questions. We cannot predict now what discoveries researchers may make in the future. It takes many years to do research, to collect sufficient data to be sure of the findings and to turn these findings into something that will benefit patients. The research may not immediately influence your care or benefit you personally. However, by participating in the biobank you are contributing to improving healthcare in the future.

What will happen if I take part?

If you agree to take part, the process of biobanking will be explained to you. You will be asked to sign a consent form and you will be given a copy of an information leaflet about the biobank. Depending on the illness that is being investigated, the biobank will collect and store different biological samples from you such as tissue, blood or other specimens. The biobank will also collect your relevant healthcare data.

Do I have to take part?

The decision to take part in a biobank is completely voluntary. Samples are only taken with your informed consent and a decision not to join the biobank will not impact on your care or treatment in any way. If you change your mind, you can withdraw at any time.