

## What about my personal information?

Your medical records are only accessible by NHS staff who are legally bound to maintain the strictest confidentiality. If your tissue is stored in NIB, we will also collect information about your case, such as your age, sex, medical history, specimen type, pathology and date of operation. This data is stored securely in the Biobank and researchers may apply to gain access to this through the NIB. This information is always anonymised and is required to help researchers better understand how these factors may influence the risk of developing diseases including cancers and how to develop new treatments. Researchers will not be given your personal information by us.

All samples stored in the NIB will have a unique identity barcode number and data will be held on a secure independent IT management system. The surplus tissue retained for NIB will not be traceable to you as samples are labelled only with this unique identity barcode number.

## What will happen to the results of research using my samples?

Researchers are unable to trace your samples back to you therefore you will not receive any personal feedback. However, details of research studies that have used NIB samples are available on our website.

## What happens if I change my mind?

You can withdraw your consent at any time by phoning or writing to the Research Nurse or NIB Administrator whose contact details are given at the end of this information sheet. Most samples collected by us will not be used for research purposes until four months has elapsed. However, we cannot always guarantee that all of your samples will still be available as fresh tissue samples may already have been released to researchers. If you change your mind, any tissue/blood samples, gifted to the NIB, will be destroyed and information will be removed from our database. After four months, however, there will be no guarantee that the intact sample will be available. Withdrawal from the NIB will NOT affect your treatment or care in any way.

## Who funds the NIB?

The Health and Social Care Research and Development Division of the Public Health Agency (HSC R&D Division) has provided the majority of the funding. Cancer Research-UK and the Friends of the Cancer Centre have also provided financial support.

## Who ensures the integrity of the Biobank?

The NIB would not exist without the support of the following organisations:

- The Belfast Health and Social Care Trust
- Queens University Belfast
- The Health and Social Care R & D Division of the Public Health Agency
- Cancer Research UK
- The Friends of the Cancer Centre (Belfast)

NIB has been ethically approved by a local research ethics committee and must conform to national rules to ensure that patients are protected. A committee structure is in place to ensure the Biobank complies with these rules and regulations.



## Contact for further information

If you would like further information please Write to:

Northern Ireland Biobank  
Centre for Cancer Research and Cell Biology  
Queens University Belfast, Belfast, BT9 7BL

Tel: 028 9097 2915  
Website: [www.nibiobank.org](http://www.nibiobank.org)  
Email: [nibiobank@qub.ac.uk](mailto:nibiobank@qub.ac.uk)

# PATIENT INFORMATION SHEET

Scientific Director:  
Dr Jacqueline James  
Tel: 028 9097 2915

## What is the Northern Ireland Biobank?

In 2011, the Northern Ireland Biobank (NIB) was awarded full ethical approval to collect, store and distribute samples of tissue, urine, saliva, blood and other bodily fluids for research purposes. Researchers call these 'biosamples' and they are vital for biomedical research. They can use them to:-

- Find new ways to diagnose and treat diseases
- Develop and test new drugs
- Try and work out which treatments work for particular groups of patients
- Find better ways of controlling side effects and symptoms

Ongoing information that is gained by a biobank about you and your samples may continue to be collected and analysed over many years, adding to medical knowledge for future generations.

## You are being invited to donate your surplus samples

Before you decide to donate samples it is important for you to understand why we are collecting them and what it will involve. Please take the time to read the following information carefully. The Northern Ireland Biobank (NIB) research nurse or your doctor will be happy to discuss this with you and will answer any questions you might have.

*Thank you for reading this.*

## Why have I been asked to do this?

Either you have already had, or are going to have, some tests or procedures performed as part of your care, eg an operation, biopsy, blood test or removal of bodily fluid such as ascites. If appropriate, these samples are sent to a hospital laboratory for analysis to help your doctor make decisions about your care. The priority of the NHS staff will be your diagnosis/therapeutic assessment, however, not all of the tissue or bodily fluids removed may be needed for this. In the normal course of events any surplus material will be discarded. It is this surplus tissue that we are asking you to 'gift' to the NIB so that it may be used for future research projects.

## Do I have to take part?

You are free to say 'no' – the choice is yours. If you decide not to take part, it will NOT affect your management in any way and your tissues will be used solely for diagnostic/therapeutic purposes. If you wish to consult your own GP before you decide, then please take this information with you and seek their advice.

## What will happen if I say yes?

You will be asked to sign a consent form, one copy of which you will keep. After your diagnosis/therapeutic assessment is complete, a specialist doctor from the clinical team will decide whether there is enough material left over for the NIB. You will also be asked for a blood sample, which is additional to the routine blood tests normally requested by your doctor (up to 40 mls, approximately 8 teaspoons). As part of your care, you may be invited back by your doctor for routine follow-up appointments. If at a later stage you have other samples taken as part of your care, the NIB may wish to have access to any surplus material and may also ask for further blood samples.

You may also be asked for a sample of urine, saliva or other bodily fluids. We will not need to collect these samples in every case and we will tell you in advance which samples we would like to collect and how this will be done. It is completely up to you which sample types you are happy for us to collect from you and store; this will be detailed on the consent form. Following collection of these biosamples, no further effort on your part is required.

## Why do researchers need my sample?

The human body is made up of many different types of cells and all cells contain proteins and DNA. DNA is used to make genes that control development, growth, eye colour and many other things. When certain genes and proteins in the body become abnormal, they can cause normal cells to become diseased. It is an important part of research to understand what genes and proteins do within cells. We may use part of your sample to analyse your DNA (genetic material). We are asking you to allow us to extract DNA so that research groups can try and find out what gene patterns may affect the risk of different types of diseases or to see whether we can predict what treatment may be best for people with particular genetic patterns.

Some scientists wish to study how diseased cells grow and are maintained in the body. They can use laboratory techniques to study how individual cells respond to new drugs and treatments. The cells may be grown on special plastic dishes or in three dimensional gels in the laboratory environment; or they may be stored in a freezer for a period of time and studied at a later date. Some cells may need to be treated with laboratory reagents to make them grow indefinitely in culture so that scientists can study how they grow over longer periods of time. These are known as *cell culture models*.

## Who can apply to use my samples?

Researchers requesting access to tissue samples from NIB will have to demonstrate that their studies are of high quality. Independent experts chosen from the NIB Scientific Review Committee will give their specialist opinion on the quality of the research proposed before access to tissues is approved.

Samples collected by the NIB are available to both academic institutions and commercial companies. Future approved research using your tissue samples or derivatives may result in financial gain to partner organisations which are developing new tests and treatments. In such an event, no direct financial benefit will accrue to NIB or to donors. NIB approved projects could also involve portions of your samples being exported to research laboratories in other countries world-wide.