

## Northern Ireland Biobank Information Sheet

We are inviting you to donate samples to the Northern Ireland Biobank (NIB). Before you decide whether to participate, please take time to read this information leaflet. Ask us if there is something you do not understand, or if you would like more information.

### **What is the Northern Ireland Biobank?**

The NIB is a partnership between the Northern Ireland Health and Social Care Trusts and Queen's University Belfast (QUB). It collects and stores biological samples, such as blood and tissue, to support research. This research helps scientists discover new ways to diagnose, understand, and treat diseases.

### **Why have I been asked to do this?**

We are asking you to consider donating samples because you are currently receiving medical treatment or care which may involve a surgical or medical procedure and/or a blood test.

### **Do I have to take part?**

No. You do not have to consent – the choice is yours. If you decide not to take part, it will NOT affect your care in any way and your samples will be used solely for your care alone.

### **What will happen if I say yes?**

#### *Surplus (leftover) samples*

When you have a procedure or blood test, samples are sent to the hospital laboratory. The laboratory will use what they need for diagnosis, but there may be leftover blood or tissue that would normally be disposed of. With your consent, we can transfer any remaining leftover samples into the biobank for future approved research.

#### *Additional samples collected specifically for NIB*

We also ask your permission to collect a small amount of additional blood from you. This is usually done at the time of your procedure and can be up to 40mls which is approximately 8 teaspoons. In certain cases, where relevant, we would also like your consent to take an additional sample of bodily fluid such as urine, saliva or ascites.

#### *Tissue from previous surgeries*

If you have had a previous surgery, some of your tissues will be stored in the hospital pathology laboratory. This tissue can also be used for research, and we would like your permission to transfer these to the NIB and make them available for approved research studies.

### *Repeated donation*

Sometimes we may ask your permission to collect several samples over a period of time, to compare samples from before, during and after treatment. All repeated donations will be arranged to coincide with your routine appointments to ensure no inconvenience to you.

### **What will happen to my samples?**

All samples are given a unique identification number. Some samples may be released immediately for current research taking place, while other samples may be kept in secure storage facilities until they are requested for a research study. Consent for donating your samples is enduring, therefore we will continue to hold samples and information unless you advise us you wish to withdraw consent.

Your samples will only be used for scientific purposes. Some samples may be used to grow cells in the laboratory (known as cell culture), allowing scientists to study how illnesses develop and how cells respond to treatments. Other samples may have DNA extracted and analysed. DNA carries instructions for how our bodies grow and function. Studying DNA helps researchers understand why diseases occur, why people respond differently to treatments, and how new treatments could work. Your DNA will not be used for any other purpose apart from research.

### **What are the risks and benefits of taking part?**

Samples will mostly be taken as part of your routine procedure or care so there should be minimal risk associated with donating samples to the biobank.

You may not directly benefit from your donation. Rather, your participation will add to medical knowledge for future generations and may help in the discovery of new treatments for serious illnesses and conditions.

### **What about my personal information?**

If your samples are stored in the biobank, we would also like your permission to access information (data) from your health records. This may include details such as diagnoses, treatments, test results, and hospital attendances. Having this information helps researchers understand the samples more fully and learn how illnesses develop and respond to treatment. Only authorised clinical and NIB staff can access this information, as it is stored within secure hospital systems that are available only to hospital employed staff. This information is accessed solely for approved research purposes and is linked to a unique NIB number before it is released to a research study.

As a biobank, we need to hold some of your personal information (name, address, Health and Care number, date of birth) along with an electronic copy of your consent form, in our own secure QUB hosted electronic database. This information allows us to correctly match your medical information to your donated samples.

NIB takes your privacy seriously. To protect your privacy, we will:

- Remove personal identifiers from your samples and data and assign a unique NIB code number instead. On release to a research study, samples and data will not be traceable to you as they are labelled only with this unique code.
- Keep the paper copy of your consent form in a secure, restricted access location within Queen's University Belfast.
- Use security measures such as data encryption and access controls to ensure only authorized individuals have access to your personal information stored on our QUB electronic database.

### **What happens if I change my mind?**

You can withdraw your consent at any time by phoning or writing to NIB (contact details are given at the end of this information sheet). Any stored tissue/blood samples will be destroyed and your information will be removed from our database. However, we cannot always guarantee that all your samples will still be available as they may already have been released to researchers. Withdrawing consent from the NIB will NOT affect your treatment or care in any way.

### **Who can access my samples?**

Only approved research studies can access your samples. Researchers must demonstrate that their studies are ethical and of high quality. Independent experts will give their specialist opinion on the proposed research before access to tissues is approved.

Samples may be released to academic institutions, the NHS or commercial companies. Future approved research using your samples may result in financial gain to commercial organisations which are developing new tests and treatments. However, no direct financial benefit will accrue to NIB or to you as a donor. NIB approved projects could also involve portions of your samples and coded data being exported to research laboratories in other countries world-wide.

### **Return of research results**

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

### **Who funds the NIB?**

The Health and Social Care Research and Development Division of the Public Health Agency (HSC R&D Division) has provided most of the funding for the biobank.

### Who ensures the integrity of the Biobank?

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

### What if I have a complaint?

If you have a complaint, in the first instance you can contact NIB (details below). If your complaint has not been handled to your satisfaction or you would rather discuss it with someone outside the NIB team, you can contact the Head of QUB Research Governance, Ethics and Integrity:

Email: [researchgovernance@qub.ac.uk](mailto:researchgovernance@qub.ac.uk)  
Tel: 028 90972572

### Contact for further information

**Write to:** Northern Ireland Biobank  
Future Medicines Institute  
The Johnston Cancer Research Centre  
Belfast  
BT9 7AE

**Tel:** 028 90972915  
**Website:** [www.nibiobank.org.uk](http://www.nibiobank.org.uk)  
**Email:** [nibiobank@qub.ac.uk](mailto:nibiobank@qub.ac.uk)

