

## 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. Participants agree to allow the use of coded data in their electronic NHS records, to check whether they might be suitable for health research studies. Researchers can also apply to obtain anonymised samples and genomic information to assist with projects.

Information governance, data security and confidentiality are paramount to the operation of SHARE. The Health Informatics Centre (HIC) Dundee, a Nationally Accredited, ISO27001 certified Safe Haven, hosts the SHARE database, 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 registrants via an interception method within NHS Blood Sciences laboratories. These samples have been taken for NHS diagnostic purposes but are surplus to these requirements. 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.

## BEFORE YOU APPLY

Please get in touch with the SHARE Studies Team if you have any questions - [studies@registerforshare.org](mailto:studies@registerforshare.org) or call 01382 383230. Please note, SHARE uses a cost recovery model; we are a not-for-profit initiative. Please make sure you discuss costs before you start.

## HOW DOES SHARE WORK FOR RESEARCHERS

SHARE can assist NHS R&D-approved studies by providing participants, blood samples and/or data. We can aid study recruitment by contacting participants by telephone, email or post; the approach used will depend on the study. We can help to identify volunteers for questionnaires, focus groups, drug trials and a range of other research projects. Your study may require participants, blood samples and/or data; please download the relevant application form from our website: [www.registerforshare.org/researchers](http://www.registerforshare.org/researchers)



Click [here](#) to hear Professor Brian McKinstry explain how you can use SHARE for your study.

## HOW TO APPLY

**A Feasibility Application Form can be completed prior to your Full Application** to check that SHARE can identify suitable numbers of participants/data/samples for your study. You may require some information about potential numbers of participants/samples in SHARE prior to your grant application. We can usually return feasible numbers within 2-3 days and discuss potential costs. There is a form for studies requiring participants and a Biobank feasibility form if samples and/or data is required.

Please ensure you complete the form as fully as possible including ICD-10 codes (diseases), BNF codes (medications), GP Read codes and Hospital Operation codes (OPCS). We will arrange a search of the database and provide you with participant/data/sample availability. **No charge is incurred for a Feasibility check.**

**Study Application Form (Full).** Do complete the relevant form (for participants or for Biobank) as fully as possible. Please ensure you enter ICD-10 codes (conditions), BNF codes (prescribed medications), GP Read codes and

Hospital Operation codes (OPCS) where applicable within the inclusion and exclusion criteria section. Please sign and date the form, and return with the required documents to [studies@registerforshare.org](mailto:studies@registerforshare.org)

**Required documents:**

- If you are conducting your study in multiple health boards, you must include details of the relevant Chief/Principal Investigator for each health board
- R&D approval for each relevant board
- Protocol
- Ethics Approvals
- Patient Information Leaflet

Please note: if you are writing your Protocol, even if you intend to have SHARE as a back-up option, please mention in your recruitment methods that you *may* use SHARE. For Non-Commercial studies, the above information can be added to the OID - Organisation Information Document as a local database being used (i.e. SHARE).

## PROCESSES FOR DIFFERENT TYPES OF STUDY



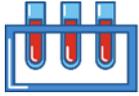
### For studies requiring participants

- Application form and supporting documents are reviewed by the Access Committee within 3-5 days. Paperwork required: Study Protocol, Patient Information Leaflet, NHS Ethics approval, R&D approval.
- We will discuss the estimated fees for using SHARE and send an invoice quote. This must be signed by the PI and returned to the SHARE Studies Team.
- You will receive a Letter of Approval from the SHARE Directors once the application has been approved.
- The application is sent to HIC for data linkage and cohort build.
- Once HIC has identified the cohort required for your study, they provide the SHARE Studies Team with access to a web-based application which is known as the 'Tracker'. The Tracker will indicate (minimal) details of those volunteers that match your study inclusion/exclusion criteria.
- The Studies Team use the Tracker to initiate contact with the candidates, initially contacting up to 5 candidates (by telephone/email/text) to test that the cohort selection is appropriate (any discrepancies in selection are quickly established and communicated to the PI and HIC). The SHARE Studies Team manage the expectations of the candidates they contact, informing that they should expect to hear from the Research Team within 5-7 days.
- HIC will provide you - the researcher, with access to this cohort through the Tracker. 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.
- Researchers are also required to keep the status of the participant updated on the Tracker (i.e. screened/consented/withdrawn/enrolled/completed).



### For studies involving questionnaires

- Researchers must keep SHARE aware of any amendments to study protocol or pauses in recruitment.
- SHARE can assist by sending emails with a link to your questionnaire, to all registrants or to a specific cohort. The Full Study Application Form should be completed.
- Please note that your questionnaire should be mobile compatible and work on all mobile platforms.



For studies requiring blood samples and/or anonymised data

- The Biobank Application Form should be completed (Feasibility form if you are exploring options, and Full Application Form when ready to apply).
- If sufficient samples are available, SHARE will arrange a Data and/or Materials Transfer Agreement (DMTA/MTA) for studies out with the University of Dundee.
- Once the DMTA is in place, arrangement for dispatch of samples will be made (via 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 form to the SHARE Biobank Laboratory Manager for record of receipt.
- Upon completion of the transfer, SHARE will issue an invoice via University of Dundee Finance Department.
- Researchers must keep SHARE aware of any amendments to study protocol or pauses in recruitment.

## ON COMPLETION OF YOUR STUDY

- You must inform the SHARE Team immediately that your study has finished recruiting candidates so that SHARE participants can be considered for new studies. If you do not inform SHARE you have finished recruiting, these participants will be marked as unavailable for any future SHARE studies.
- SHARE will issue an invoice. We will also request you complete our feedback questionnaire.

**Please note that SHARE must get acknowledgement in any publications and the standard recommended text is:**

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

Please also cite reference: McKinstry B, et al. Cohort profile: the Scottish Research Register SHARE. A register of people interested in research participation linked to NHS data sets. *BMJ Open* 2017;**7**: e013351.

## COSTS

SHARE operates on a cost recovery basis; not running a business. We are funded by the Chief Scientist Office and supported by the Scottish Universities and Health Boards and Councils.

Please note, costs for each project can be discussed and negotiated before we start, and an agreement reached.