Glossary of Terms

Anonymous information/Data. The processing of personal information/data in such a way that it makes it impossible to identify individuals from these sources, all identifying information is removed from the data.

Chief Scientist Office (CSO). The Chief Scientist Office is a department within one of the Scottish Government's Health Directorates. The CSO aims to support and increase the level of high-quality health research in Scotland. The CSO and the Universities of Scotland fund SHARE.

Data Protection Act/UK-General Data Protection Regulation (GDPR). The Data Protection Act 2018 is the UK's implementation of the GDPR. Organisations which are responsible for using personal data must follow strict Data Protection Principles to ensure personal information is collected, used, stored and disposed of in a safe, confidential and secure manner. The Date Protection Principles are:

- Lawfulness, fairness and transparency
- Purpose limitation
- Data minimisation
- Accuracy
- Storage limitation
- Integrity and confidentiality (security)
- Accountability

De-personalised/De-identified information/Data. This is information/data that does not identify an individual, because identifiers have been removed or encrypted. However, the information is still about an individual person and so needs to be handled with care.

Genetic data. This is personal data relating to a person's genetic characteristics inherited or acquired through DNA or RNA analysis of blood samples.

Heath Informatics Centre (HIC). The Health Informatics Centre is part of the NHS and is responsible for securely accessing personal data for the SHARE register and also the Health Board. HIC is a nationally accredited and ISO27001 certified remote access Safe Haven (see **Safe Haven**). HIC carry out coded data searches within NHS electronic records to find SHARE registrants who are eligible to take part in research. HIC send the list of eligible people to SHARE staff. SHARE staff contact people to ask if they are willing to participate in the project.

Health records. When you visit an NHS service, (e.g. GP, hospital), information about you and the care you receive is recorded and stored in an electronic health record so people caring for you can get the background information on your health status. This information can include but is not limited to your name, age, address, health conditions, treatments and medications, test results and details of any hospital admissions/discharge. These records are confidential and held securely within the NHS.

NHS Research Scotland (NRS). NHS Research Scotland is a partnership between Scottish NHS Health Boards and the Chief Scientist Office which works to ensure that NHS Scotland provides the best environment to support clinical research.

Personal data/Identifiers. This information that identifies an individual. Identifiers include name, address, full postcode, date of birth, NHS number or detailed information about your health. Personal identifiable information must be stored in a highly secure way.

Safe Haven. A Safe Haven is a secure environment whereby health data can be processed and linked with other health data and made available in a de-identified form for analysis to facilitate research. There are four regional Safe Havens in Scotland (in NHS Grampian, Greater Glasgow & Clyde, Lothian and Tayside), and one national Safe Haven based at National Services Scotland. The Health Informatic Centre is a Safe Haven based in NHS Tayside; this Safe Haven carries out searches in NHS electronic systems to identify suitable SHARE registrants for research projects.

SHARE Biobank. The Biobank collects and stores blood samples taken for NHS diagnostic purposes from individuals listed on the SHARE register (who have consented to their blood being used for research). Blood samples are collected via an interception method within NHS blood sciences laboratories. The samples are collected after the laboratory tests are complete (and prior to disposal as clinical waste) so these samples are surplus to requirements. Once collected, these samples are de-identified and may be used to assist researchers with their projects.

Tissue Biorepository. There are four accredited tissue biorepositories in Scotland. The Biorepositories oversee the governance of the collection, storage and release of any blood samples obtained from SHARE registrants who have consented for their spare blood to be used in medical research.