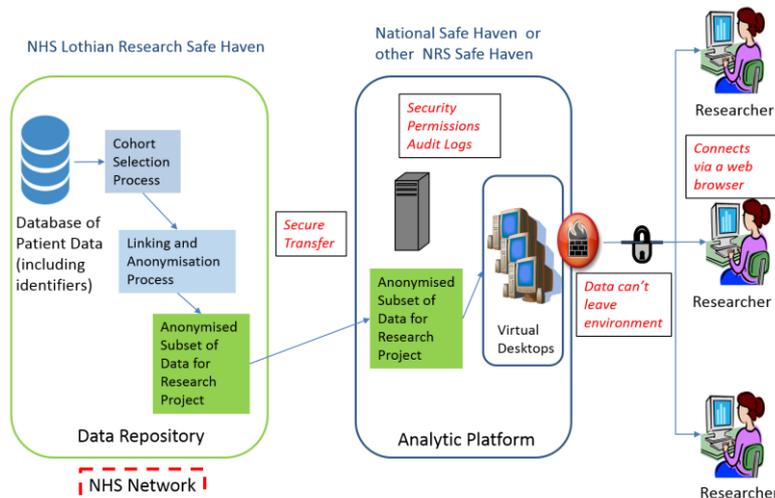


NHS Lothian Research Safe Haven

The **Lothian Research Safe Haven (LRSH)** provides support for researchers seeking to access data held within electronic health records of patients within NHS Lothian for use in health-related research while protecting patient privacy and confidentiality. Extracts of data are securely linked and de-identified within a secure environment before being made available through restricted access to named approved researchers for specific approved projects.

The LRSH secure environment comprises trained and approved staff working on a range of datasets held within dedicated secure servers within NHS Lothian. These staff curate hosted

Secure Safe Haven Infrastructure



data and undertake data processing and linkage of extracts of data for specific projects.

Named approved researchers are granted restricted remote-access to de-identified extracts of data on a secure analytic platform, within a safe haven environment, to carry out their analyses. Only aggregated data can be released from the safe haven after being assessed for risk of disclosure of any potentially

identifiable information. Individual level data may be released if access to the data is consented and/or the appropriate additional approvals are in place.

LRSH hosts a range of datasets used to support health-related research, these include extracts of NHS Scotland national databases (e.g. births, deaths, prescribing, SMR) and clinical systems (e.g. TRAKCare) and comprise routinely collected data on individuals accessing the relevant service within NHS Lothian. LRSH is working closely with DataLoch™ to develop a repository of health and social care data for the Edinburgh and South East Scotland (ESES) region, through which access to more comprehensive data including from primary and social care is anticipated.

LRSH also hosts bespoke health or clinical collections, study data and registers. LRSH supports researchers seeking to curate and facilitate onward sharing, through controlled access, of their study data.

Datasets and cohorts:

Linkable routinely-collected health datasets

- Vital statistics
- Health data (e.g. TRAK, SMR, A&E)
- Disease registries
- Population surveys

Local bespoke 'specialist' datasets & cohorts Study/cohort data

LRSH offers a range of services and support to the research community in facilitating access to data for use in health-related research. Researchers are encouraged to liaise with the

Advice and support:

- Availability of data for research
- Project design & research methodology
- Advice on data management and linking datasets
- Data annotation of tissue studies
- Advise and support on the required approvals
- Links with analytical expertise/services
- Links with Researchers & Clinicians
- Provide cost estimates for the proposed activity

LRSH team at an early stage in developing their projects to ensure requirements can be met and to obtain an estimate of cost to write into grants.

Applications for access to data and data linkage activity are reviewed by the LRSH Project Review and Advisory Committee to ensure appropriate use of the

data including whether it is suitably justified and within public interest. The Research Ethics Committee has granted generic Research Database approval to LRSH to process data for a range of health-related research that has been approved by this Committee.

A range of projects and activities can be supported by LRSH. The activities and outputs are developed to meet the needs of researchers and to address information governance and security requirements for handling patient data. Although supporting research is the focus of activity, audit and service evaluation is also supported.

Data management and linkage:

- Dataset acquisition, hosting/curation
- Data linkage
- Vital status checking
- Data extraction, processing and anonymization
- Disclosure and Risk assessment
- Facilitating remote access to data via a Safe Haven analytic platform

Types of studies and activity:

- Feasibility studies & cohort identification
- Linkage to study data (consented as part of research project) – SHARE register, CTs
- Data hosting for onward sharing
- Data linkage and annotation of tissue
- Real world studies

LRSH works in collaboration with NHS Lothian Analytical Services, NHS Lothian eHealth, NHS Lothian BioResource, Edinburgh Clinical Trials Unit, the Usher Institute and DataLoch

LRSH is also part of the NHS Research Scotland (NRS) Network of Data Safe Havens established to promote sharing of expertise, working to common

standards and support delivery of multi-centre projects. LRSH primarily engages with eDRIS to access the National Safe Haven analytic platform, however data for approved projects can also be transferred to other Safe Havens within the network.

Collaboration is invaluable in sourcing the right data and services to meet the needs of the research and technical solution required for hosting and analysing a range of data formats within an environment that maintains patient privacy and confidentiality.

LRSH is part of NHS Lothian R&D and receives funding from the Scottish Government Chief Scientist Office (CSO).

For further information contact LRSH@nhslothian.scot.nhs.uk

Web: www.accord.scot/researcher-access-research-data/lothian-research-safe-haven