

SHARE- the Scottish Health Research Register is a NHS Research Scotland initiative created to establish a register of people interested in participating in health research and who agree to allow SHARE to use the coded data in their various NHS computer records to check whether they might be suitable for health research studies. The initiative aims to create a resource of up to 1,000,000 adults (25% of the Scottish adult population). Currently over 250,000 people are registered for SHARE, and the contact data is held in secure NHS systems within the safe- haven in The Institute of Health Informatics Research, University of Dundee. SHARE also holds spare blood samples for many of the registrants which can be requested through a separate application process (GoSHARE).

SHARE will deliver to you a list of eligible participants for your study who have been through a coded pre- selection after applying eligibility and inclusion criteria, and who are willing to participate. They will have been triaged by the SHARE team indicating they are interested in taking part in your particular study.

SHARE will not provide details of individuals without getting their permission first. All searches for feasibility and cohort building are done centrally by SHARE.

Before you apply:

- Please chat with the SHARE 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 Admin team can be contacted on 01382 383230/ 383235 or share@dundee.ac.uk
- Please ensure your protocol lists “SHARE” as a method of recruitment / selection. For commercial studies this information should also be in the new OID–organisation information document.
- Ensure you have Ethics and R&D approvals
- Project should have “eligible funding” / or a commercial source of funding-please see link below: <https://www.cso.scot.nhs.uk/wp-content/uploads/2013/05/NRS-Funding-Guidance-Annex-2-Eligible-funders-v4.pdf>
- SHARE uses a cost recovery model; please make sure you discuss costs before you start.

Application process:

How does SHARE work?





Download the relevant form;-

- Feasibility
- Application
- GoSHARE (if you are applying for biobank samples.)

Complete the form and email it together with required approvals and documents. The SHARE team are at hand to help you complete the form and provide guidance and support. It is essential that the inclusion and exclusion criteria are listed using disease codes (ICD-10), medications (as BNF-codes) and hospital operation codes (OPCS).

Searches are conducted by database experts who are programmers, with no clinical knowledge. It is vital that this form is completed accurately as corrections after the cohort has been built will take more time.

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's, on the application, and you need R&D approval for each relevant board.

What happens next:

- Your application is circulated to the SHARE Access committee. This takes 3-5 working days for their decision. Once approved you will receive a letter of approval from SHARE Directors.
- You will be told of the estimated charges for using SHARE, and an invoice quote will be sent which needs to be agreed and signed by PI.
- 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 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 web-based tracker.
- You will be informed when this is ready and the SHARE team will discuss with you how, when and at what frequency you wish to receive eligible candidates. The SHARE team manage the expectation of the candidates they contact and will need to inform them of when they will be contacted by the research team if they wish to go ahead.
- The SHARE team usually undertakes initial contact by telephone to try and gauge the suitability of the study and to test that the selection is appropriate. Any discrepancies in selection are established very quickly and are communicated back to the P.I.
- Emails and letters can also be sent for large scale projects.
- When the SHARE team identifies the initial five interested candidates, the researcher is sent a password to view the web-based tracker which is populated with the contact details of the candidates who are willing to proceed. Researchers are also invited to suggest recruitment status categories for the tracker. The default list is "contacted", "changed mind", "ineligible", "in-study". This is to help you to log the progress of the candidates, but also allows the SHARE Team to monitor progress. Additional status categories, for example, "PIL sent", "waiting for call back" can be requested.



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. SHARE will automatically remove names from the pool in 6 weeks, unless prior arrangement has been made to extend this time frame
- Researchers must also inform SHARE of candidates who have been randomised so that they can be recorded as “engaged” for the duration of the study and will not receive further invitations to participate in other studies. Be sure to inform the SHARE Team when the study is completed so that a candidate’s status can be updated.

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, which is supported by NHS Research Scotland, all the Universities of Scotland and the Chief Scientist’s Office of the Scottish Government”

Costs for Project (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