



## What is SHARE?

**SHARE- the Scottish Health Research Register and Biobank** is a register of people aged 11 and over, interested in participating in health research and who agree to allow SHARE to use data in their various NHS computer records to check whether they might be suitable for health research studies. The Health Informatics Centre (HIC) Dundee, a Nationally Accredited, ISO27001 certified Safe Haven, hosts SHARE and provides an environment which protects data confidentiality and ensures secure management and processing of data.

The SHARE Biobank collects and stores consented blood samples from individuals listed on the register, via an interception method within NHS blood sciences labs that have been taken for NHS diagnostic purposes but are surplus to these requirements. These samples are collected prior to disposal as clinical waste. Once collected, material such as DNA, RNA and protein may also be extracted from the samples and stored for future use.

Researchers may apply to SHARE to aid recruitment of participants to health research studies and they may also apply to SHARE for access to stored samples and/or data.

## Before you apply

Please chat with the SHARE studies team to see if your project is feasible through SHARE before submitting an application. You may want to have this chat before you apply for funding. The SHARE studies team can be contacted on 01382 383230/ 383235 or [studies@registerforshare.org](mailto:studies@registerforshare.org) / [share@dundee.ac.uk](mailto:share@dundee.ac.uk)

Please note SHARE uses a cost recovery model (see below); please make sure you discuss costs before you start.

## **1. Application Process for studies involving participant contact**

- SHARE can aid study recruitment by contacting potential participants by telephone, email or post. The approach used will depend on the individual study and SHARE studies team will discuss the best options with you. We can help to identify patients for simple questionnaires, focus groups, drug trials or other research projects.
- Please download the relevant application form from our website:

**Feasibility applications:** You should complete a **feasibility** form if you just want to determine if SHARE can identify suitable numbers of participants for the study. Please ensure you complete as fully as possible including ICD10 codes (diseases), BNF codes (medications) and hospital operation codes (OPCS).

SHARE will request a search of the database and feedback numbers to you. We will also provide an estimate of costs. There is no charge for feasibility checks.

**Full applications:** Please complete the application form as fully as possible ensuring you enter relevant ICD10 codes (diseases), BNF codes (medications) and hospital operation codes (OPCS) within the inclusion/exclusion criteria. Please sign and email the form together with required documents i.e. protocol, ethics approvals, R+D approvals and PIL.

## How does SHARE work?



The SHARE studies team are at hand to help you complete the form and provide guidance and support. The form must be signed and dated by the Chief Investigator. If you are conducting your study in multiple health boards, you must include details of relevant Chief Investigator / Principal Investigator for each health board, and you need R&D approval for each relevant board.

### What happens next?

- We will circulate your application to the SHARE Access Committee. The SHARE studies team will communicate any queries raised by the committee. Once any queries have been answered and the application has been approved you will receive a letter of approval from SHARE Directors. It usually takes 3-5 working days for their decision.
- We will discuss with you the details of how recruitment will take place i.e. telephone, email or post and we will discuss the estimated charges for using SHARE. We will also send an invoice quote. This must be signed by the PI and returned to the SHARE studies team prior to commencement of recruitment.
- A search will then be initiated and HIC Dundee will be asked to provide the linked data for selection of potential candidates. Local safe-havens in Aberdeen, Lothian and Glasgow may be invited to get involved to refine searches if required.
- A suitable cohort of potential candidates is usually delivered to the SHARE team within 5-7 working days on a secure web-based tracker. The tracker is supported by HIC services and they will provide you with login details.
- You will be informed when the cohort is ready and the SHARE team will discuss with you how, when and at what frequency you wish to receive interested participants.
- The SHARE studies team usually undertakes initial contact of up to 5 candidates by telephone to test that the cohort selection is appropriate. Any discrepancies in selection are



established very quickly and are communicated back to the PI and HIC services.

