



# Participant Information Leaflet

## What is SHARE?

SHARE - The Scottish Health Research Register - is a register of adults and children aged 11 and over who are willing to be invited to take part in medical research projects and have also consented to allow SHARE to use any leftover blood following routine clinical testing. SHARE is for healthy people and also for those who have medical conditions.

## Why is SHARE needed?

In order to develop new treatments, tests and to improve services, volunteers are needed to take part in research. Previously people could only be invited to take part in research projects by their healthcare professional. SHARE allows individuals to register their interest directly.

## How does SHARE work?

SHARE uses NHS computer systems to match the right people to the right research projects. You can choose if, and when, you wish to participate at any time. Your help will be greatly appreciated but there is no obligation to take part in any given study.

## Why would you want my blood for SHARE?

Every time you give blood for a routine clinical test, a small amount is left in the tube. This leftover blood can be valuable to medical research. To do research we need your permission to keep and study any of your blood that is left over after a routine clinical test. This will greatly enhance our ability to study the role of genes in disease and health and to improve future healthcare.

By joining SHARE you are giving us permission to access your surplus blood after clinical tests have been carried out. You are also giving permission to securely store this material, carry out genetic analysis and use any of the information gained for

further research. This information may also be combined with your coded medical data and we may invite you to participate in future clinical research projects.

### **Will you take blood from me for SHARE?**

We will use blood from samples you may give in the future for testing when you visit your doctor or hospital. You are simply giving us permission to use any of the leftover blood after testing is complete. No more blood will be taken than is usual for standard clinical tests. You will not have to give an extra sample.

### **What will happen to any samples I give?**

We will store some of the samples indefinitely for future research, so that we do not have to ask you again. However, we may retain multiple samples when they are processed by the NHS laboratories. This will be used when the original sample runs out, but will also be used for the analysis of nongenetic biochemical markers that may change through time. For example, researchers may seek to examine how molecules change throughout the course of disease, or during specific treatments. Samples may also be sent to other research groups, including those outside the UK. Some of these research groups may work with pharmaceutical companies. The sample will be anonymised so that you will not be identifiable from it. These transfers of samples will be strictly governed by the relevant Tissue Bank to ensure your privacy and that appropriate research is being performed.

### **What is the purpose of this genetic research ?**

Recent advances in early diagnosis and treatment of diseases have been due to understanding genetics and how specific genes influence disease severity and response to certain medications. This is an important growing area of research as the discovery of gene variations could be used to develop new, more effective drug treatments for individuals.

Many people in Scotland have already been involved in genetic studies. 10% of the Scottish population has already volunteered for genetic studies into diabetes, obesity, cancer, heart disease, asthma, eczema and COPD. The SHARE register will greatly expand the valuable research being carried out in these disease areas.

### **What kind of research will be done on the samples that I give?**

You are giving consent for samples to be used for genetic research. This may eventually involve the reading of your entire genome (all 3 billion letters of your genetic code), and information may be gleaned that could provide useful direction for future treatment. Researchers will not be able to pass any findings on your genome to your GP. Your GP will not have access to your genetic data at any time.

### **What if relevant new information becomes available?**

We are at an early stage of understanding the importance of

most of your genetic code, however it is hoped that clinically useful information will be produced by the research on your sample. Researchers will produce reports and publications summarising their overall findings of how sequence information may be used to improve health and treatment.

In the future it may be that specific information which may be important and useful in treating diseases, may be made available to your doctor, but only with your permission at the time. This will only be done under strict ethical and regulatory approvals. For example, we may have information that tells us how well you will respond to certain drugs, then with your permission only, this information will be retrieved by your doctor.

### **What will happen to me if I take part in SHARE?**

Following the registration process which will take just a few moments to complete, your details will be stored in our secure database. In the future, if you are suitable for a research project, a member of the SHARE team will be in touch to give you the relevant information. You can decide at the time if you are willing to take part. There is no obligation to participate, and you can say no at any stage of this process.

For the spare blood aspect, no further action is required on your part, as you do not need to come to the hospital, and no special blood tests will be requested. We will only store blood that remains in the NHS laboratory after you have had a test requested by your doctor.

All of the stored samples will be coded so that they cannot be directly traced back to you as the donor. Your identity will be kept separate from your coded samples. Any medical information and samples used in research will have all personal information removed so that it cannot be identified as you.

### **Can blood I donate for transfusion be used?**

SHARE does not access any of the blood you donate to the Blood Transfusion Service. If you are a blood donor please continue to donate.

### **What are the benefits of taking part in SHARE?**

Research Projects will be completed in time as SHARE will be able to get in touch with participants who may be suitable and are happy to be involved. You will also be able to keep up to date with research taking place in your area from our SHARE website and can also approach us proactively.

However, genetic research is complex and time consuming so we cannot say a specific study will benefit you directly, but the knowledge we gain will help to find ways of preventing and treating disease more efficiently. It will enhance discovery of newer better targeted medicines.

### **Will my taking part in this project be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential.

## What if I change my mind after registration?

If you no longer wish to be contacted for research you need to simply contact us by email or telephone and we will arrange for your details to be removed from the register. If you no longer wish us to study your blood samples please let us know and we will destroy any stored samples and data derived from these. You can do this at any time in the future, and you do not need to give a reason.

## How long will the research last?

This register does not have a defined end date. We would ask your permission to store your sample and data (in anonymised form) so that we can consider it for use in future research. You are free to end your involvement at any time.

## Do I need to declare this for Medical Insurance?

The agreement to have blood stored for future research purposes and sequenced is not a diagnostic genetic test and therefore insurers do not need to be informed.

## Will I be paid for taking part?

No, you will not be paid for joining the SHARE register, or for allowing us to use your spare blood.

## Who is organising and funding SHARE?

The collection, analysis and research on spare blood is being organised and sponsored by the University of Dundee in collaboration with the Universities of Edinburgh, Aberdeen and Glasgow. The SHARE register is part of NHS Research Scotland. Funding has been received from the Chief Scientist Office, and the Wellcome Trust.

## Who has reviewed the study?

The East of Scotland Research Ethics Committee REC1 has examined the proposal and has raised no objections from the point of medical ethics.

This register has also been reviewed by members of the scientific review board of the Wellcome Trust.

If you have any questions or wish to register by telephone please call the **SHARE Team** on **01382 383230** or **01382 383471**

Alternatively, you may contact us by email **share@dundee.ac.uk** or **enquiries@registerforshare.org**

Many thanks for taking the time to read this information.

**www.registerforshare.org**