- The contact details of the interested participants will be visible to you on the tracker along with any notes e.g. person prefers to be contacted in evenings, works shifts etc. The SHARE studies team manage the expectation of the candidates they contact and will inform them of when they expect to be contacted by the research team (usually within 10 days).
- Researchers must keep SHARE aware of any amendments to study protocol, or pauses in recruitment
- Note, e-mails and letters can also be sent for large scale projects or for contacting participants who have not provided a phone number.

## **When you have finished recruiting to your study**

- Researchers must inform the SHARE team immediately so that any potential candidates still in the selection pool can be released.
- Upon completion of recruitment SHARE will send an invoice. If happy with the costs the researcher should sign and return the invoice to SHARE. University of Dundee finance will then issue the invoice.
- SHARE will issue a simple feedback questionnaire which we kindly request you complete. This helps us monitor and improve our service.

**We hope that SHARE can help with successful recruitment to your study. We request that you acknowledge SHARE in any publications resulting from this collaboration.**

SHARE has agreed standard text for the Acknowledgements section that should be included in all papers:

***“Recruitment to this study was facilitated by SHARE - the Scottish Health Research Register and Biobank. SHARE is supported by NHS Research Scotland, the Universities of Scotland and the Chief Scientist Office of the Scottish Government.”***

## **2. Application Process for Studies requiring Samples and/or Data**

- Please chat with the SHARE studies team to see if your project is feasible through SHARE before submitting an application. You may want to have this chat before you apply for funding. SHARE studies team can be contacted on 01382 383230/ 383235 or [studies@registerforshare.org](mailto:studies@registerforshare.org)/ [share@dundee.ac.uk](mailto:share@dundee.ac.uk)
- Download an application from our web site (feasibility or full). [www.registerforshare.org/researchers](http://www.registerforshare.org/researchers)
- Complete the application as fully as possible and return to the SHARE studies team.
- For feasibilities, we will carry out a check to see if we have the samples and/or data and return numbers to you along with an estimate of costs.



- If it looks like we can identify sufficient suitable samples/data we will ask you to complete a full application (download from our web site). You must complete the application as fully as possible, sign and return to us.
- The application will be sent to the SHARE Access Committee and SHARE Biobank sub-Committee. If approved, a letter of successful application will be sent to you. We will discuss costs and send a quote. Once costs are agreed (quote signed and returned) SHARE will send the application to HIC services for sample identification.
- If sufficient samples are available, SHARE will arrange a Data and Materials Transfer Agreement (DMTA).
- Once the DMTA is in place, arrangement for dispatch of samples will be made (secure courier). A sample transfer form will accompany the samples. Upon receipt of samples the researcher should check the correct number and type of samples have been received, sign the sample transfer form and return this to the SHARE Biobank lab manager for record of receipt.
- Upon completion, SHARE will issue an invoice via University of Dundee Finance Department and also a feedback questionnaire. We kindly ask that questionnaires are completed and returned. Applicants are required to reference SHARE in any publications from research which utilised SHARE samples and/or data.

### **3. Costs for Projects (Indicative charging structure)**

*Please note SHARE is not profit making, it is purely cost recovery.*

*There is no cost for initial feasibility to find out if SHARE has the potential participants for your study. Researchers are encouraged to enquire prior to applying for funding and in cases of commercial studies at the feasibility stage.*

*Costs are estimated per project and are based on the amount of time and effort required to select the right candidates for each project.*

Non Commercial; eligibly funded projects with NHS Ethics and R&D Approval.

Set up costs - £500

Estimated cost per potential participant sent to researcher depending on work required; £5-£50

Commercial Projects;

Set up cost; £1000- £2000

Estimated cost per potential participant sent to researcher depending on work required; £50-£200

Genomic enrichment of cohorts;

Set up cost; £1000

Estimated cost per potential participant added to cohort; £50-200

Costs for Samples;

Set up Cost; as above for Commercial and Non-Commercial projects

Estimated cost per sample; dependent on type/number of samples and data requested (HIC data costed separately).